WE'RE IN THIS TOGETHER

Stories & Tips *from* Patients *with* Rare Diseases

compiled by

Ben's Friends
Patient Support Communities
www.BensFriends.org

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FOREWORD

THE PAST

This e-book is dedicated to all people across the globe affected by a rare disease—patients, family, friends, and caregivers (including medical professionals).

A rare disease has different definitions in various parts of the world, but in general, it's a disorder that affects less than 1 out of every 1,750 people.

Did you know there are more than 6,000 rare diseases in the world?

All told, there are more than 300,000,000 people around the world who have a rare disease. Yes, 300 *million*; that's nearly 1 in 20 people who have a rare disease.

Most companies choose not to focus on these rare conditions because they are not lucrative. Because the patient populations are small, these diseases are often not attractive enough for funding or massive awareness campaigns (such as the amazing Avon Breast Cancer walks or terrific Team in Training fundraisers). Thus, these rare diseases remain outside of mainstream attention.

Most people affected by a rare disease suffer alone.

That shouldn't be the case.

We've proudly filed for nonprofit status. At the time of publication, we have been recognized by the State of Texas, but are awaiting final approval by the IRS.

THE PRESENT

Fortunately, the Internet has increased awareness of rare diseases and options for those affected.

Our organization, Ben's Friends, builds online support groups for people with rare diseases. Ben's Friends was started by Ben Munoz after his own battle with a rare condition. Here's Ben's brief story in his own words, or you can watch in the 1-minute **video here http://www.youtube.com/watch?v=YBeRFnJkleU**

My name is Ben Munoz and my organization, Ben's Friends, builds online support communities for patients with rare diseases. People affected by rare diseases struggle to find support offline and on-line because these conditions lack the critical mass to organize local support groups and Internet sites don't cater to these patients because they are not economically viable through advertising.

Even your family lacks the information and understanding to give you all the support you need. It can be very lonely and depressing—I know, because in 2006, at the age of 29 while at Kellogg Business School, I nearly died from a rare condition similar to a brain aneurysm.

*My condition is called Arteriovenous Malformation (AVM) and it's extremely rare. While recovering from my AVM, I couldn't find a single support group in the Chicago area so I turned to the Internet for help. Unfortunately there were no Internet support groups for AVM patients either! I finally found the support I was looking for by creating my own group at **AVM-Survivors.org**. Other AVM patients found us and we grew into a close-knit online family of AVM survivors.*

In 2008 we started more patient communities and Ben's Friends has been growing rapidly every year since. Today, my friends and I have built a network of 30+ support communities, each catering to a specific rare condition. Collectively, we're reaching and helping tens of thousands of patients, friends, family, and caregivers affected by rare diseases every month.

On a personal note, I was saved by emergency surgery but 50% of the people who have an AVM bleed are not so lucky. My condition changed my entire outlook on life and I decided to give back further to patients who have rare conditions by becoming a Doctor. After finishing business school, I enrolled at UT-Austin to complete my medical school pre-requisites. In the summer of 2011, I took the MCAT and applied to medical school. Following my interviews, I landed in Houston at Baylor for the Fall of 2012. In the meantime (and going forward), I look forward to continuing the growth of ***BensFriends.org***

Almost all of our members tell us that before Ben's Friends, they had never spoken to anyone with their condition in their entire lives! They are excited and comforted to find hundreds of people experiencing the same emotions they are experiencing. They don't feel so alone anymore.

You can find more info about **BensFriends.org** below.

Main website (where you can watch a 1-minute summary video): **BensFriends.org Patient Testimonials**:**YouTube.com/BensFriendsVideos** and **blog.BensFriends.org**
Press: **http://www.bensfriends.org/InTheNews/**
Media Kit: http://www.bensfriends.org/presspage/media-kit/
Contact: **info@bensfriends.org**

THE FUTURE

Ben's Friends' mission is to ensure that everyone in the world with a rare disease has a safe place to go and connect with others like them.

Along those lines, Ben's Friends decided to create this e-book.

So to our awesome Ben's Friends Community Members and Moderators who helped contribute to this project, THANK YOU! You have played a huge role in helping people affected by rare diseases receive support.

If you or a loved one is affected by a rare disease, Ben and all of his Friends can provide support. If you want to help in any way, please visit BensFriends.org—we are always grateful for help.

Please note as we told our members when collecting submissions, we made a few small cosmetic changes in editing (e.g., spelling, punctuation, grammar), but 99% of what you will read is directly from the members who have given permission to publish their thoughts in order to help others affected by rare diseases.

All proceeds from this e-book go towards helping more rare disease patients, providing additional member services, and creating new rare disease communities.

In sum, this e-book is by, for, and about people affected by rare diseases with a focus on support (like our mission!). We hope this e-book will tell the rich, inspiring, and moving stories of BensFriends.org members, and provide tips for the millions of people around the world affected by rare diseases.

Please remember that people affected by rare diseases are not alone and BensFriends.org is here for your support.

TABLE OF CONTENTS

This e-book is arranged in several parts. Please feel free to bounce around to sections that are most useful to you. If you have comments, thoughts, additional stories and tips to share, please visit us at **BensFriends.org**. We hope to create another e-book with more helpful tips and inspirational stories, plus you'll be able to read many of them online. We did not include any direct personal information such as emails; if you wish to contact one of the authors, please email us at info@bensfriends.org and be sure to include the author's full info provided here or join the community and connect online in the support group.

TIPS

SECTION 1 – Tips

The following tips come directly from members of BensFriends.org and our various rare disease communities.

PLEASE NOTE: Any tips, recommendations, medications, or any other advice should be reviewed with your doctor before making any changes or decisions. BensFriends.org is here to help, but we are not doctors and these tips come from patients/friends/family/caregivers, so we cannot be held liable for any actions based on the e-book.

We were going to organize the tips by specific disease, but realized that while a few tips are targeted for a specific rare disease, most can still help others affected by any rare disease. Therefore, the tips are separated into for whom the tips are designed:

- Newly Diagnosed (Section 1A)
- Patients Trying to Cope (Section 1B)
- Non-Patients (friends/family/caregivers) (Section 1C)

We also found that tips in each section might help just about anyone, regardless of whether you're a new patient, experienced patient, or non-patient, so feel free to read everything!

Each disease community on **BensFriends.org** has a section for members to continue submitting tips (e.g., through the discussion forum) or you may also email us at **tips@bensfriends.org**. If you are affected by one of our rare diseases, please join us. If

your rare disease is not currently covered, please send us an email to **info@bensfriends.org** with your condition and we can discuss getting a community started.

Please remember that you are not alone in this and we are here for your support.

If you are looking for more information, feel free to check out **bensfriends.org**

Section 1A - Tips for those Newly Diagnosed

The best tip I can give anyone diagnosed with a rare disease is to find a doctor who cares, who will really listen, and is someone you can trust with your life and well-being. This may take some time. It took me three years to find my wonderful doctor. No matter what, there IS a doctor out there who is the doctor for you, so don't quit looking!

The next best thing you can do is find a support group, a really good one where there are people suffering with the exact same disease and have similar symptoms and might be on, or have tried, medications your doctor has suggested.

Knowing there are people like me out there has helped me tie a knot at the end of my rope to hold on to at any time.

Gwen
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
St Louis, MO

Tip #1: Don't suppress your emotions. If you are afraid, confused, sad, disappointed, etc., let it out and talk about it. Talking about it will help you work through the emotion and not let it overcome you. You have more to deal with, and emotions not properly handled can blow things out of proportion.

Tip #2: Learn as much as you can about this. Do a Google search, and get informed on the condition. Support groups can be very helpful, as it helps to know you are not alone. You'll be amazed at what someone else's story can do for you.

Tip #3: Find a good doctor. Talk with your PCP (Primary Care Physician) and insurance company about the importance of finding the best doctor.

Kene
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Atlanta, GA

Please know that you are not alone!! There are lots of people with the same condition you have, so find a support group! I have found that I have learned more about my condition from others who are living with it too, than I have from doctors.

Sally
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Van Horne, IA USA

I don't know if there is anything that I could say as a "tip" for someone just diagnosed with a rare disease because everyone will find a different way to deal with it. For me though, I think I spent the first two to three days in shock and googling every tiny little piece of information I could find on the Internet about AVMs (arteriovenous malformations). While some information I found wasn't overly helpful there were a few sites that were absolutely amazing and avmsurvivors.org was DEFINITELY one of them. A support network is going to be the best thing for you. Also talk about it with people you know. I found venting about it really helped me to try and come to terms with how my life had changed.

Kat
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Auckland, New Zealand

Live your life day by day. Do not do too much Internet research (which can bring more anxiety) but do ask physicians who are the top physicians in that field. It is extremely overwhelming in the beginning; so taking baby steps is the best way to handle the situation. Keep your daily routine going to help your brain relax as it knows the routine.

Emmanuelle
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Bellingham, WA

Do all the research you can about your disease. Research all treatments you so you can help make an informed decision about what might be the best avenue for you. Find a specialist that you find like and feel comfortable wit. Ask lots of questions and write down your questions, even make a copy of them to give to your doctor to look at while talking about them. Take at least one other person with you to the appointment, so they can hear and interpret things you might miss. A good support group website is a great avenue to find info and to know that you are not alone with your disease and feelings.

Scott
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Creston, Washington

It's important for you to understand that having an AVM is not your fault or a result of anything you did; it is a condition that develops in utero or shortly after you're born.

You should do a lot of research on this condition once you're diagnosed because there are many different treatments that can solve this problem. Don't always take your doctor's first suggestion unless it's a life-threatening situation where immediate surgery may be your only option.

KELLIE
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
SKOKIE, IL

#1. Communicate with your family about reasonable goals and expectations. I have found that in my case, my family feels like the AVM happened to them rather than to me. They seem almost more wounded than myself. In our situation it was so sudden and extreme with a previously undiagnosed rupture that there was little time for staging and planning. So possibly family meetings or strategy sessions would have greatly eased the transition for my caregivers and minor children.

#2. Keep a notebook for yourself and jot down ideas and questions as they come. You'll find your new condition dominates your life and it is difficult to remember (even) important questions and ideas. A little 4x4 spiral notebook successfully stores all my concerns and frees up some mental disc space! I also understand that it is good for your health to transfer stress to paper rather than carry that baggage around on your heart!

Nicole
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Pittsburgh, Pennsylvania

Surround yourself with people who love and support you. Look up the spoon theory.

Talk, don't hold anything in. Ask as many questions as you can think of, and write everything down that you need to talk to your doctor about because you will forget something.

Jenny
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient

If you were just diagnosed with a rare disease, the first step is to take a breath! Then search the Internet for support groups so you can identify with people who have been in your situation. They can be either online or a group in your city. After that you can do some research to see what you can expect with your diagnosis. Keep a journal of everything that happens to you. You think you're going to remember [everything] to tell your doctor at your next visit, but chances are you won't. This way you have everything handy and won't be left regretting questions or concerns you forgot about.

Andrea
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Tonawanda, NY

Don't be afraid to speak up. You are your own best advocate. Ask questions and clarify everything. Make sure that you understand what is happening and why. If there is something that you feel your health care practitioner has left out, persist until you are satisfied. If need be, make a list of questions/concerns and don't be afraid to use it. Doctors work for you. Also, if you are not satisfied with your treatment, find another doctor who will serve you better.

Melissa
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Bradenton, Florida

Accept that it takes time to figure things out; don't be isolated. Seek out information and read up on studies.

Sharyn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Brain Aneurysm
Brain Aneurysm Foundation (www.BAFSupport.org)
Patient
Manchester, CT

1. Learn as much information as possible about the condition.

2. Don't always listen to what the doctor says will happen afterwards. Take everything with a grain of salt. For example: My AVM was found at 11 days old. My parents were told that I would most likely die during the surgery or be unable to do anything for myself in life and be severely handicapped. I am now 19 years old and healthy. The aftermath is so minimal that nobody is able to notice anything.

3. Go to all your appointments and get regular checkups.

4. Live life like it's your last day. Don't take anything for granted.

Alicia
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
North Bay, ON, Canada

Find the best neurologist in your area.

Louisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Rhode Island

Find peace within yourself. Expect nothing. Make things happen for yourself, and make a time out zone. Run from anything that causes stress. Make Lupus [or whatever your disease is] the enemy. Fight!! Find the right doctors and medications that work for you. Ask questions of your doctor and let them know each visit if the medications are working!!! Once again—the fight is yours to win.

Beverly
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Stone Mountain, GA

I researched everything I could get my hands on... Wikipedia actually had the least information at times. The national rare disease center was great, and PUBMED had a lot of "cases with the study" listed, and so did oxfordjournals.org, ncbi.nlm.nig.gov/pmc.

First of all, it helps to email some of the doctors' offices to find out if their "experts" have worked with the ion channelopathy disorders rather than just wanting to study you as a guinea pig! Or call some of the doctors listed at the national ataxia centers to see whom they recommend in your area.

Keep an account of what, when, and where your attacks are coming on. What you eat, too. I should be better at this, but am not. The doctors can at least see a pattern at times.

Debbie
Ataxia
Living With Ataxia (http://www.livingwithataxia.org)
Patient
Algonac, Michigan

My first tip would be to get a few doctors' opinions. Try to find someone or a group to talk to about this situation; possibly someone who has gone through a similar situation and someone who is positive. Try not to read too much information from websites that are not used by other patients or friends. It can be information overload and at times you can read stories that may not have anything to do with your situation. When going to see a doctor be prepared, write your questions down so you don't forget anything, and don't feel rushed even if you feel you are being rushed. Stay positive at ALL times.

Melissa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Make sure that you speak up. Make the doctors hear you, how you are feeling and what's going on.

Mandy-Sue
Patient
Georgia

It seems my disease was diagnosed by a dentist who had injured a nerve while doing a root canal. Did I, in fact, just have a damaged nerve or did I have Trigeminal Neuralgia before? I didn't know, but I sought out many professionals to see what they could do. I found livingwithtn.org to be a great resource and support system. I also kept a detailed record of my medications, pain, etc.

Julianne
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Durham, NC

If you don't feel comfortable with what one doctor tells you, get another opinion.

Rob
Patient
Alexandria, MN

Do research and learn as much as you can.

Jamie
Adrenoleukodystrophy Support (www.AdrenoleukodystrophySupport.org)
Patient, parent
Lancaster, California

My #1 thing to tell someone that has just been diagnosed with my condition, which was an AVM or blood clot, is don't let it define who you are. I beat it…

Jerrod
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lubbock, TX, USA

Contacting help groups, like Macmillan Cancer, is a great place to start. They can give you lots of information and other places to contact to get either information or help.

The hardest thing I have found is not doing everything and actually asking for help and assistance. Do not feel guilty for putting in a claim/benefit—that's what you have paid into your policy for!

Julie
Synovial Sarcoma
Synovial Sarcoma Survivors (www.SynovialSarcoma Survivors.org)
Patient
Brandon, Suffolk, UK

It's a good idea to get as much information as you can get about doctors and ways of treatment before you go ahead with anything.

Sarah
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Israel

Ben is right—find a support group. Don't shut anyone out trying to help you. Be positive; I know it's hard but for any situation there is always hope. Do research and write down all the questions that pop into your head. This will also educate the other people involved in your life—be it family, siblings or friends.

Alexander
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Parent/Friend/Family/Caregiver
Toronto, Canada

My tip is knowledge, books, support groups. The Rheumatologist can be helpful but you do need to learn on your own. I write everything down on paper before I see my Doctor because I will forget things. I had positive swine flu in 2009, and did not know what Lupus even meant. Swine Flu brought on my Lupus. I found a book called "Lupus Q&A" by Robert G. Lahita, MD, PhD and Robert H. Phillips, PhD. This book has it all!! I'm also gluten-free and avoid acidic foods. You HAVE to learn what foods you can have or you will flare, especially with Discoid Lupus.

Rachel
Lupus
Life With Lupus (www.LifeWithLupus.org) *Patient*
Warren, MI

See a neurologist for advice, certainly. Get on lumosity.com, a truly fun site of brain games, which is backed by impressive research and was recommended by my neurologist to work and train my brain. Engage in physical activity on a daily basis, a scientifically proven method to improve brain function. And eat a very nutritious diet. I also recommend reading *The Brain That Changes Itself*, by Norman Doidge, which really is the most important book I've ever read—truly inspiring and comforting.

Definitely do the above, all truly important and proven actions.

Kelly
Traumatic Brain Injury
Traumatic Brain Injury Support (www.TraumaticBrainInjurySupport.org)
Patient
Ashland, OR

Once you have been diagnosed I would go find as much information as you can about your disease. Find someone you trust to talk to and/or find a support group online, if at all possible. Finding a specialist that will listen to you may be hard for some, as it is for me. I am still in search for one that will listen. Thankfully my family doctor is on my side and spends all the time I need when I go to see him. Bringing a tape recorder is the best option when you see your doctors, but if that is not possible then I would suggest bringing someone with you who can write everything down for you, help remember questions that need to be asked and to support you through it. Don't take no for an answer from any doctor. Some may try to blow you off. Let them and move on to another until you find one that wants to help.

Allison
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Albany, NY

Educate yourself and find a doctor who is familiar with your condition.

Fran
Chiari (www.ChiariSupport.org)
Patient
Erath, lA

Try to chat with people who have the same condition as you. There is nothing worse than feeling like you're the only person with your condition and feeling the way you do.

Try to take happiness in the little things. For example, I have trigeminal neuralgia at age 21 and it gets worse and worse. Every day that I am pain-free I appreciate, and that can help me feel more positive.

Mica
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Liverpool, UK

Find a support group; after 1 year I'm still in denial.

Kim
Fibromyalgia
Living With Fibro (www.LivingWithFibro.org)
Patient
Tempe, AZ

Get yourself a good specialist, MD. I am very lucky to have a renowned Hematologist.

Dianne
Von Willebrand's Disease
Living With VWD (www.LivingWithVWD.org)
Patient
Washington, DC, USA

Keep looking for the right doctor, the doctor who is willing to work with you to either find the cure or at least the best way to live your life with your condition.

Carol
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
San Diego, CA

Anyone just diagnosed should read as much as possible about the condition and rather than taking it all as gospel—take it in, digest it, and compare it. We are all different and suffer in many different ways, so there are no strict rules with this illness. Taking in all the information out there, you will find some similarities to yourself. It's all about comparisons.

Jeanette
Psoriatic Arthritis
Living With Psoriatic Arthritis (www.LivingWithPsoriaticArthritis.org)
Patient
Bedford United Kingdom

Get educated and get connected. When I say get educated, I mostly encourage others to read material written by doctors. If they read patient stories, read with caution. It's good for patients to share their stories, but they may not understand what's really going on with their health even after years of symptoms. I certainly did not understand for years what I was dealing with. Now that I have a real diagnosis I can speak only about what I'm experiencing. Blanket statements from others are [usually] not helpful.

Julie
Ataxia
Living with Ataxia (www.LivingWithAtaxia.org)
American Ataxia Networking
(www.AmericanAtaxiaNetworking.ning.com)
Patient
Colorado Springs, CO, USA

Search for all the information you can find, and one of the best sources is the support groups available online.

Beth
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Grand Rapids, MI

Tip #1: Try and bring someone to ALL of your appointments. The initial shock of the diagnosis often prevents you from hearing what the doctors have to say. They use medical language that may be unfamiliar to you so stop them as much as you need to to clarify anything they are saying. Have this other person take notes on the conversation so you are free to focus.

Tip #2: You need to be 100% comfortable with your specialist since this person may be involved in your life for a long time. Don't be afraid to shop around for other specialists that may be recommended to you via support groups in your area. They need to be constantly looking for treatment options for you so make sure they are putting your care as a priority.

Tip #3: I used to feel like I shouldn't call the specialist's office too much; that I was bothering them. I needed to get over that hesitation. That is their job to answer any questions you have, even if you need to ask it more than once.

Tip #4: Ask for copies of ALL your path reports and surgical notes. You will need to start a binder of all of your procedures so if you get a copy as you go along, it is easier to pass it on to the next

Paula
Synovial Sarcoma
Synovial Sarcoma Survivors (www.SynovialSarcomaSurvivors.org)
Patient
Cohasset, MA

Information is key. Google can be your best friend. Anything you do not understand, just Google it.

Tessa
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Raleigh, NC

Research as much as you can on your condition and make sure to get second and third opinions; doctors are not gods.

Carolina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Homestead, FL

Having hereditary Ataxia, and just recently being notified that my younger sister has just been diagnosed with Ataxia herself, has changed our ways of dealing with our lives. I have a daughter who has been my rock. I know that when I need someone to help me deal with medications or anything else she helps me out. My husband of course is my friend and partner through all of this and talks a great deal with me about all that may bother me. To me, family discussions help all of us to deal with what changes may appear, along with having those who care to help you through the acceptance during the changes.

Diagnosed just in October 2010, I have come across many changes and I know there are more to come. I have learned that it is what it is and I just don't worry about it. I try to just go on and do the best that I can and be thankful that I have loved ones who are there for me. I chose to start using a cane within the month I got my diagnosis. My younger sister and I have come up with a way that has helped us walk a bit better than before. We found that if you concentrate and look up to focus on something ahead of where you are walking you will have a better-controlled walk. Balance seems like it's more controlled.

In this past year I have also been diagnosed with Nystagmus of my eyes. This is causing my eyes to feel as if they are moving all the time even though you cannot notice it when you look at them. Along with that I have also Diabetes and RLS (restless leg syndrome). All problems diagnosed within 5 years time.

I wish I could give you other pointers on how to cope with my situation but it is all so new to me. At this point my advice to others with similar situations would be to take it day by day. My situation is just a problem for me to deal with and that is it. The other day I watched on the Dr. Phil show a woman that had a rare flesh eating disease and had to have both legs and arms amputated. How could I possibly sit and complain of my small situation knowing that she had just had another child and has other children at home to tend to. As it is said there is always someone worse off.

Vickie
Hereditary Cerebellum Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Durand, IL

Find out as much as you can about your disease and keep a list of your concerns and questions for your doctor. Then ask someone you trust to remind you to bring the list and accompany you when you actually meet with your doctor. This way, even if you've forgotten to write something out, or if you're unaware of how a symptom may be affecting your behavior or someone you care about, he can address it with the doctor himself. Then do your best to follow your doctor's instructions and advice.

The other tool that has become just as important as good healthcare is family support, and for which there is no other 24/7 substitute. This may come as big a surprise to you as it was to me.

After years of unnecessary suffering and frustration, I finally humbled myself and found (the hard way in my case) the immense value in coping with my illness and improving my outlook. It was as close as my keyboard when I, in doubt and desperation, finally joined a good support group that focused specifically on my chronic disease, SLE (systemic lupus erythematous). This difficult, but easy, act was a lifesaver for me.

Patricia
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Boynton Beach, FL

Take things a day at a time. I've always been an avid gardener, but there are days I just can't do as much as I'd hoped to. I still garden, and this year I've made three new flower gardens.

I am on disability and have my own home. My two best life-long friends who used to be around when I needed help with something, both died in the last three years. I have another friend who is helpful when he has time.

Jim
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Kansas City, MO

Do your own research. Today, with the availability of easily reached information via the Internet, I found the answer to what was going on with me before my dentist, primary physician & even the first neurologist I went to! After "googling" facial pain, I found many websites that described "exactly" what I was going through. I had never even heard of trigeminal neuralgia!

Karyn
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Tampa, FL

Don't accept a death sentence. There may be help out there that you know nothing about. Be an advocate for yourself, educate yourself about your condition as much as you possibly can, laugh, pray, love and stay optimistic!

Katrina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Find out as much as you can about your condition! Get a medical terminology book & study it! This is so you can understand "medical-ese!"

Chris
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Chicago, IL

Read everything on the AVM Survivors site. Don't take no for an answer from any doctor. There are ways to live with this.

Joanne
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Glendale, AZ

Definitely find a support group, learn from others and yourself. You have to be knowledgeable as the doctors often aren't. Trust yourself !!

Chrisa
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Pittsburgh, PA

My first savior was the Internet. It really does help to read all you can about this illness. Also the book *Striking Back* is the bible for Trigeminal Neuralgia. Whether you want to or not (and I didn't think I needed it) try to find a support group online or in your area because one day you might need them!

Tanya
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Spotsylvania, VA

My tip would be to have a positive outlook on your situation, to trust God that He won't give you anything you can't handle. Relax, do the necessary steps one-by-one. I understand you can feel frustration but that's just a side thing. You have to move to be cured. Please do not stop fighting.

Eddi
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Philippines

SUPPORT GROUP, SUPPORT GROUP, SUPPORT GROUP. Find one as soon as you can and go to the meetings as often as possible. Even if you go to one and feel like you don't need to be there because you think you're not as bad off as some of the group members. There are no two people who experience the exact adversities. I had a brain aneurysm, rupture, and just living put me on the top of a special group, but having a severe stroke at the same time? I am a serial survivor. Yet some of my support group friends are in wheel chairs or can't speak. I am there every meeting to receive information from those with more serious issues. I also go so I can encourage others to a better recovery and life. So go to a support group and learn from people who know the shoes you are in, and who walked your path before and after you.

Philip
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Santa Rosa, CA

I would encourage anyone recently diagnosed to find a support group immediately. I made the mistake of initially searching about Trigeminal Neuralgia and some of the information was very disheartening and upsetting.

Secondly, and this applies particularly to people in the UK, I would encourage you to research different consultants. You are entitled to be referred to any consultant that you wish to see and don't forget that if your first consultation doesn't go as planned then you are entitled to a 2nd opinion. Always write down any questions you wish to ask. Personally I find most of what the Doctor says goes 10 feet over my head so I always take my husband or a friend along with me.

Jo
Trigeminal Neuralgia, Arteriovenous Malformation
Living with TN (www.LivingWithTN.org)
AVM Survivors (www.AVMSurvivors.org)
Patient
Hemel Hempstead, United Kingdom

Finding a support group is the biggest help. Being able to talk to people who really understand your fear and what you are going through is amazing.

Do not give up on finding a cure—if one doctor says it can't be done, find another one who says it can. Take someone with you to specialist appointments—not just for the support but because you always pick up different things from what the doctor says and s/he may have different questions that you sometimes don't think of at the time because you are busy trying to take everything in.

Never give up hope.

Kylie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
New Zealand

My tips, so far, would go as follows:

1. Fight, Fight and Fight. Only a strong spirit will let you go through any of the steps that you need to take to go through any kind of illness. Remember, your symptoms, the pain and even the knowledge can take you down. Prepare yourself for what is coming.

2. Inform yourself: Doctors don't have to be your only source of information. Most of the time, (as It happened to me) good websites like Wikipedia (that was my first source of info), AVMSurvivors. org, and even YouTube, helped me to understand that what I have is a condition, a disease, and also the details about it and possible treatments.

3. Be part of a support group, even online. These help you feel that you are not alone.

4. Look for books, and other sources of information about how to energize your body and heal it by using positive attitude. Even if you don't believe in our own healing powers, the positive feedback is always very useful.

5. With Steps 1-4 done, you will be prepared for your next doctor appointment. Ask and WRITE DOWN as many questions as you can.

6. Look for second, third or more opinions = wisdom.

Rosario
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Fort Lauderdale, FL

My #1 tip is, of course, to seek the most information you can about your disease from people that have it and are going through it now. Try to have an open mind and write everything down. However make sure you share this information with your family, too, so they can help you make sense of it.

My #2 tip is to read up on the disease with an easy-to-read book. For instance, when I was diagnosed with Fibromyalgia, I bought the book "Fibromyalgia for Dummies" and learned more from that book than my Rheumatologist could tell me.

My #3 tip is to find a doctor that will treat the disease and not just say you have it. The doctor needs to believe you have it and be willing to treat every aspect of it.

Millie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Billerica, MA

My tip for anyone just diagnosed with a rare disease is try to find a support group as they are the ones who can give you information about different drugs that may offer relief that your doctor doesn't know about as it is so new to doctors, as well. Also having the support of a group allows you to know that it isn't all in your head and it isn't just made up like some people will make you believe. I go to as many support group sites as I can find and write down information that people pass along if I ask questions and if I don't I see what other people are writing. Even just seeing other people have the same issues as I do is comforting.

Sandra
Erythromelalgia
Living With Erythromelalgia
(www.LivingWithErythromelalgia.org)
Patient
Edmonton, Alberta, Canada

Don't give up.

Kimmy
atypical, eye pain Patient Vancouver, WA

I'm 29 at present but did not find out about my diagnosis of Friedreich's Ataxia until I was 6, and was in a wheelchair by 12.

Here are some tips I would like to share:

Make friends with fellow sufferers, either online or out-and-about (but always make this your end goal). However, do not be afraid to mingle with anyone else.

Keep your eyes peeled (or ears clear for all the visually impaired readers/listeners) for the latest technology, as even seeing improvements in technology not suitable for yourself should be inspirational.

Anthony
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Rock Ferry, Merseyside, United Kingdom

Stay positive, stay close to God, and most of all never give up. Where there is a will, there is a way. Remember no disease has control of you; you have control of it. Find a support group, it was the best thing that happened to me, because who better understands you than someone who has experienced what you are going through firsthand. It can be a perfect place to vent and get encouragement when times get tough, and believe me they do get tough. Always ask questions at your doctor visits and do research and ask your support group—they are a great source for information. Most of all find the best way to take care of yourself to help you keep control of your disease.

Sarah
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Houston, Texas

Research the disease; find out as much as possible through Internet and or medical books. Find a support group and ask questions to others that are effected. Find out what the symptoms are and how it has affected others.

One of the most important things I can recommend is having good family and friends who also are educated to your diagnosis and keep them updated. You are going to need all the support, and who better than the people that love you. Then find the best Doctor out there for the disease, make sure you research in your area and keep in mind that you may have to travel outside your state to find that specialist that deals with your illness. Ask your new friends in the support group who they recommend, you will get a wealth of good information. Lastly, make a list of all the questions you have before you see the doctor, write them down so you don't forget, take a family member with you to your appointment. Never think a question you have is "silly"—ask it anyway. Take notes and be prepared to become your own health care advocate. If you are of the faith in God, find a minister/pastor that can pray with you and for spiritual guidance. I believe the physical needs are better when our spiritual needs are being met.

Brenda
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Osage Beach, Missouri

First, don't psych yourself with all the negatives that are on the Internet. It will cause you much unneeded stress. This includes looking up medication side effects. Gain knowledge but do it through reputable sites only, or even better, have your Doctor print out (for you) what you need.

Laura
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Apache Junction, AZ

There are many things you can do to help yourself. Join a support group, take the proper medicines and vitamins (for your brain), and find the proper doctors. There are medical doctors, naturopaths, physical and cranial therapists, etc. There are also special exercises for your disease.

Joanie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Des Moines, WA

I am 26 years old, getting married in 3 days (AH!) and working at the Hereditary Neuropathy Foundation, which supports those of us with CMT. With a recent grant from the CDC (Centers for Disease Control), Hereditary Neuropathy Foundation, which supports those of us with CMT, has launched a great website, www.help4cmt.com. It's a resource center for people with CMT, caregivers and medical professionals, and is growing every day. It is a great resource for me and others affected by CMT to have everything in one place!

Laura
Charcot-Marie-Tooth
Charcot Marie Tooth Support (www.CharcotMarieToothSupport.org)
Patient
New York, NY

Once you get past the stages of anger, bargaining, disbelief, isolation... well let's say you don't get over them or past them, rather back and forth through them. Then start your research for your best option. When ready, ditch the "why me," however I did have many pity parties myself!

I personally had to back down off of the medicine that was keeping me from doing a successful job interview of any type. I had to back down and endure some pain with some topical help. For researching microvascular decompression (MVD), I had to get my words back in order to ask, ask, ask questions of anyone that had "been there, done that."

Kimberly
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient

Lee's Summit, MO

Find a neurologist that is familiar with an AVM or can refer you to a specialist that does. Find a group in your community or get one started.

Caryn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lufkin, Texas

Try to find others with same condition; it is very lonely trying to live with a condition when no one else understands how you are feeling and what you are going through.

Estelle
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Luton, UK

The love and support of family has been key. Understanding husband.

I have a strong personality and did not want to succumb to drug therapy for rest of my life.

I found an excellent neurologist in Geneva.

Jo
Patient
Switzerland

When my son had a bleed three years ago, my life changed forever! He has always meant the world to me, however this made me realize so much more. My life has been on hold for 3 years, I've spent every day and every pound I've had on trying to improve my son's life. He's been living with a time bomb in his head and I've had to take every day as it comes. But this week we've had the most amazing news, Ethan's AVM appears to be gone. Through this testing time so many people have been there to help and support Ethan and me, while others have taken it as an opportunity to "get one over on me." They've seen a weakness and made a move like animals. But that's okay because I've seen their true colors. I've realized who I do and don't want in my life. I've prayed for my son's health and asked others also to pray. I've had to remain strong for him; if he sees me cry he'll worry. I have cried though, in my room; but I've mostly felt numb. As a mother it's okay to feel numb and emotionally drained but keep faith in the doctors.

Lauren
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
UK

Get a 2nd doctor to look at the person/patient.

Casie's mom
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Taft, CA

Receiving a devastating diagnosis is a frightening time, especially for a rare condition that most have never heard of. I found it helpful to research reliable medical websites for information on what to expect from my condition, and to find information to manage my disorder. Search for a physician, who is familiar with your condition. You should not have to educate your health care practitioners on your disease. If your doctor, PT, etc is not familiar with your condition, insist that they take the time to research it and learn about it before your office visit. Always carry pamphlets about your condition to share with all of your health care people, family, friends and coworkers. I would caution getting too caught up in some chat sites right away, especially if they are negative and worrisome.

Melinda
Charcot-Marie-Tooth
Charcot Marie Tooth Support
(www.CharcotMarieToothSupport.org)
Patient

No surprise here; my #1 tip would be to find a support group and connect with others who have the same rare disease. You can get some really good information on Wikipedia or WebMD, but that only scratches the surface of what you're going to experience, what are the advantages and disadvantages of each treatment, and how to deal with the emotional aspects of living with your rare disease. We've had some members whose lives were saved by information offered by someone they met on a support group. At the very least, you'll feel better knowing that you're not alone.

My #2 tip would be to find the right specialist. You may have to travel a long distance, but it's worth it. Before your initial appointment, learn as much as you can from the members of the support community you join. Ask them for recommendations. Ask them what questions you should ask. Write down all of these questions in a notebook, tape record the consultation, and then write down the answers in the notebook afterwards.

Ben
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
AVMSurvivors.org, Patient
BensFriends.org, Founder
Austin, TX

Find out all the information you can about your rare condition from your doctor, the Internet, books, libraries, wherever you can. It is very important to not feel alone in your situation so find support quickly such as a Bipolar chat room in my case and the LivingWithTN website as I have newly been diagnosed. Psychotherapy is key to learning how to live with your illness/condition.

Anastasia
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org*)*
Patient, Friend/Family/Caregiver
Eunice, LA

Try to get any help you can find. You need to find someone to help you or you will hide in your home away from things. I know since I did this for 15 years.

Marie
Post-Traumatic Stress Disorder
Patient
Waynesboro, PA

Hot/Cold Compress, warm bath.

Try and do some exercise so as to limber up the joints. This is not a full body exercise.

Family members are very helpful. Don't be afraid of telling someone about your medical issues. There are those that look at you who are unbiased and can't figure out why you are parked in a Wheelchair Parking Spot. People think that if they can't see your pain (inside) there is nothing wrong with you. I can't tell you how many times a dirty look is given because people can't see inside of you as well as your age. These things can happen at any time so please be patient with those who don't understand what you are going through. It only causes you to get depressed.

Rita
Fibromyalgia, Psoriatic Arthritis
Living With Fibro (www.LivingwithFibro.org)
Living With Psoriatic Arthritis
(www.LivingWithPsoriaticArthritis.org)
Friend/Family/Caregiver
Canada Ontario

Define what you want from your care and share it with your doctor as well as your family and friends. Do you want to not feel pain? Do you want to not miss work or school? Do you seek a cure? Understand that everyone's idea of "best care" is different and it's not a one size fits all.

Thus communicating your needs for ideal care will help to guide the physician in treating you and your family and friends in supporting you.

Take ownership of your health. Your power as a patient resides in being the center of care and having knowledge of your illness. Be active in your health care; know what medications you're on and your medical history (including family). Ask probing questions of your doctor; take notes or bring a recorder to recall conversations. Don't be afraid to challenge your care, especially if dissatisfied. Give your doctor constructive criticism.

Know that you are not alone. While your experience is unique to you, there are others out there that can empathize and give you support and advice. It's through word-of-mouth that the tricks of the trade are learned: where to get a good wig, how to deal with a symptom that no one warned you about.

Danielle
Multiple Myeloma
Life With Multiple Myeloma
(www.LifeWithMultipleMyeloma.org)
Tomball, TX

Section 1B - General Coping Tips for Rare Disease Patients

What got me through the 3 years of suffering with the pain and the effects of the medication was simply "hope." I knew I would get through this & I would find a way to stop it come hell or high water!

Karyn
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Tampa, FL

You need to know that you did not do anything wrong and you're not being punished. We all deal with something in life and yours just happens to be this! Remember—you may have the disease, but the disease doesn't have to have you!

Katrina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Never give up! Keep asking until you find answers—Knowledge is power!

Don't forget to rest and have "you" time. Set priorities and limits. Ask your family to take on extra tasks. I believe in prayer and asking for others to pray for you and with you. It's always great if you have a best friend, a great spouse, or children that you can talk to. Sometimes you may need a professional psychologist to help you sort through your emotions if it becomes too much for close family or friends. I have found that at times your close friends will not come around as often. I think they are dealing with fears of their own and just don't know how to respond or help. That is normal especially if you are in pain and they feel bad and don't know what to do. Just remember to let others know how you are feeling and learn how to say no when you can't do what is on your schedule for the day.

Brenda
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Osage Beach, Missouri

As cliché as it sounds, stay happy. Count your blessings. Be thankful for all the good in your life. Yes—we have our bad days but we have good days, too. Also, do whatever it takes to live the life you want. We only get one life. If that means taking a loan out to get the helios braces so that you can walk, DO IT. If that means taking a different job so you have more time to work out, DO IT. If that means pushing your body a little harder to increase muscle strength, DO IT. Live YOUR life to its fullest, whatever that may be for you.

Laura
Charcot-Marie-Tooth
Charcot Marie Tooth Support
(www.CharcotMarieToothSupport.org)
Patient
New York, NY

Tip #1: I was diagnosed with an AVM and had a gamma knife surgery. I had a grand mal (seizure) the next day, and have been taking anti-seizure medication since. The doctors said I'd most likely be on it for the rest of my life, but I am determined to not have to depend on it. My new doctor feels the same way, and we have started the process of getting off the medication. Stay positive and believe in miracles.

Tip #2: Be grateful for what you have and think of how you

can make life better for others. I think of Senator Max Cleland who lost 2 legs and 1 arm and still lives an active and fulfilled life.

Tip #3: I am a believer in Christ, and my faith and relationship with Him have been critical to dealing positively with this. I have had my down times, and fear-filled times, but closing my eyes and seeing Christ with me helps immensely.

Kene
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Atlanta, GA

Don't go to any "pity parties"—it can be hard enough to cope without feeling sorry for yourself and think that the world is against you. I try to think of a good thought during lightning attacks, or I used to count how long they lasted. When I start to feel down on the bad days I always think of the people that are worse off than me. One thought is how well my mother's attitude is dealing with her cancer (on her fourth round of chemo), or all the children that spend most or all their lives with terminal diseases that will never have a full life, but still can smile.

Scott
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Creston, Washington

Find a good doctor—one who is willing to be your partner in this!

Melissa
Lupus
Life With Lupus (www.LifeWithLupus.org)

Well, for the most part, I've taught myself that I have control over all matters and that I am a fighter refusing to give in without a fight. I have also learned to pay attention to my body more and to change the situation for the moment that is present... and to deal with less stress.

Lupus
Life With Lupus (www.LifeWithLupus.org)

My friends in the AVM Survivor Network have been the best help for me to deal and cope with my AVM because they totally understand.

Louisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Rhode Island

Find your inner spirit and have faith and belief that you will conquer Lupus.

Beverly
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Stone Mountain, GA

Stay positive and don't be scared to get help from professionals. Also don't be scared to have a bad day; not every day has to be great!

Melissa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Find someone that you can talk to. Even if they don't understand what you are going through, it helps if someone will just listen.

Mandy-Sue
Patient Georgia

GET SUPPORT, but also try not to complain too much to friends. I found that ice works when it is really bad. How particular is that when cold actually sets it off!? Well, the ice seems to numb the nerves.

Coping is knowing that you are going to be ok, but you may be going through a very hard time. This, too, will pass. You will grow stronger and learn to cope. Use your friends who can relate on livingwithtn.org

Julianne
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Durham, NC

Be proactive.

Rob Slack
Patient
Alexandria, MN

The number one thing I would almost force on everyone is don't let it take over your life! Yes, you may have a rare disease, but you can't let it take over and ruin your life. Sure, you may have to alter some things that you do and you may not be able to do certain things anymore, but don't let it control you.

Kat
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Auckland, New Zealand

Knowledge is power; you must be an advocate for yourself and family.

Jamie
Adrenoleukodystrophy
Adrenoleukodystrophy Support
(www.AdrenoleukodystrophySupport.org)
Patient, parent
Lancaster, California

Friends that are caring can help in many ways.

Jerrod
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lubbock, TX, USA

My personal preference has been to research in great detail what a synovial sarcoma is and what it means to have it. I am now fully aware where I stand and what could be the worst case—anything less than that is therefore a bonus.

Julie
Synovial Sarcoma
Synovial Sarcoma Survivors (www.SynovialSarcomaSurvivors.org)
Patient
Brandon, Suffolk, UK

Talk about the situation with whomever you can.

Sarah
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Israel

I would suggest a support group—it's always good to talk to people who are dealing with the same condition because I found that talking about my experience is great therapy for me even till this day.

KELLIE
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
SKOKIE, IL

Ask questions a lot. Be open to your family on what's going on. Be in a support group... it always helps to talk it out, even when you think it's a miniscule problem, to people who are in the same situation and may not think of it that way.

Alexander
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Parents of AVM survivor/Friend/Family/Caregiver
Toronto, Canada

My advice would be to follow the doctors' and therapists' advice and do what they say with all you've got. It's worth all the trouble.

Karen
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Clifton Park, NY

Support, support, support. Groups really help. I am a follower of Jesus, but I still need my friends who know what I'm going through. Some days you can do a lot and some days you can do absolutely NOTHING... I have attitude with this, but I'm learning that it is what it is. I just try to be patient until the next day. Sometimes it can take weeks to feel better.

Rachel
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Warren, MI

The only tips I can suggest for coping with this disease is to try to keep you head up. Depression may set in but don't let it take over. Go talk to someone.

Triggers may set off your attacks also. Mine are sleeping on my left side, chewing on my left side, chewing crunchy or hard-to-chew foods, and wearing my C-Pap mask at night. I have stopped doing these things and it helps.

Be very careful with your pain meds if you have been given some. Take them ONLY when needed. If they stop working for you, don't ask for more. Addiction could set in and that will cause even more problems for you. For me I found that they stopped working after the first bottle was finished. My doctor finally gave me Cymbalta and it worked for pain management and it even perked up my depression.

Allison
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Albany, NY

Always have plan B! Allow yourself to feel bad at times and rest accordingly.

Fran
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Erath, lA

Develop a new interest or activity!

Nicole
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Pittsburgh, Pennsylvania

Don't outdo yourself. If you try to do more than you're able, it will only make things worse. Don't be too hard on yourself if you can't do something or you need to sit down and take a break.

Jenny
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient

Keep searching for advice; different things work for different people.

Kim
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Tempe, AZ

Take someone with you to your doctor appointments. They can help you remember what to ask and what was said. Also take a notebook so you can write down questions and to help document what was said. It is hard to do but try to be calm and ask for help!

Sally
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Van Horne, IA USA

Coping is challenging. Bad days are followed by bad days. Depression is assumed for anyone that has cancer. At some point even the best cheerful facade becomes obviously fake. So don't be brave and say you don't need antidepressants.

Find a good doctor and hospital. If you ever feel rushed by a cancer doctor, then find another one. Rush Hospital in Chicago is great.

Chris
Synovial Sarcoma
Synovial Sarcoma Survivors
(www.SynovialSarcomaSurvivors.org)
Patient
Chicago, IL

Try not to be defined by your condition; put a good face on it!

Dianne
Von Willebrand's Disease
Living With VWD (www.LivingWithVWD.org)
Patient
Washington, DC, USA

Have a sense of HUMOR please. If you don't, it will make it a lot worse... physically and mentally on yourself and all others around you. If you are more relaxed with it then so will your loved ones... it makes life so much easier. I know it doesn't always come out that way... I also get frustrated and have a meltdown with all the tears but you won't scare the ones you love away from you for acting sad, mean, depressed, angry, spiteful, and self-absorbed.

Debbie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Algonac, Michigan

I have been suffering from severe fibro for over a year. My life is difficult. I rest most of the time but when I have energy I do gentle yoga and a water therapy, both are very useful. I'm taking enough meds to keep me moving and trying to have positive thoughts. It's very hard to live this life when we have so much to do and so many limitations.

Carol
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
San Diego, CA

Never give in to it totally. You will have days when you feel like there is no tomorrow, but to sit and let the illness take over will leave you feeling stiffer and in more pain. It may hurt to continue with daily life, but subtle changes can help a great deal. I find that my best asset to continue to work is having a really good chair that my company supplied. I have heard that swimming is really good but I have yet to check that one out... sometime I shall give it a try.

Jeanette
Psoriatic Arthritis
Living With Psoriatic Arthritis
(www.LivingWithPsoriaticArthritis.org)
Patient
Bedford United Kingdom

Confide in someone and talk to them about what you have, how it feels to live with it. Then when you're feeling down, talk to them about it. Even just getting a cuddle can help sometimes when you're feeling awful about your condition.

Mica
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Liverpool, UK

Keep pushing to get tests, more specialists and doctors who will listen to you. Keep a sense of humor and have an advocate.

Give yourself permission to make mistakes along the way of learning how to deal with your diagnosis. Also give yourself permission to grieve about it. Don't stay in the grief forever, but do know that it's part of the process.

Julie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
American Ataxia Networking
(www.AmericanAtaxiaNetworking.ning.com)
Patient
Colorado Springs, CO, USA

The support groups are available to provide information and also to allow you to vent when necessary. Remember, these are all people who share your issues and know what you are facing.

Beth
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Grand Rapids, MI

Do as much research as you can regarding your disease. Knowledge is the key in your situation. If you feel overwhelmed, have a friend or loved one do it for you. My husband was a godsend in his research of my disease since he kept me grounded on treatment options and then was able to talk to the surgeons and specialists when I was too sick to do so.

Paula
Synovial Sarcoma
Synovial Sarcoma Survivors
(www.SynovialSarcomaSurvivors.org)
Patient
Cohasset, MA

Coping with a rare disease is bad enough. Coping with a rare disease that comes with chronic pain is another thing all together. The best advice I can give is to take it one day at a time. Take in hour by hour if you have to. If you start thinking ahead you will send yourself into a downward spiral. If you are in pain today, accept that and do what you can to help yourself. Do not worry about tomorrow, or next week, or that wedding you have in a few days. You will make yourself crazy.

Gwen
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
St Louis, MO

Taking Humira for the Plaque/Psoriatic Arthritis as well as supposedly helping with Fibromyalgia. Pain can sometimes be excruciating—to the point of not being able to do even the simplest of tasks of going shopping, even if it's just a short walk through the grocery store.

Housework can only be done on a good day, which is very depressing. I have always been a neat freak and now have to leave it for the next day or day after. All depends on the pain I am experiencing.

Rita
Fibromyalgia, Psoriatic Arthritis
Living With Fibro (www.LivingwithFibro.org)
Living With Psoriatic Arthritis
(www.LivingWithPsoriaticArthritis.org)
Friend/Family/Caregiver
Canada Ontario

If the patient has a gamma knife treatment, s/he:

1. Should go for MRI scan every year even if he feels fine.
2. Should try to lead a routine life.
3. Should not bend head to lower level.
4. Should not lift weight that can put strain in the brain.
5. Should not overlook slight inconvenience—like in my wife's case, she was having slight loss of vision.

Rajasri
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
India

Diet is very important and so hard when you feel bad. But eliminating the junk foods and anything with chemicals will help.

Look up alternative therapies.
Tessa
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Raleigh, NC

Surround yourself with positive energy. Look for others who have—or have survived—what you are going through as they can offer you a better perspective on coping than those who have never had to deal with the same.

Carolina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Homestead, FL

Keep yourself in control of depression or feeling low. Negativity is something I believe people bring onto themselves. Keep a positive attitude and keep yourself busy and think positive at all times. Your life is what you set your mind to make of it. Yes, you will not do some things like you used to but hey(!) it's not the end of your life. Keep yourself motivated and be happy you have life still.

Vickie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Durand, IL

Since you can't call your doctor with every concern or stress about your illness, after joining a good, responsive support group, listen to your body and emotions and ask for help when you need it.

If you're suffering from a symptom that you feel is new, more intense or lasts longer than usual, go with your gut and ask your doctor if it needs attention. Also ask other patients about how they deal with the problem. Sometimes just talking about your suffering is enough to ease it a bit, but you may be as surprised as I was at just how helpful others' experiences can be.

Most important, be easier, kinder and more tolerant of yourself and your limitations and with those of the people around you. The hardest person to live with when you suffer from a chronic illness is usually yourself, and it's no cupcake walk for your loved ones when you're miserable.

I am currently without health insurance (National single-payer health-care now, please!), but have set up significant cash discounts with my doctors and lab where my blood work is processed. Found out that most doctors welcome cash payment rather than screwing with lousy insurance reimbursement, so it wasn't difficult at all to set up. I also ask my doctors to prescribe only generics, if possible, and found that Walmart sells trazadone, tramadol and about 400 other generic meds for $4 per 30-day prescription, which is another lifesaver.

Patricia
Patient

Coping with an AVM is an "every day what's going to happen" feeling for me. I can go months with nothing new and then all of a sudden something different happens and I get freaked out. Just realize that you shouldn't be afraid to call your doctor with any questions you have. No matter how silly you think the questions are, that is what the doctors are there for. Don't keep things bottled inside—speak with someone to keep your stress level low and this way you can live a little easier.

Andrea
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Tonawanda, NY

After doing a lot of Internet research and finding stem cell therapies in other countries, my husband and I decided our best hope for buying more time with our normal, healthy son was to go for stem cell therapy in China. Doug and I were not able to talk to anyone at first; we just had each other. We didn't want to tell Nate until his junior year of high school was over and his final exams were complete. We started out telling our 2 older daughters, then family and a few close friends. Of course no one at all was familiar with this condition.

We made the arrangements for China to leave the end of May for 5 weeks. A few days after Nate's classes ended we told him of the diagnosis and of our plans for the treatments in China. The week before we left, the news media found out of our trip and did a story for the community. This turned out to be one of the best blessings because Nate received an outpouring of support that followed us to China via our blog. Nate and I came to depend on the comments and support that were posted on our blog every morning.

We have moved to Denver, Colorado from Nebraska in order to go to the Neurologist who specializes in Ataxia as well as an Ataxia support group and many other resources for Nate.

Nan
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Friend/Family/Caregiver
Nebraska/Colorado

Join a support group. Make friends with your doctor. Ask questions! Write things down. Join the national disease group & get all the literature & handouts about your disease. Hand them out to your family to back you up!

Chris
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Chicago, IL

One thing we can all do is get in touch with Dr. Robert Smith at Children's Hospital in Boston. He is coming out with a simple urine test that will detect AVM's. Can you believe how simple that will be!? We need to stay on him and do anything we can to make sure his test becomes available. Help make the test mandatory upon birth and general physicals for everyone in the world. Early detection will prevent what I, and so many others, have lost—our children.

Joanne
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Glendale, AZ

Educate your friends and family as those are the people who are around you the most. Find a doctor who's willing to listen to you and work with you.

Chrisa
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Pittsburgh, PA

I've learned that I can still do what I enjoy in gardening by always having a lawn chair with me. I can work until I get too tired or hurt too much, and then sit down for a while.

My Rheumatologist gets on me when I tell him I did things like climb a ladder to clean gutters, but I've learned on my own that there are things I really cannot do anymore. The pain from doing some things in my legs, knees, and hands can be almost too much to handle at times. But sit down and take whatever pain meds you've been given and remember there's always tomorrow.

Jim
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Kansas City, MO

When diagnosed with a rare disease you feel lonely and since nobody has heard of it, sharing the disease with others is about educating them—it's almost your job and takes a lot of time. Starting a blog is a great way to not have to educate each one of your friends and family. It takes time to learn about the disease and its impact on your life. Again, baby steps, living in the present is crucial, trying not to refer to your wonderful past life is best and do not assume a dark future either (miracles do happen, it happened for me).

Emmanuelle
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Bellingham, WA

Here is where I would have to say YOU the patient have to be an advocate for yourself!! If something doesn't feel right then say so. An example—I was having an allergic reaction to a medicine I had been taking for at least months. I had a blood-red body, felt like I was on fire, and I couldn't swallow. The ER doctor said he really didn't see an allergic reaction but said he would take the "precaution" and give me steroids. Wouldn't you know, in 2 days I was feeling a lot better. So please find your voice and if you can't, please take someone to your appointments who can speak for you!

Tanya
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Spotsylvania, VA

My daughter is newly diagnosed with a rare condition called Chronic Mononucleosis. Most people only have this once and the virus lays dormant in your body for life but you have immunity; her body is not like this. She can get mono at any time, over and over again; I know all about mono since I had it in high school but I am not familiar with the Chronic condition so my advice to everyone with a rare disease is to absolutely locate correct information from a reliable resource and educate all around you so they know how to support you.

And learn quickly that you are not alone in your "rareness." My attitude is that I am special and that I will be special forever. I have a high place waiting for me in the Heavens!

Anastasia
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient, Friend/Family/Caregiver
Eunice, LA

Carry a small notepad and pen—it is very useful to write things down that you may (and probably will) forget. Good luck with the memory.

Jason

Find out everything you can about your condition. Use the Internet, read books, and join a support group such as this one (LivingwithTN.org) to learn. Sometimes, the answers you seek may be found in others' anecdotes.

Try the suggestions of others. I have been surprised by how well things that I otherwise would never have considered have worked. Whatever you do, do not shy away from your endeavor to feel better. It's worth it.

Melissa
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Bradenton, Florida

Surviving a stroke is only the first step in recovering from stroke. Brought on suddenly, it takes months, years, and for some, a lifetime, to recover.

Patients, and all that care for them, need to be patients. Starting off with paralyzed legs and arms, or unable to speak? Your recovery is up to you. Therapists, loved ones? They will teach and support you. But ten little words will make you well again. "If it is to be? It is up to me." Only you can do the hard work it takes to recover. Many stroke survivors regain some of their deficits in a short time, maybe weeks or a few months. But they plateau in therapy, and become discouraged, wanting to quit. I have gone on trail hikes with other survivors after six or eight months, and not one of them was

a quitter. You can still recover after a plateau if you continue to work hard and do the best you can. If you don't put in the time recovering, you will do the time, living with those adversities. Learn everything you can about your affliction; read every book. You need to know this invader in your life so you can fight it.

Philip
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Santa Rosa, CA

I try not to plan too far ahead. In the past I made plans to meet friends, or take my daughter I try not to plan too far ahead. In the past I made plans to meet friends, or take my daughter somewhere and then on that day I would be too unwell. Now I take each day as it comes and do things spontaneously. I also try and get a nap during the day and if the housework isn't done so be it. Learning to pace yourself is very important as it is all too easy to wear yourself out.

Jo
Trigeminal Neuralgia, Arteriovenous Malformation
Living with TN (www.LivingWithTN.org)
AVM Survivors (www.AVMSurvivors.org)
Patient
Hemel Hempstead, United Kingdom

Never give up hope and take every day as it comes. Feel grateful for the life you have and hopeful for your future.

Allow yourself to have bad days. Tears can make you feel better but always dust yourself off and list all the things in your life that you are grateful for; it helps to restore your balance.

Positive thinking is a very powerful thing, always remember that!!

Kylie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
New Zealand

My main tip considering that I've been dealing with an AVM in my spine without knowing for 39 years of my life would be:

When you have a rare disease (like mine) things won't get worse quickly. It is a process. So, always look for the difference in symptoms (if any) for every year of your life. In that way, you will understand the way (how) your body works. Understanding your body is very useful, even with new symptoms, that will let you go on with your life, slowly, but it will help you a lot. Remember, waiting for answers and treatments may take time. You need to accept your new body as much as possible.

Rosario
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Fort Lauderdale, FL

Find a support group online and one you can get out of the house to go to... I feel talking face-to-face with people with the same disease is very important because they can SEE the emotion you are having as you talk about your disease and if you need a hug they are willing to give it to you...

We are always willing to give hugs on the Internet, but to me there is nothing better than feeling the warmth of someone's arms around me when I am feeling down & out because of a "Fibro Day."

Millie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Billerica, MA

Research and think outside the box.

Kimmy
atypical, eye pain
Patient
Vancouver, WA

It can be hard dealing with any disease. Really, I look at saying: "do I want this disease to be my life or do I want my life to be what I can do?" I say: "I want to take control of my life and do as much as I can." There are days when you do have to throw your hands up and allow the disease to take a day but I usually try to only allow a day and then put myself back on track—that way the disease is not controlling me (at least that is what I tell myself).

Sandra
Erythromelalgia
Living With Erythromelalgia (www.LivingWithErythromelalgia.org)
Patient
Edmonton, Alberta, Canada

Become as informed as possible; be your own advocate!

A'Lisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Bossier City, LA

Don't be afraid or feel awkward about discussing things with people, nor should you be scared to ask for help; I remember a few occasions in my teenage years when irrational attitudes stopped me asking for help and dampened some of my experiences, so please do not fall into this trap, too.

Do not feel envious of anyone else, as there is always someone worse off than yourself if you have coherent thought.

Find a purpose in your life and stick to it, but never give up on friendship, both old and new.

Try to be altruistic and utilitarian in your thoughts and you can never go wrong if thought about correctly.

Anthony
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Rock Ferry, Merseyside, United Kingdom

The first thing you have to do is accept that you have the disease and it is not gonna go away. Second, Support Groups are the best way that I have found for dealing with any disease. You are free to talk about your innermost thoughts without ridicule or judgment; just a lot of understanding and spiritual advice.

Sarah
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Houston, Texas

You need to accept your situation before you can deal with it. Your life is different now. You have been diagnosed. What you are feeling *is*real. You're not making it up and the point you have been trying to prove to others is now validated so "you" must accept it.

Laura
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Apache Junction, AZ

A support group with other people with the same condition really can help.

Joanie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Des Moines, WA

Don't be hard on yourself. I already had unemployment depression on top of having Trigeminal Neuralgia type I. Luckily I have very emotionally supportive and understanding family and friends.

For those who can't find a local support group, reaching out on the Web is the only way to go. My pets (sorry, family) were the most help for me to play and cry with.

I spent years online receiving and giving help to other moms who have Bipolar/Autistic kiddos. It was my lifeline at 3 am... post a question, wake up to 4-5 suggestions and virtual hugs! Online Support lets you pour out your deepest fears. bpkids.org and CABF.org kept my son and I afloat—literally.

Feel lucky when you can... I am very lucky that I got diagnosed and put on meds within 4 weeks of my onset in October 2010. I can't imagine all of those who did not get a correct diagnosis for years after onset. My tunnel of hell just lasted a year so far from diagnosis to treatment.

Kimberly
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Lee's Summit, MO

Find people or group organizations that are AVM survivors or family of an AVM patient.

Caryn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lufkin, Texas

Live every "good" day to the full.

Estelle
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Luton, UK

Do your research. Ask for second/third opinions then weigh [them]. Fight! You can do it. It's all in the mind... However rare it is, there Must be a cure for it.

Eddi
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Philippines

#1: Become an expert at your challenge and focus on healthy changes you can make that you can also enjoy. Consider your doctors your advisors, and consider your doctor's appointment your time to ask any questions you want. I always bring a pad of paper and questions and write down anything important. You'll forget a lot when you leave the office.

#2: Read stories from people who've overcome huge challenges. Very inspiring and instructive.

#3: Focus on what you can control and do; not what you can't.

#4: Exercise and relation techniques are huge for me. Daily walks with my dog keep me sane, and when I couldn't walk, any little exercise was a step forward.

#5: Be grateful every day for everything good about it; let the rest go.

Sharyn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Manchester, CT

1. Don't panic

2. Don't worry about what could happen, worry about the present

3. Try and keep your mind off it

4. Keep yourself as healthy as possible

5. Live your life how you want to

Alicia
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
North Bay, ON, Canada

Being told you have ataxia is very like a bereavement. You need to allow yourself and those who love you time to go through all the different stages of grief. But then you need to try to accept that this is your life. OK it is not perfect and it is certainly not what you wanted but this is it, so it is up to you to make it work. Nobody else will.

This is much easier said than done and it has taken me time to get here and I regularly have hiccups along the way. At times you will need help. It is hard to accept at first, but do not be afraid to ask, and say thank you. You cannot win but you can fight every step of the way

Various things have helped me over the years. People are inspirational. My dad's determination against all the odds. Seeing others on LWA (LivingWithAtaxia.org) cope with far worse than me. Also stay as active as possible. It is very true—"use it or lose it."

Having hereditary ataxias in your family brings a multitude of different challenges. It can be like a black cloud hanging over you, but you need to try to come to terms with it. Talking can definitely help.

My main way of coping is my art. I LOVE ceramics. When I discovered that I had ataxia coming, and I had more time as my family was growing up, I thought "do I have any regrets?" I wished that I had been more creative. I am very lucky and was able to go back to College and do an Art Foundation and then a degree in Art and Design. Like all things, some of the course was very inspiring and some incredibly frustrating. I did discover my love for clay. I have built up a SMALL busi-

ness making and selling my ceramics. My aim is to cover my costs and I try to make more people aware of ataxia. I make a small donation from every sale to Ataxia UK.

My top tip is to use extended walking poles for walking instead of traditional walking sticks. If you hold onto the shaft and not the top, they are always at the correct height depending on the terrain. They are also very good for maintaining good posture. LWA always has excellent advice too.

Lit
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient

I read a lot and did a lot of research. I decided to remove my mercury fillings. Gradually reduced my drug dependency.

Jo
Patient
Switzerland

Make the most of every day, seek support where you can, remember it's ok to want to spend time alone and look after yourself. Be around the good people, always make doctors' appointments, and try to keep life as normal as possible.

Lauren
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
UK

Get lots of rest and take care of yourself first. My mom cannot stand or sit for a long period of time, which makes it difficult for her on an hourly basis, every day. Remember that you're not alone, other patients are out there as well. Your diseases are real; they're not in your head. For heaven's sake there are commercials now for these two diseases! It took years, but doesn't that prove that it's real? Migraines are real, and so is Fibromyalgia.

Julie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Friend/Family/Caregiver
Huntington Beach, CA

You just have to push forward and get any help that is available.

Marie
Post-Traumatic Stress Disorder
Patient
Waynesboro, PA

I wish I had an answer.

Casie's mom
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Taft, CA

My one major tip for people is—if your hometown offers transportation services for disabled—[then you should] apply. Make sure you have a doctor (preferably neurologist) vouch [for you].

Eric
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
New York State

It helps if you can attend a support group meeting or join an online community where you can meet others with your condition, who understand what you're going through.

Find out as much info as you can from reliable sources. Don't worry that every symptom you experience is from your rare disorder; it may be something completely unrelated and treatable.

Melinda
Charcot-Marie-Tooth
Charcot Marie Tooth Support
(www.CharcotMarieToothSupport.org)
Patient

I know finding out you have a rare disease can be scary but you are not alone. In my experience with Ben's Friends, half of the members are parents looking for support and advice, etc. from other parents and the other half are adults looking for support, advice and helpful information. When these new members realize there are others like them, they get a sense of comfort—they are not alone and there are others who have been, and/or are, going through everything they are.

I adore and think the world of my heart surgeon, who closed my Atrial Septal Defect, and the care I received at the Cleveland Clinic. But only other ASD/heart patients and patients in general with a rare disease know what it is like to be a patient with that particular condition. Don't be afraid to ask anything of the members within your community site. They all have amazing experiences and stories to tell and share.

The role of your surgeon and/or doctor is to make you feel as comfortable as possible. These are big decisions and cannot be taken lightly. Don't be afraid to ask anything of your doctor. No question is dumb!!! During my five months of research on how to close my heart defect, I pushed all of the doctors and surgeons to the limits. Frankly I knew right away when I interacted with Dr. Mihaljevic at the Cleveland Clinic over email less than two months into my search that he was my guy but I still turned over every rock possible to make sure I was 100% comfortable with my decision. In the end, going with Dr. Mihaljevic and the Cleveland Clinic was the easiest decision I have ever had to make.

In the case of heart surgery, the statistics for all closure are amazing and for open heart surgery the mortality rate is less than .01%. The statistics are extremely favorable—this is a proven technology, which has been around since 1952, and many of these surgeons are doing two per day (like brushing your teeth).

I had no fear going into open heart surgery because I did my extensive research, knew everything, double checked my will, wrote personal letters to my family and friends in case anything happened to me and I had funeral plan sorted as well. I know this sounds grim but it is something you have to do.

John
Atrial Septal Defect,
Von Willebrand's Disease
Atrial Septal Defect Support
(www.AtrialSeptalDefectSupport.org)
Living With VWD (www.LivingWithVWD.org)
Patient
BensFriends.org, Partner
London, England, UK

Section 1C – Tips for Friends, Family, and Caregivers

Please be there for your loved one but don't add extra pressure by trying to "fix" them. There is nothing you can do but be there with your love and support.

Laura
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Apache Junction, AZ

Tip #1: Understand the condition, be patient with the emotional state of the patient, and understand the side effects. However, do not let them abuse you verbally, as well. Having a health situation is no excuse for mistreating those around you that want to help. Firmly and politely set them straight if and when they get out of line. It also helps bring them back to reality.

Tip #2: Help them but do not enable them. Don't let them become helpless when you know they can help themselves. Don't get into feeling sorry for them; they need you to be strong and maintain as much normalcy in their lives.

Tip #3: It is important that you talk with them and know exactly how they feel when reacting to a medication or if they have events like seizures. Make sure they form the habit of taking their medication. They need to be responsible about this, as well.

Kene
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Atlanta, GA

Join a support group to really understand, empathize and help yourself and your loved one or patient cope with what is often a vastly different or diminished lifestyle. My experience has been that having a good support group in which you can vent, ask questions, get help and read about the daily frustrations and fears of living with a particular illness, whether as patient or caregiver, is the best and only medicine to consistently feel and cope better with chronic illness. But like any medicine, you can't appreciate its value until you actually use it.

We all get more forgetful as we age, but a symptom for people of all ages who suffer from a number of rare or chronic diseases is foggy thinking, which usually impairs memory. So encourage your loved one or patient to write down his questions or concerns as they arise and remind him to take the list along to his next doctor's appointment. With his permission, ask the patient if you can accompany him when he actually meets with the doctor in case you think of or remember something the patient hasn't brought up.

Patricia
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Boynton Beach, FL

My beautiful nine-year-old daughter died unexpectedly due to an AVM. Didn't really complain of headaches; she had about five or six over the last year that didn't last long. She also had what I thought were night terrors from time to time—I now know those were seizures. I had no idea at the time.

Please, please—if your child has any type of sleepwalking or night terrors please have them checked out. Insist on an MRI. A lot of AVM's are not found on a traditional CAT scan. I don't want anyone else to go through this time of pain.

Joanne
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Glendale, AZ

If you have someone that's going through any kind of rare disease, become more understanding and give more support to that person. It's harder if that person can't rely on their home, family, and friends they know. That support makes the situation less stressful for the patient.

Lupus
Life With Lupus (www.LifeWithLupus.org)

Remain supportive of the patient and show love at all times. Take needed breaks to ease the tension.

Beverly
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Stone Mountain, GA

Be there for the person, learn their needs and wants and do it for them. Listen very carefully, even if you have heard the same thing 500 times. What is 501 times? Be sensitive to the person's situation (e.g., if they are not comfortable traveling then don't ask them 20 times a year why are you not going here or there?). Just be there for them...

Melissa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Just continue to be patient while the "patient" searches for answers. Also, be willing to reach out for support, whether it's with a psychologist or a friend and be sure to take good care of yourself, too.

Julianne
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Durham, NC

Understand and listen.

Rob
Patient
Alexandria, MN

You just need to be there for them. Whether it is for a shoulder to cry on or for them to yell and complain and vent at, or even just to hold their hand before they go into a surgery. Don't always say, "I know what you are going through" because I think personally that is my most hated comment from people, so just listen. I think that what we all really need, at the end of the day, is just someone who will listen and show that they really do care, even if we are too stubborn to ask for help.

Kat
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Auckland, New Zealand

Just because you can't see lupus [or another rare disease] does not mean it is not there.

Melissa
Lupus
Life With Lupus (www.LifeWithLupus.org)

Support—mental, emotional, and in all other ways.

Jamie
Patient, parent
Adrenoleukodystrophy
Adrenoleukodystrophy Support (www.AdrenoleukodystrophySupport.org)
Lancaster, California

Caring, loving, and understanding are key.

Jerrod
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lubbock, TX, USA

Talking about it without fear is huge. Make light of it if you can. Remember laughter is always the best medicine regardless of what is wrong.

Julie
Synovial Sarcoma
Synovial Sarcoma Survivors
(www.SynovialSarcomaSurvivors.org)
Patient
Brandon, Suffolk, UK

For family members of people who are dealing with this condition, please be very sensitive because once this occurs it is a life-changing situation and sometimes very devastating to the person who has it; I know it was very devastating for me.

Kellie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
SKOKIE, IL

As a parent, you always pray that your child will be healthy all throughout their life. But that is wishful thinking. You will literally feel that the world has crumbled down in front of you and the feeling of not having that control in your life. My advice? Let go of the control, pray more, this will open your mind to make the right decision for your child. We, as a family, had to be educated on what needed to be done. We all had to work as a team—or may I say as a unit—in order for this to work. We discuss a lot of things, we don't hold any secrets of what will happen, and we discuss how we feel. It's the only way to go. I am just thankful that the people at Sick Kids Hospital in Toronto have a lot of support including counseling for people involved in my son's life.

Alexander
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Parents of AVM survivor Friend/Family/Caregiver
Toronto, Canada

For the caregiver I stress patience. Your loved one is usually not aware of how different they may be and all they want is to be "normal" once again. Love them, tell them you love them, and help them.

Karen
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Clifton Park, NY

BRING them to support groups—my husband learns from these groups and my teenage son is going to the next one for the first time. They will not understand until it is explained to them with others. Plus you always get free food (LOL); I bring my own food, but the relatives can eat :)

Rachel
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Warren, MI

Help your loved one remember to do the recommended tips here (such as see a neurologist for advice, get on lumosity.com for fun brain games backed by impressive research, engage in physical activity daily, eat a very nutritious diet, read *The Brain That Changes Itself*, by Norman Doidge), and support him or her when struggles appear. Also help to engage in your community and find purpose.

Kelly
Traumatic Brain Injury
Traumatic Brain Injury Support (www.TraumaticBrainInjurySupport.org)
Patient
Ashland, OR

For non-patients, PLEASE be supportive. The patients are not faking; they are in pain and until you realize how bad the pain is with TN you may have a hard time understanding. Imagine a hot poker plugged into a wall socked and stuck into your face. That's the only way I can describe it where you could understand. Graphic, but true. This disease can upset loved ones in many ways. It can cause problems with jobs—as in my case, I lost mine. It can even break up relationships. Please don't let this happen.

Allison
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Albany, NY

Do your homework! Research the condition your loved one has and try to understand!!! You don't have the condition, they do; and their lives can be drastically affected by it, so what might be a good day for you, or even just a normal day, might not be for them. Be patient, listen and sympathise! And appreciate the fact that you don't suffer with it! Because if I could swap places with my husband, who doesn't have it, I would!

Mica
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Liverpool, UK

Keep a good balance of humor and support, but mostly we need you to BELIEVE us. We have dealt SO LONG with everyone in the medical field not believing that we have something rare going on that we need all your belief and support we can get. As with the medical community, we even start self-doubting ourselves whether our disease or condition is just in our head. We sometimes feel that we are "unlovable" because we cannot do the same job or responsibilities as we used to… help us feel that nothing has changed in that respect. And most of all, let us have our pity party, meltdown, breakdown from time-to-time and don't let it scare you away... please stay close to us... we need your understanding that it is OK to cry.

Debbie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Algonac, Michigan

Support! Ask often how they are feeling.

Fran
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Erath, lA

My hands-down favorite phrase—"Is there anything you need? What can I do to help?"!!! I think we already feel like such a burden, we are often afraid to ask for some things that appear silly/inconsequential at face value—in my case, I suffered my whole life with reflux/heartburn and even having someone bring me an extra roll of Tums is a huge Gift! Tums cost what—like 40 cents, maybe, at the checkout, but help my acid pain beyond belief. Probably way more information than you needed to answer this question, but I was making a point!

Nicole
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Pittsburgh, Pennsylvania

Listen and be supportive; my pain doesn't show, but it hurts badly!

Kim
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Tempe, AZ

Patience is important, and listen carefully because when your loved one is on certain meds they don't always mean what they say. Keep giving the TLC!!

Sally
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Van Horne, IA USA

Stop asking, "How you are feeling"? It just reminds us of what we have. Tell us we look good or something positive.

Chris
Synovial Sarcoma
Synovial Sarcoma Survivors
(www.SynovialSarcomaSurvivors.org)
Patient
Chicago, IL

Learn about their condition, take your time to understand when they don't feel good and need time alone. Be kind and do not force them to participate in activities when they would rather be at home.

Carol
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
San Diego, CA

Help to uplift them and be the best listener you can be. Sometimes they aren't looking for an answer; they just need to go through their own emotions, which can change often!

Beth
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Grand Rapids, MI

If you know anyone with Psoriatic Arthritis then you will understand it when I say that it is a fairly difficult illness to understand. The sufferer doesn't always have obvious symptoms, quite often it is the constant pain and exhaustion that the sufferer experiences but you cannot see. Be patient and supportive and be a great listener... that is most important to me.

Jeanette
Psoriatic Arthritis
Living With Psoriatic Arthritis
(www.LivingWithPsoriaticArthritis.org)
Patient
Bedford United Kingdom

Be a good listener and sounding board. Be an advocate. Go to doctor appointments and ask questions. Bring a list of questions to ask that you and the patient have decided are important to ask. Write down everything the doctors say, so you can go back over everything with the patient later. Appointments can sometimes be a fire-hose of information and far too much for a patient to grasp all at once. Paraphrase back to the doctor what you think they said. E.g., "So what I'm hearing you say is..... Is that right?" It gives the doctor a chance to clarify if needed.

Give the patient permission to just cry or complain about how they are feeling. Be that shoulder to cry on.

Julie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
American Ataxia Networking
(www.AmericanAtaxiaNetworking.ning.com)
Patient
Colorado Springs, CO, USA

Take care of yourself. Get enough sleep. You are the key to navigating the disease since we rely on you so much. If you are taking care of yourself, it is one less thing that the patient has to worry about.

Paula
Synovial Sarcoma
Synovial Sarcoma Survivors
(www.SynovialSarcomaSurvivors.org)
Patient
Cohasset, MA

Family members and friends—please have a care with your loved one. Think before you speak. I have been hurt terribly by well-meaning family and friends. I have been told to just ignore that "little face pain" or "it's all in my head" or "I must be depressed and the pain is a symptom of that" ... I could go on and on, but the point is that your loved one needs your support, not your rash statements. They need your love and understanding. If you don't understand the condition, please, please, educate yourself. It will help you and your loved one in the end.

Gwen Miller
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
St Louis, MO

Understanding. Just because you personally cannot see or feel your loved one's pain does not mean that it does not exist.

Tessa
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Raleigh, NC

Try to be forgiving and patient. The person who is now the patient will not always be tactful and at times might be insensitive because they themselves are overwhelmed with what is going on with them.

Carolina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Homestead, FL

Non-patients, my best advice is to not to make life so easy for the patient that they give up trying. I usually tell my family if I am unable to accomplish certain situations that I will first give it a good try a few times before giving up. I know what my limits are; no one else knows but the person that is going through their situation.

I am not a person who tries to get pity from others due to my health situation. Pity is not necessary. I do not like drama whatsoever. The less I have to talk of aches and pains the happier I am inside. Repeating my health problems over and over can be tiresome to me. Like I said, "It is what it is." People see with their own eyes that a person has a handicap. Talking about it all the time can become habit and boring.

Vickie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Durand, IL

Be patient with your loved one. They are just as scared as you are; maybe even more so. It's okay to get annoyed with them but remember that more than likely it's not personal!! Hang in there and be strong.

Andrea
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Tonawanda, NY

Be patient and educate yourself. Try to understand as much as you can.

Chrisa
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Pittsburgh, PA

I would tell all friends and family to not judge the patient as it is very overwhelming. Also to be "patient," to listen and guide only if needed. Be there often, offer calm company. When family and friends are overwhelmed—and it will happen—the best way is to withdraw from the patient, recharge your batteries and be there again. The patient completely understands how hard it is for everybody. The patient is in a self-survival mode during that time and communication can be difficult. Just be there and be fair.

Emmanuelle
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Bellingham, WA

The only thing I can say is please be patient. People who have Trigeminal Neuralgia are thrown for a loop, as you can say. It is something you would never expect to have nor want to have. This person is very upset, tired and in a TREMENDOUS amount of pain.

Tanya
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Spotsylvania, VA

Learn all you can about the disease and be supportive. Let the patient tell you about their feelings and accomplishments. Be sincere in your support and interest.

Scott
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Creston, Washington

Read up on what your friend is going through and know that when they say they're fine, they may not be. I live alone, so having a friend stop by and just visit can be a blessing. And if you are able, find out what he / she is trying to work on and offer to help, or even look for some affordable help. I often have to hire someone to do a job for me.

Jim
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Kansas City, MO.

With me, I felt my co-workers, friends and family (except for my husband) didn't really believe me. When I would describe what I was going through, they would just look at me. Probably mainly due to the fact that no one had heard of TN, so the information I was giving them definitely sounded a little strange. I would advise everyone that has a connection to someone with a rare disease to take the time themselves to get educated & find out the facts themselves so they can give the understanding and compassion people with rare diseases desperately need.

Karyn
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Tampa, FL

Be a good empathetic listener, not judging. Or be sympathetic; we need love, care and time!

Katrina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Try not to do everything for the patient—allowing independence will promote self-confidence and a feeling of having some control over your own life. It may take longer but it gets done.

Nan
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Friend/Family/Caregiver
Nebraska/Colorado

Have Some Compassion & Try To Understand The Condition That The Patient Has!!!!!!!!!!!!!

Chris
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Chicago, IL

My number one tip for caregivers, family members and spouses—Support, and love your patient, with patience. Immerse yourself in their affliction, imagine yourself in their position, and remember, the slightest positive moment in their recovery should be celebrated and praised. Any negative people or thoughts need to be kept away. Positive visitors are welcome any and all times. We do get tired, so moderation should be considered. You are the patient's advocate. Watch out for their wellbeing. If you don't understand something a doctor or nurse says, make them explain it. Ask for second opinions or alternative treatments. Take charge of your loved one's care. They are counting on you to do what's best.

Philip
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Santa Rosa, CA

I think it is equally hard on the family of the patient. My husband knows when I'm having a TN attack and if we are out he will carry on the conversation if I'm unable or he will eat slowly as I find eating very difficult and I'm painfully aware of the other diners waiting patiently for me to finish. My best friends Nadine and Helen have researched both conditions I suffer from and keep an eye on me without being overbearing. I consider myself so fortunate to have such a strong support network.

It's very important for close family members to have time for themselves. I encourage my husband to keep up his interests and get out whenever he can. Having cared for both my parents in the past I know how exhausting it is.

Jo
Trigeminal Neuralgia, Arteriovenous Malformation
Living with TN (www.LivingWithTN.org)
*AVM Survivors (*www.AVMSurvivors.org*)*
Patient
Hemel Hempstead, United Kingdom

Just be supportive in any way your friend or family member needs.

Don't try and wrap them up in cotton wool—trust me they don't need you to remind them of their condition; they will never forget they have it as it's always in the back of our minds.

Notice and comment positively on any improvements (especially following surgery). It may seem small like "wow you are walking so much better" but it makes us feel that you notice how hard we have been working to get back to normal.

Let us have bad days—it will happen.

Give us your ear, cuddles and love.

Kylie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
New Zealand

My husband is a clear example. I admire him. He is a Polio survivor (quadriplegic), and even with a lot of different medical issues, he just knows how to step in my shoes. Feels my pain. He is working a lot, to keep our "independence," so we can keep raising our kids and run our house "as usual." He is always with me at every single medical appointment. But most important, he makes me feel like everything will be okay.

Rosario
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Fort Lauderdale, FL

If you have a family member that has any disease, try to understand what they are going through. If they are trying to share information with you to help you understand the disease, read about it and ask questions if you don't understand. Don't just "assume" they can just go on with life as usual just because they "don't look sick" or you see them on good days. Some diseases can have a few good days in a row where the person can be playful and do housework or even dance at a wedding or party; however, the next day that same person may end up in bed with the worst pain you can imagine. Don't take how they look for granted.

Millie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Billerica, MA

My tips for non-patients are to first and foremost not go in with the belief that this is all in the person's head and it is not real. This is really something, even if you can't see it or touch it. Second would be to just give support—so if the patient is stuck in bed for the day, ask if they want something, can you bring them a laptop so they aren't bored, maybe a video or anything else as taking their mind off the pain is great. Sometimes just being there with a phone call is helpful, as well.

Sandra
Erythromelalgia
Living With Erythromelalgia (www.LivingWithErythromelalgia.org)
Patient
Edmonton, Alberta, Canada

Have compassion.

Kimmy
atypical, eye pain
Patient
Vancouver, WA

Important traits to have generally, but are essential for family, friends and caregivers, are patience and empathy.

Anthony
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Rock Ferry, Merseyside, United Kingdom

I have recently been on that side (of non-patient/caregiver/family) also. My husband has lung cancer. You may not always know how to help or what to do, but be there. We both laughed, cried, became scared, offered comfort to each other and most of all, we found strength we never knew we had. Just like when I had my Chiari decompression surgery, we have to hold on to our loved ones. Bring the home movies in, pictures of kids, grand-kids, furry friends, etc... they all help to lift our spirits and help give us the strength to fight. Family needs to bind together with support, phone calls, fixing a meal, offer to help with shopping, doing the outdoor chores. Be there for them... they need you!!!

Brenda
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Osage Beach, Missouri

I found out that I had a disease called "ataxia." It was a relief to have a name for it. All my life I thought that I was really clumsy, no hand-eye coordination (why?), and that I had a speech impediment (why?). I am 62 years old and I found out in 2007. One day after I visited the doctor after another fall and shaky balance, he recommended a neurologist and I had my first MRI. Then it was discovered. I've since had another MRI and I went to the Amen Clinic in Bellevue, WA. Dr. Amen does a lot of brain-work and has developed a special brain-scan machine. He has recommended physical therapy and so has my naturopath. There is a special cranial therapist right where I live, in Des Moines, WA. I have to use handrails on stairs, my husband helps me a lot with walking and making sure that I always use those handrails and am very careful in how I move. But, I am still walking and driving short drives, thank God. I have always had depression and I guess it goes hand-in-hand with Ataxia. I have learned to live with both. There are medicines and vitamins to take for both problems. I have a lot of support from family and friends and that is important, and from my church, too.

Joanie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Des Moines, WA

The number one tip that must be addressed here (well, there are several actually) is to let the patient know they are loved very deeply no matter what.

Do NOT ostracize them just because they have a disease (this is happening to my daughter already). Never accuse the patient of wanting attention; can sound like they're making up the condition just to get said attention. Yes, this happens all the time in families of patients with mental illness...this is so sad. We must change these thinking processes!

Learn how to prevent yourself from getting an infectious disease and get inoculated if you can.

Anastasia
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient, Friend/Family/Caregiver
Eunice, LA

My new husband said that since he is an information guy—meeting with the support group, reading what I printed off and meeting the surgeon were the best things for him. And an occasional night out for us to dance and be "normal."

Kimberly
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Lee's Summit, MO

Don't pretend like you get it. Sometimes, saying nothing can go a long way. If you don't have CMT, it is very hard to understand. Some days I can do things and some days I can't. There is no method to the madness so don't try to figure it out. It also goes a long way when people think of your disability for you. For example, my fiancée will often ask me privately how I feel before we do something. This way, if I need a hand he already knows. He also will scope a place out for me if he can, which really means a lot. It helps me to be mentally prepared.

Laura
Charcot-Marie-Tooth
Charcot Marie Tooth Support (www.CharcotMarieToothSupport.org)
Patient
New York, NY

Please do not get discouraged. Your loved-ones appreciate everything you do for them. Even when it seems that your efforts are futile, the fact that you are there and that you care enough to try can mean the world to someone who is suffering from a rare disorder. Too much emphasis cannot be placed upon how isolating it is to suffer from something that most people don't comprehend.

Help the sufferer think about other things. There can be a tendency to want to concentrate on what is wrong and feel pity. Your concern is appreciated but sometimes the best thing to do is change the subject. Humor is great medicine.

Melissa
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Bradenton, Florida

Ask to help in specific ways, not just the "can I help?" Be specific and focus on what is easier for the person to do and what you both like. With me, my friends would pick me up to do things when I was first recovering, which made it TONS easier for me. Others would send me cards, emails and phone calls. Each one helped. Remind yourself that your friend is doing their best and when they're angry, it's the challenge, not you.

Sharyn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Manchester, CT

1. Encourage them to be the best they can be
2. Don't let the person have their condition overcome them
3. Encourage them to help themselves
4. Spend as much time as possible with the person
5. Enjoy any time you have with them

Alicia
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
North Bay, ON, Canada

Need patience.

Jo
Patient
Switzerland

Stay strong for them. Never show your true feelings. Don't tell them things will be ok if you don't know for sure; be realistic, but not cruel. Don't brag about good things going on in your life as it could make them feel worse. Accept that they might sometimes be nasty, crammed sometimes, they're dealing with a lot and you don't know how it's affecting them. Give them space, but not too much. Never judge and always listen.

Lauren
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
UK

Be a good listener & understand that your loved one cannot control their diseases. The diseases & medications alter their lives in a terrible way. Ask them how they are feeling—it will help them to discuss how they are doing. And do research on how you can understand (and be understanding of) their pain.

Julie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Friend/Family/Caregiver
Huntington Beach, CA

Try to be available to help with talking or listening; you may learn something that can be helpful to both of you.

Marie
Post-Traumatic Stress Disorder
Patient
Waynesboro, PA

Pray pray pray

Casie's mom
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Taft, CA

Learn as much as you can about your person's condition. Be sympathetic, show empathy & understanding. Ask questions. Don't try to pretend that there is nothing wrong with the "patient." Take responsibility and help your family member, friend in any way that you can.

Melinda
Charcot-Marie-Tooth
Charcot Marie Tooth Support (www.CharcotMarieToothSupport.org)
Patient

All I can say is be there for your friend and/or family member. You would be surprised how much it means to a recovering patient to receive emails, phone calls, text messages, etc. Just knowing that people are thinking about you is so important to the patient.

For those non-patients, just be supportive and understanding. I am beyond grateful for all of the love and support that I received from my family and friends. They were amazing.

John
Atrial Septal Defect, Von Willebrand's Disease
Atrial Septal Defect Support (www.AtrialSeptalDefectSupport.org)
Living With VWD (www.LivingWithVWD.org)
Patient
BensFriends.org, Partner
London, England, UK

Be patient.

Mandy-Sue
Patient
Georgia

STORIES

SECTION 2 – Stories

The following stories come directly from members of Bens-Friends.org and our various rare disease communities.

Each disease community on BensFriends.org has a section for members to continue submitting stories (eg, profiles & blogs) or you can email us if you want to share at stories@bensfriends.org*. If you are affected by one of our rare diseases, please join us and feel free to share your story, if you're ready.*

If your rare disease is not currently covered, please send us an email to info@bensfriends.org *with your condition and we can discuss getting a community started. Please remember that you are not alone in this and we are here for your support.*

If you are looking for more information, feel free to check out bensfriends.org

Since our diagnosis with our son Nate, we have done some genetic testing ourselves. Last week, Oct 17, 2011, we found that my husband Doug carries an expanded mutable gene for SCA 7, which is a condition caused by too many repeats of a 3 nucleotide chain. A normal number is 18, my husband has 30 and Nate has 60 repeats. What this means to us is that #1, Doug's siblings are also at risk for inheriting and passing on this gene, #2 our daughters could have the condition and just not manifested symptoms or they could also be carriers of the expanded mutable gene, #3 Doug will not ever have the condition since he is in the expanded mutable range—34 or more repeats will show the disease. Wow! Our daughter had their blood drawn on Friday and Doug's 2 brothers and sister are next in line.

Nate has had a normal, healthy childhood. He played soccer, football, wrestling, marching band, basketball, and he always passed all of the PE physical fitness tests. He started having a decline in his vision in 2004 that started us on a 2 year search for the problem. He was finally diagnosed as having Stargardt's disease by the University of Iowa—this is juvenile macular degeneration. We were given a few low vision aides and sent home. In school, Nate received help with his vision but it didn't really become a problem until his sophomore year in high school when he really needed large print books. From large print books he went to audible books and learning Braille just in case. Nate was given special bioptics so that he could pass the drivers test and drive in Nebraska. Nate adapted well to his vision problem and continued in all of his physical activities including piano and band. That is, until his junior year of high school wrestling when he found he just could not jump rope, and also was always falling behind when the team ran stairs. We started a new search

for the problem in November of 2008 that led us to the neurologist at Children's Hospital in Omaha whom we had previously seen when we were given the Stargardt's disease diagnosis. Here is where the story above begins.

It has been a difficult time for our family, I would say our lives are divided into before the diagnosis and now after. It was a total paradigm shift—we no longer had a "normal" and never have had since. For me, the more I am around Nate the better I feel. He takes things so well, he never complains or gets angry at his situation. He is not going to let this condition stop him from doing what he wants in his life, his certainty and perseverance are my salvation. As for the rest of the family, my husband has dedicated himself to research for treatments and making sure we will be involved if and when trials become available. Nate continues to pursue things he loves, music, weight lifting, riding his bike (a three wheeled recumbent), and being around friends and family.

Nan
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Friend/Family/Caregiver
Nebraska/Colorado

When we received our diagnosis, we lived in Nebraska. Our pediatrician, neurologist, and eye doctor—none had any experience with SCA 7 (Spinocerebellar Ataxia type 7) or had even heard of it (besides the neurologist). We found out in the worst way possible. Our son's blood was drawn and tested in December of 2008 and we were told it could take up to a month for the results. So after a month of waiting we started calling the neurologist's office for results and were always told they had not come in yet, that the mitochondrial tests did come back and were normal but we were still waiting on the SCA panel.

In the meantime, we decided to go to another neurologist for help and had our records sent from Children's Hospital; this was in March. What the new Doctor discovered is that we did have a diagnosis but she didn't break the news to us. On April 18, 2009 (my birthday), while driving in a snow storm to the mountains in Colorado—we got a call from the first neurologist with some excuses about how our diagnosis must have gotten filed in our records without being reviewed, etc., etc... Then said your son has SCA 7, it is progressive and there is no treatment. He will soon need a wheelchair and that she could help us get the equipment we would need. That was it... we never heard from her again.

It really took us a few years to actually meet with another neurologist for an explanation of what this condition was and what it means to our family. On Sept 9, 2011 we met

with our first genetic counselor for help understanding what this diagnosis could mean for our other children as well as our own brothers and sisters.



Nan
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Friend/Family/Caregiver
Nebraska/Colorado

Hi, my name is Sydney, I'm 18, I live in North Carolina. I have a disease and I'm raising awareness about it.

Spinocerebellar Ataxia is a degenerative condition that affects the cerebellum. The main job of the cerebellum is to coordinate the body's ability to move. Ataxia is a Greek word that means lack of order, and medically it indicates lack of coordination. Ataxia leads to a progressive atrophy of the cerebellum and because of the loss of this quintessential function, there can be wasting away of muscles. Spinocerebellar Ataxia is a rare disease in the U.S today and there is no cure for this disease. It is also a genetic disease, which means it was not caused by injury or illness. When I was 13 I was diagnosed with Spinocerebellar Ataxia and when I was 14 and 15 I would always worry about dying soon.

Today I don't worry about death because I have made it this far and I know I can go the rest of the way. I am also encouraged by the amount of research taking place on this disease that might bring a cure or treatments. I have had many obstacles in my life that have been difficult but I have fought through them. People ask me all the time "How I live everyday with Ataxia?" or I hear "if I had Ataxia I would have given up a long time ago, how do you do it?"

I have had a lot of days where I have had enough and I wanted to give up and kill myself. Something inside of me told me to never give up and keep fighting. On November 12th, 2010 my high school show choir hosted a Talent Show/Ataxia Fundraiser for me; we had a silent auction and a bake sale. All of the proceeds were donated to the National Ataxia Foundation, to help researchers find a cure. The choir raised $1,484.00 dollars for the National Ataxia Foundation.

I found out that my friends call me a best friend and a big sister. I feel honored hearing them call me that. A video was

made for the talent show; the video was of me, my mom, and some members of my choir family. The video taught me a lot about myself and members of my choir family. In the video I talk about my struggles, my mom talked about me and my strive to do things, my choir family talked about how much I mean to them and what it's like to have a friend who has Ataxia.

We made the video a week before the talent show and I was not allowed to watch it till the night of the talent show. When it was time to watch the video I didn't know what I was in for. One of my friends came to sit with me and I'm glad she did. In that 15 minutes I cried so much but they weren't sad tears they were happy tears because what everyone said touched me so much.

I know I struggle through life with this disease but I try to make the best of it. I inspire my friends, family, and other community members. I was recently asked "When they have found a cure for Ataxia would I get the treatment?" I answered "I'm not sure because Ataxia made me who I am today and I would miss my old self." People who don't know me or anything about me judge me by what's on the outside and not what's on the inside.

I don't let it get me down when people talk about me; but when someone who doesn't know me or my story talks about me or judges me, know that hurts. I try to be strong for the ones I love by not showing when I'm in pain, holding in my anger, not letting the names I get called bother me. But the truth is the names I get called do bother me. It's not good to hold in my anger and any other emotions. I've gotten to a point where I feel like I'm not good enough for anyone.

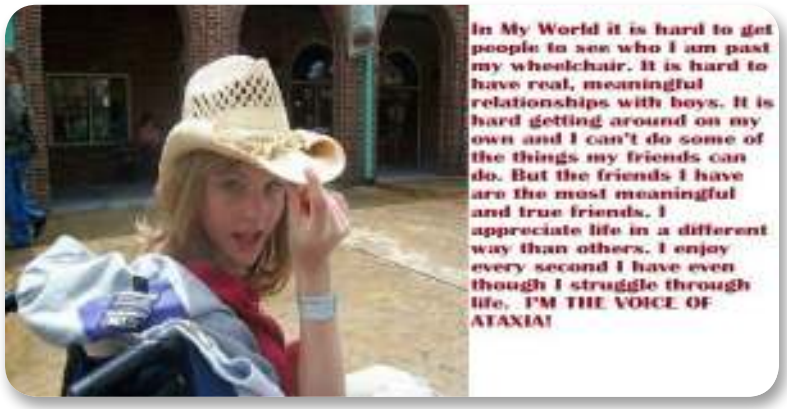
Everybody has a hero; they could either be fictional or a real person. My hero is not fictional but a real person. That person is me. I am my own hero because the obstacles I face every day are a challenge and I strive to be strong for everyone and to never give up no matter what happens. That sounds like a hero to me.

I get called people's hero or inspiration. That means a lot to me because if I didn't have the best support group behind me I would have no one to inspire. One of the most important things in my life is friendship. My friends mean the world to me and I would be nothing without them. I know I can be moody and I say the wrong things to my friends but I would do anything for them. In the past I have made bad choices in friends but I finally have the best group of friends.

Three of my friends have made my senior year an unforgettable one and they have changed my life for the best. Jessica, Ariana and Diana are my BFFer's and my little sisters. I don't know what these girls think of me but I don't care as long as it's not bad. I would hate to do something stupid and lose them. It would be difficult to continue living life without them.

When I was growing up, a boy lived down the street from me. He was either 8 or 9 years old and he had Friedreich's Ataxia. A blood clot formed in his leg and he had to be transported by helicopter to Duke Hospital. As the doctors tried to remove the blood clot he died. My choir teacher was talking about a book that we were singing a song from and as she explained it I start relating it to my life. The book was called *Wicked* and she said it was about a girl who got judged all the time and just wanted to fit in. I know that life is difficult, but if we choose to fight through these difficulties instead of giving

up it makes life worthwhile. I don't know what the future has in store for me and my disease but I do know this—I am going to keep on fighting. ATAXIA WILL NOT WIN THIS BATTLE!!!! Because I am the strength behind ataxia.



Sydney
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org) *Patient*
North Carolina

I was diagnosed with an AVM in October of 2007 and the doctors chose to use a gamma knife because of the position of the AVM. My biggest fear was the mention of a possibility of weakness or paralysis on one side of my body. I was very afraid of that happening. When I had the seizure, all I could think of as I was fading was "what would become of my life, how would I live with paralysis?" It was scary and the emotions are hard to describe. Fortunately, I did not become paralyzed or weak even though I had minor seizures after with some coordination issues immediately after each minor seizure.

I have not had a seizure in 2 years, but any sensation still brings it to my mind, and I ensure my wife is aware of any strange sensation I feel. If I feel awkward for too long, I go to the ER. Forget the money, it's better to be safe than sorry. I had to travel a few times in the first year after surgery, and I made sure my colleagues knew to check on me if they did not see me in the morning. I also had them on speed dial in case something happened.

I don't know if you'll call it a defining event, but I remind myself that I'm alive for a reason, and that God will use everything I go through to bring glory to His name.

Kene
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org) *Patient*
Atlanta, GA

February 16, 2001 started out as a normal day for me. I was newly married, 24 weeks pregnant with my first baby, working at a job I loved. I had always had headaches for as long as I can remember. So the two-week long headache I had been having was not a big deal for me. I got up and went to work as usual. I worked at [a department store]. I was the cosmetics go-to person at the moment. Since it was a slow day, I was rearranging my area. I liked keeping my product looking neat and fresh. I had an armful of white gardenia scented candles and was taking them to another shelf. I remember smelling them and thinking, "I'm going to throw up, these stink!" It was then that my headache increased a million times over. I set them down hastily on the counter and had to put my head down. The nausea grew and I knew I had better scoot to the bathroom or I'd have one heck of a mess to clean up. The cosmetics area was at the front of the store. The bathrooms were at the rear. En route there I was swaying and dizzy. I made it just inside the door and plopped onto the floor. I was so tired all of a sudden. Two little old ladies came in and looked at me funny and after doing their girly things, left. I crawled to the handicapped stall they had just vacated and lost the entire contents of my stomach. That consisted of a candy bar. I then remember thinking. Oh I am pregnant! I shouldn't have eaten that candy bar... It made me sick!

My friend Heather who was eight months pregnant came in as I was being sick. She took the stall next to mine. When she realized it was me she leaned down and looked under the dividing wall and said, "Missa?" At that moment I couldn't respond to her. I lost all control of my muscles and fell over. I smacked my head on the stall wall and couldn't even reach up to feel it. Heather freaked out a little bit. She tried

getting in the stall with me but with our pregnant bellies, there wasn't enough room for her to maneuver. She left the bathroom and I thought, I'm alone!

She came back very quickly with my manager. He was at first refusing to go in the women's bathroom. After being told he had to, he came in and just stared at me. I was so embarrassed. He had to be told more than once to pick me up and put me in the wheelchair. He was too nervous about putting his hands around my top and violating me. After he finally put me in the chair and wheeled me out of the bathroom, his next step was to just send me home. He thought it was normal for a pregnant person to be sick like this. I can't fault him. I did too.

Heather insisted he call 911. I was sitting in the chair slumped over and being stared at by dozens of rubberneckers. It was the ultimate humiliation. When the paramedics arrived they tried to get information out of me. All I managed to say was to please call my husband. That was the last time I spoke. They hurried to put me in the ambulance and I was sick again on the pretty lady's shoes. I was even more embarrassed. I couldn't even apologize. I lost consciousness for a minute or two. When I awoke next the guy in the ambulance was taking off my shirt. I was very modest and turned red I'm sure! When I awoke again it was the E.R. techs saying they needed to intubate me. That scared me so much. I passed out again. The last time I woke up was when they were dry shaving my bangs off to put a drainage tube in my head. I had never cut my hair. I was horrified. I spent the next week in a glascow scale three coma.

My new husband was finally contacted and he spent the first little while alone at the hospital. I'm sure he was devastated since he had just been told his wife and baby would not survive the night. My entire family was called in to come say goodbye. The guilt over their pain will never go away. If only I could have told them I wasn't leaving them yet. My one night I wasn't supposed to survive turned into a full week.

When I woke up I didn't realize how long it had been. I felt lost and confused. Everything hurt. My hands were tied down, I had a tube in my throat to help me breathe, a tube in my nose to give me food, a tube in my head to drain the blood, a central line to my heart to give medication, and numerous other probes, tubes, and wires. For the first little while I could only communicate by writing. When they removed the breathing tube my throat hurt so much. I could only muster squeaks for a while.

The doctor visited me the day I awoke. I was told that I had suffered a massive brain hemorrhage due to a rupture in an AVM I was born with at the base of my brain. Where my bleed was located was the center that told my heart to beat, my lungs to breath, muscles to move, and so on. He went on to tell me that in order to prevent future bleeding, he would have to do immediate surgery to remove the malformation. Since this was anticipated to be an eight-hour surgery where I'd be on my stomach the entire time, my baby could not survive. She would in essence, suffocate. I pleaded with him to just deliver her. He refused. My husband and I had lost our first pregnancy in miscarriage and it took sixteen months to conceive this baby. We wanted her! She was loved. I couldn't just allow her to die on my behalf. I said this to the doctor. He was very cold. He told

my husband that his choice was me or the baby. He couldn't have both. I was devastated. Just coming out of the coma, being on all the pain medications, and heartbroken I had initially conceded to proceed with the surgery.

Later that afternoon when the medication had worn off more and I was less groggy, I was flabbergasted that I had said yes. I talked to my husband and said, "If the choice comes down to me or the baby, you keep me on life-support until she is born. We want this baby." He sobbed and said that there was only one me. We could have another baby. I said no. This is already a little person with their own personality and is loved. She cannot be recreated. I am an adult and have had my chance. Please just promise me that you will work with me to save this baby.

When the doctor returned the next morning, we both told him our decision to wait. He was so angry. He started his tirade against me for the next week. He refused to address me when talking about my case. One day when my speech therapist was there working with me he stormed into the room and proceeded to yell at me for ten minutes. His first issue was the blinds. They were closed. I am sensitive to light now, but when he had asked that I keep as them open to stave off depression I attempted to open them numerous times. I had my mother try, my husband, two nurses, and my therapist. They were broken and would not open. That was in my chart. Then he berated me for being in bed. He said I should be walking. I was only allowed to walk with a nurse or two with me and while wearing a leash to prevent falling since my balance was gone and I was weak. I had walked so much and harassed the nurses so much to help me that they said I was to stay in bed. Being on bed rest I was not to exert

myself or I could re-bleed. This too was in my chart. Finally he started to scold me for not eating. Being six months pregnant I could not eat eggs. That is what they brought me for breakfast. The mere smell made me vomit. At the present moment when he was chiding me for not eating I was eating a grilled cheese sandwich and had a bite in my mouth, which was by then hanging open. I was so humiliated to be scolded like a disobedient child. I just cried silently.

After he left the room my therapist asked me if he always talked to me this way. The answer was yes. She was furious and told me to just disregard whatever he had said. After mulling over the events that had taken place I decided on my own to fire this doctor. I called him in and told him that he was no longer in charge of my care and that I would be seeking other advice from other neurologists. This made him livid. He went from scolding me again to blaming my mother for my decision. He gave me two weeks to seek alternate care, which I did.

His colleague was much more sympathetic to my plight. I think this made him madder that someone in his own office was taking over my case. My new doctor, although really gruff, understood what was important to me. He explained in black and white my decisions, the complications that could arise and what the future could hold for me. He said that the pregnancy itself could instigate another bleed. If I were to carry this baby full term, it would have to be on complete bed rest. I wasn't even allowed to sweep the floor or get myself a drink of water. He also told me that I was not to go into labor and do nothing that would raise my blood pressure. I would have a scheduled C-section and he would be on hand in case things went wrong. I was instructed to

immediately go to the E.R. if my headache increased which I ended up doing several times. I cannot tell you how many CAT scans and such I have had.

When it came time to deliver my baby I was really scared. I did not want to lose her. The delivery went off without any hitches aside from the nausea and vomiting. When the doctor pulled her out she said, "My god! This child is ten pounds!" She was nine pounds and six ounces. She was perfect in every way. She and I had beaten the odds. My daughter is named after a nurse I had in I.C.U. This nurse gave me 200% every day. She sat by me and comforted me when I was writhing in agony, or sobbing in fear. This woman saved my sanity, my life, and my child. I am forever in her debt.

The next decision was when to have my craniotomy. My doctor wanted to do it right away, but understood that I wanted the best start possible for my child. I wanted to nurse her at least six weeks to ensure she had as much protection from sickness as possible. At five and a half weeks post-partum, he called and asked if I was ready. I said I wasn't. I asked if I could go a few more weeks. He was reluctant, but relented insisting I stay in bed and not pick up anything other than my baby.

When it had been nearly nine weeks I called to schedule my operation. The day before I was to have it, I went to what I assumed would be my last family reunion. It was bittersweet. I remember sitting in the grass with my very best friend both of us holding our newborns. We were sobbing.

I asked her to please watch over my child and pray for me. I also asked her to be my baby's godmother. If my husband and I could not raise her, I wanted her to. When I went in

to have my surgery, I had made as much peace as I could. I didn't expect to wake up. Not raising my child was the hardest thing I could imagine, but I had to try. The odds were stacked against me for surgery, but equally for a re-bleed. If I were to die on the table I wanted her to know that I had tried everything to be her mom. The doctor worked on me for eight and a half hours…

I woke up. Coming out of anesthesia is painful and scary, but I woke up. I wasn't blind, paralyzed, deaf, or confused. I could have been any of those. I had been warned that I might have to relearn everything including eating, walking, and talking. My side effects? They are minimal. I have depression, memory loss, jerky thumbs, headaches, and sometimes stutter. I have had to re-teach myself how to think, and write, but I am alive. I have my beloved daughter. I have also had two more daughters since. I have never forgotten my struggles to have them. I am grateful for them every day. I am reduced to tears at the thought of choosing another path. The thought of choosing to save myself and not try to save my child is devastating. The nurses and doctors that stood by my side and gave me every ounce of their knowledge are true miracle workers. And I cannot ever forget Heather. Had she not been alert to my plight in that bathroom and insisted urgently that I receive help; I would not be here nor would my three daughters.

That is my story. I am alive. I am a mother. And I will never forget.

Missa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

My name is Melissa and I have Lupus. Before finding out I had Lupus I went to a lot of doctors who said there was nothing wrong with me... except for a high Sed rate (also known as ESR or erythrocyte sedimentation rate—a blood test indicating inflammation). But, I knew there had to be more.

I finally found a doctor who would listen, and week after week he had me in for blood draws and to check on my symptoms. Finally he found the problem.

While there was a sense of relief for knowing, dread set in as I learned what Lupus was and how it was/is going to affect me. That was 2003.

Melissa
Lupus
Life With Lupus (www.LifeWithLupus.org)

Hello, my name is Beverly. I am a 44-year-old, single mother of three grown children, and a grandmother of three. Before Aug. 20, 2010, I was a very outgoing person, doing almost anything for the moment. Two days later, I experienced this crazy pain that went from my head to my toes. During the next two days, I found myself not able to get out of bed during the night. My oldest son heard me screaming and came running to my room to help me get out of the bed, go to bathroom, and get back into bed. On the third day, I was sitting in the family room and could not move so the family called 911. At the hospital they removed me off the gurney and asked me to take a seat in the waiting area. After the ride I was totally in tears at this point! I just wanted some kind of drug then. But after maybe about an hour later the doctors came back with "You're okay and it is Rheumatoid Arthritis with muscle spasms," and gave me some Ultram 50mg (which is a pain pill). The pills didn't work!! From Aug. 24, 2010 to Dec. 18, 2011, I was in chronic pain, losing my everlasting mind. When someone wanted to touch me, I automatically would scream, before the actual touching.

Dec. 18, 2010, was my very first visit to the rheumatologist at our state hospital in Atlanta, GA. The doctor ordered a collection of tests. I was in total pain, and of course the air conditioner was on and my body went CRAZY (the air or cold temps. in places make me ache). They gave me some more Ultram 50mg, and asked me to return on Fed. 7, 2011 @ 10:00am/et, to get my results. Well that day came and I was over-excited wanting to know!!! And of course, I was hoping for the BEST. I started to cry in the waiting area. My oldest son, said, "What are you thinking about?" I really didn't want to do Native thinking, or any WILD thoughts about anything,

so I replied nothing and wiped my eyes, but thinking what's wrong with MEGOD????

Suddenly, my name was called, Beverly. My heart jumped out of my body, my eyes closed and my son helped me up from the chair. We got to the room, An intern doctor asked a series of questions going back to the day I can remember—Aug. 2010 up to that particular day (Feb. 7, 2011). Well of course depression became part of this, because of memory lapse—"bummer", right????? It was really hard for me to remember simple things.

Going on with the story, the doctor wanted to examine me—(LOL) OH my GOD (he has to touch me) went into every word as he spoke them to me. I cried like a baby!!! My son explained to them, that any little thing would cause me to cry!!! I felt like a whining spoiled baby (smile). So he did examine me, then the doctor stepped out of the room for almost 15 minutes. He came back with the Lupus doctor, who is from the Lupus Clinic here in Georgia, and head doctor at the Hospital in the department of Rheumatology and Lupus. The head doctor took a seat and pulled the computer to where we (me and my son) could see the results. He started explaining everything step by step (I really did feel like he cared about ME!!!!). Relaxing but still nervous and excited, he continued to read and explained the test to us. Well, he turned and said, to sum everything up with the word, "You have LUPUS!"

What is that? (I was crying asking this) I'd only heard of LUPUS at that time (Feb. 7, 2011), What is that? (I was crying asking this) I'd only heard of LUPUS at that time (Feb. 7, 2011), once… He then tried to explain it to me, but having no knowledge of it I assumed that I was going to die

soon—in months or weeks. Then he asked, “Why are you crying?” My reply was, “I don’t want to die!!! He comforted me, by saying, “It’s all up to you, if you want to fight to live for years with LUPUS!!!”

Well it clicked, “Beverly, GET IT TOGETHER NOW!!!! RIGHT NOW!!! And from that day on it’s been JUST that! This part has come to a close. To sum it ALL, your HEALTH IS WHAT YOU MAKE OF IT, so LIVING with LUPUS is going to be GREAT!!!!! …. Beverly

Beverly
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Stone Mountain, GA

Smile of an Angel

by Nicole Siva dedicated to my daughter Taitlyn Shae Hughes

1-11-99 to 11-06-11

A smile that is captivating
A beauty unsurpassed
A heart filled with love
A memory that will last.
A young life lost
A legacy gained
for she is our angel
that's the way it remains.
A tear shed
A silence within
A longing for her touch
A hoping to end.
A gentle breeze
A wonderful sight
she came to me
in my dream last night.
A bit of peace
A distant light
A loving smile
A fulfilling might.
A wispy feel
A glowing array
A wonderful feeling
A blessed display.
My angel showed me
she's in heaven this way.

Well, my story begins on Friday, November 4, 2011. I went into my 12-year-old daughter Taitlyn Shae's room to wake her for school. It was around 5:15 a.m. She woke up immediately and said that she wasn't feeling so well. I told her that she would need to try to go to school as she had already missed one day that week because she had a headache, was fatigued and wasn't feeling just right. She said she would try to go that she didn't feel so bad to not give it a try. Since my daughter had to get ready so early to catch the school bus in time, I would wake her and then go lie back down for about 30 minutes until I saw her off in the mornings. Approximately 10 minutes after I woke Taitlyn up, she came into my room and said, "Mommy, Mommy, my head really hurts." I said, "Okay sweetie" and immediately jumped out of bed to begin caring for her. Taitlyn was crying quietly and therefore I knew she wasn't feeling well because she rarely, if ever, shed tears. I told her to lie back down and I would go and get her some Advil. She went and lied down in her room on her bed. I got Advil and a can of Sprite and attempted to have her take the pills. She sat up in her bed and said, "I can't take them Mommy. I think I have to throw up." I ran down stairs, grabbed a bucket and placed it on the floor. Taitlyn picked up the bucket and vomited. She lay back down. I put a migraine patch on her head and was trying to comfort her as best I could.

I thought for sure she had a migraine. Her father and I both get migraines and therefore I knew all too well how such a headache felt. I turned out the lights and lay back down with her. I asked her if she was feeling better, she said no. My husband, Taitlyn's stepfather, woke up. He said let's run her a very hot bath to see if that would help. He and I went into the bathroom closest to Taitlyn's room to start the water. I

said she really doesn't feel well, I am concerned. Chris said the bath should help and he stayed there to watch the water while I went back into Taitlyn's room to wake her for a bath. When I went into her room I heard a very loud snore. I turned the lights back on and said, "Tait, wake up sweetie. Let's get you in the bath to help you feel better." There was NO response, only the sound of snoring. I began patting on Taitlyn's shoulder to try and wake her, NO response. She appeared to be in a very deep sleep. I called for Chris and said, "Taitlyn isn't waking, hurry please come here." Chris came in and began calling her name. NO response. He then lightly patted her cheeks in attempt to wake her, still NO response. I told Chris to call 911.

Throughout the 18 minutes and 26 seconds it took for the ambulance to arrive, I continued trying to wake her. I began crying and became frantic. I in my heart knew something was seriously wrong. This was not my bubbly, energetic, beautiful, smiling 12-year-old. Something was different. Taitlyn's eyes began to roll back in her head and she continued to snore loudly! Finally the paramedics arrived. They assured me that they had thought Taitlyn had experienced a drug overdose. I said I certainly do not think so but, whatever, just do anything to help her!! After 2 attempts at reviving Taitlyn with anti-narcotic drug shots, NO response. At this point, I am sick! My sweet little girl appeared to be losing her life. She was rushed by ambulance from our home in Hedgesville, WV to City Hospital in Martinsburg, WV. We arrived there around 6:30 a.m. A CT Scan was done and the ER physician came to me with the results. His expression was extremely concerning. He looked white as a ghost. I asked, "Is she going to make it"? Please tell me….the ER physician said in these very words, "I am NOT optimistic!" Oh my

GOD, I stood there stunned. Expressionless, numb, emotionless and scared! What? My beautiful daughter, only 12 years of age is DYING? It cannot be. Just last night she was hanging out with friends, taking a walk in the neighborhood, eating ice cream. How could she be DYING? I was told that Taitlyn suffered a SEVERE brain hemorrhage most likely due to an AVM rupture. What? What is an AVM? How did this happen? What could I have done to prevent this? How can I save her now? God will NOT take her, I know it. The physician said that Taitlyn would be airlifted to Children's National Medical Center in Washington DC for further treatment. I WAS NOT permitted to be on the flight with my daughter so my husband, brother and I rushed to Washington DC.

I remember that 40 minutes which should have been an hour drive, as if it was happening right now. I sat there, stunned and numb, praying to God to save my baby girl. Once arriving at Children's National, the chief neurosurgeon met with us and told us that Taitlyn had a severe brain hemorrhage caused by an AVM rupture. Her brain was swelling which was causing herniation of her brain stem and a medically induced coma as well as possible brain damage or death. However, the surgeon said he was "cautiously optimistic" that she could survive. Oh, thank God there is a chance I may be able to take my beautiful 12-year-old home again to resume our everyday lives, thank you GOD!! The surgeon said the next 24-48 hours would be crucial and that she was most definitely "not out of the woods" yet. So sit and wait is what we did. That evening around midnight or so, things took a turn for the worse. Taitlyn suffered what I believe was a stroke and we were told on November 5th that "brain death was inevitable"! Taitlyn would not make it. Again, I was numb! My ex-husband (Taitlyn's father and I) sat there

at the table with the neurosurgeons, speechless. Then my ex-husband asked, "What about organ donation?" I had forgotten Taitlyn told me that she wanted to be an organ donor if anything were to ever happen to her. She obviously told her father that as well. So on November 6th at 11:32 a.m. our daughter's heart stopped beating. The ventilator was removed and she passed from this life. Her kidneys, pancreas and liver were donated and we later found out they went to an 18-year-old male, a 37-year-old female, a 37-year-old male and a 56-year-old female.

I am very proud that my daughter at such a young age thought of others by specifying she wanted to have her organs donated. Taitlyn was a beautiful child, both inside and out. Her memory lives on in my heart and I will be forever changed since she parted this life. My goal is to carry out her dream of making the world a better place and hoping that someday soon I will be reunited with my babygirl!

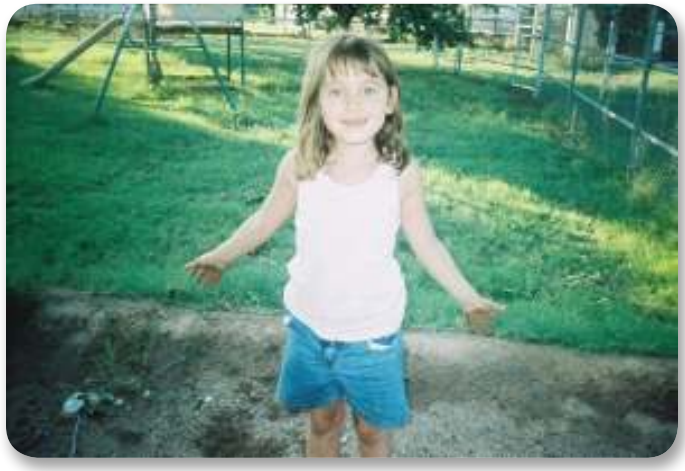
Nicole
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)

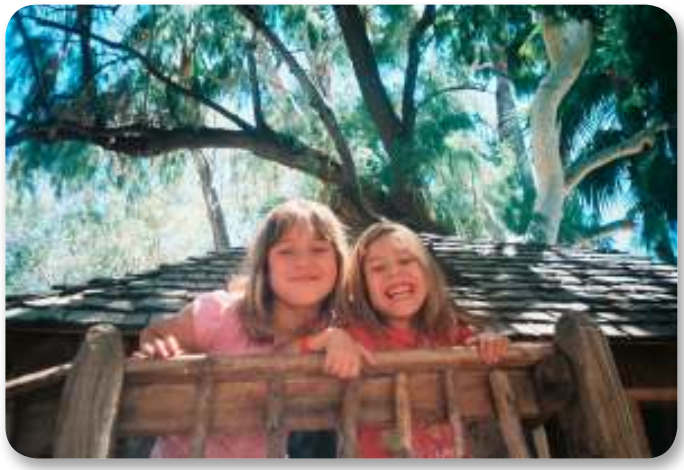
Lauren

Lauren is my angel from Heaven above
Always bring smiles, joy and lots of love
Under a blanket of soft beautiful cries
Revels a spirit that flies through the skies
Ever little beauty that enriches my world
Never do I tire watching this beautiful
little girl.

Our hearts are deeply broken. We don't understand what happened and why you had to go away.

You are the love of our lives. The best person we know. WE can't wait to see you one day.





Joanne

My name is Melissa, born Aug 11, 1980, at Toronto General Hospital. My parents, Helena and Edward, must have suspected I was going to be a handful at an early age. I was a traveling baby; before I could walk I was flying back and forth for 2-3 months a year to my parents' place of birth, Portugal. I had (and have) grandparents, aunts, uncles, cousins and friends on two continents. I was so lucky! I learned to walk and talk in Portugal; the beach, family and friends made these trips so memorable. I was a happy baby; I grew up surrounded by my younger sister Jessica and so many friends in Scarborough. Our Lady of Grace was my elementary school, Libermann was my high school and Seneca was my graduating College.

I was attending Seneca College (2000) when I was first diagnosed with my AVM. It was a total fluke, for a long time Mom and my aunt had noticed a very slight tremor in my right hand so they asked our doctor to recommend something. He set up an appointment with a Neurologist at Centenary Hospital. Mom, dad and I met with the Doctor and discussed our options. She checked me out and didn't think it was anything significant… in her opinion it was not worth pursuing. She mentioned a CT scan as a possible start but didn't think it was necessary. That's when dad spoke up and said, "We're here now, let's cover our options by eliminating anything to do with the brain and do the CT scan." On the day I did the scan we immediately got asked to return to the doctor's office. I had never seen Mom and Dad react the way they did. We had no idea what to expect. We all went into a trance from the moment we left the CT Room to the time we reached the doctor's office (in the same building)....

The doctor made an appointment with Toronto Western.

That's when I became familiar with those 3 letters "AVM." They explained all the symptoms of a bleed, and to that point I had never experienced a bleed or the type of headaches they described I could have, stiff neck, seizures, etc.

It was March 24, 2003, when I was in my room and got an indescribable headache, stiff neck and shoulders. I immediately remembered what Toronto Western had described and as I headed to the top of the stairs I called out for mom and dad, describing my symptoms. Without any delay, they jumped into action. We first went by ambulance to [a different] Hospital, just two minutes from my home. In triage, we informed the nurse of my symptoms and the AVM. The nurse's reaction was: lights are on nobody home. "What's an AVM?" she asks. It's the standard question most asked by any hospital or person other than Toronto Western. I was given a muscle relaxant and sent home. After being at home for a few hours and still having a painful headache we went back to [that other] Hospital. They decided to do a lumbar test to see if there was blood in my spinal fluid. They saw blood. It was communicated to Toronto Western Hospital and I was quickly wrapped up and sent by ambulance. Toronto Western is not like Area 51 out in the middle of a desert, it's in downtown Toronto; so why did the ambulance driver get lost? No one will ever explain that one to me!

Just to make things really interesting this was also around the time when SARS (Severe Acute Respiratory Syndrome) hit and killed 44 people in Toronto, 800 around the world. Being my first bleed, in a hospital and the introduction of SARS, I was terrified! I spent over one week in a hospital bed before they could finally release me. The ordeal was traumatizing even though my mom, dad and sister stayed with

me the whole time while sleeping in chairs or trading places. On my release day I was packed and ready to go home when Toronto Western Hospital went into SARS lock down.

I found myself for the first time totally alone, my mom and sister had gone home to prep for my homecoming and dad was caught at the hospital doors, dad stood outside trying to get the attention of the Toronto Western Hospital CEO and kicking up enough fuss they finally released me nine hours later. Dad never left the hospital doors until I was released. That's my family, one for all and all for one; from 2002 till 2011 it's been our sacred motto.

My first year and half at Seneca College was not my best. I was young and felt out of place. The 3-year course I took was demanding and I struggled to the point where I was not accepted back after my first bleed. I took an 8-week summer trip to Portugal with mom, dad and my sister. Dad's employer allowed him to work the extra 3 weeks he didn't have as vacation from the Lisbon office. It was relaxing, but still, every day I thought of a second bleed "and then what?" I can't get to Toronto Western from here; no way would the ambulance driver ever figure this one out!!!

In March 2009, after recently purchasing a beautiful condo villa in Markham with my husband Hugo, I experienced my second bleed while in the shower at home, alone. I was rushed to Toronto Western and stayed for one week again doing a re-run of 2002, this time without the SARS. At this point the doctors circled the wagons and decided my AVM was too unstable, plus I was young so something had to be done to prevent further bleeds. The AVM team sat on a 60-70% chance of success however; surgery was out of the question. They elected to go with Gamma Knife. I read, dreamed and

slept thinking Gamma Knife. I could not stop thinking of the 30-40% not being successful and the unknowns. I was and still am so scared, my confidence was shot, my happy and love-life personality was gone. I could see the fear in my family's eyes while still being supportive and encouraging. Whatever I missed or didn't understand in meetings or discussions with the hospital and doctors—my mom, dad, sister and husband would be on it like a dog on a bone. This was part three of a bad movie with no ending.

In September 2009, I did Gamma Knife. It was a 12-hour day. In the bed beside me was Sister Mary. As we both prepped for Gamma Knife we began to talk. I felt like I had found new strength. She made me a rosary while both of us lay in our beds waiting for our turns. They physically screwed a helmet to my forehead, I felt pressure for a few seconds then it went away. They did an MRI, CT scan and an Angiogram. I was mentally and physically ready to go in for Gamma Knife when the doctors brought us new news about my AVM. For a minute I thought I was doomed with this AVM for the rest of my life. They had re-imaged it and calculated new measurements determining the AVM was even larger than the Gamma Knife could treat, meaning that a new strategy would have to be laid out; which is what they did and finally got me into Gamma Knife.

A year and a half into Gamma Knife treatment, I'd had some scary focal seizures, convulsion A year and a half into Gamma Knife treatment, I'd had some scary focal seizures, convulsion seizures and swelling of the brain as a result of radiation. I was regrettably on 3 cortisone tablets per day (now down to half), my seizures are minimal, almost unnoticeable. I have gained a ton of weight, which is a side effect.

I am now two years into my Gamma Knife treatment and I had the most amazing news from Dr. Schwartz, he informed my family and me that 90% of my AVM has disappeared due to the treatment. We were all amazed. I had a good feeling but I didn't think it was going to be this great! Now I wait again, as next year on Aug 29, 2012, I will go for another MRI and hopefully Dr. Schwartz will inform me that 100% of my AVM is gone and I can move on from this chapter in my life...

And so the journey continues with my fight against my AVM.

Melissa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

I started having headaches about 3 years ago, I never thought much about it until one day when I was asking my son to please be quiet, he finished my sentence by saying "you have a headache." That was when I started to realize I might have a problem.

I went to get my eyes checked because my vision had gotten pretty bad and the eye doctor told me my optic nerves were swollen. So from there I went to the optho-neuro. I had an MRI done and no tumor was seen so she told me I had Pseudotumor Cerebri. She put me on Diamox and ordered a spinal tap.

I was better for a few months, and because the Dr. made it seem like no big deal and the side effects were awful, I stopped taking the Diamox. I mean all she could tell me was that this was common in healthy overweight women. I am 5'6" and I have never weighed over 150 in my life.

It took a couple months but my headaches returned and my vision got worse again. I went back to the optho-neuro, where she put me back on Diamox, and still showed little concern about the issue.

On my next visit as I am telling her about the side effects and she is not listening and telling me it is all normal, I mention that I have a rash. She tells me to stop taking the Diamox and sends me to a neurosurgeon.

He goes over my MRI and decides that I need an LP shunt (Lumbar-peritoneal shunts are usually used to drain excess cerebrospinal fluid in neurological disorders). A month later (on Valentine's Day), I am in the hospital recovering from my surgery. When I wake up I feel great (except for the pain in my side and back). My head feels fine and I can see. And

I was fine, all was great… for about 5 days. Then I started getting swelling in my back around the scar and it got bigger and bigger, so I went back to the neurosurgeon. His theory was the catheter around the shunt was not connected properly, so they did a blood patch, but it did not work. So they did another one, yet it did not work either. So I went back in for a revision.

So 1 month later (on my birthday), I am in the hospital again for my revision. Afterwards I felt OK; not better, not worse, but OK. About a week before the revision I got sick and every time I would cough I would get the worst headache ever.

No one seemed to listen or put the two together, I don't know. But my husband took me to the ER for the headache 1 week after the revision and they decided that I needed a CAT scan and another spinal tap.

When I went back to the neurosurgeon for my post-op visit and told him what was going on, he ordered another MRI. After comparing the previous MRIs and cat scans he decided I had a Chiari Malformation. Apparently I had it this whole time, just no one noticed it.

The next few weeks were awful as the symptoms got worse and at this point all I could do was lay around and do nothing.

When I went in for the decompression surgery I was hopeful. Even afterwards I was still hopeful. Even though the headaches never went away, they made it seem like it was all normal. But now all of my symptoms are back, and getting worse. My neurosurgeon has retired, and the optho-neurologist has me so sad that all I want to do is cry. She told me that there is no one else here like him, no one that does what

he does, and the chances of finding a surgeon that will do surgery to fix a problem that another doctor started fixing is hard to do.

So here I am—I have headaches every day, my vision is getting bad again, my ears hurt, my head is tender to the touch, my periods are excruciating, I have severe abdominal pain, and now back pain from the shunt. So now I wait. As the doctor said, "let's procrastinate; maybe it will go away on its own." Not that that's what I want to do.

Mandy-Sue
Patient
Georgia

My episode began, I feel, in the dentist's chair. While having a root canal, I felt him hit the nerve in the mandible (the lower jaw bone). The next day, however, I was riding my bicycle, taking pain meds and had an accident hitting my chin on the concrete. When I went back to the DDS (dentist) complaining, he sent me to an endodontist (who work on root canals), who did the same. It was so painful an event that both times, I came out of anesthesia. The pain was unbearable and the DDS said that I had a neurological condition and he told me to see a neurologist. After many neurologists, radiation surgery and then a micro-vascular decompression surgery, nothing had changed, except now the pain was affecting more of my facial nerves.

When I returned to UF after the MVD (microvascular decompression), I was told, "If you didn't have it then, you definitely have it now." I went directly to the neurosurgeon that had done the radiation therapy. He had warned me that I could end up with Anesthesia Dolorosa. I guess I was too desperate and grabbing at whatever I could to help me. He diagnosed me with that disease afterwards. I eventually had a Medtronic pain pump placed under my skin and connected to my spinal cord to receive opiate meds directly to my spinal fluid. Eventually I was taking an enormous amount of pain medication within 2 years. Some of it was oral and some intrathecal (pain pump). Granted, this all happened within a 12-year period.

At some point, the pain doctor thought that I might have opiate-induced pain. I was so afraid of pain and this was hard to comprehend. However, I did go get help to get off these medications and after several months, the pain wasn't as bad. However, I did still struggle with incredible pain on

bad days. I still do. I am now taking Tramadol, Xanax and Neurontin to help me cope with the pain and anxiety (and stress does also set the pain off). They help me very much and if that is not working, I go get an ice pack and/or take a dose of Trazodone to fall asleep. Sleep seems to be my only refuge from the pain.

I am however, going to see a new doctor at Duke Medical Center. I will never give up on finding a cure or a better way of coping. This all started when I was an active scuba diving professional and world traveler. Happy to say that I lost 50 lbs. when I stopped taking the narcotics and that I am going to be diving again soon.

Julianne
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Durham, NC

I basically had all of my teeth pulled, got dentures, and have been dealing with TMJ (inflammation of the temporomandibular joint that connects the skull and mandible/lower jaw that results in pain and impairment) and Nerve issues for the last 8 years. I have had 4 nerve blocks done, 2 TMJ injections, and am still dealing with issues.

Rob
Patient
Alexandria, MN

On 11-03-1999, I learned a new word, "Adrenoleukodystrophy." This is the day that changed my life.

I got to meet my mother and my half-sister for the first time.

At that meeting my li'l sister wrote this long word down for me to look up when I get home.

Wow, sis, thank you.

Jamie
Adrenoleukodystrophy
Adrenoleukodystrophy Support (www.AdrenoleukodystrophySupport.org)
Patient, parent
Lancaster, California

I was nine when I had my stroke. I had just gotten home from school and off the bus in my neighborhood. I sat down at our dining room table like I had for years to start doing my homework, when I began to have the hemorrhaging and nausea.

Jerrod
Arteriovenous Malformation
*AVM Survivors (*www.AVMSurvivors.org*)*
Patient
Lubbock, TX, USA

My name is Reginald Sr. (Reg for short). I am 53 years old. I live in the City of Calgary, Alberta, Canada.

It was April 7th, 2011, when my world was turned upside-down when I had a "Stroke." I woke up that morning and my roommate, Sharon, brought me up a morning coffee. I got up, put on a vinyl record album, and went down on my bed. I was busy typing on Facebook—"A Thought For The Day" for all of my "Friends" and "Loved Ones." I reached over and took a sip of my coffee, grabbed a tissue, and blew my nose. Next thing I knew... I was on my way to the hospital.

I was in the hospital for 10 weeks. I went from wheelchair to walker and now I have a cane. I discovered that I have Diabetes Type 2 as well as "Ataxia." It has affected my left side of my body.

I feel soooooo alone... due to the fact there is no "Ataxia" Support Group here in Calgary (not too my knowledge anyways). I'm in my bedroom almost 24/7. And I feel so useless. If anyone out there knows of an in-person support group, please [let me know].

Yours Respectfully...

Reg Sr.

Reginald Sr.
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Calgary, Alberta, Canada

I have a Synovial Sarcoma in my calf on my left leg. I have only had one treatment of chemotherapy so far which seems to have gone quiet well. I will have a further treatment in three weeks and then they will review my CT scans to see how things are progressing. This is pre-surgery chemotherapy and I will either have a 3rd treatment or they will try radiotherapy to reduce the size of the tumor prior to the surgery. I will then have post-op treatment.

The hardest thing at the moment is just not having the answers or being able to plan what I will be doing or where I will be. IF's and BUT's are currently the order of the day.

Julie
Synovial Sarcoma
Synovial Sarcoma Survivors (www.SynovialSarcomaSurvivors.org)
Patient
Brandon, Suffolk, UK

My daughter, Tal (now aged 8½), started complaining about a severe headache on Friday night (25th December 2010). She suddenly started throwing up. I took her to the bathroom where she passed out. I ordered an ambulance and we were taken to hospital. There, the doctors debated whether or not to give her a CT Scan. They eventually gave her the scan and told me that she had had a bleed from an AVM and explained the meaning. Tal was in the hospital for three weeks; two of which were in the PICU (Pediatric Intensive Care Unit), during which time she had a drain put into her head to get rid of the blood.

People all over the world were praying for Tal's recovery. When Tal woke up ten days later, she was admitted into the hospital, where she could hardly talk and move. Slowly, and with help of physiotherapy she started walking and moving around again. Since then Tal has had a few angios including one embolization to "zap" part of the AVM, and a long brain surgery in order to get rid of the rest of the malformation. Tal is now a regular kid, just like before and we thank God for saving her life and all the people who prayed for her and helped us through the difficult times.

Sarah
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Israel

It was Christmas morning 2008 as I was standing in front of my bedroom mirror, getting ready for a big family breakfast that we do every year when an EXTREME headache came from the right side of my head and I mean EXTREME! I fell to the floor because instantly I lost all the feeling on the left side of my body. My mom barely heard me screaming her name as she was just in the bedroom next to mine. I was rushed to the hospital and they did an immediate CT scan and found that I had an AVM that had ruptured and I had bleeding in my brain the size of an apple. I had to have immediate brain surgery where they removed part of my skull and also discovered a second smaller AVM. I remained in the hospital for 4 months, and I had to learn how to walk, talk and do everyday normal things again like holding a fork and using a knife. I went through extensive physical, occupational and speech therapy. 1 month after being released I developed hydrocephalus and had to have a V.P. shunt (ventriculoperitoneal—to relieve pressure inside the skull) placed and a month after that I developed SEVERE epilepsy, for which I am currently taking 3 different meds and just recently had a VNS therapy stimulator (VNS = vagus nerve stimulation) placed to help control the seizures. I must also mention that when my AVM rupture occurred that Christmas morning, I was 24 years old and 6 weeks pregnant! Thank GOD my daughter survived and was born healthy in 2009 and I also have made a great recovery. I still have some lingering issues but the surgeons originally told my mom that I had an 8% chance of surviving that 1st surgery. This has taken a toll on my life emotionally for sure, but I keep pushing forward through my faith and my loving friends and family. It's helped me not take life for granted anymore and it's made me a better person. I can deal with the side effects

because I could have died, and my daughter, who is now 2 years old, could not have had a chance at life. So in a weird way I'm grateful that it happened.

Kellie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Skokie, IL

I had been ignorant about AVM till it hit my family. My son was diagnosed with it last January 2011, and has gone through a lot of appointments and tests and finally surgery. I literally came down on my knees and prayed when it happened. It was the most devastating day ever for me and my family. I couldn't think straight but I had to force myself to face it because there was no other way. I wasn't prepared for it since what he had was asymptomatic. I didn't realize the headaches he had been experiencing were part of it.

Alexander
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Parents of AVM survivor Friend/Family/Caregiver
Toronto, Canada

Immediately after my daughter was born on 7/29/04, I developed a bad headache, though this wasn't abnormal for me as I'd had migraines for years. The headache was soon joined by a stiff neck, which again wasn't uncommon, so I ignored it. I couldn't take medication because I was pumping breast milk, and the headache got progressively worse. On 8/4/04 I woke my husband up at 1:00 a.m. to take me to the ER. Once we arrived there I soon passed out from the pain. I was rushed into emergency "rescue" surgery, which saved my life. I spent 7 weeks in the neuro ICU and was finally transferred to Kessler Institute for Rehabilitation, where I had to re-learn how to walk, talk, eat, etc. again. While it was a horrific experience, I now have a new appreciation for life and my family. I have some short-term memory loss issues, but that is minor in comparison to what could have been.

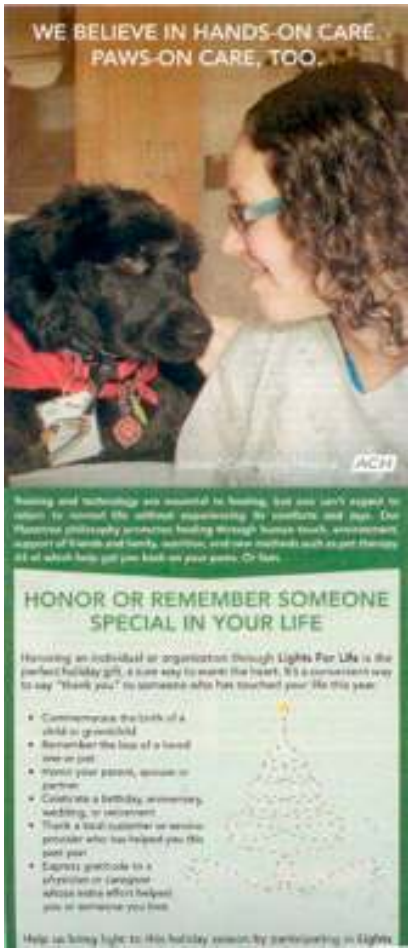
Karen
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Clifton Park, NY

My story started when I tested positive for swine flu 2009, which was followed by Lupus. I had to learn how to re-live my life, including how to eat things, which means I can no longer eat the things I used to eat. I have to watch germs. I had flu and pneumonia twice each last year. I cannot do fluorescent light or sun.

That brings me to a topic here… WE NEED to do something about our stores, libraries, doctors offices, and public places where people might be photo sensitive, as they took away regular light bulbs. I would have NEVER cared about these lights until I got Lupus of the skin (Discoid). I also had seizures from those lights.

Rachel
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Warren, MI

In 2005, I operated a very successful orthodontic practice; I was presenting cases and even invited to participate in an exclusive clinical excellence organization. I loved my wonderful office team and all of my patients. We laughed, cried and shared stories. I also raced bicycles, à la Lance Armstrong, and was second in the state for road competition. I decided to participate in the Masters National Championship competition. The most important thing I was to experience was marrying my favorite human being. We met racing, became training partners, and "whadda ya know." My gift to him for the wedding was a custom racing bike, a Landshark, of which I had three. We went out for a blessing ride, his first time on it. As we came back into the valley I challenged him to a sprint. I was ahead but then went down. I will never know why. Fortunately, a car was coming the other way and the woman driver called 911. The ambulance got me to the ER where I was in a coma for 11 hours. When I awoke, I could not speak and was completely paralyzed on my left side, eyebrow to pinky toe. I had split my brain in two and crushed my right side, a serious brain injury. I stayed in the hospital for six weeks, re-learned how to speak and walk, got out,



sold my orthodontic practice and started a new life. I still cannot remember all of the first five weeks of hospitalization and when I got home I didn't remember my city, my house, anything in it, or anyone except my then-fiancée.

As soon as I could understand the process, I got online to read as much as I could about brain injury, including medical research articles. So I began to undertake actions as described to help myself recover. I then got a Portuguese Water Dog and began to do therapy with him. We go to a hospital, to the local Veteran's Administration Domiciliary to work with the Veterans (truly inspiring), to an elementary school where we taught three troubled second graders how to read last year (and are working with them again this year), and we also see Hospice patients to comfort them and make them feel seen and make them laugh.

When I lost my orthodontic practice, the thing I mourned the very most was connecting with others. My dog, Rondeau, is my vehicle to regain this ability, to re-become inspired with purpose. I now have to think really hard to find something to complain about. Life is full and beautiful.

Kelly
Traumatic Brain Injury
Traumatic Brain Injury Support (www.TraumaticBrainInjurySupport.org)
Patient
Ashland, OR

Mine started last winter of 2010 with a slight earache. I had this all winter with it coming in spurts and jabs, and sometimes as a slight ache for longer lengths of time. I let it go because I was a school bus driver and thus was outside and in a cold school for hours every day. Needless to say, I thought it was an ear infection coming on from the cold and wind, so I went to the doctor. "Nothing wrong," he said, so I simply wore a hat. Not helping, I dealt with it all winter.

As the spring came, it got worse with more intense pain. I went back to the doctor in June and saw a different doc in the office who told me he thought it was a virus and sent me home. By July it was unbearable and was starting to spread to my jaws and cheek. I went back again and saw my regular doc who said he thought it was a bad sinus infection and put me on antibiotics. Within a week I was in a full-blown attack. The whole left side of my face, ear, upper and lower jaw, cheek and eye…. zaps and mind-blowing hot poker-like pain. I thought maybe it was a bad tooth so I went to my dentist, who in turn took x-rays and said that it was not the problem and he thought it sounded like TN. I ran to my regular doc who was quite surprised at the diagnosis and agreed. He put me on a few different meds throughout the month of August, during which none were working. By September I could not take it any longer. On the evening before my first day of school (Monday) I had the worst attack yet and it had started the Saturday before. With no sleep for 3 days I knew I could not make it to work or drive children in that shape, so at 4am I went to the emergency room. The nurse there said she had had TN also and knew what I was going through and the doctor there gave me pain meds. He agreed that it was TN, suggested a Neurologist and sent me home. I called and went to the specialist, who was a mean man who insisted I

had a cranial headache… that I did not have the pain where I was saying. I ended up arguing with him that he was wrong and he started treating me as a child. By the way, he was young enough to be my child. He ordered an MRI and sent me away with 12 months worth of Gabapentin. He faxed the results to my doctor and his results were that there was no sign of TN and that I had some sort of cranial head ache. My doctor told me that he feels that my TN may be caused by something else besides the Trigeminal nerve and, further, thinks there may be a cure if we can find the real cause. He now has me on Gabapentin, Trazodone, Prednisone and Cymbalta. The meds were not helping 100% and I was still having attacks here and there with jaw pain still happening almost every day. It wasn't until he finally gave me the Cymbalta that the pain finally went away. It is now October 2011, and he finally told me not to go back to the specialist and to go to a medical center here in town that has a special neurology group. I have a call in there with them now and am waiting on them to call for another MRI and maybe a cure.

Allison
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Albany, NY

I was diagnosed with Chiari malformation at age 48 and had decompression surgery at age 49 (10 months ago). Now, I feel much better; but am not cured, just relieved of some symptoms.

Fran
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Erath, lA

For the last 37 years I have questioned my own mind... Is there something wrong with my head? Is this really happening? Because the doctors tell me nothing is wrong so go see a "shrink." SO I DID... but it didn't help. I have EA2, which is ataxia that comes and goes, and it would disappear by the time I saw a doctor.

With the help of the Internet I became a research fanatic. I found out all I could and went to my family doctor and asked for a good neurologist in M.S. I didn't even bother telling my family doctor about any of the research I did. The neurologist did all HER tests and everything came out fine so I then approached her about doing a DNA test for episodic ataxia (they do not want you to tell them how to do their job and I understand that). She listened but there was no test for EA2, just a test for mutations in the CACNA1A gene for Familial Hemiplegic Migraine type 1. She explained that those with FHM1 usually will also have EA2. A month later, she called with results showing a mutation of 3-base-pair deletion of AAG in nucleotide position 3607_3609 at Codon 1203 with an Amino Acid Change. This one was never documented before I was told. I was DELIGHTED that it was not my imagination finally. Now I am researching something called Hypokalemic Periodic Paralysis (an owner's manual). I believe this is overlapping the EA2. I am on their website and studying the similarities, as I did with the ataxia sites. Once again I am in the process of emailing doctors, universities, etc. to see if they have worked with ion channelopathies of this sort. It saves time on useless tests, your frustrations and peace of mind. I have many stories but this is where I start and I hope others will too.

Ben's Friends is for the well-being of your mind and heart... people listen... and people believe... It is our future's HOPE.... SO LET IT START THERE AND MAKE IT YOUR HOPE TODAY.

Debbie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Algonac, Michigan

I was 39 and "living the dream." We lived near the coast in Florida, were happily married with 5 beautiful children, and I was a stay-at-home mom. I volunteered most of my days away… worked at the elementary school as a room-mother and fostered some stray pets left homeless as a result of Hurricane Katrina. For some crazy reason I decided I needed another baby at 39. I thought that since I could still run and win a Marathon that a pregnancy would be a piece of cake! Getting pregnant was the easy part. Then, as my husband says, "the wheels came off." I suffered a previously undiagnosed AVM (brain aneurysm), resulting in a stroke with paralysis and mental injuries. My husband was at my bedside for 4 months in an already-weak economy and thus lost his job! Our home went in to foreclosure and was eventually lost, forcing us to move out of state away from all friends and our support system. The whole slide has been way too much for my husband to bear and he has since filed to Divorce me (I know; not a happy ending).

Nicole
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Pittsburgh, Pennsylvania

In 2008 I got pregnant and became very sick. In February 2009, my son was born two months early and had to spend a month in the NICU (Neonatal Intensive Care Unit). I thought that after I gave birth I would feel better, but I did not. One morning in August, I woke up feeling like I had an elephant sitting on my chest. I went to the emergency room, where the doc listened to my lungs and said that they were clear but my breathing looked like asthma. So he sent me home with an inhaler and told me to follow up with my doctor. Well, two weeks later I went to the doc, with no change, and she said the same thing the ER doc said, but also decided that it was time to do an x-ray. Well, it turns out I had fluid in my lungs. She put me on meds, but they didn't work. So she put me in the hospital. The doc there thought I might have a blood clot in my lung so he sent me for an MRI. That is when they found an extremely excessive amount of fluid around my heart. They sent me to Indy to have heart surgery. The only thing I really remember about the hospital is when I first got there, coming around the corner on the stretcher and seeing HEART FAILURE UNIT on the wall in big letters. My only thought was why can't it be heart CARE unit; I'm only 25 and I shouldn't have heart failure. Well, after the surgery they ran a bunch of test and learned that SLE LUPUS (systemic lupus erythematous) was the cause.

Now 2 years later it still hits me hard sometimes to think that Lupus almost took my life before I even knew what it was. It's so frustrating dealing with this. Being so limited and unable to work at only 27 is not what my life was supposed to be. But it is my reality and I'm living with it. There are days that are harder than others but I push through and do what I have to. When I'm feeling down I look at what I have and know that no matter how I feel in that moment, no

matter what happens, my life is good because I have the love of a wonderful man and our son.

Jenny
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient

Having GPN has been an experience that I wouldn't wish on anyone. When it hits it feels like someone shocks me with a cattle prod at the back of my throat. Sometimes it doesn't last very long, but sometimes it lasts for 15-20 seconds.

With this last session that happened I am wondering if I brought it on myself. I went on a bungee swing ride with my son in Colorado, that kind of jerks your head and the symptoms started the next day. After I got back home and thought about it, I made an appointment at the chiropractor's office and got an adjustment, and symptoms lessened and then went away. Also, I went to a neurologist so am not sure if it was chiropractor or the drugs, but either way I'm not complaining!

Sally
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Van Horne, IA USA

Diagnosed 4 months ago. Stage II synovial mass on my left hip. Surgery was 1 week ago to remove enough margin around the mass; they removed 20% of my quadriceps and 50% of the tensor fascia latte muscle.

Ever since being diagnosed, I've been a full-time patient. And every day, it seems like I'm living to make it to the next. This is very short-sighted, because I'm healing well, and in good health overall. The mental game is so crucial, but it's difficult because everything is in terms of life expectancy and 5 years.

Chris
Synovial Sarcoma
Synovial Sarcoma Survivors
(**www.SynovialSarcomaSurvivors.org**)
Patient
Chicago, IL

I have Von Willebrand's that was only diagnosed when I was 50 years old. I now am living with not only this condition, but also Osler-Weber Syndrome (AVM's). Just this weekend I was released from the hospital after my 15th transfusion in the last 26 months! I had my first transfusion at 5, due to a severe case of chicken pox.

Menopause was a relief for me—no more 10-day very heavy periods or DNCs to stop the bleeding. I got my gene from my mother, so nose bleeds, heavy menstruation, anemia, etc. were part of the normal landscape. I was diagnosed only after a sibling didn't clot following a wisdom tooth extraction.

WE MUST GET BETTER DIAGNOSING! Especially for women of reproductive age!

I hope this forum will now help myself and the rest of us to get the general public more informed—ignorance is not bliss!

Dianne
Von Willebrand's Disease
Living With VWD (www.LivingWithVWD.org)
Patient
Washington, DC, USA

My daughter was 18 when diagnosed with a large, grade 5 AVM on the left side of her brain. While she is in good spirits most of the time, she has an occasional rough day and my heart just breaks for her on those days. After meeting with several doctors in two states, we feel blessed to have decided on the ones we chose. Not only do they seem knowledgeable, they have wonderful demeanors and admit that they don't always have the answers we may be hoping to find. To date, she has had CT scans, MRI's, a functional MRI, an angiogram, fiducials placed and LINAC radiosurgery treatments. Now it's a wait-to-see if the treatments will work. She will have MRI's about every 6 months until they determine there is no more progress. At that point, they will also determine if she should have another round of treatments or if they may be ready to get in there surgically to begin removing some of the AVM. We are currently told that this will be in stages as it is quite large and complicated. They are concerned about the potential risks of motor skill damage, speech and language issues, and mostly vision loss. So, while we are all anxious to have this mass disappear, we do not want to rush into that final step.

We have so many family, friends, co-workers and those we don't even know who are praying for her and for her doctors, and we are so thankful for each one of them. It truly helps to know others out there care and we are not alone through this journey. My hope is that all who read this will find the same peace in the midst of uncertainty.

Beth
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Grand Rapids, MI

Hello, everyone. I have Psoriatic Arthritis; diagnosed 1 year ago, although I believe I have had it for many years prior to diagnosis. This disease appears to be very difficult to diagnose as it moves the goal posts on itself. I have had bad lower back pain now for approximately 15 years. The Psoriasis appeared about 5 years ago but at the time only inside my right ear canal. I still have bad lower back pain as well as pain in my left buttock, down my left leg, and in both ankles and feet. I sometimes get it in my right elbow but steroid injections are holding, so have paid off at the moment. Approximately 2 years ago I was suffering with extreme pain in my coccyx, which made it impossible to sit unless leaning forward. After trying many painkillers, physio, etc., I found success in joint injections—a lumbar epidural followed 4 weeks later by injections directly in to the coccyx area. I now take Methotrexate and also have a morphine patch to help with the constant pain. This enables me to continue working although some days I feel very uncomfortable sitting and I also get extremely tired, which can completely wash me out.

I try not to give in to this illness although there are many times that I have to listen to my own body telling me to give in and rest, not fight it all the time. I have found it best for me to take the methotrexate on a Saturday morning—after breakfast. I stay standing for at least a half hour afterwards and I think this helps a great deal in avoiding the nausea that some people get from this medication. I find it hard to wear shoes/sandals as comfort now is most important. I take in all the advice I can and use it to help me in whatever way

necessary. I take my hat off to all sufferers and send hugs to you all. X

Jeanette
Psoriatic Arthritis
Living With Psoriatic Arthritis
(www.LivingWithPsoriaticArthritis.org)
Patient
Bedford United Kingdom

I have Gluten Ataxia. What that means is if I eat even microscopic amounts of wheat, barley, or rye then I can't walk, talk, or think for the following three weeks.

It started slowly about seven years ago when I became progressively fatigued and weak. I worked part-time then and would be barely able to get my work done, then dragged myself home and laid down the rest of the day. It took everything out of me. I was too exhausted to do anything. Over the next few years I noticed I was becoming quite clumsy. I was dropping and breaking things all the time. I broke every coffee cup we owned in four months. I could no longer stand for more than two minutes at a time. Eventually I would just drop to the ground to sit if there was no seat within reach.

My walking became odd. My right leg would drag and my left leg would swing out and forward too much. I was hanging on to walls to walk and would shuffle along so the dragging wasn't so obvious to others. My right arm stopped swinging naturally during walking. My head began to droop. At work I would find myself so exhausted I would lay on the floor of my office cubicle.

My brain felt fuzzy. I called it a brain cloud (from the movie, *Joe vs. the Volcano*). I began to not understand what people were saying to me as if they were speaking an unfamiliar language. Emails were hard to understand and I complained, "Why isn't this in bullet or list format" because I just couldn't wrap my brain around the information. I started making HUGE mistakes at work. It was brought to my attention a number of times and I was pretty sure at first it was someone else's mistake. I had never been incompetent before.

I was diagnosed with many things that really just related to my symptoms, but did not address the underlying cause of all of my health issues. They found I had osteoporosis (at 47), fatty liver disease, and neurological pain (it feels like I'm getting poked with an electrical cattle prodder). I was told I had Fibromyalgia. I don't. Everything hurt. Extreme dizziness and super dry skin were also a problem. Thyroid disease.

This went on for years. I had been active and "bright" and then would come into the doctor in a wheelchair with my head dropping and the doctor would say "what are you here for today?" I was too fuzzy-headed to ask or explain anything. Finally my husband came to a doctor's appointment with me and pushed for referrals to specialists. After about nine months of endless testing, my rheumatologist (I also have a lot of joint pain) called to say, "You have Celiac Disease (CD) and need to see a G.I. (gastrointestinal) doctor." I had NEVER experienced any tummy symptoms and had not ever heard of CD.

It took about 2 months to see the right G.I. doctor in town who was very knowledgeable about CD. I got an upper G.I. scope done and was in fact diagnosed with CD. The treatment; a 100% gluten-free diet for the rest of my life.

Fortunately my G.I. doctor was willing to work with my neurologist and they both agreed I have Gluten Ataxia. My neurologist had never heard of this before, but now sends patients who look like they have multiple sclerosis with negative MRI's to my G.I. doctor to get tested for CD.

I had been tested with what's called a neuropsych eval (neuropsychological evaluation) before I was diagnosed and have had two (since going on the required gluten-free diet) a year

apart. The first test clearly showed my short-term memory was in the low 9% for my age, educational background, and IQ. My focus was in the low 7%. After being gluten-free for about a year the short-term memory and focus were significantly improved and I was close to the "normal" range. The following year I happened to have accidentally ingested some gluten and my test results again showed me back in the low single digits for short-term memory and focus. There are other functions of my brain that are also affected by ingested gluten, including walking, depth perception and language. The doctors are not sure if it's inflammation reaction or an autoimmune response in my brain, but it's not good. Every episode of being "glutened" I seem to not regain some of my function. So it's progressive in that regard.

Our entire home is gluten-free and I'm grateful for that. Yet hidden gluten still shows up in processed foods. Recently a salsa we had purchased many times as it was gluten-free changed its recipe and started adding barley as a sweetener. No warning, of course. There is no law in the USA that says what constitutes labeling for gluten-free. So any manufacturer can slap on a gluten-free label and it really means nothing. Dining out is a huge challenge and I rarely do dine out because it's just not worth the risk of cross-contamination. It only takes 20 ppm (parts per million) for a reaction.

When I have a gluten episode I need to use a cane or wheel chair for a least three weeks and I'm too fatigued to do much more than lie down all day. I can still (Praise the Lord) get myself to the restroom, but that's about it.

Because it's so easy to get accidentally "glutened" and then be unable to work, I am receiving disability.

Neurologist Marios Hadjivassiliou, MD, of the UK, is the only doctor I'm aware of doing research on Gluten Ataxia. I have provided my doctors with copies of his research and my G.I. doctor has even called and discussed my case with Dr. Hadjivassiliou.

My husband has been wonderfully supportive and has even switched to gluten-free in support of me.

Some of my health issues were resolved eventually by going gluten-free, but not all. Because I was older (51) when I was diagnosed and had been sick for years it's likely many problems will never be resolved. Keep in mind that Celiac Disease was causing me to suffer from malnutrition, so every part of my body was affected.

Julie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
American Ataxia Networking (www.AmericanAtaxiaNetworking.ning.com)
Patient
Colorado Springs, CO, USA

I think I always feared in the back of my mind that at some point in my life, I would get cancer. My mother had passed away 5 years prior to my diagnosis from leiomyosarcoma, an equally rare and bizarre form of cancer as mine. However, I thought I would be late into my 60s or 70s after raising my small children, not at age 35 as it actually happened.

My journey began with having leg cramps during my second pregnancy, but I foolishly made excuses for 4 years of why it was not significant. Finally, when my calf was too tender to the touch and coupled with not being able to fit it in my dress boot, I decided to have it checked out. I must say that if I have learned anything from this experience it is to be tenacious with my own, as well as my family's, health care. The first two doctors I saw, read the MRI results and told me that although there was a tumor in my calf, they would not recommend removal since it was so small and unremarkable. Further into my treatments and test results, I've learned to love the word, "unremarkable." For once in a person's life, getting "unremarkable" test results can be a good thing, which is counterintuitive going through school.

The final doctor, an orthopedic surgeon at UCSF, concurred with the previous doctors but said that if it was bothersome, let's take it out. I'll never forget the apologetic and surprised look on his face when he told me I had synovial sarcoma. He had to write it down on the paper drape over the examining table since I kept saying, "What is it? How do you say it? What are you talking about?" He had just removed the stitches from my incision when he cleared his throat and told me the results of the pathology report. I was in shock, totally devastated and what came to mind immediately was, "This is just like my mother." I couldn't fathom dying at age 35.

He looked me straight in the face and said emphatically, "This is nothing like your mother. We are going to get through this together." Those words stuck with me throughout 3 surgeries, 36 radiation treatments, and a scare it had spread to my lungs resulting in more surgery. He said we, not you. I never knew how two small pronouns could have such a huge impact. By including himself as a member of my treatment team I felt empowered and never alone in this terribly scary journey.

My doctor truly believed in me… and my recovery, and modeled this belief each time I saw him. His confidence was so crucial to my state of mind since my only other experience with cancer had been with my mother when her oncologist recommended she begin her good-byes and plans for her own funeral. He gave up so she did too. My oncologist never gave up on me.

Someone once said to me, "I'm so sorry you had cancer." But I'm not sorry I had it since I thought it would reach me eventually. I consider myself lucky to have the support system in place with my family but also to have a tenacious oncologist who believes in his patients. I am now nine years cancer-free.

Paula
Synovial Sarcoma
Synovial Sarcoma Survivors
(www.SynovialSarcomaSurvivors.org)
Patient
Cohasset, MA

My story started in 2002, with a regular trip to the dentist. I went in feeling fine and left in pain I had NEVER experienced in my life. The dentist told me I needed a root canal in a back molar. This was a surprise since I had no pain in my teeth at all. I went ahead with the root canal wanting to save the tooth. I knew before the procedure was even done that something was horribly wrong. I was in so much pain I couldn't speak, or think. My husband had to leave work to pick me up because there was no way I could have driven. He was shocked at my appearance but the dentist assured him after the pain pills took effect I would sleep it off and feel better the next day.

Since that day I have had pain. Mostly in my teeth, but I do have some in the left side of my face where the root canal was done.

All I could do was cry from the pain and so my husband took me back to the dentist. First he said it was a tooth that could not be saved and pulled it. I passed out from the pain right after the procedure. I went home with more pain pills and antibiotics. Still nothing got better.

Yet again, I went back to the dentist. This time he stated I had a dry socket and packed the hole in my gum with some gross smelling cotton. By the time I got home it had popped out and I thought I would die from the pain.

By this point my face was throbbing and felt like thousands of little knifepoints were being repeatedly stuck in my face. My teeth—both upper left and lower left hurt—as if they each were abscessed.

Fed up with the dentist, my husband took me to the E.R. My first of many, many trips there. They were tentative about

treating me; at this point I still had no idea what was wrong with me. It took two more trips to the E.R. and being dosed with pain meds so strong I couldn't tell anyone my first name, before a dental pathologist and neurologist were called in to look at me. In the meantime, I had MRI's, CAT scans, blood work, and every other kind of test imaginable. Everything came back negative; they could find nothing wrong with me.

It was a younger med student who was the one to diagnose me. I was lucky she came in and knew what I had. She only recognized it because her own mother and brother suffer from the disease.

I finally had my diagnoses but there was no relief in it. I have Trigeminal Neuralgia. And it has no cure. I was told it could be controlled with the right medications, which did give me some hope.

This began a series of doctors pumping me full of medications that made me sick, made me gain tons of weight, made me unable to function with any decent ability, made me more depressed than I already was, and that is not even counting the pain pills they put me on.

From Hydrocodone all the way up to straight Morphine. I was put on all of them at some point. At my worst I was taking 80 mg of Morphine, liquid morphine, a day. While Morphine could at least take the edge off the pain, where no other pain medication came close, I ended up with an addiction to it. I spent 7 weeks weaning myself off the Morphine slowly and even as slow as I did so, I still suffered terrible withdrawals for weeks after that.

I finally found a doctor wiling to treat my condition with something other than pain meds and went on Tegretol. Within weeks I felt as close to my old self as I had in three years. I still had pain but it was almost bearable. And I also had a day here or there that I had little to no pain.

The Tegretol was a miracle drug for me. At least for the first year, then my blood cell count went way down and I had no choice but to stop the Tegretol. From there they tried, Prozac, Gabepentin, Dilantin... nothing worked.

I was so depressed that I stopped eating, drank only enough water to survive and stayed in a dark room, in bed. I really thought my life was over. I had a family, a husband and three little boys to take care of and I could not even take care of myself. Those were dark days for me, very dark thoughts passed through my head.

Fearing for me, my husband brought me back to the ER where they treated me for extreme depression. They put me on a stronger dose of anti-depressants along with something for the anxiety I was feeling over my pain. Within days I was out of bed. I still couldn't do much but at least I wasn't laying bed all day feeling so hopeless. I steadily got better, depression-wise, but my TN pain was not better. I could not take any pain meds because of my previous addiction to the Morphine so I sought out other options.

I now do yoga and practice meditation. Sometimes I find great help in both, sometimes I do not. The only medication I am currently on is Lyrica. It has caused me to gain a bunch of weight, which I am not happy about, but I do get some pain relief. Humidity is my worst enemy and living through St. Louis summers is very hard on me.

There are things I have not done since my first day of pain that I know I will never do again: play soccer with my sons, swim, jog, horseback ride... But there are things I CAN do: I have taught myself to quilt by hand, something I never thought I would be able to do, I still read when my pain is not at its worst, I can go for short walks on very mild days, with no wind.

I have learned to accept that, right now, this is my life. Until more is known about TN, this will be my life. I do hold out hope for better treatments and more medications soon. Until then, I take life one day at a time and love the people who love me. That is all I can do.

Gwen
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
St Louis, MO

I ended up with PS/AP about 2 years ago. I am allergic to the sun so I had to go on Humira. There are so many negative issues in taking the needle. Contracting TB, Crohn's, and Fibromyalgia. If this is not something you know of please don't hesitate to go to the Abbott Site. There is a list of many things that can happen.

At this point I honestly don't know what's happening. I have never been in so much pain on a daily basis. Even though I am on anti-depressants and pain meds, after a certain amount of time I feel that they don't work. My Dermatologist is sending me to a Rheumatologist due to this excruciating pain. Apparently the Humira is supposed to help with this, but it's NOT!! At this time of writing my fingers are swelled, I won't even go into where my pain areas are—they are everywhere.

I am on Canada Pension Disability however if it weren't for my hubby I'm afraid we wouldn't have our home. My son is very helpful. Taking me to Doctors, Dermatologist, etc. I can't say how much I appreciate him.

Again as I said you have to try and keep a positive outlook however after so long this turns to negative, anger, feelings of being useless, angry at the fact that I'm not the same person I once was.

Rita
Fibromyalgia, Psoriatic Arthritis
Living With Fibro (www.LivingwithFibro.org)
Living With Psoriatic Arthritis (www.LivingWithPsoriaticArthritis.org)
Friend/Family/Caregiver
Canada Ontario

Hi, I have previously written a story about my wife, the late Rajasri, and how she was in control of the situation and had a purpose to do whatever she wanted to do in India. There was an arranged marriage and at the first meeting my future wife told me she had a time bomb in her head (as told to her by her doctor at the prestigious AIIMS hospital in India) and gave me a bold option to either marry her or not with this frankness. I was clear about the marriage in 2003 when she wanted me to get established in my field. So the next 2 years she was moral support for me to get a steady job and in 2005 she wanted to start a family. In the meantime in January 2004 she had a gamma ray session at AIIMS and prior to that she had 6 embolizations at the same hospital and it was a painful process though she never did complain and always was in command of her life.

Coming back when she wanted to start a family, the doctor advised her to wait for 2 years after the gamma ray therapy. So she was very clear about starting a family in 2007 and when we were going nowhere she went to AIIMS at in vitro section wherein they did some painful test on her, like sampling from uterus. It was a very painful operation and on that day she went with me to visit the Vaishno Devi shrine that is a walk of 26 km. With pure determination and purpose, she completed that trip in April 2007. The very next day she was diagnosed with TB and she took the prescribed 6 months of medicine and with natural course she got pregnant in November 2007. We had a wonderful daughter in July 2008. I insisted a checkup for my wife's AVM though she was determined that until she is lactating she will not allow any radiation to her body for the baby and before her demise on the 3rd of June 2009 she frequently told me she will not live long and will go to the doctor after our daughter is 1

year old. Our daughter was 10 months and 10 days old when my wife died on the 3rd. The post mortem said a severe brain hemorrhage... I feel she was brave and knew her fate and achieved what was a miracle from the doctors' point of view with her sheer willpower...

Rajasri
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
India

I know my fibro was brought on by a very stressful life—the most stressful being my son's passing in 1997. He was just 17, trying to get away from a gang. When his best friends used him to save their own lives. Life will never be the same.

But you have to get up every morning put one foot in front of the other and try. You can do it! No matter how dark your dark days are. You will survive.

Trust me it gets easier with time.

Tessa
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Raleigh, NC

I was diagnosed with a left sided cerebellar AVM in April 2009. At the time my only option was to have it embolized and since I had a strong family history of cerebral aneurysms in my family, I felt this was rather urgent. My procedure was done in two parts as the AVM was rather large. After my second embolization, several days post and 1 day prior to discharge I suffered a bleed, I was rushed to a CAT Scan where I coded twice. My husband at the time was told by the neurosurgeon on call that if they operated on me I was likely to die but that if they did not operate on me I was for sure going to die. I spent 25 days in the critical care unit where I suffered a stroke and had a shunt placed. My family was told to not expect too much.

I was later transferred to the inpatient rehabilitation unit where I received rehab to strengthen myself as I had shown miraculously that I had no problems talking or walking other than issues with my balance. I have recovered almost to my old self, except that I am a lot slower in my cognitive processing, I still have balance issues and suffer from nastagmus and peripheral vision problems in my left eye and was recently diagnosed with sleep apnea. I get headaches more frequently than before and get tired quicker, but I am able to drive (that was my birthday gift to myself 7 months after I was discharged—after I made sure to take a special driving test at the hospital). I only drive during the daytime and only in the early day, not late. I went from taking 13 or 14 pills a day to 4, which are the absolutely necessary ones.

Most days I consider myself one very lucky person but as anyone who has ever gone through a traumatic event knows you have your good days and your not-so-good days.

Carolina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Homestead, FL

After suffering for many years with a wide, seemingly unrelated variety of the usual SLE (systemic lupus erythematosus) symptoms (including two bouts with a specific lupus-related form of meningitis), and then about five years with incredible joint pain (so intense I would often collapse climbing stairs or trying to stand from a sitting position), sudden skin rashes on my face and chest, and recurring kidney and lung infections, I was only diagnosed soon after my younger sister (with whom I shared many symptoms) died at 47 of previously-undiagnosed lupus-related heart complications. It took her death to inspire my first visit to a rheumatologist, where he examined me, x-rayed my joints, and took my entire symptom history going back 20-odd years (no one had been this thorough, but my symptoms had only been severe for about five years) and said that he was pretty sure I had SLE, but he'd have to run some tests to be sure. The next month he confirmed it.

He immediately prescribed as preventatives to further flares Placquinil, methotrexate. To quickly alleviate the most acute symptoms of the long-term flare from which I was currently suffering, he also prescribed the Most Holy Prednisone, the only drug for which I've ever 'jonesed' because of its miraculous ability to alleviate the worst lupus symptoms so quickly. But wouldn't you know, after plying me with a healthy stash of it after my initial diagnosis for about a year, and once my worst symptoms were greatly alleviated, he began to wean me off it due to his concern about its negative long-term side effects, which are documented and easily available on the Internet, so I won't bore you with them here. Since then, he and even my new rheumatologist act like the drug pushers in those cheesy afterschool specials, becoming stingy and demanding whenever I

am desperate for it in a flare, and require extra lab work to prove I need it and make me promise to make it last. When I occasionally get to pick up the precious commodity at my local Walgreens, I feel like a common criminal copping a fix. It wouldn't surprise me to learn that either of these doctors have their own limo, convenient neighborhood fence and an entourage of school-aged bodyguards.

Today, although the worst of my SLE symptoms can be fairly well controlled with preventive medicine and measures (avoiding the sun and alcohol, for instance), I have experienced progressively worse neck and spine pain, not caused by any trauma, and developed several other symptoms that are not lupus-related, but debilitating and frustrating nevertheless. After complaining about these symptoms to my rheumatologist, she now suspects that the culprit may be another rare and chronic auto-immune disease, ankylosing spondylitis. She explained that this AS effects joints and organs too, but mostly the spine, neck, and lungs, all of which torture me regularly in spite of the relief my other joints get from the methotrexate, Plaquinil, tramadol and the now scarce Prednisone. Since I don't have health insurance at this time, and the tests to confirm AS include specialists and at least one MRI to start, I have to postpone a diagnosis and treatment plan until my husband's insurance kicks in, hopefully by the end of 2011.

In the meantime, I pray a lot and use my support group to help me cope with the stress and frustration of living with unexplainable and life-diminishing symptoms. But at least

I've been through the process before and the light at end of the tunnel was not the oncoming train I feared, so there is still reason to hope for relief.

Patricia
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Boynton Beach, FL

For over a year I had been dealing with daily headaches. After realizing that they weren't going away, no matter what medicine I took, my husband made me go to our primary doctor. After insisting to him that I was not having migraines, he sent me to an eye doctor. That doctor did a through exam of my eyes to rule out a tumor that could have been behind my eyes where I felt the pressure from my headaches. His report showed no tumor and he didn't see anything that I needed to worry about. After seeing him my primary doctor decided to send me to a headache specialist to see what they could figure out. After speaking with him he scheduled me for an MRI and 2 weeks later (December 13, 2006) we got the results that I had an AVM on the left side, temporal lobe. Measuring in at 5cm (the nidus) and a 5 on the AVM scale. In other words it's a big AVM. He showed us the scans and before he said a word, I saw that on one side something was wrong. So we sat there and let the words seep in that there was really something wrong. From there we saw and spoke to 2 neurosurgeons. I had an angiogram done in January 2007, then 2 embolizations—one on March 6th, 2007 and one on April 9th, 2007, my first Gamma knife on June 20th, 2007 and a second one on November 17th, 2010. There was finally a change in my AVM at the end of the third year. But it's still there aggravating me, LOL. A lot has happened in the past 5 years.

So here I am 5 years later still waiting to hear the words "your AVM is obliterated." Someday I will hear those words and be happy again!! There is more to my story; too much to type and my memory lacks a lot of what has happened. Thanks for reading this, hope it helps someone!!

Andrea
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Tonawanda, NY

I have to write a book about myself so I will opt here to share the story about my 19-year-old daughter who was newly diagnosed with a chronic rare form of mononucleosis. She was born prematurely, 8 weeks and 4 days early and weighed in at 2 lbs. 14 oz. and her lowest weight was 2 lbs. 6 oz. She was born with a microscopic stomach and lived in incubator for 2 months. Finally came home at 4 lbs. 6 oz. and shortly after came down with Salmonella poisoning (common among preemies) so was re-hospitalized and medicated. She was sent home, then it was a long time for growth and development.

She has had many problems due to immaturity; she is asthmatic but only has periodic episodes of it. She had pneumonia as a 5-year-old. She had ear tubes 4 times. She went to Disney Florida in July 2009 and 60 days later came down with mononucleosis and became bedridden due to swollen spleen. High school became a nightmare due to this illness; she was homebound. Later cleared to go back to school, she got sick shortly after with horrible tonsillitis that resulted in the removal of her tonsils with complications of dehydration. So she wound up getting her GED after that. She got better from that only to get sick over and over again and finally a blood culture was sent off for diagnosis and it came back positive for mononucleosis yet again...her body will have Chronic episodes of mono from here on out.

Our family is on a trail of finding out about Chronic Mononucleosis since most people get immune after having it once. People around us are beginning to ostracize her because they believe that mono is contagious. Yes, it is contagious if you exchange SPIT (saliva); that is the only way you can get it. But there are ways to prevent that from happening...do not KISS

her please and do not drink after her...very simple! I fear that we will have to do much educating to a lot of people so they won't be afraid of her! She will also carry her own drinking glass so as not to use water fountains! Easy!

Anastasia
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient, Friend/Family/Caregiver
Eunice, LA

I worked at the same manufacturing company for 31 years when they suddenly decided they could have the work done overseas cheaper. I got out with my 401K, 6 months paid health care, and a thank you.

After working that long in manufacturing, including working my way up from a machine operator to plant manager, I figured I wouldn't have any trouble finding a job. That was 2004. After eight months of looking for work, I took a job for the state at a local medical school in the landscaping department making a third of what I was making per hour.

For probably two years, I knew something wasn't right. Sun sensitivity, often being so tired I had to make myself get up and work. (At my previous job, I seldom took a vacation, I guess I was a company man).

One week after working for the state, I was sitting at home on a Sunday morning reading the paper when first the left side of my face went completely numb, and then within seconds my left arm went numb. I told my friend who was sitting across the room, then my left leg went numb. In my mind I knew I was having a stroke. But I'd never had high blood pressure or arterial problems. We quickly decided I needed to go to the hospital so he started to help me up and I knew that wasn't an option so he called 911. I only lived eight blocks from a hospital, so I was there within 20 minutes or so and got that clot-busting drug. The stroke also affected the right side of my body to a much lesser degree. I spent three days in ICU before being moved to a rehabilitation hospital. I had daily physical and occupational therapy and went to stay with a friend for three months. I had three months of outpatient therapy three days a week. My Doctor and a neurologist kept looking for what caused the stroke.

Finally they ran one test that showed it could be Lupus. I started seeing a Rheumatologist and started on the right drugs for my condition. I honestly think I have more problems now than earlier on, but he helps me through them as much as he is able. A lot of my problems are related to the stroke and the area of my brain it affected. Pain is still a big part of my everyday life.

Jim
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Kansas City, MO. 64133

My TN crept up on me so very slowly. I thought it was a tooth problem & would brush it aside, telling myself I would mention to the dentist at my next appointment. Then one day taking a shower I got hit with the electric sensation. Talk about a "shock!" I was like, what the crap was that? But like I said, it slowly crept up on me, not happening again for several weeks. But when the never-ending pain finally did hit me I just thought of course "I" would get this unheard-of disease.

After a few years of taking medication that left me "stupefied" and forgetful and lazy and tired and old, I knew again I had to take matters into my own hands. So again I hit the Internet & found out about the cyber knife procedure all on my own. No referral from any doctor, only a TV commercial & several websites. I made an appointment on my own and that day was the beginning of the end for me. I had the procedure a little over a year ago and even though the pain was still there for a while, it is now completely gone.

Thank God I took matters in my own hands because I know I would still be sitting here "stupefied" from the meds!

Karyn
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Tampa, FL

I had just turned thirty, had a good job that I actually liked, was married with three children of our own, and a baby that we were fostering from birth and at this time was about a year old. I was at work one day feeling very flu-ish. But I continued to work assuming the feeling of illness would pass. After all, I was working ten hour days, taking care of my husband and children, and managing a house and several responsibilities at church, not to mention a self-paced class I was taking to better myself. It was somewhat stressful, so perhaps I was acting like a hypochondriac. That was just my life, and I loved it!

Well, as that day went by, I started to feel worse. A friend had told me that since I visited the doctors so much and he routinely asked me himself why I kept coming to see him so much when there was nothing wrong, she felt that I was acting like a hypochondriac. So going to see a doctor was out of the question! I struggled with photophobia, feeling faint, and pains that would every now and then shoot up and down my thighs. Finally, a co-worker who had a shunt in her head, heard me shriek from the pain I was experiencing in my thighs, suggested that I see a doctor right now, but then it went away because the location of the pain was a sign of a neurological issue. I hesitated at first but then I decided to go to a fast track place where I would be seen by an intern who took one look in my eyes and sent me to have a CAT scan. I went home after that and then, about twenty minutes after I got home, my family doctor called.

It was then that I received news that would change my life. It happened so fast, one minute I was like everyone else, or so I thought, the next minute I was dying! I have had five bleeds hours of surgery, and my husband divorce me because he

says he couldn't deal with the sickness, paralysis on my entire right side including my face. I have been in heart failure several times and now have an AED (Automated External Defibrillator), I lost my income due to not being able to work, I lost my home and my vehicle along with the ability to drive, and further I have nystagmus in both eyes along with right eye double vision and legal blindness. I actually lost custody of my youngest child because the court felt I was in no shape to take care of him. Maybe they were right, after all, I was in a wheelchair with people feeding, clothing, bathing me, and everything else I couldn't do.

But today, I'm not just existing; I am living. I regained most of my abilities including walking. I am a full time student who lives.

Katrina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Lauren, our 8-year-old died all of sudden Sept. 19th, 2010 of an AVM. We never knew she had an AVM. We we're running errands and stopped at the post office. She told her father she had a very bad headache and I was mailing packages. He massaged her head and she broke away from him and ran to me and I told her after I get the next package through the package slot we would go to the car. She collapsed in front of me. At first we thought she was playing around—she did that sometimes. She had a bit of eye and head movement. We put her in the car and backed out of the post office and realized she wasn't moving and her breathing was gargled. We raced her to the hospital—10 or 11 minutes away. We thought she had a concussion. Once in the hospital she had seizures, which she'd never had before and they gave her medication for seizures and took her for a CAT Scan. The ER doctor told me it was grave and that she had an aneurysm. They air lifted her to Children's Hospital in Phoenix. It took forever for them to get her there. We were in the first hospital for almost two hours before going to Children's Hospital.

Once at Children's Hospital the neurosurgeon gave us hope and told me he was going to do emergency surgery. We started praying and after 5 minutes he came back and said he studied her films and he didn't think surgery would help.

I begged him to open her head and relieve the pressure and try to do the surgery. He agreed and told me since it had been almost three hours since she collapsed that he just didn't know what would happen. After an hour the surgeon came back and told us she was pretty much brain dead. He tried to relief the pressure on her brain but the swelling wouldn't go down. She was on life support after surgery and for the rest of the day and part of Sunday. My husband and I spend the night with her—praying and praying, crying and praying. Hoping for any kind of change. Sunday morning there was no change. We didn't know what to do. The swelling in her brain was 85% and most people with head injuries that come back with some coordination and speech is 40%.

I kept hoping for a change. All the time the donor organization keeps coming in asking if you want to donate her organs. Which we didn't.

We took her off Life Support Sunday and our beautiful angel died. It's the worst pain ever.

Joanne
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Glendale, AZ

When I turned 30 my world changed. It started with a simple eye twitch, progressing into dizziness, two bad falls, horrible boring ear pain, a lump and pain in my throat, pain under and around my eye, 80% taste loss and lip numbness, and so on. After four neurologists, a spinal tap, numerous tests, MRIs and CT scans, it was decided that I had GN and TN. I was put on tegretol, which helped me to function again.

My job involved talking on the phone all day and one episode left me nearly unable to talk. I had to call off for four days. Eventually I was also put on Neurontin. My tegretol level was at one point toxic, causing me extreme migraines and sickness. Being on 1200mg of tegretol and 2400mg of neurontin, I was a zombie! It was very hard, especially as a single mom to do anything with my son due to pain and lack of energy.

While visiting family out of state I had such a bad episode that I begged my parents for help. My neuro, who was adamantly against MVD surgery, finally suggested it. I was very angry, feeling that he gave up on me, but I consulted with a surgeon. I was given a 50% success rate or less because I have atypical pain, which means it's constant and boring. I was also told I have geniculate neuralgia, as well, which was causing my ear pain. I was told they would also section a nerve. I was terrified. I talked with many people in the support groups and asked every question I could think of.

I decided to have it done. I fully believed the surgeon would find a lot wrong even though he disagreed. Turns out there was a lot of compression so surgery took longer and they didn't cut anything. Unfortunately I woke up unable to swallow and my left eye wandering back and forth.
The first two days were very hard, and I regretted it for

sure. I felt totally unprepared by the doctors as to recovery time, side effects, etc. I had a feeding tube, lots of tests, and had to stay in the hospital 9 days instead of 3. I came home with the tube but with determination was off of it in 2 1/2 weeks. I still can't fully swallow, eyesight and balance are improving, and my ears still really full, but so far I am GNand GPN-free. I still have eye pain but that's it! I wanted to be totally off meds although with TN pain I will probably still be on it to some extent. I hope the surgery was worth it and research would be done. I'm glad in the end I listened to my body and hopefully decompression works.

Chrisa
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Pittsburgh, PA

I was diagnosed in September 2008 with a spinal AVM. The finding was accidental (maybe). July 4th, 2008, started the nightmare I was going to live with for a year and a half. Pain came suddenly in my low back, radiated to my head and all the way down to my toes with a feeling of getting paralyzed for a few seconds. I had to lie down, couldn't move much, and I was in pain for the rest of the night. The next day was okay as I was able to move. 4 days later I decided to get checked out since I was not really improving. I was sent home from the emergency room with anti-inflammatory painkillers and was told it will go away in 6 weeks. 6 weeks later and not feeling better, I went back to the doctor, who prescribed an MRI. During the 2-hour long MRI they discovered a disc protrusion and the spinal AVM. By pure luck, the MRI operator recognized the AVM. My doctor had no idea what a spinal AVM was and gave me the sad puppy look. A week later, drenched in anxiety from not knowing what was happening I was able to see a neurosurgeon who knew about AVMs. He showed me the MRI images of my back with veins going in all directions. His diagnosis was clear, the pain I was experiencing came from the disc; my AVM was asymptomatic at this point but needed attention in the near future as the risk of paralysis was great. This is what needed to be done: discectomy for the protruded disc, angiogram to locate the AVM and surgery on the AVM.

At this point, my anxiety became so bad that I was shaking all night from fear. I made my decision and decided to do the angiogram first; I needed to know more about the AVM. The angiogram was done in Seattle at the Swedish medical center at the end of September. The pictures showed that the placement of the AVM was not ideal and the risk of paralysis was too much and I should leave the AVM alone—this was

the opinion of the neuro-radiologist. I came home from the procedure completely desperate and sick from the anesthesia. 2 days later I had a blood clot from the procedure and spent 4 days in the hospital. The next 3 months I spent taking Coumadin (blood thinner). In January 2009 I did my discectomy L1S5, which was a success they said. I should start feeling much better now. Except I never felt better; I started feeling a lot worse actually. Physical therapy made it even worse as I could not stand anymore for more than a few seconds. The pain was located in my left hip and in the groin area. Lying down will make the pain go away so I spent most of my days lying on the couch. It is not easy when you have two young kids, a job and a house to take care off. But we managed, I am not sure how, but this is what you do—when it is tough you get tougher and you keep going even if you don't want to anymore.

The pain became pretty bad so the neurosurgeon sent me to all kind of tests: MRIs, EKG, dopplers, blood tests (at this point I was deficient in Vitamin D). I ask for my mother to come (she lives in France) to help us. I did find a medication that helped my pain a lot and was able to get going. The diagnosis was still the same, my AVM was asymptomatic and the pain I was experiencing came from something else (cancer maybe, I was told). I was sleeping on an inflatable bed as sleeping in my bed was too painful. At this point my anxiety, despair and wondering "what should I do next" were at the max. Thank you to my husband and kids for cheering me up and being supportive.

At this point we decided to research the best specialist in the world who specialized in AVMs and to contact them. We contacted Dr. Rodesh in Paris, Dr. Bernstein in New York and Dr. Spetzler in Arizona. They all told me they could operate. Paris and New York would be an embolization of the arteries and veins. Arizona would be embolization and surgery to remove the AVM completely.

It took many months to think about it and I decided in September—as the pain was getting unbearable—to go see doctor Spetzler. For him it was no mystery that my pain was coming from my AVM compressing nerves in my spinal cord. At this point I didn't have any more decisions to make, I will have to go through surgery and Dr. Spetzler will be the one doing it with Dr. Albuquerque.

It was not easy; surgery never is. I also had to leave my kids behind for 10 days since I live in Bellingham, WA. But the embolization and surgery were successful, lumbar laminectomy T12- L3 for AVM resection. The AVM was removed and nothing major was damaged during surgery. I was numb on the back of my left buttock, thigh, and groin. Took a plane home 10 days later with a catheter (no need to tell you this was not my favorite plane ride). A week later they removed the catheter successfully. I had a urinary tract infection after that with high fever for three days. Nothing that a good antibiotic didn't fix. I decided to stop the narcotics on Christmas day—this was my present to myself—and had a glass of wine to celebrate.

At the end of January I was doing pretty good, no more pain anywhere, just recovering from the surgery still. I can walk,

stand, and drive. It will be 2 years in November since my surgery and beside some numbness and stiff muscles, I live a normal life—I ski all winter long and most importantly live with no pain.

Emmanuelle
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Bellingham, WA

My story is not inspirational as of now, I am still waiting for help and still on meds but here goes. On July 11, 2010, I woke up, went to brush my teeth and felt this weird zing in my ear and mouth. I thought that was weird but went about my day and didn't feel it again (that day). On Tuesday the 13th I was in the shower getting ready for work and I had this intense pain that went from my ear through my lower and upper jaw, it was so painful that it felt like someone was taking a knife and slitting my face open then pouring molten lava in. I went to my ENT on Thursday the 15th and was told that it was not my ear, but might be my nerve. So an MRI was ordered, but I would have to wait till the next Friday. However, the very next day, I "woke up" (I say this because I had no sleep the night before) and I told my husband to take me to the ER. At the ER the doc gave me a shot that brought little relief but I did have the MRI that day. Was told that I had to see a Neurosurgeon on the following Monday and it was very important. I was very scared the whole weekend finally get to the Doctor and was told that I had Chiari, a Cyst and oh yeah—that pain thing is Trigeminal Neuralgia (he wrote this on a sticky note) and he said to look it up. But he barely wanted to give me any medication for it.

I finally found a neurologist whom I trust and was told that I do not have Chiari and so we got the Trigeminal under control as much as we can. I had Gamma Knife (surgery/treatment) on 08/02/11 and it worked for the typical TN but it did not work for the atypical TN. So now I am pretty much back at square one. But I have found that my husband, parents, brother and friends are GREAT supporters. They

have been there for me through everything. And I really need them. That is one thing I really have found out… that family and friends—true friends—are really there for you.

Tanya
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Spotsylvania, VA

My TN (Trigeminal Neuralgia) started in 2005 with waking up to the left side of my head numb. My first thought was stroke, but I wasn't paralyzed. Second was Bell's palsy, but my face wasn't frozen. I went to MD and he referred me to a Neurologist. After two MRIs they said it was in my trigeminal nerve deep inside my brain, but didn't know what caused it and there was nothing they could do anyway. More tests and they could only find that I was anemic. In early 2008, my jaw started hurting off and on for days at a time, making it very painful to eat or brush my teeth. The dentist thought it might need a root canal, but couldn't find a cause. Thankfully I declined. I did a lot of research and came up with TN as my best diagnosis. I told my doctor and he agreed and started me on gabapentin. I don't know if that helped or not. I had another MRI and Nuero visit, yet they said there was nothing he could really do and referred me to U of W Med Center.

I was actually able to cancel because of my improvements. I discussed my symptoms with my sister who is a PT and was studying cranial sacral treatment. She wouldn't try anything until her studies were complete on whether she could help. On 8/3/10 at 3:30am, I was blasted awake screaming with a blinding white-hot pain in my head. Next night, same thing. The following days continued with more attacks each day, but pain lessened to an "8 or 9" and then less as time went by. I got to where I was getting between 150 and 200 attacks a day, sometimes more than 300 and once over 500. I had started with cranial sacral treatment and acupuncture. I was taking 3600mg of gabapentin and 30mg of baclofen. I now

have more days without any lightning attacks than with, and am getting better all the time. I have cut down gaba to 900mg per day.

Scott
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Creston, Washington

In September 2008, I started getting severe pain in my gum, which I thought was tooth related. My dentist thought so, too, and extracted a wisdom tooth. On the way home after the extraction the pain started again whilst my gum was still numb and I realized that the extraction hadn't helped at all. Many more dental visits followed and it was during a visit when the dentist pushed his mirror into the inside of my cheek and I nearly passed out from the pain that he first mentioned Trigeminal Neuralgia.

He referred me to a Neurologist who confirmed this diagnosis. He prescribed me Tegretol, which I continue to take.

The past few years have been difficult as I have been suffering from increasing difficult symptoms, which include a very weak left side, severe headaches at times, and dizziness.

My Neurologist, who has been wonderful, was concerned about my symptoms and I had lots of tests. This year I found out that I have an AVM, which is also the cause of my TN. I have found out that due to the location of the AVM, surgery and embolisation are not a treatment option. At the moment I'm waiting to hear if I will be a candidate for Gamma Knife treatment.

Jo
Trigeminal Neuralgia, Arteriovenous Malformation
Living with TN (www.LivingWithTN.org)
AVM Survivors (www.AVMSurvivors.org)
Patient
Hemel Hempstead, United Kingdom

I had been having focal seizures in my left hand since I was 15 but was unaware what they were, I was originally told by a chiropractor that I had a pinched nerve so I just accepted that and got on with it. After having the focal seizures for a while I collapsed one night and when I went to the doctor the next day it was discovered I had Glandular fever so once again there was another explanation.

Finally at age 18 I was working as a rousy (common New Zealand word for wool handler in the shearing sheds) when my fingers started to go numb as usual which signified my fingers would soon start twitching. Usually I would have kept working but I started to feel really sick so I went to tell the others that I was going to go and sit down when I collapsed and had a full tonic clonic seizure. I remember opening my mouth to say something to one of the girls but nothing came out, instead I felt myself fall sideways and hit the floor but felt no pain. I watched in horror as my left arm curled up and I knew what was happening and tried to fight it but everything went black.

When I woke I was on the floor, an ambulance had arrived to take me to Gore Hospital. My friend's mum was one of the attending paramedics, and I still remember bursting into tears when she wrapped her arms around me, I may have been 18 and fully independent but I felt like a scared little kid. When we reached Gore hospital they decided to transfer me to Kew hospital in Invercargill for a precautionary CAT scan but they weren't particularly worried, thinking it was just epilepsy.

I was so upset. Everyone kept saying don't worry epilepsy is manageable but I knew there was something more serious going on. I remember being told I had an AVM and then they had to print something off the computer for me as AVM's

were unheard of then. I felt numb but put on a brave face and rang my parents who raced to the hospital. None of the doctors could tell me anything they just said it's very serious and could burst and kill you at any time and you were probably born with it.

The next ten years I spent trying to pretend there was nothing wrong with me which most of the time was pretty easy as besides the focal seizures in my left hand and some nasty headaches I had no other symptoms.

Don't get me wrong though, some days I would cry my eyes out and ask, "Why me, why me?" And I was always scared that it was going to burst and kill me; the thought never left me.

In the early days I dealt with it by partying a lot. I figured I was as good as dead anyway so I may as well go out having fun. Mum and Dad tried to wrap me up in cotton wool but I was having none of it and carried on with life as usual as best I could.

Inside I was a wreck and so scared of what was going to happen. Every time my hand went numb, my heart would race and I would think this is it. I got so bad at one point that things like grocery shopping terrified me because I was scared I would have a seizure or a bleed in the middle of the shop and no one would know who I was.

I discovered I was pregnant at 20 weeks (yes a big surprise) and everyone went into panic mode. Two doctors said we had to terminate immediately otherwise it would kill me so I was raced to Christchurch hospital. When I arrived, after much discussion, I was told by my original neurosurgeon (the one I had seen ten years before and never since) that as long as

I made it to 28 weeks I should be fine. It was agreed that the pregnancy would be allowed to proceed but would be closely monitored, which is how I came back onto the radar.

My little miracle baby boy was born 6 weeks premature by cesarean on September 26 2007. After my son was born I had new MRI's and another angiogram and the results were sent to Professor Morgan. We met with Professor Morgan and decided that despite the risks, which were approximately 15% of something bad happening, we had to try because I also had signs of wear and tear. He believed I would be at significant risk of it bursting within the next ten to twenty years.

Professor Morgan made me pencil in a date for surgery while I was in his office and told me to call and confirm. To tell you the truth as soon as I made that date I was already planning on putting it off. I don't know when I changed my mind but all of a sudden I knew I just had to do it. I thought if I was told I had cancer I would do everything I could to fight it. Chemo, surgery, whatever so why was this different? Why was I not saying, right, this is my chance to fight for my life? As soon as I started looking at it like that I decided that surgery would go ahead as planned.

Aaron and I held each other all night the night before surgery, both of us sleeping in the single hospital bed with the sides up so we didn't fall out.

The next day April the 6th I had my surgery. I have never been so scared in my life, I was very upset first thing in the morning, the Professor came and saw me in the ward before we went to theatre and told me it wasn't too late to back out but we both knew what I needed to do.

Aaron walked with me right up to the theatre doors where I proceeded to sob, I was so scared, I mean truly terrified that this was the end of the road for me and as I kissed him I wondered if I would ever see him or anyone else ever again.

What followed was a nightmare five weeks for my fiancée, family and friends. Although my initial surgery was a success I had 2 post op bleeds one straight after surgery and one a week later. Because of these I was kept in an induced coma for five weeks to minimize the damage. After the second bleed I was in serious condition and Aaron was warned that it was all up to me now. They said they hoped I was a fighter because if I bled again there was nothing they could do as another surgery would kill me.

When I finally woke I was shocked to learn how close I had come to death from Aaron who had been at my bedside every day.

In the beginning I couldn't walk or move my left side at all. Within a couple of days I could lift my leg and physio started pretty quickly to try and get me walking. James was all I could think about so Aaron and I practiced and practiced. By the time I left Sydney 2 weeks later I could walk short distances assisted and could raise my arm. Mum and Dad bought James to see me the next day and oh what a relief to see them all. James looked like he had grown about a foot! I was scared he wouldn't come near me being that I had no hair and was in a wheelchair but after about twenty minutes he finally climbed onto my knee for a cuddle. BLISS!

It's now been two years since my surgery and even though it has been the toughest few years of my life I am so much better. I still have a dropped left foot and walk with a limp

and my fine motor skills in my left hand are not great but I am hoping that physio and time will keep improving this.

I wish so much that I had known about Ben's Friends Website right from the start, because no one truly understands what we are going through unless they have been through it themselves, and there was a million times I could have used a sympathetic ear.

Aaron was truly amazing, picking James up from craeche, (he finished work first) organizing tea, washing and general housework, he never complained knowing I was doing as much as I could.

On June the 8th, 2011 in front of small group of family and close friends in Rarotonga, I married the man of my dreams, my best friend, and the man who has stood beside me through it all. When I walked down that beautiful sandy aisle towards him I felt like the luckiest woman in the world. Every cloud has a silver lining they say and in my very dark cloud my silver lining has been Aaron.

I don't know what the future holds next for me but whatever it is I'm ready now to face it, I know sometimes it will be hard, there will be frustration, hard work and tears but I also know there will be plenty of love, laughs and happiness, what more could a girl ask for?

My advice to anyone who is beginning this journey is to take strength from those of us that have gone before you. Everyone will have found a way of coping with life and its limitations and sometimes the answer to something that you can't see is easy to someone who's outside the square. At all times never give up on life, fight for it. We only get one and be dammed if we will let an AVM ruin it.

Photo One—The morning of my surgery

Photo Two—About week 3 into the coma

Photo Three—Just come out of my coma

Photo four—First cuddle with my son in Isis rehab Dunedin NZ

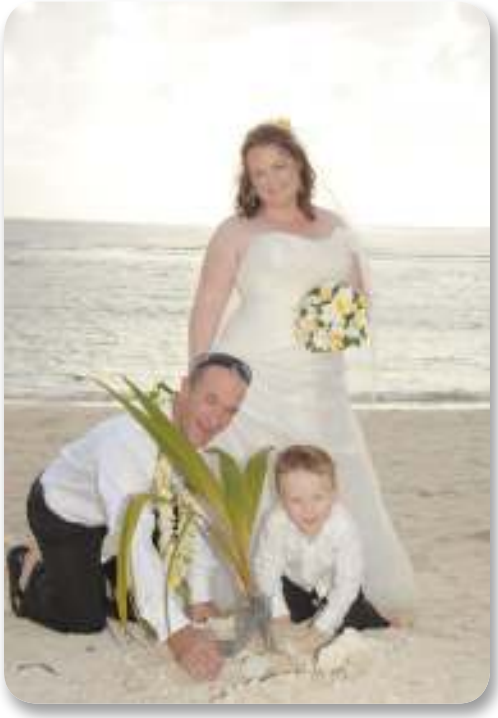


Photo Five – Our wedding, June 8th 2011, Aaron, me and James

Kylie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
New Zealand

Here is "my story"—I included in a letter to my senators asking them to support legislation for funding for HHT (Hereditary Hemorrhagic Telangiectasia), a genetic disorder affecting 1 in 5,000. 30-50% of people with HHT have lung AVMs, 15-20% have brain AVMs…AVMs in the spine and GI tract are also possible. It's a dominant gene, so if one parent has it, each child has a 50/50 chance of inheriting it. I think it's important that people suffering from AVMs realize there MIGHT be an actual cause. I have been horrified at the number of people commenting that AVMs are NOT hereditary, and yet they seem to be describing the symptoms of HHT! Since HHT can manifest in different severities and organs, 90% of people (entire families) don't even know they have it. The importance of HHT awareness, if anything so that people with AVMs can rule it out, is enormous.

My life truly changed last March. Not in the dramatic fashion you might imagine as with those shocking medical stories you see on TV, but in a slow, informed, and chilling sort of way when the hairs on the back of your neck stand up as you are reading and realize, "This sounds like me… I am a 1 in 5,000 statistic."

I'd previously had surgery on my nose for frequent nosebleeds, and I was prepared to have it again after moving to Shreveport, LA. My new ENT had heard of HHT—he pulled out his medical text and we read about it together. He joked that he knew I'd go home and Google it, which I did, and it all fit like pieces in a puzzle… my mom and grandmother's nosebleeds they had always shrugged off… my great-grandfather's death due to a brain hemorrhage… no one had ever connected it as actually meaning something.

I did not yet have a general practitioner in Shreveport, so I went to that first appointment armed with my suspicions,

printed out screening/info articles, and a contact number for an HHT specialist in Dallas. I truly think he thought I was a nut! He dubiously agreed to refer me.

After confirming my HHT diagnosis and being screened, I learned that I had a pulmonary (lung) AVM. This could have, at any time in my life, caused a stroke, brain abscess, or hemorrhage—especially since they have a tendency to rupture during pregnancy—and I've had three children! 30-50% of people with HHT have AVMs. I had mine embolized in Dallas last June.

I am thankful that I have found this road and now have the same chances as you to grow old with my spouse, see my children get married, etc. I believe everyone with HHT deserves that same knowledge and an opportunity for simple medical prevention.

As I look at my three precious daughters—Haley, 7, Annah, 5, and Kara, 2, I am dismayed that, though each had a 50% chance of inheriting HHT, all three have been identified through genetic testing as having this disorder. I owe it to them to become as informed and humbly vocal as possible. Many people with HHT decide not to have children due to witnessing devastating situations in their immediate families. My hope and prayer is that enough advancement will be made in the next decade so my daughters will not have to consider it a decision.

Immediately after finding out that my 3 daughters had HHT, we began the screening process, which involves brain MRIs and "bubble tests" (echocardiograms with contrast) through the HHT Center of Excellence in Dallas. My girls were troopers (see attached pics), and as difficult as it was to watch

them endure this, I am so thankful that I know and can prevent a possible life-altering consequence of an AVM... I once heard them called "ticking time bombs." Other parents out there didn't know; others lost a precious child, a parent, a cousin, etc. to something that could easily have been prevented, if only they or their doctors had known about recommended screenings.

I'm a 2nd grade teacher. The difference between the start of this school year and the previous twelve was that when, on the first day of school, I joked with my students about the fact that they WILL see my nose bleed at least once this year, and not to worry about it, it's not a big deal…well, now I know that it kind of ***is***.

A'Lisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Bossier City, LA

My story started when I was born, so I divided this by 'bullet' points:

My birth was by a normal delivery back in March 26, 1971, in Lima, Peru. My mother noticed a malformation on my spine (hyperlordosis). By age 2 my walking was very limited but got better with therapy. By 1973 doctors found a 'Cardiovascular Tumor' at the L5 area, on which they performed a surgery. They closed immediately after making the first incision, however, as it created my first bleeding during surgery. I finally was diagnosed with a large Hemangioma. One of the doctors mentioned that it will grow and I will need radiation; however, a big earthquake right after the surgery forced my parents to pick me up from the "Hospital del Nino" during my recovery. I never went back. My recovery at home was not easy, with lots of pain, especially on my RIGHT LEG. I never got any sensibility and movement back (from my knees down). My RIGHT LEG was the most affected.

- At age 5, I was admitted to "La Alegria en el Senor," the first complete Catholic school for students with disabilities (just physical, not mental). I received a high level of education, finishing High School by the age of 16. At school, I received therapy, learning to walk with crutches and braces since I was 6. I met my husband at school.
- I receive Supplementary Education (3 years of Graphic designing and Architectural design)
- Set up my own business when I was 20 (I had left home by then) and closed the business by age 27.
- At age 27, I got engaged to Jesus, my husband, and we have lived here in the USA together since.

- By age 30, I had my first child, Christian.
- When Christian was about 1 1/2 years old, I started to work and run my house, but had this feeling of... well, pain (but that was a constant in my life, right?).
- At age 31, I decided to sit in a wheelchair full-time to take care of my baby, husband, and house; though I could always use my crutches as needed.
- At age 35, I discussed my pain issues with a Neurologist. After checking my MRI, he said that there was nothing to do. He did not find any pinched nerves, so my pain was just part of my condition. He prescribed Naproxen 500 mg and another strong medication for pain that I don't remember. He sent me back home without letting me know that the "Hemangioma" was a potentially big AVM monster growing around my spine.
- At age 39, my second child, Alex, was born. I enjoyed being a mom as much as the first time, even with more pain and mobility issues. Just one thing; at the time of delivery (same C-section/asleep/general anesthesia as the first one), I felt a strong burning sensation at an AVM level. Now I know that I was experiencing my second bleeding.
- At age 40, I was admitted to the ER with severe pain, but this time on my LEFT LEG. My mobility was seriously affected and my bladder was out of control. The MRI came with several tumors on the lower/left area of my spine and bone destruction (2-3 vertebrae had collapsed). I was admitted in Coral Springs Medical Center for 15 days, plus 5 more days after being transferred to North Broward Medical Center for a different test and

treatment for possible Spinal Cord Infection. Finally, (as I thought) the results of the second biopsy showed that the tumor was not cancer, just AVMs or Hemangiomas as per my limited understanding and knowledge.

- On August 09, 2009, the Neurosurgeon decided to wait and monitor my AVMs for 6 months (and every 6 months thereafter). I am still looking for second opinions. I am going to my first appointment at the Neurosurgical Clinic at Jackson Memorial / Miami Project on November 14.
- My symptoms are still there. The pain is strong, especially in left leg and L5 area. My right leg still in pain, but that is different, I have dealt with it since when I was 5 and it comes and goes. Trying to control pain with Neurontin 600 mg, Percocet 725 and Naproxen 500 mg (2 per day for each one). I can use my left leg a little. I won't be able to walk with crutches again. Still having bladder issues that are out of my control.

Rosario
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Fort Lauderdale, FL

When I was first diagnosed with Fibromyalgia back in 1999, it was immediately after my RA diagnosis. However, my Rheumatologist sent me to 3 other doctors before he would even accept the diagnosis (hmmm). Then he wouldn't even treat it as he didn't believe there was treatment for Fibro. I should have known then I needed another Rheumatologist, but I was still new to this field and didn't know another person with the diagnosis. A year later I needed a disability form completed to continue my disability and he would not complete it. He referred me to one of the other Rheumatologists that had made the diagnosis of Fibro (who was no longer at the same clinic) to complete it.

A few years later I was rushed to the hospital with chest pains, of course, thinking the worst. However, all the tests for heart problems came back negative.

While I was in the hospital, my PCP asked my Rheumatologist to come in for a consult and he examined me but couldn't find anything related to my RA... as he was leaving the room he turned to me & my husband: "You are in pain; you are a challenge; I don't know what to do with you." It was a good thing the door closed behind him because I knew my husband was ready to go after him.

It was a few days later I found out from my physical therapist that the pain in my chest was a condition called costochondritis, something he should have been able to diagnosis.

It was at that point I knew I needed to find another Rheumatologist to take over my care. One that would not only treat

my RA but also one that understood Fibromyalgia and was willing to treat all of me.

Millie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Billerica, MA

My story really started in 2003 with a car accident and it went downhill from there. I have numerous issues and EM (Erythromelalgia) is just the newest one. My doctor can't even diagnose half the things that are going on because he doesn't know. It makes it difficult to go through life knowing things are wrong but not knowing what is causing them. I actually cheer when I get a diagnosis because at least I know what it is. Even if it isn't something that can be fixed, or treated, or whatever, I know it isn't something that my brain just made up—which my doctor likes to think. So every day I wake up, take stock of what is going on that day (what hurts, what is bothering me, etc.) and decide what pills are needed and what I need to do to make my day easier. I love my life and love making it as full as possible.

Sandra
Erythromelalgia
Living With Erythromelalgia
(www.LivingWithErythromelalgia.org)
Patient
Edmonton, Alberta, Canada

Good Morning. As I write this, it's the ninth day of my recovery from my "neuralgias." Each day gets better and better and I learn more about my illness. My neuralgias began when I was seventeen. I had a bad time with varicose veins; they became inflamed and felt as if battery acid ran down my legs whenever I stood up.

Around Thanksgiving 2008 my neuralgias went ballistic. My face and eyes were burning and it felt as if I had a steel dagger stuck right between my eyes. My doctor said I had herpes zoster, which then became post herpetic neuralgia. It was bilateral across my face down my throat and neck. My neurologist said it wasn't shingles but offered no clue.

I continued seeing countless doctors. I had my sinuses tested, MRI's, cat scans, blood work and each time the results came back with nothing.

In March of 2011 I began taking the Chinese herb astragalus for my immune system. I noticed within 72 hours my intense pain was gone and I was able to quit the recommended drugs. My pain was less but I felt as if I was fighting something in my body. I never felt good but I was in less pain.

August of this year I quit my job to stay home. I thought staying home would give me rest. I started sewing in my basement, designing clothing and trying to have somewhat of a life. Things became worse, a lot worse. I knew I was in trouble, I had a loud constant ringing in my ears, noise hurt, light hurt, everything looked flat, I couldn't see my neighbors. I never waved; I felt so horrible. My body was burning and no one could help. My eyes and face were on fire.

Early in October I noticed water on the basement floor. It was the water heater. I told my husband and he went to

investigate. “Holy s@!^” came up from below. He had found mold, lots of it. Mold was growing behind the walls, under the carpet and in the ceiling. Apparently the previous owners had covered it up.

I immediately called all of my doctors. Not one of them called me back. “Hmmm,” I thought. “After spending nearly $25,000 on doctors and one psychiatrist, no one is going to help me.” I called my neurologist and asked for a prescription for physical therapy and one of my choosing. My doctor said “try to find someone dealing with myofascial pain.”

I did. My therapist immediately pointed out that my scalp was hard as a rock; it was stuck. We began working on it slowly. I began thinking that my face was inflamed, like an infection. I went to my local nutrition store and told him that it felt like a thousand bee stings. He recommended quercitin, saying it works great for sinus and facial pain. Within a few days my inflammation was down and between working with my PT and me sitting for hours gently rolling and lifting my skin away from my face and scalp I could scrunch my face up like a rabbit. I continued scrunching, yawning and making faces. WOW.

I then decided to take it to the next logical step. If this is from mold, I want it out. I made another journey down to a nutrition store. He raved about oil of oregano. I bought a bottle, went home and began a journey that is still unfolding.

Around the 17th of October I noticed that things were really loosening up. I began really working my scalp. I started feeling it. I could feel the muscles begin to loosen up. Each night I would rub arnica onto my face, across the brow, down the nose, it was beginning to feel good. After a few days I could scrunch my scalp, I kneaded it every which way using my

hands with a very strong force. It felt good as little by little blood was returning. Something was getting better. My husband didn't quite get it, I would say leave me alone I'm rubbing. At 9 pm on October 21, 2011 my pain broke. A flood of blood and oxygen rushed in and flooded down my head. I fell to the ground trembling, shaking and began sobbing because I knew I was out of hell.

My therapist was shocked the following Monday because I had been in that inferno, now I was only sore, beat up, exhausted, but happier than ever before.

My therapy now was dealing with getting the toxic slime out. I knew I had killed the fungal infection because my entire body was filled with slime. I was gooey and delirious. I was also dehydrated. I continued rubbing working out the snot and trying to comprehend what had happened.

The next day my hearing changed, then my voice became familiar and I could see myself in the mirror. Over the next few days Mo worked on releasing the toxins. I took lots of vitamin C and selenium to help with my detox. It was a wild ride when the toxins would release, that old ringing came back, I had nightmares but I kept saying that this too shall pass. I drank gallons of water but my skin was still dry. I had no idea what to expect. During this time I drank keifur to help my gut and I bought a jar of Macro Greens as I felt I wasn't absorbing food.

Two days ago my skin began to breathe and I could feel oxygen rushing through every pore. Each day my vision got better and better. Everything today is in vivid 3D. My feet and hands are deliciously plump. My fog is gone; I am now part of the world. I went for a walk yesterday and was overwhelmed at the things I saw, the colors, the wind rushing through my body.

I have also noticed that my gums are receding, my varicose legs are no longer swollen, and my skin is tighter. I can swallow, my complexion is clear and when I lay down I can feel the blood in the head muscles squish back and forth.

I bought a flat round rock at the gem store as I am constantly rubbing out those sore spots. Mo has rubbed away the "arthritis" that was in my neck. I have to work over my entire body to get rid of it, but hey every time I rub and eliminate a sore spot the pain lessens.

I have no idea how far my recovery will go but I did recover and I will be shouting my message out. Only those of us who have suffered this get "it." Well, let's get rid of "it." I am praying for everyone who reads this and hope you take a chance with a few herbs, lots of manual work and find the salvation and joy that true recovery can bring. I will be writing doctors, Erin Brockovich and spreading this message. We have suffered enough. I will not sit idle and watch the medical community make money off of our symptoms.

Kimmy
atypical, eye pain
Patient
Vancouver, WA

First I was born (which does seem blatantly obvious as how else would you expect me to be writing my biography?). It was a naturally gloomy English winter morning, judging from all the preceding English winter mornings anyway, but maybe Loki, the Norse god of mischief, made it sunny just as a final screw you to me. Can someone please tell me how "screw you" is meant to be an insult, it simply can't be, especially if you're bi-sexual.

Forgive me for the long introduction and my exaggerated emphasis on the weather, what can I say apart from that I'm English. I will get on with the main gist of my story.

I had a generally normal and happy upbringing living in the Wirral, England. To be honest I cannot really remember most of my time living in our first residence but I do remember that we only lived around the corner from my Nan and Granddad. Let us fast forward to when I was 6; this was a significant year as it was the year that I got meningitis in America whilst I was on holiday in Florida. I was put into a CAT scanner as the doctors thought they noticed a worrying issue, and then after the CAT scan they sent the results back to England. Once we returned to England we had a diagnosis of Friedreich's Ataxia. Although I was not in a wheelchair at that point it was still decided that I should announce my disability in my primary school. The head teacher, Mr. McNut (That WAS his real name), came into our classroom and told the entire class about my diagnosis but obviously not using any long, tricky words. It was decided that I would stay in my mainstream school and I am very glad about this as it still allowed me to have a generally "normal" upbringing until secondary school. My only worry about this school was

the fact that I was to be the only pupil from my old school going to this next one.

My secondary school was a special needs secondary school, but I did not feel this was suitable for me as it did not even do GCSE's (High School Graduation Exams). To make up for this I went to another mainstream secondary and a college to study English and IT, but unfortunately I was one year out to take my exams there. Though luckily a local college noticed I had some talent when I was playing Scrooge in a Christmas play at my secondary school and was the only student who did not need to read the lines on the day of the performance.

So I attended Birkenhead 6th Form College (BSFC) and re-took my GCSE's as well as a business studies GNVQ course before going on to an advanced IT GNVQ course and then an English language AS level course. With all my new qualifications I managed to get into university. I chose to study combined science at Lancaster University as I was a glutton for punishment and I did not think one degree was enough.

I was really pleased I had made it to university, as I promised myself I would go to university ever since late primary school. I was even more pleased that I had an ever-expanding social circle of friends.

My university choice was around a 2-hour drive from my mum's house, which I shared with my mum, 2 younger brothers and sister. To be honest, I loved the thought of living away from home; as I was not too sure how quickly, or even if, my condition would deteriorate and I did not want to miss out on having my independence (besides, I was a randy

and frustrated young adolescent; as exam delays meant I went at 20, not 18).

I was so proud at my graduation, but pride was not a sin that I minded indulging in for the day, as it felt so good. My university days were spectacular; I met so many decent and kind-hearted people from all over the world, but by far the most important people to me were all my carers, whose care and devotion I will always be grateful for.

I moved back home and continuing my gluttony for punishment, I took a few long-distance study courses, got a few voluntary work positions and maintained an active social life.

My most recent achievement being that I have moved into my own flat and have been living independently for just under 18 months.

Now, my life has been no relaxing stroll in the park, but at least I've enjoyed the scenery along the way.

Anthony
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Rock Ferry, Merseyside, United Kingdom

I was diagnosed with Lupus in 2008. Along with that diagnosis also came the diagnosis of Sjogren's Syndrome, Polymyositis, hypertension, and hyperthyroidism. That was a hard pill to swallow when you are the caregiver for your handicapped daughter whom has severe cerebral palsy and mental retardation.

It was hard at first, but once I accepted the fact that, hey it's here, you have cried, now let's handle the situation, because as long as I have the Lord on my side there is nothing that can't be fixed. It's very hard sometimes, and no day is ever the same, so you definitely never get bored having lupus (it won't let you). It's a very unpredictable disease; you never know what to expect. So far I have had a blood transfusion, because with lupus the dead red blood cells that your body kills off are not replaced as fast as they should be, which causes much fatigue, like you need that.

I describe Lupus like fighting a professional boxer that you fight with every day. You give it all that you have and yet you still get knocked down, but never knocked out. So you get back up and you go another round the next day. Sometimes, you may have to take a couple days off to recuperate, but you still come back for more rounds. That's why people with any type of rare disease are warriors, because warriors never give up; they fight to the end, and that's what the Lord expects us to do.

But I am blessed to have my family and my Lupus support group, these are the angels the Lord has sent to give me strength to fight my battle, and when I am too weak to continue, they know how to build me back up so that I can continue my battle.

I AM A WARRIOR AND A FIGHTER

Sarah
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Houston, Texas

I've been a nurse for 26 years now. In 2004 I was finding my body was hurting all over. I had developed daily headaches that were debilitating and my legs hurt so bad I could hardly walk first thing in the morning. I fought daily fatigue and found it hard to just make it through 8 hours of my job. I was misdiagnosed for 2 years with fibromyalgia, chronic fatigue, migraines, and was handed medications that did not help. I finally started having muscle spasms/tremors in my face, neck and shoulders along with a headache that had me down in bed. I had numbness, tingling in both hands and around my lips and tongue. I called my family doctor and she ordered a MRI the next day, which diagnosed the Chiari Malformation with SM and showed extensive cervical syringomyelia. I was so scared and did not know what to expect and was terrified when my Doctor stated she was not familiar with this condition and wanted to know if I knew any neurosurgeons. I called a few of my doctor friends and to my surprise they had never heard of this and had to research it also. My daughter and I did a lot of searching on the Internet and found Dr. Oro at Columbia Regional Hospital and within a few days we had an appointment. He spent a long time with us (my husband and I) and explained everything, right down to the surgery, risk factors, and long-term outcome. The information was quite overwhelming. I did not know what to do, so I went home and talked it over with my adult children. Then that week I called his office and had scheduled my surgery. A lot of fears and tears came the next few weeks. My symptoms kept getting worse and I was having new ones. So I was sure I was making the right decision to go forward with the surgery.

My surgery day was scary, and I wanted to back out, but with God's help and my family to encourage me, I agreed. My hospital stay was quite "normal" without any major events

or setbacks. I was in ICU for 24 hours, then off to a floor, and was up walking on day 3. To make a long story short, I healed and was back to work in 12 weeks. I started off with 4 hours a day for 2 weeks, then was back to my full time schedule. I can tell you, it has not been easy, but I refuse to let Chiari have any more control than it already has. I continue to work full time. I have pain on some level every day, sometimes it is a 2 and other days it is a 6-7 on the good ol' pain scale, which I understand so well. My pain is manageable and I still set limits to a day and at times other people, mostly my co-workers do not fully understand. You know in my field some days the work does not stop in 8 hours. But what I have found, I have become a better nurse for what I have been through. I see PT's through different eyes now. I feel with Chiari I have to set limits, get more rest and follow up with my neurologist, but I'm more determined not to let it win this battle. I have a lot of living to do yet. So I'm not giving up or in, although there are days when I certainly feel like it. But one of my goals is to help others who have been hit head on with this terrible thing called CM/SM, and offer my support, knowledge and a good ear when needed. I hope in some way I have offered hope to others and I pray to God for a cure. God Bless you, Brenda

Brenda
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Osage Beach, Missouri

My name is Laura. I am 37 and was diagnosed with Chiari Malformation Type I at 36. We had no insurance these past six years but I had known for some time now that there was something really wrong. They called it degenerative bone and disk disease and fibromyalgia at first but that isn't what it was. In fact, my neurosurgeon said I was the second worst case he has ever seen. Mine got so bad it was like stroke symptoms including paralysis.

I am grateful for the diagnosis, the surgery and the outcome. However, I wouldn't wish this on anyone. Learning my new norm is very scary. I'm 23 weeks post-op and have psychological issues now but I am getting better. :)

Laura
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Apache Junction, AZ

Hi, my name is Gerry. My wife joined this site to share and read other people's AVM's, as well, and I want to share my situation with all of you. It happened one day when I came back from work and was sweating on a 110-degree day. I came inside my house and right away I took my boots off, stepped on the cold floor and decided to take a cold shower. I felt a small headache, and after I finished I started to pick my things from the floor, when I felt the headache get worse. I couldn't take the pain so I called my wife and tried telling her what was going on with me. She took me to the closest hospital. We ended up being in Loma Linda Hospital where, in an MRI scan, they saw my AVM and made a decision to operate on me and they took that AVM out for good. Well it's been 8 weeks since my operation and I'm coming back, getting myself back to doing my usual things. My Doctor told me that I couldn't go back to work for a while. Now home, I get to spend more time with my little girls and my wife. Now I'm doing things around the house.

Mr. Walker brought me his attention to his situation and I'm interested in taking care of myself and making a better body. Well, I would like to thank those that are on this site and give thanks to my loving wife for entering into this site.

Gerry
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Rancho Cucamonga, CA.

JUST DO IT! I was working on Wall Street doing that whole scene and was so tired all the time. I was trying to pretend like I didn't have this disease and I could be like everyone else. Any time I had off I needed to rest, almost to an extreme of not being able to get out of bed on the weekends. It was hard but I had to step back and step away from the money and reflect what I wanted my life to be. I could make money and never have time or energy to spend it or I could take care of myself. So, I made a bold decision and never looked back. A little while later, an opportunity to work at HNF crossed my path and I jumped at it. It's been a few hectic months but the feeling of value to my daily living is worth all the money in the world.

Laura
Charcot-Marie-Tooth
Charcot Marie Tooth Support
(www.CharcotMarieToothSupport.org)
Patient
New York, NY

I had an oral surgery appointment last October. Four hours later I was in the ER. Dillaudid did nothing for the pain on the opposite side of my surgery side. He finally sent me to get an MRI with a local neurologist. I was ruled out for MS and tumors.

I could not work at the state job I had only been on for 8 weeks. I was a crazy woman, wondering why I kept getting shocked and brought to my knees!

I started reading on the Web, when I heard the name—trigeminal neuralgia. Diagnosis confirmed when pain came from wind on my face and Trileptal worked.

A lot of this may be disjointed since I just came back from Michigan 48 hours ago from our weeklong trip to see Dr. Ken Casey.

While I was researching, I put on lidocaine patches on my face and had treatments of Reiki. I did not know what Reiki does, but I can tell you twice for me—it lessened the pain to 1%. Not hokey pokey after all. I wasn't skeptical—I just had no idea how much energy and electrical and heat can change your makeup!

Quotes:

Self-pity in its early stages is as snug as a feather mattress. Only when it hardens does it become uncomfortable.

"I can be changed by what happens to me. But I refuse to be reduced by it."

LYRICS FOR ME ON TRILEPTAL—WHEN HEADED TO SCARY MVD

Listened to it a couple of times today—before I used to associate it with a break up—now.... well... maybe this will help my new hubby know how it feels to be feeling like an idiot with these meds! My other anthem was "Haven't Got Time for the Pain"

Matchbox 20 /* "Unwell" / *Partial Lyrics

All day
Staring at the ceiling
Making friends with shadows on my wall

All night
Hearing voices telling me
That I should get some sleep

Because tomorrow might be good for something

Hold on
I'm feeling like I'm headed for a
Breakdown
I don't know why

I'm not crazy, I'm
just a little unwell
I know, right now you can't tell
But stay awhile and maybe then you'll see
A different side of me

I'm not crazy, I'm just a little impaired
I know, right now you don't care
But soon enough you're gonna think of me
And how I used to be

Me
Talking to myself in public
Dodging glances on the train

I know
I know they've all been talking 'bout me
I can hear them whisper
And it makes me think there must be something wrong

With me
Out of all the hours thinking

Somehow
I've lost my mind

But, I'm not crazy,
I'm just a little unwell
I know, right now you can't tell
But stay awhile and maybe then you'll see
A different side of me

I'm not crazy I'm just a little impaired
I know, right now you don't care
But soon enough you're gonna think of me
And how I used to be

Well I'm just a
little unwell

How I used to be

Kimberly
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Lee's Summit, MO

September 1985, just two days before my sixteenth birthday, I suffered a cerebral hemorrhage caused by an Arteriovenous Malformation. The lesion had been growing in my brain since birth, though I was not aware of it until the day it ruptured.

Since the age of 12 I had complained of headaches, but tests had not been ordered. On the day of the rupture, I woke up with a headache, but it wasn't severe so I took 2 Excedrin and went to school. During my physical education class I began to have pains in my chest and left arm. My coach had me raise my arms above my head and take a deep breath. After doing that a few times the pain went away. I went to my next class, but didn't feel right. I asked permission to go home. While I was waiting to use the phone I began to feel dizzy, light-headed and severe pain on the left side of my head. I found my way back to my class, but my vision had become blurry and I passed out on my desk.

By the time I got to the hospital the aneurysm had ruptured and I was semi-comatose. Ten hours later I began vomiting and holding both sides of my head I screamed "my head." My parents took me back to the hospital and had a CT ordered. The CT showed bleeding in the left anterotemporal lobe. I was taken by ambulance to Texas Children's Hospital in Houston, Texas. The neurosurgeon there said it would be three days before they could do surgery because there was too much pressure in the brain. Then I began lapsing into a [potentially] irreversible coma. They rushed me into surgery with little hope that I would survive. After 9 hours of surgery to repair the damage my family was told I had 50% chance of survival.

The next morning I woke up, recognizing everyone as they stood around my bed singing "Happy Birthday." It was my 16th birthday and I wasn't going to miss it.

Two days later I was moved from ICU to a private room and began to feed myself with my right hand. The fourth day after surgery I was walking unassisted. I returned home after ten days to attend a football game.

I suffered some aphasia, drooping of my right arm and leg and double vision in my left eye. I required no physical therapy, but worked to strengthen the use of my right hand playing the piano and using the typewriter. There were times of emotional difficulties, which is common after a brain injury.

I returned to school two months later and passed the Texas State TASP test.

I received a lot of support from my family, friends, churches and the staff at Texas Children's Hospital. Support is needed at a time in your life when you have lost your self-confidence. The stroke made a big change in my life. I was given a second chance to live, and it made me appreciate things more.

Today I am 42 years of age, and have been working for over 13 years for the same ophthalmologist that was treating me for my eye problem after the stroke. I enjoy freelance photography, camping and fishing with my husband of 19 years.

I was thrilled when I found the avmsurvivors.org website and have enjoyed making friends with other AVM survivors. It is good to know that we are not alone.

Caryn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lufkin, Texas

Learning that I had TN felt like I had lost part of myself. About two years ago, when my disorder began to affect me, I felt hollow inside. So much of my life has changed. Including the people in my life. I have literally gone through the five stages of grief that people experience when they learn that they or a loved one is dying. I don't mean to sound dramatic but that part of myself, or the me that was pain-free and capable of so much more is gone. Yes, I am still here but so much has come to pass for me. I have had to learn to live around my condition and prematurely accept limitations such as giving up driving at 35.

I must prepare the people around me for what could happen when I have a flare-up. I must accept that when I have pain and must go to bed for the rest of the day, for example, people are going to react to me in whatever way comes naturally to them. I cannot change people's reactions to me nor would I want to and I have had to say good-bye to some [people] as a result.

Still, I cannot say that my life is bad. I am glad to be alive and there are moments since the start of my illness that I would not take back for anything. Further, I have come to appreciate the good things so much more than I ever did before.

Melissa
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Bradenton, Florida

Hi all. A new member here...just want to share my son's case of AVM and hopefully get some helpful tips and advice from this group. Thank you so much for welcoming me and my son.

He's the one on my profile pic, 6 years old, who was just diagnosed with AVM on his left foot (already 5cms) and in his lumbar area (around 3cms). The doctor said he has to undergo surgery on his left foot first because it's already symptomatic and too big. After his left foot is treated, we'll go to the one in his lumbar area, where a pulsating vessel can now be felt, as well. :(I'm just so sad that my son has to undergo all these in his childhood... :(God cure him...

Eddi
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Philippines

Brain AVM and aneurysm rupture, emergency surgery, 6-day medical coma. Initial vision issues and re-learned to walk again. Remarkable recovery but minor residual issues happened while studying my MBA, and completed my MBA in finance and marketing.

Sharyn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Manchester, CT

I was diagnosed with AVM in the Vein of Galen at 11 days old. My family was told that I would most likely die during the surgery or be unable to do anything for myself in life and be severely handicapped. As well, I had a stroke and went into heart failure. I am now 19 years old and healthy. The aftermath is so minimal that nobody is able to notice anything. I am also on no medications; I just go for checkup every couple of years at the hospital I was treated at as a baby.

Alicia
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
North Bay, ON, Canada

I was born with severe type 1 Von Willebrand's Disease (VWD) but only diagnosed when I was six. VWD is a bleeding disorder that impacts a VWD patient's ability to clot. There is no cure for VWD but I have lived a very eventful life thus far and certainly kept my surgeons and doctors on their toes. My VWD has to be carefully managed during bleeding episodes such as preand postsurgery. I live and work in London and was due to have sinus surgery in NY City in December 2009; however, my internist spotted a right bundle branch blockage on my EKG during pre-clearance for sinus surgery. She then sent me for an Echocardiogram where it was obvious I had the congenital condition, Atrial Septal Defect (a hole between my left and right atrium). Despite the heart condition, I was cleared and had successful sinus surgery in December 2009.

From late December 2009 to February 2010, I went to a number of major hospitals, where I saw many great doctors but I could not find the hard facts and data on how to deal with my case—VWD and ASD. All of the doctors I had seen during those three months recommended fixing the hole but via a 30-minute simple and least invasive catheterization procedure.

This procedure is done percutaneously (through the skin). The device is attached to a catheter, which is inserted into a vein in the groin and advanced to the heart and through the defect, guided by X-ray and intracardiac echo. As the device is slowly pushed out of the catheter, it opens up to cover each edge of the defect, sealing it closed. Over time, tissue grows over the implant and it becomes part of the heart.

This procedure requires patients to be on blood thinners for six months and in my situation is more complicated because

of my blood disorder and the inability to clot. Those devices would require me to be on anti-platelet medicine (aspirin, plavix, etc.) for six months to ensure no clots formed around the device, which would be very risky for me due to my blood disorder.

After a lot of research and speaking to various doctors all over the country and London, I figured out in February 2010 why the combination of my conditions was so rare. Assuming the statistics on the Internet are correct, 1% of the population has my blood disorder (Von Willebrand's Disease—VWD) and 0.004% or 4 out of 100,000 newborns annually has my heart condition Atrial Septal Defect (or 160 babies born in the US) which means only 0.00004% of the U.S. population (120 people) have both Von Willebrand's Disease and Atrial Septal Defect.

In March 2010, I met with the lead interventional cardiologists at two major and well-known hospitals for heart conditions separately (these doctors repair the defects with the device). They both recommended I have the procedure done via open surgery route—robotically (robotic open heart surgery) or the regular way open heart as opposed to using the device because they both did not feel comfortable with me being on aspirin and plavix.

I chose to have the procedure done at the Cleveland Clinic because my surgeon had experience with cases like mine, the recovery time would be dramatically quicker with the robotic option and I was nothing but impressed with every aspect of my visit to the hospital. My procedure, Robotic Heart open heart surgery, is a less invasive alternative to open heart surgery and my surgeon has successfully operated on cases exactly like mine.

This is clearly an invasive procedure but made the most sense to me and for my long-term health and state of mind. If need be, my surgery could shift to the regular way open heart surgery (he does robotic, regular open heart surgery and heart transplants).

This procedure is still open heart surgery but he would not need to crack me open (sternotomy). Instead, he made a couple of small incisions between the ribs on the right side of my body and operated robotically through those incisions. To be clear, long-term survival after repair of this defect is similar to that of a healthy person of the same age.

During the operation, my surgeon used a specially-designed computer console (Da Vinci) to control surgical instruments on thin robotic arms. Robotically-assisted technology allows surgeons to perform certain types of complex heart surgeries with smaller incisions and precise motion control, offering patients improved outcomes.

The risk of surgery is minimal (mortality < 0.01%, risk of stroke < 1%). The heart is stopped for the surgery (cardiopulmonary bypass and cardioplegia), and a heart-lung machine oxygenates the blood and circulates it throughout the body for approximately 30 to 40 minutes. The defect is then closed with my own pericardium (the membrane that surrounds and protects the heart).

Once the procedure is completed, the heart is restarted. When the surgical team was satisfied that the heart was beating strongly again, the heart-lung machine was disconnected. The rib incisions were then closed. The operation took approximately four hours to perform, and required four days in the hospital.

I was back at the gym three weeks post-surgery which is dramatically shorter than the regular way open heart sur-

gery and I ran NY City Marathon less than six months post open heart surgery.

I want to reiterate that I am grateful for my health, my family and friends, my amazing medical team, my support network, my physical therapist and for my amazing family at Bens-Friends.org.

John
Atrial Septal Defect, Von Willebrand's Disease
Atrial Septal Defect Support
(www.AtrialSeptalDefectSupport.org)
Living With VWD (www.LivingWithVWD.org)
Patient
BensFriends.org Partner
London, England, UK

Turned 50 and was so happy. Was in the U.S. for a senior management retreat. Sang at the farewell party. But at 4am, was awakened with electrical shocks in my mouth. Went to a dentist on Long Island and he found nothing. Took strong painkillers and on the way to U.N. office in NYC by bus, pain went into my brain and was so searing that I fainted. Rushed to the hospital but was misdiagnosed. Spent an agonizing night at the hotel with friends feeling helpless in the face of unbearable pain. Rushed backed to hospital and seen by neurologist. Diagnosed with tic douloureux and given strong drugs by IV. Next day lost balance and returned to Geneva in a wheelchair. Spent two weeks in hospital. MRI and spinal tap. Put on Tegretol and neurotyn. Spent months feeling like a zombie. Had three major attacks: one after the dentist gave me a needle, one after speaking on the phone and one from cold mountain air. Have an intellectual job and rebelled against the medicine and its side effects. Gradually got used to medicine but could not drive or concentrate well. Decided to take mercury fillings out over period of a year. Decided to lower dose of medicine with the help of my wonderful neurologist. For two years, no medication and no attacks and understanding. Be there to hold a hand during intolerable pain.

Jo
Patient Switzerland

My son had a bleed 3 years ago, our lives changed forever. I didn't matter anymore; nothing mattered other than him. Ethan went to hospital for surgery, but it was unsuccessful. At the time I was unable to speak. I felt as though my heart had been ripped out. The doctors explained if they had continued with the surgery it would have been dangerous and at least they returned him back to me the way I had given him them. At the time I was angry as I wanted his AVM gone. Ethan had radio-surgery last year. He didn't suffer any side effects, which I was so thankful for. We've had our ups and downs and sometimes I've questioned my faith, however I believe that faith in God and the doctors really helped. We visited the hospital two days ago and Ethan's AVM appears to be gone!!!!!!!!!!!! YES!

Lauren
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
UK

My mom has been suffering with fibromyalgia & RA for 16 years. Her doctors diagnosed her, and she has been to several doctors. Even doctors appointed by the state. She cannot stand or sit for a long period of time, and is extremely exhausted. The medications to stop the pain while she sleeps do not help, and it's hard on your heart if you do not get the rest you need. I've watched her for all these years, and it pains me that permanent disability may be taken away from her.

Julie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Friend/Family/Caregiver
Huntington Beach, CA

I was treated very badly and I let it get to me. I hid in my room for years with only my pets and television set. I finally found that if I trusted in God and found someone to talk to it seemed to help.

Marie
Post-Traumatic Stress Disorder
Patient
Waynesboro, PA

My daughter Casie is 19 and the doctors can do no more for her. It is so hard sitting here watching my daughter in so much pain. The doctors have given her so many pain meds yet they do not take the pain away. So I just sit here crying. She is in the living room lying on the couch crying, but doesn't want anyone to even talk to her because she is in so much pain. Can someone please tell me what to do because this is so hard? Her AVM is in her pelvis. We have almost lost her so many times. We've been dealing with this from the time she was 5. Now I just wish I could take her place. I hate not being able to help her.

Casie's mom
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Taft, CA

Dear Scott, Shalon and Ben (aka THE MAN!): Received my awesome AVM Walk Tee last week and absolutely LOVE IT! Between frequent washings, I have worn it to bed every night and will continue to do so until it falls apart and off my body. :-)

As a fiercely proud AVM survivor, wearing my tee each night not only comforts me, but more importantly, gently reminds me that for so many the struggle continues on!

As of March 16, 2011 after a 6-hour craniotomy I was miraculously AVM FREE! Unbelievably, within only a few days I was an improved version of my "old self"—upright, hungry and literally beaming from within!

Since that day, I have made almost a 100% recovery with very few side effects and am happily living a more full life & definitely more BELOVED than before the day of my fateful hemorrhage.

That being said…

I, my husband, my 2 beautiful children, and all those that surround me w/ love every day. THANK YOU and the 1000s that stand behind you, for your endless volunteer hours & tireless work, your never-ending commitment and unselfish LOVE that you give to this Network & all of its life-sustaining projects & programs.

Thank you, thank you, THANK YOU!

With Deep Appreciation and Admiration,
Deborah
Proud AVM Survivor and Warrior :-)

Deborah
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Fox Point, WI

After beginning my day getting out of bed, taking a couple of steps and falling on my face, I finally listened to my husband and made an appointment to see my physician. Lately I had been bumping into the furniture more than usual and was having difficulty climbing stairs. Just the other day, when gardening, I had to crawl over to the fence in order to pull myself up, since my legs would not cooperate. After blood work and a spinal MRI ruled out some possible causes, my neurologist suggested I may have some form of a genetic peripheral neuropathy.

Researching online, my symptoms seemed to indicate I might have Charcot-Marie-Tooth disorder, or CMT1A. Athena diagnostics genetic testing confirmed I have CMT1A, a progressive neuromuscular disorder, affecting approximately 1 of 2,500 people. I had to give up my career as a pharmacist, since I cannot stand for long hours, and frequently lose my balance, trip and fall. Also, I have lost function in my weakened hands, leaving me unable to open containers, and frequently dropping things. Also, buttons and zippers are a challenge. Additionally, I cannot scrub anything as my hands just collapse. I started a support group to share information, resources and hope with others affected by CMT. Physical therapy and aquatic exercises have been helpful in strengthening muscles, which are not affected by CMT.

Melinda
Charcot-Marie-Tooth
Charcot Marie Tooth Support (www.CharcotMarieToothSupport.org)
Patient
Upstate NY

I just want people to know I may be the oldest AVM survivor there is. At least I have not found another yet. I am 52 years post craniotomy, not long after vascular surgery became a possibility. I was 9 and scared. I had my head shaved, and there were no easy scans then. Terrible and hurtful X-rays to see the blood vessels were all they had, except for the EEG. I had a pneumoencephalogram, where some spinal fluid is removed and replaced with air. Then you are strapped into a chair that moves all over the room and goes upside down to make the air move. It was horrible and it hurt. I had a headache for a week afterwards. The diagnosis—none. The EEG showed the area of irritation and then an exploratory craniotomy was done. I thank God for the neurosurgeon I had. Dr. Sheppard of Long Island. The year was 1959.

Thanks,
Beans

Irene
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

I was diagnosed on November 13, 2010. I live in Knoxville, TN, where treatment was not available for the type and size of the brain AVM that I have. My AVM is 9cmm, right front temporal lobe, the AVM involves my memory and optical nerves. I was sent to Dr. Ayad in Nashville at Vanderbilt Hospital. Dr. Ayad felt one artery feeding the AVM needed immediate attention, because I was taking a blood thinning medicine at the time and was at greater risk of a major brain bleed. I was set to have one of the four brain embolism surgeries within two weeks. The first surgery was successful, except for a little nerve damage above the roof of my mouth, for which I take Lyrica three times a day to calm twitching in my face.

The next was not. After the first surgery, one month later, I was set for the second one. Dr. Ayad discovered my AVM was larger than first thought, deeper than it appeared on screen, and was in fact inoperable. I was devastated.

After meeting with a radiation oncologist I decided to have radiation, to radiate the part of my brain we can live without. Radiation has been a long process, my energy is gone, sometimes the headaches are so bad you just medicate go to bed and try to rest. Stress is a big enemy. It will bring on a massive headache that can last for days. I have short-term memory loss. In the past 12 months I've forgotten so many small details, my family and friends know this is a problem, so we deal with it. The twitching in my face is still a problem.

It's now November 2011, I will go in 9 days to see what the radiation has done. Until then, I wait. Sometimes you feel you're alone, since so little is known. The government does not recognize this brain disease as a disability, and so I've found it impossible to get assistance of any kind. Some doctors don't even know what an AVM is. Faith, a lot of faith. You learn a deeper way of praying. Then there's Family and

Friends, you gotta have 'em.

My hope is a story like mine will open doors for this disease to be better recognized. I'm hoping for a story on Good Morning America... I've been told all it only takes is one person. Best wishes to all who are dealing with this. It's a battle, but one of us can make a difference.

Sheila
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Knoxville, TN

I started with Swine Flu in 2009. Shortly after having the swine flu for several weeks, and being a confirmed case in the hospital, Lupus symptoms appeared. I never even knew what Lupus was until these symptoms appeared. Since the swine flu I have stayed very sick, from face rash, to fatigue, joint pain, hand swelling, short-term memory.

It's been 2 full years living with this.

I've changed to a Gluten Free, very low sodium diet, and rest helps. Stress can flare me the most so now things that are petty I will try to ignore. I have done chemo for 6 months, plaquenil, and prednisone. I would get so tired I could not move and end up on prednisone again. They are currently checking me for MS also because of family history and brain tumors; my Mother passed of that. I had MRI done two years ago, which is going to be repeated soon. I had 4 miscarriages before I had my son who is almost 17 and autistic.

How do I cope? It's hard some days because I had to relearn how to live my life again, like resting, listening to my body, eating certain foods and staying de-stressed is also hard in our fast paced world. I am in support groups in Michigan and I am online LifewithLupus.org, on which everyone is really nice.

Well that is part of my story, I went to a top Doctor here in Michigan but now I have most of my tests done and am relocating to a closer one in November.

Sincerely,
Rachel S. From Michigan

Rachel
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient

Pulmonary AVM: My 3 daughters and I all have HHT. They have on numbing patches to prepare for their IVs for their "bubble test" (echocardiogram with contrast) to check for lung AVMs.

A'Lisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)

It was December 8, 2006, and my buddy that called 911 said I was complaining about a really bad headache but we had just eaten at a teriyaki place that I'd never eaten at before, so I thought I just had food poisoning, nothing more than that. I really don't remember much more than that. Well, that's what they tell me happened.

Jason
Patient

My name is Melissa. I'm a 45-year-old mother of 4 and although I wasn't diagnosed until 14 months ago, I have known for over 20 years that I had something wrong and it "wasn't all in my head." When my sister had an MRI done several years ago, she called me right away and told me, "Melissa, I know what you have, but you must have a MRI to be diagnosed." Unfortunately, at that time, I was not insured, so I could not get the MRI. Once I was able, what we already knew was confirmed.

You see, I had been living with this for years. I just didn't know what it was. I knew that I started having headaches when I was in my early twenties. I delivered my first child when I was 20 by natural childbirth, my second with an epidural at 22, my 3rd at 29, and my 4th at 34. With the last 3 I received epidurals, not knowing I had Chiari or the dangers.

When I was 17 I had a minor car accident. When I was 8 months pregnant at 22, I T-boned a lady who ran a red light. Then about 2.5 years later, I was T-boned again. Looking back, I realized that it was after that accident my pain really got bad. I started noticing that I couldn't turn my head around to talk to my children in the car & there where many physical activities that I once enjoyed that I was no longer able to do. That's also when I noticed the vertigo began.

Now 20 years have passed. There's not a day that goes by that I'm not in pain. My head hurts from the moment I wake up until the moment I fall asleep. The only thing that changes is the degree of pain I feel each day. That can be influenced by a number of things, such as: stress, crying, arguing, lack of sleep, sleeping the wrong way, sitting the wrong way, many physical activities, bending over, heavy lifting (doing laundry kills me & I do a lot), excessive traveling in a car (bumpy rides

are the worst), loud noise & bright lights, turning my head to look over my shoulder and I experience a lot of back pain. There's more, but that's the everyday things that come to mind right away.

The most frustrating part is finding help and actually getting a doctor who takes the time out of their busy schedule to LISTEN. You'd think they'd be fascinated by this and want to know more. I know I would, but that's not what I'm finding. Now I'm considering talking to a Neurosurgeon, for the first time. The thought has always frightened me in the past, but living another 20 years or more with these symptoms frightens me more.

I really just want some relief. I try not to let this influence my life. I push through and try to ignore and not talk about or think about the pain, but sometimes that's very hard to do. I find that if I focus on it, it's worse. I know that something like this can take over your entire life and that's a battle we must fight every day. It can be very difficult to stay positive some days and not let the pain affect my attitude or my relationships with my loved ones. (I think that's a symptom that sometimes gets overlooked, or maybe it's just me.)

God Bless each of you having to deal with this painful disorder. May you find comfort.

Melissa
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Surfside Beach, SC

Hi, my name is Carol, and up until a couple years ago I thought I was amazingly healthy. At 52 I tried to eat well, had never smoked or drank alcohol, I had high blood pressure for many years but was on meds for it, and it was under control.

At a regular doctor visit the doctor heard a bruit while listening to my carotid artery. A bruit is an abnormal sound of the blood flowing through the artery. She had me go for a carotid ultrasound, the results where 60% to 70% stenosis in both carotid arteries. She then sent me to a Vascular surgeon, he repeated the ultrasounds and told me to be extra careful about my diet, because I was just one of those persons that develop plaque at a young age. He had me come every 6 months. On the third ultrasound, I knew something was different, because the PA, didn't spend any time with me as she usually did, she said the doctor has to talk to you about our findings. I was very upset knowing they had found something, the doctor came in with his sheet of paper to show me the stenosis. He said we think you have Fibromuscular Dysplasia, a vascular disease that causes the walls of the arteries to be lumpy and bumpy resembling beads, he showed me on the paper. At that time I remember this very disease on one of those medical mystery shows.

He sent me the very next week to the hospital to have an angiogram to check my carotids and renal arteries. During the angiogram they found I have FMD of the right renal artery and it needed to be ballooned open at that time, and they also found a brain aneurysm. Believe me this was a lot to take in when I thought I was so healthy. I stayed overnight in the hospital. The next day I went home on aspirin and Plavix, since there's no cure for FMD, you have to be able to keep the blood flowing through the arteries, hence the Plavix and

aspirin to thin the blood. After taking the Plavix almost 2 weeks I had an allergic reaction and was taken off of it.

I saw a doctor about coiling the aneurysm, but after 6 months research and getting a 2nd opinion I decided to have the aneurysm clipped. Yes it's hard to make that decision, knowing they are opening your skull and going into your brain... I had complete peace about my decision.

As I type this, in a few days it will be 1 year since my surgery. I have done great; no bad effects at all. I can feel the screws in my skull and it's weird. I still see the vascular surgeon every 6 months to keep a check on my arteries, and will have an angiogram soon to check my brain clip and my FMD I have met some wonderful people through FMD support groups, I felt so alone until I found others that understand.

Carol
Brain Aneurysm
Brain Aneurysm Support (www.BAFSupport.org)

I have had TN (Trigeminal Neuralgia) since 2007. It started as a dull toothache. I even had my tooth pulled for no reason. I was set to find out if I had TMJ. No TMJ. Going to the doctor monthly and weekly, I had so much pain for one year till I was sent to Neuro and then placed on medication. I tried this but it made me sick. I got into Neuro Surgery having a hard time talking, eating and a month later I had surgery. WOW, then I was waking up after 6 days so sick from all the medication and the heavy feeling on my head and realize it was a big cut from the doctor and still some pain, but this pain was different—a heavy feeling, very numb but the pain on my face was gone. Was able to go back to work after 4 weeks and there I was for one year pain free, only the numb feeling from the surgery. Woke up with this pain—pain all over my right side of my face; so much pain I'd never felt before. On medication for a bit and then back in the hospital again. Had rubbed my face raw, given medication, face hurts, can't say letters so writing it down to let doctors know that I'm dizzy and can't walk from medication.

Getting worse each day and after 6 days cannot talk, cannot walk! Get me out of here!

He was here every day, helping go through all the bad days and getting sick, all of it. He got me out of there and got me to my regular doctor who after 2 weeks got me back to talking and walking again. Still, the pain is there and now on medication, the dizziness, falling over, getting hurt, still in pain, washing my hair, wrapping it in a towel, blow drying it, fixing it, putting on makeup, sleeping, pain when moving around, waking up—never enough sleep, trying to eat, drinking, pain all the time. Now being told I can never work again. Needing a walker now. Medication there but now told I need more medication that, yes I am now feeling stupid, will make me

more stupid... I am a single mother of three children at home with one daughter who is taking care of me and if I take this new medication she will now have to do everything. She cannot even be a normal teen. Feeling so bad and try to do as much as I can by myself but know they are still doing so much for me. This is talking over my life and I cannot let it. I will not. Cannot wait to see my Neuro Surgery again. Please, soon, 3 more months…

Victoria
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient

Mine started in 1994. I was at work. I am a barber and my hand on the right side started to go numb, then a tingling feeling in my face and lip, then I dropped my scissors a couple of times. My friend took me to the doctor on call. He sent me right away to the heart specialist because he thought I was having a stroke. No stroke, but then he sent me to Vancouver for a whole lot of tests. Test came back then off to San Francisco for the Gamma Knife Surgery. Had that done and have been good. A few headaches here and there, but nothing like before. Also, when this was going on my eyesight got really weird. I would see some parts then not others.

My memory is a little short but still good for me. Ha ha. I think you are doing the right thing about writing this—it's what we all need. Info can save lives. Thanks for taking the time and bless you for it. Bye and good luck.

Josi
Canada

In 2002 when I had just turned 64, I fell badly at the end of the swimming leg of a triathlon. While I previously had problems, this accident got the attention of the doctors, and I was soon diagnosed with Episodic Ataxia (EA). My symptoms were a lack of balance and muscular coordination, leading to difficulty in walking and slurred speech. That was the bad news. The good news was that there never was any pain, and I was able to cope. Then in September of 2010, the neuros finally came up with a medicine that works, namely 4-Amino Pyridine or 4-AP. This mitigated my symptoms, in effect giving me my life back, but I still need my wife's shoulder, a cane or a rollator to walk any great distance. I also still swim for fitness (no balance issues) and am in reasonable shape.

Peter
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Greenwich, CT

I have Cerebellar Ataxia and am a member of Ataxia UK and Living with Ataxia.

I was diagnosed about 4 years ago at 47 and although the disease can be frustrating I can honestly say that I am happier having a physical disease like ataxia rather than being incapacitated by some mental illness. On the plus side we can get more understanding and care from the government and when people see me with my rollator [walker] they are keen to help even if it just getting out of the way. I know how negative I could be as I was very mobile and my hobbies all involved co-ordination and movement. Now I have learnt to count my blessings although I occasionally get upset on a bad day.

I am not in any pain.

Still read a book or magazine.

Parking is not the headache it used to be with my blue badge.

There are quite a few concessions if you ask.

People and relatives love helping.

I can still walk with the aid of a rollator.

I can look around at the lovely scenery with the help of some means of artificial balance.

I can hold hands all the time with my husband—others don't realize he is propping me up.

I have a good excuse for not talking as much as I used to.

I can listen more which is a good thing.

I can watch television and participate in debates.

I can still drive very short distances. I still have my Cognitive Abilities.

I can still see relatives and friends and they make allowances for me being a bit slower than I used to be.

I can get tips and communicate with other online Ataxia friends.

I can and do belong to a local support group and we have a good laugh and a meal.

I can still care for my dog and exercise for about two hours a day walking with help.

I can still swim.

I can still do very light gardening and can plan.

I can still make light meals.

I can still use the computer and keyboard.

The list is endless. I do realize that this is a progressive illness and some of the things I can do now will become difficult but it is now I am concerned with. I think most of us have learnt to live in the day.

I am constantly amazed by the courage of people with disabilities. It just goes to show that we choose to be negative or positive. I grew up with disability as my father had Parkinson's Disease while I was growing up. He was always hoping for a cure and he lived in hope. My mother on the other hand didn't have an easy life and was very negative. I can't choose events but I can choose how I react to them.

Marie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient

This is a little bit of my story... At 33, in 2006 when I was 5 months pregnant, I had what could have been my last experience alive. I was out shopping when I suddenly felt my balance was impaired and I was not quite myself. I shrugged it off and ignored the signs. When I returned home I still did not feel quite right, and then at around 11pm I developed a severe headache. This headache was unlike any migraine I've ever suffered. I called for my daughter and had her call 911. Everything I viewed was upside down and I couldn't stop vomiting.

When the EMT got there they said it was probably food poisoning because I had just returned from Puerto Rico or bad morning sickness. I was in and out of consciousness, but kept telling my daughter as we were in the ambulance that I had a blood clot in my head. My mother met us at the hospital.

They were afraid to give me an MRI because I was pregnant, but once the brain surgeon got there he performed the MRI. It was during the MRI and the angiogram, that he found the amount of the hemorrhage, the size and the location. I had what was called an AVM that had now ruptured. Arterio-venous Malformation. Which is basically a tangle of blood vessels. The surgeon told my mother and daughter that the AVM was large and that he didn't think I would survive. He also was afraid to operate because I was pregnant so he said he would place a shunt in my head in the hopes that the pressure of the bleed would be alleviated in order to avoid surgery. He was hoping we could wait to remove the AVM after I gave birth.

When the shunt was placed, it was not able to stop the bleed longer than 2 days and surgery was necessary. The doctors

told my family they didn't think I would survive and if I did I would be dysfunctional in different ways and there would be a slim chance of survival for the child. The surgery was 13 hours with 2 surgeons and they were able to remove the AVM. The baby was still alive and so was I. I remember being in and out of consciousness, but really I vividly remember the breathing tube they kept inside me. I still have nightmares about that tube.

Once I was fully awake, I was unable to walk. I could only take Tylenol because I was pregnant. The pain was excruciating. My speech was slurred and it took quite a few months to be understood. I wasn't able to sit up, and had to re-learn how to walk. Even walking to the bathroom was an impossible task.

All the doctors said I was a miracle and I should be grateful to be alive. Secretly… I wasn't. I was so angry. "Why me," I thought. It was a gradual process, but I'll never forget the day I was able to actually handle sitting in a wheelchair. I stayed in the hospital for nearly 2 months. I developed sepsis from the tube in my neck and had to be on all sorts of antibiotics. I had to stay longer because I developed sepsis. I was so disappointed. I just wanted to leave.

When I finally left, I stayed at my dad's to recuperate. I was still using the wheelchair but progressed little by little into a walker. I was 8 months pregnant and between the discomfort of my head and the pregnancy, life was a nightmare. I kept worrying for my child's well-being. Wondering if he was handicapped, or missing limbs, God forbid. It was an obsession. I was so nervous.

I was scheduled to have a C-section on June 9. I wasn't allowed to push because it would cause pressure to my head. However, I didn't make it that long. It was in the middle of the night when all of a sudden my water broke. I quickly called my mother. She rushed me to the hospital. I told myself that if the baby was able to survive that he'd be a miracle baby like Noah in the bible survived. Noah represented a miracle and so did my baby, and so is every day of life. I named him Noah.

Now that I am pretty much back to the post-surgery state, I look at life and its circumstances differently. When I sit in traffic, instead of cursing the delay I'm happy that I still have the chance to experience traffic. When my baby cries at night I no longer get angry at the lack of sleep I am getting because I am thankful he is crying and I am able to wake up to him. I not only got a second chance at life but I also got a different perspective on people and circumstances. A perspective I don't think I could have ever gotten.

Susanne
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Hi all, here's my first go at this—none of this will instantly solve your aphasic I'm afraid, but sometimes you can get past it. We all have different degrees of aphasia—but if you can get to be around 75% back, [then] it's possible to work in an office... and not even have to tell them your aphasic! Well, I have anyway LOL :) Hope this could be useful.

Aphasia—an aggressive, bad tempted beast that never gives up—it can attack without warning! As communication is the key of all things that brings society together, when you are hit by the "mozzie bite" itself, everything you know can suddenly become difficult. So why do I say it's a "mozzie bite?" Because it can creep on to you, uninvited... suddenly can hit you—make you scratch and worn under the rawness; and then it just won't go away. Then it can clear, BUT... suddenly can strike again! And there's not much you can do. Reading, writing, typing, understanding, speaking... things that used to be easy, so simple, suddenly become remarkably difficult. Then again though, you can get past the "mozzie bite"—notice the rascal early, smack the sod and you don't have to itch so badly... not every time but there are ways.

And so after years of "practice"—working in an office environment, there are certain ways to get past it.

1) One of the most frustrating things of the mozzie bite for me can often be NUMBERS—you get that info on the phone, it can be difficult to store them correctly. The digits are always very similar, e.g., 4 or 5? 6 or 7? Very similar. And for a telephone number, often the amount will be minimum 11 digits! Something to manage to get across quickly—say for example, a client suddenly says he will give you his number. Getting 5 digits all at once can be too much—ask for 2 digits please, straight away. Yeah ok, maybe most people never

ask for this, but there's nothing wrong from asking for that. Something like—"OK, just to make sure can you give me 2 numbers at a time?"—99% they will just say "sure." 2 digits sometimes can be enough.

2) Always ask for email—say "thanks for the number, just to make sure, can you send me an email?"—I may have missed half of the numbers anyway, so you can say "yeah thanks, good, just in case could you send me the number by email and info by email?" I've done that countless times!

3) If you haven't asked for 2 digits, and suddenly you get 5 digits—if it's got you, just don't bother, concentrate on the next lot. [Pass] on the last amount or do the best you can. Then, after a small conversation, you can ask, "just to make sure what was the number again?" You know you will get 5 digits, so be ready to store the first numbers.

4) One day, you may have to phone up someone and there's nothing you can do about it. You may have to question a shop for some details, etc. Can be stressful—just be ready for all details beforehand! Write down the core details (everything you can think of) on a bit of paper beforehand. The product, the address, the question, and whatever else may be useful. Just don't phone up unless you have as much detail as you can, otherwise you can have serious stress you don't need.

5) Sometimes it depends on the job, or how important the job may be. If your boss suddenly comes in—all guns blazing with info—you haven't got a chance of getting the whole lot—yet it may not be a must do in the next 10 seconds—take your time. Write down what you could store, and then in the next hour or so, you can say "sorry boss, but I was

just finishing off a last job earlier—and I lost my paper I had written down, can you just give me the last bit?"—you couldn't do that every day, but once every now and then, you can use it. Just blankly saying "what?" a hundred times won't do anyone any favors.

6) Recording device—there are some very useful recording devices on the market, excellent way of storing information that you may not be able to store. Very simple—start recording, take the phone, and off you go. Then play back, and all the info you just couldn't store... is there. You don't even have to ask "can you say that again?" a thousand times, magic.

7) Caught off guard!—OK, you could be walking across the office, when suddenly your boss pops up and fires off a job needed quickly; you haven't got a pen, nor were you ready for the info! Whenever I get this, I make sure that I store the most crucial bit of info—the name of the product. The text and the reason of the job are important, but the best info would be the name of the product. If you don't get all the data you need, then find the name of the product, and any info from it—come back and say—"boss, that's the one isn't it?"—the boss will then give you the needed info again. Should be enough this time.

8) There are times when you maybe in a conversation with a colleague, when the words just won't make much sense—this is aphasia, these things happen! Certain words, or a sentence, just won't quite merge into a full understanding. And they may expect an answer—what do you do!? "What?" or "Huh?" ten times? Sometimes it just won't work out. You may be able to even remember the sentence after—but not to fully comprehend. So sometimes I deflect the question—"OK, I will have to check that out"—"Perhaps, but are you

sure about that?"—Deflection can be enough sometimes, and once again you could send an email after. In fact, I probably say that every day.

9) Limit the problem beforehand—e.g., I asked a friend to play golf over the weekend; we agreed to play at around 12-3pm. I also said I would arrange the booking (oh er!). So, if I now phone up and ask for any possible time from 12-3pm, I could get all sort of options—quarter past one, half past two, twelve forty-five, etc.—it could be a problem for any aphasic person. So although I will have 3 hours, when I first phone up, I'm going to limit the responses—"Hello, is there a round of golf from 12 to 1pm?"—if there's nothing for that slot, I will then ask for 1-2pm; and that follows to 2-3pm. It's easier to limit the responses, as long as it's not a problem afterwards.

(Article submitted at AVMSurvivors Forum: "Aphasia—Trade secrets")

Richard
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

My story has no equals and I'll attempt to keep it short. On 6 Feb '72 at age 30 and in the PRIME of my life, my AVM ruptured and bled into my brain causing a mild stroke of which I was not aware. I was a roofing contractor at the time and was so for over 2 years. After being seen at various hospitals near where I lived in my custom-built home in Steilacoom, Washington, my wife drove me up to the Seattle VA hospital since I was a veteran (A Vietnam veteran, unfortunately) where a spinal tap was performed. There was blood in my spinal fluid and an AVM resection was performed on the AVM that was located deep within my left frontal lobe whose main function is with judgment. I was operated on the 15th of Feb '72 and have NOT been the same since! I'll interject a pertinent item that I found out in 1988 (!) at the Seattle VA hospital.

Phone contact with an individual who knew Mr. Dettrey before 1972, revealed that the patient was very different before 1972, before his AV malformation, that he was afterwards. Previous to 1972, the individual noted that there was nothing wrong with the patient. He was described as a very successful roofer who had no emotional problems and was never depressed. He described the patient as gregarious, friendly, likeable, very smart and always organized and goal-directed in his speech. The individual noted that the big change came when the patient had to be hospitalized in 1972. He described the patient as currently being disorganized, easily frustrated and has a hard time getting to the point. The friend noted he had not seen any improvement of the patient in five years.

I, unfortunately, returned to the state of PA in 1975, to get the unannounced grand mal seizures that resulted from

the AVM surgery and were a "problem" for over 6 years and for which I was being drugged! The seizures were FINALLY brought under control with the right medication, something that was necessary for me to get my life together and live it like I was used to! Unfortunately, my wife divorced me in or about 1977. I USED to be an excellent bridge player and was looking ahead to my life Masters which was the pinnacle of the bridge world. After about 4 months of ridding myself of the hospital where I had the surgery, I suffered my 1st grand mal epileptic seizure at a bridge game. It was, completely, unexpected, and ruined my thinking ability as evidenced by my trip out [one] night to PA and my parents who lived there.

That was BAD judgment on my mildly traumatically injured part and would NEVER have been made IF the seizures hadn't interfered with my life as they did, unfortunately and for 6+ years!

I've been "living" in low cost housing since I was about 40 (I'm now 70) and needed something that was productive. I "chose" Amway, which offered me a business of my own with very little money up front unlike the roofing business. Yes. The AVM surgery was a success, but the patient died—figuratively, not literally. The end.

Dick
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Well it all started after a trip to India in 2000. Came back with sepsis! Not a good thing. But I used to live in Florida without any health insurance so I didn't investigate any further. I was on antibiotics for 1 1/2 month! Never felt the same after that but still didn't know I had MM (Multiple Myeloma).

Two years later I was getting more and more tired, grouchy, nervous, anxious memory loss, you name it. So it was kindly suggested to me to take a Sabbatical year off.

So, off to France! What a beautiful country. Two months after being there I woke up in the middle of the night with a very high fever. Tried to stand up but both of my ankles gave out!

So I ended up at the local "village" doctor who sent me for blood work. So I went for my blood work in the morning on my own a few miles away and went back home.

Got a call I the same afternoon from the doctor telling me to get my butt to the hospital ASAP. The lab had called him and said that I was such in bad shape that they could not believe I made it to the lab on my own.

First diagnosis, sepsis again! This time my kidneys were failing. Spent 10 days there thinking (It's just sepsis, I'll be back playing tennis in no time, ya right!) as if it was nothing! Did not know the dangers of sepsis back then! On the 11th day that's when they told me I had Stage 3 Multiple Myeloma with too many bone lesions to count! My cranium is full of holes. I had been wondering why I was breaking ribs one after the other (18 so far)! That was June 13, 2003! 88% of my bone marrow was cancer. So I was told not to lift anything, ride too long in a car in case we hit a bump and I break my spine or whatever... Gee, I was playing tennis 3 weeks earlier! What a shock! So the next day I had my first port a cath

installed and 1 hour later my first round of chemo called VAD. That's short for Vincristine, Adriamycin and Dexamethasone. They plugged in a pump in my porth that delivers the chemo drop by drop for 4 days. Did 6 months of that and it was working pretty well the cancer was down to 11%. I then decided to stop all treatments, had my porth removed and tried alternative medicines. You name it, I tried it!

Came back to Canada and in 2005 started to feel tired again and I knew that feeling. So I consulted with an Oncologist in Montreal and the cancer was back up to 72%. So by then I knew that I had to go through the chemo and transplant and all! When I decide I get into something I do it with all my will and heart! So I went for it like a fighter! Had my first "Picc Line" installed for more VAD chemos. The Picc Line was a temporary thing until there was room available for them to install my second porth. And 4 more rounds of VAD. But they switched me to thalidomide and dexamethasone because the VADS were starting to affect my heart. Did 8 months of thalidomide with dex. That was pretty tough. But it worked. Ballooned up to 240 pounds! I was 185 before. Numbers were down to less the 10% of my marrow and M Spike down from 57 to 14. (Now 2, 6). So off to the first transplant July 18, 2005. Three Months after the first transplant my M-Spike was down to 4.7 but wasn't moving up or down.

So I was offered my second transplant right away. I refused it. I wanted to work on myself. On being a better person. Eight months after the first transplant all the markers disappeared completely to my doctors amazement. I was sure I was "cured"! Then about 4 years later I was in pretty good shape. Playing tennis again back in the gym and all. Then in March of 2010....I fell off the roof! Not a good thing when you have MM! A few weeks later I started to feel tired again and

yes, it was back! Hit me like a ton of bricks! I was told that any kind of trauma either emotional or physical can "wake up" the cancer. So another good reason to stay positive and have good attitude towards everything in life.

But I was able to lift myself up, dust myself off and off to war we go again! Had 18 rounds of "CyborD" protocol and as you know by now I am just waiting for the call for the second transplant! Should be Monday or Tuesday.

Right now I'm feeling pretty good since my last chemo was 2 months ago. So I'm ready for it. After that my priority is to get back in shape to enjoy life again. I wish I would have started the Blog sooner so I could have more followers. Just wish to help as many people as possible.

Yvon
Multiple Myeloma
Life With Multiple Myeloma
(www.LifeWithMultipleMyeloma.org)
Patient

Indoors, at my kitchen table on a sunny day in 2001, I was struck by lightning. Sitting one second, on the FLOOR the next second, with a 30 pain on a 1-to-10 scale—No exaggeration. I had always heard there doesn't need to be a storm around, and that it can come through your outlets, etc., and now it's happened to ME! Never did hear a thing. The pain gone, as if it never existed 5 LONG seconds later, I spring to my feet and frantically ask my Dad if my face is gored. He's looking at me like I'm possessed. I run to the mirror. I'm fine. Nothing. What in God's name??? I guess it wasn't lightning. What the hell just happened? I call ask-a-nurse. She asks me if I have any sinus issues. No. She tells me to see a doctor. It happens again that night, as I sit up in bed, like I've done 10,000 times before. Fast-pulsing electric shooting intense pain in my forehead and nose and eye. Bite the popsicle stick and tough it out. 25 on the pain scale. Gone in about 5 seconds.

Our local family doctor (thank God he didn't blame dental issues, I would later learn) said "It sounds like some kind of neuralgia. It should go away on its own in a few days, or weeks; problem is, pain meds aren't gonna work on this, since it's a nerve pain." No WAAY! WEEKS?

It happened again about 8 times over the next 5 days, maybe a little less intense and a little shorter, down to 3 seconds of 20 pain, and I could start to notice the bodily moves I was making that increased the chances, but often it just happened for no reason.

Two weeks later, two months later, eight months later, it was all a freaky memory.

But then one day upon brushing my teeth I got a twinge—in my gums and cheek. And it got worse and worse each time,

and they went for longer and longer, until I was afraid to brush. And speak. And drink and eat. Intermittent stabbing electrical pain, 20 on the 10 scale, 1, 2, 5 seconds at a time. Weeks turned into months and it wasn't going away. I re-learned how to bite and eat and sip strategically through straws. I was messed up. "Maxillary" Type I TN.

That's when I Googled "pain in face" and saw that I was in a very exclusive club of people with bad, bad luck. I saw with no question that I had gone through "Ophthalmic" Type I Trigeminal Neuralgia, and now it was "Maxillary" Type I, and things were gonna get worse, since all the best info seemed to agree it would. And since I was in my early 30s unlike most victims who are in their 60s, this thing would have another 50 years to get worse and worse and take me down. I was VERY afraid of taking drugs or getting surgery, but it looked like that's where I was headed. Bullet points from here, so I can stay within the page limit:

- We tried "carbamazepine" which is supposed to work for 85% of people. It did little.
- We added "gabapentin" which did little. The dosages went through the roof.
- We tried the Cadillac operation: the microvascular decompression (MVD). They found an artery and two veins, and fixed me up!
- It worked, and a year later, my wife and I did a celebration dance around the toilet, pouring the meds down, to close the book.
- One year later it was back with more intensity. I was depressed as hell and so angry. I was a good guy who took care of myself.

- Why ME??? I didn't deserve this!!!!
- I am SO screwed. The best meds didn't work. The best operation didn't work. And I'm so damned young.
- I became fatalistic, not looking forward to living, and started acting weird, and angered my wife, and my boss.
- Pain was so bad one day I cried through closed eyes in a fetal position on the street. Me, a tough guy.
- Back to the doctor, for what was worth.
- Grasping for straws, we tried carbamazepine again. I was NOT hopeful.
- But it helped—a lot!!!
- Turns out, that people who have failed an MVD have a better chance of meds working after!!! Yipeeee!!!!
- High doses? Bring 'em on! Liver damage? Who cares! Jitters, loopiness, and inconvenience? Pff!
- Any day with no pain is heaven—and now, pains and discomforts that other people can't handle—I laugh at.
- Two years ago I transitioned to and through Type II TN, with its burning bee stings pains, up to 18 minutes long…
- And since then, I only get single, strobe light speed shocks if I do the "wrong thing" with my trigger area (upper left gums).
- And this summer has been the best since I've had the disease. Med dosage is down, few side effects, and pains are rare.

- But I feel like I'm in the witness protection program—that any time, I this effing thing could mow me down through my dining room window when I least expect it. But I do expect it. So my life is not as happy as it should be. However, I always know it could be much, much worse. Luckily the meds do something for me. And they don't hurt my liver. And in the same 50-year period I'm worried about escalation, good people will be advancing ways to help me. Thanks for listening.

Scott
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient

Here's Ben's Story: http://www.youtube.com/watch?v=YBeRFnJkleU&feature=youtu.be:

http://www.AVMSurvivors.org/photo/avm-survivors-bbq-pics

http://www.avmsurvivors.org/photo/img-5283?context=latest

Ben
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
BensFriends.org, Founder
Austin, TX

My name is Eric Clark, New York State. I am a patient with SCA. The official diagnosis came when I was 26. I have been declared "totally and permanently disabled due to spunocerrebellar ataxia."

For the last three years, my walk has worsened. I use a cane. I cannot walk very far. I use what is called here Dial a Ride.

Eric
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
New York State

Now that I know for certain that it is Psoriatic Arthritis, I wonder about some episodes in my life. For example when I was 9 and my knees and ankles would hurt and the doctor chalked it up to "growing pains" or when I woke up with a badly swollen toe that did not itch the doctor said it was either an insect bite or I had broken the toe and not realized it. They seem silly now and I sort of wonder why the doctors did not think of PsA. I guess it is "rare" enough that it would not occur to the average general practitioner in the 1960s or 1970s. I have very mild plaque psoriasis and have even had one rheumatologist tell me I was stupid to think I might have PsA. My mother had severe plaque psoriasis, my sister and son have what I would call medium and I have heard that my grandmother and great-grandmother suffered with psoriasis. I think I have a family history!

By the time I was a teenager I definitely knew that I had joint problems. The usual answer was that my butt was too big. I started wondering if everyone with a butt my size hurt as badly as I did. Suffice it to say it was many years and a few knee surgeries before I found my current rheumatologist. She treats me like an adult and validated my fear that I have PsA. My mother probably suffered from it too, but I no longer have her to compare notes. I have been on prednisone and anti-inflammatory drugs for years. My skin is so thin that my dogs keep my arms covered with these lovely scratches of broken blood vessels. My doctor started me on methotrexate and biologics. I do feel some positive effects from the drugs, but I have also had 3 sinus infections. I just keep taking my medicine and hoping for the best.

I try to exercise, but it is difficult when it hurts so much. I try to use my above ground pool every day during the summer.

I reward myself with reading time on the pool's deck. I walk one of my dogs down my very long driveway and up my very long and uphill street. I do a little yoga, but it is hard to get up off the floor, so I save that for my very good days.

I don't need a cane to walk all of the time since having my right knee replaced. I keep the cane in my car for those days when I need some reassurance or just need it to walk. When I have a flare up I sometimes even need a walker to get around.

In 1994 I herniated a disk in my back. I had surgery where part of the disk and a chunk of bone were removed. By the time that I should have been returning to work, I was still in tremendous pain. An MRI showed heavy scar tissue around my spine and sciatic nerve. I had another MRI of my lumbar spine several months ago and the doctor who performed my back surgery looked at the images. He said that there is severe arthritis in my lumbar spine. He said there is nothing that can be done surgically to help me with my pain. In his opinion I need to continue with my pain specialist who I have been seeing since 1995. I would rather not be retired on disability. I miss my career as a systems analyst and so I have done a few websites either in exchange for other services or for a few extra dollars. Fortunately in those situations I can make them wait until I feel well enough to do the work. I don't have deadlines imposed by government regulations or by my employer trying to keep up with their competition. I would not be able to pass a routine drug test now since I am prescribed at least 1 class 2-narcotic.

The fatigue is awful. I feel tired all of the time. That's hard when I have an 11-year old granddaughter who loves to spend time with me. It was the fatigue that got me to a rheumatologist finally. I even went through 2 sleep tests and

suffered 3 months with a CPAP machine just to find that it did not help me sleep any better. In fact the CPAP forced me to sleep on my back, which is very painful. Since the surgery on the right side of my spine I can only sleep on my left side.

I used to think my mother was being overly dramatic about the arthritis in her hands. I did apologize before it was too late. My hands are very weak. I have trouble driving some days. I have an assortment of tools, gadgets and machines to remove lids and compensate for my weakness. I use a trackball rather than a mouse and have for many years. The part that is the most difficult to deal with is losing sensation in my hands. I like to crochet and want to learn to knit. I have given up sewing since lifting and moving and pinning the fabric is just too painful. I have had a Kindle for over 2 years because I had almost given up reading. I could not handle paperback books and got tired of dropping hardback books.

The one thing that really disappoints me is not being able to hold my 7-month old grandson and move around normally with him. It means that I cannot babysit Dexter and it breaks my heart. It's a good thing that my granddaughter is 11. If I am needed to sit for Dexter, I will need to have Liz with me to hold the baby while I stand or sit. I don't know why I expect anything to be different; I am barely competent living by myself. I can do the housework needed to keep my home clean as long as I do a little every day. I cannot do yard work and must hire someone which I can't afford some months.

The number one thing on my mind is my grandson Dexter. He has psoriasis in his family. We have had it in every generation since 1900 that I can confirm. Is Dexter doomed to have Psoriasis and Psoriatic Arthritis?

Marta
Psoriatic Arthritis
Living With Psoriatic Arthritis
(www.LivingWithPsoriaticArthritis.org)
Patient

When I left school I was a very fit and able person, Taking part in all sorts of physical activities so I joined the Army—this was a fantastic move. I found lots of new friends and had a great time. Whilst in the Army I went to Northern Ireland twice. After leaving I became a HGV driver (Trucker) and again had a long successful career.

Then one day I felt very tired and my left leg felt as if it had been crushed, The pain was quite unbearable so I went to see my Doctor who told me to slow down a bit.

After about 2 months I had another day very similar so of I went back to see my Doctor again who sent me for a test at the hospital but the test came back with nothing found my Doctor told me I was getting no younger and I should consider changing my job to something less physical, the only problem with that is you don't tell a trucker to change his job because once you get into it, it becomes a way of life.

Anyway, sometime later my Doctor told me I had Fibromyalgia. Well this came as a big shock and to be honest I still don't think I have accepted it to be the way of life I now have to put up with.

I have had to give up my job, give up ALL my sport activities, and struggle to even play with my grandson. So for me Fibro has changed my life. In fact I would say Fibromyalgia has TAKEN my life and left me with something I didn't want at all. Now I just sit at home struggling to do the things I took for granted. Keep taking the medication and hoping that someday there will be some relief from the pain for all us Fibromites.

Arthur
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient

My name is Tania. I am 38 years old and this is my AVM story to date.

I was born in 1973 with an AVM. At the time of my birth it was diagnosed as a port wine stain on my left leg however over the first few months of my life the AVM grew 3 times faster than I did.

My parents were not aware of anything like this, as none of my family had anything like it. Doctors and surgeons mis-diagnosed my condition for most of my life; we were told that the port wine stain was an AVM in July 1982, however we were told there was no cure for this condition as it was too rare.

I have suffered all of my life with severe swelling and pain; my leg has had bleeds where blood vessels cannot cope with the pressure. In 1992 I underwent surgery for the first time on the lower part of my leg, however as soon as I stood up the veins popped back out and looked like a mass of peas under the skin (this is the only way I can describe how my ankle looks).

My whole leg from hip to toe is purple and lumpy, it swells up to 7 inches bigger than my right leg and it's very painful. I then underwent another surgery in 1995 via key hole, however again this was not successful—all that happened was more lumps occurred as soon as I stood up.

I have never had a day without swelling or severe pain. I have had 3 children who do not have this condition, however it's extremely distressing for them and my husband to see a grown woman crying in pain most days and nights.

My parents told me that surgeons had always said it would be detrimental to my health if I were to have any form of operations on the leg due to the extent of the AVM. I had looked into sclerotherapy however I was told this would not be possible for my condition as it's too extensive. I claimed disablement benefits, which were at first granted, however as I would not give up and continued to work this was soon stopped. I then applied to work for the local police force as a PCSO (Police Community Support Officer) even though walking and standing caused the swelling to be worse; I felt I could not give in.

I have arthritis in most of my joints in this leg and I have suffered several DVT's (deep vein thrombosis), for which I now am on Clexaine injections to help prevent further clots. I take several different types of Morphine for pain control, however never seem to have a break from the pain.

I am working still after 6 years as a Police Community Support Officer and I wear calipers to enable me to do my job. I saw another vascular surgeon 4 weeks ago who had told me that the only option I have now is to have the leg removed above the knee. I am waiting for this operation to happen and I am really hoping this will work for me. I would like to know if anyone else has had a limb removed due to the AVM and how they have coped with it.

In my whole life until 4 weeks ago it seemed I was alone, no one ever (and still don't) seem to understand the pain I am in constantly. Doctors and surgeons never seemed to listen and as they were (and still are) not aware enough about AVM's, they seem very unhelpful to sufferers. It is a very lonely place living with rare conditions, and I was so thankful when I found the AVM Survivors Website. The only way I can

cope with this condition is NOT to give up, continue to work and keep busy, I feel living with severe pain has made me the person I am today, and I will continue to serve the community once the amputation is completed.

I'd like to thank the AVM Survivors website members as they have answered many questions and also kept me sane at rough times."

Tania
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Hello. Here's an image of my Rondeau working as a therapy dog at our local Ashland Community Hospital. We also go each Wednesday to our Veteran's Administration Domiciliary to connect with the Veterans. Last year we helped three troubled second graders learn to read and we get to work with the same ones this year. Next week we get to provide our first Hospice patient whatever she needs. Rondeau has just received awards from Therapy Dogs International and American Kennel Club for all the work he's done so far, and this is only our first year.

When I had to give up my orthodontic practice because of my severe brain injury, the thing I mourned the very most was the connection I made with each of my very loved patients as well as my phenomenal staff. I now think that I had the bike wreck for a reason, so that I could get Rondeau, wouldn't be able to do this if I still raced, and so I could be inspired to do this important work, give to the good community in which I live.

Last year a good friend asked me that if I could turn back the hands of time, would I give up my life now and have the one I had before the wreck. I thought a good long time and said no. Life is so beautiful now, I have to think really hard to find something to complain about and I am really excited to work the way I do with Rondeau and will always look for new opportunities for us to participate with my fellow human beings.

I send strong good energy to everyone who connects with Ben's Friends so that they all find inspiration to achieve absolutely anything that inspires them.

Blessings,
Kelly

My Life Story before I was diagnosed with an AVM: I loved my life….I have a wonderful daughter, granddaughter and family.

I loved my job….I was a Human Resource Manager who adored the people I worked with. Though I worked extremely hard at my job, when I had vacations, I traveled not only around this country, but around the world. I became a scuba diver at age 50.

I did have many difficult periods in my life—the divorce of my husband, losing my parents, my best friend and then having the love of my life pass away from a heart attack, I carried on.

My AVM Story: My AVM was diagnosed in January of 2007. I did not have any symptoms except that I had a headache after having my teeth cleaned. Therefore, my dentist sent me to have an MRI and from that my AVM was discovered.

The first neuro doc I went to said I should do nothing, however, as I am a true believer in getting a second opinion, I went online to look for the best doctor that treated AVM's in my area. From that, I found Dr. Christopher Ogilvy at Mass General Hospital.

His office asked me to send him a copy of my MRI. Once Dr. Ogilvy reviewed my MRI, he wanted to see me right away. After that appointment, I knew that Dr. Christopher Ogilvy and Dr. Paul Chapman at Mass General Hospital were my best options.

Due to my AVM being large and deep back in my brain, my only option was to have Proton Beam Radiation with beads included, by Dr. Paul Chapman, which was performed on

May 22, 2007. Dr. Chapman put in three beads exactly in my AVM area (which will never be removed), for the radiation to go to the perfect spot.

Unfortunately, six months later, on 12/24/2007, I had a massive hemorrhage in the left temporal lobe, as well as in the occipital lobe. Doctor Ogilvy performed a craniotomy to remove as much of the bleed, as possible. They could not do anything to remove my AVM, due to its location and size. I was in the hospital for 8 days, and then sent for Rehab for 3 weeks before I was sent home.

After my craniotomy, I was diagnosed by a Neuropsychologist at MGH was Cognitive disorder due to the AVM rupture, Anomic aphasia and Alexia without agraphia. I now have temporal lobe seizures and take Keppra to prevent them.

However, on 8/21/09, I had my third angiogram performed by Dr. Ogilvy and was told that my AVM had totally disappeared! The Proton Beam radiation performed by Dr. Chapman worked! Thank God!!!!!

Because of my disability, while I can't still travel or scuba dive, every day I do something that makes me happy. I must admit that I am on an anti-depression med which helps.

I want to thank my Daughter (my constant caregiver) and my Family who from the beginning were with me through it all.

Louisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

My name is Jan; this journey has been very bumpy for me. Originally diagnosed with MS in 2006, treating with Betaseron for 4 years, I was shocked when my Dr. left the MS clinic & the new Dr. looked at me & said "I question your diagnosis." She explained that to diagnose MS, you had to rule out everything else. That had not been done. Plus, I had some other problems that had been totally ignored. Thus began this trip. My story is still being written.

In short order, the problems the Dr. mentioned (B12 deficiency) were assessed, & treated; not necessarily corrected. The brain tumor in my stem, mid brain, the other Dr. told me was "gone, just gone," she assured me was indeed not gone. Being inoperable, but not causing any issues, it took a back seat to the progressing neuropathy destroying my reflexes, balance, causing me to no longer be able to climb stairs, walk without a cane, unable to break a fall. I was sent to the specialist in neuropathies once she had exhausted her knowledge. He proceeded to conduct the appropriate tests, EMG, lumbar punch, specialized blood tests & felt comfortable with a diagnosis of CIDP.

I could not catch my breath, feeling betrayed & scared. My lb was 123 for protein & the fact that I had the brain tumor could potentially cause a high protein count. My nerve conduction tests showed slow conduction to support CIDP, along with no reflexes, the ever-encroaching numbness, tingling & tuning fork sensation, only in my fingertips at that time. My feet, which started as feeling as if they had socks on all the time, now were beanbags, feeling as if the arches had fallen, touching the floor. The neuropathy Dr. scheduled me for IVIG.

I went in-patient for a five day treatment on 7/25/11, one a day. On the second day I developed a fever of 102.5, which I kept for two days, with flu symptoms, headache, etc. Using an ear thermometer, the nurses seemed to me to just blow it off, registering a fever of 97. I finally insisted they get an oral thermometer & they did totally panicking. It left me feeling uncomfortable asking for those nurses to be replaced. My Dr. was out of town & when he returned he was concerned. When I went in 6 weeks later for a 2nd round, he did not want me to do a one-time large dose because of my reaction, it was worse. Got the high fever again, with a rash, some large wart like skin things, itching, and when I came home, another fever. Both times my white cells & platelets dropped very low. He said I cannot have them again. The first round helped me; the second helped me minimally. Both caused bad things that were not happening before, a tuning fork sensation in my entire legs & arms. FYI, I did have pre-treatment with Benadryl & Tylenol.

I am facing IV steroids. I had the option of oral steroids for 6 months. I am not sure I could tolerate them as I am already nervous. There is no treatment option that gives me comfort. The Dr. says that MS is much worse than CIDP. But when I was diagnosed with MS, I was not so afraid; I was doing well with the shots, etc. Since I was diagnosed with CIDP, which began 10/2010, my life has rolled quickly downhill. I think the progression has been quick & it is progressive, not remitting. To me, this is worse."

Jan
Chronic Inflammatory Demyelinating Polyneuropathy
Living With CIDP (www.LivingWithCIDP.org)
Patient

How I came to Ben's Friends: In August 2000, the one person I knew to be invincible, to be infallible, and who I called Dad, was diagnosed with multiple myeloma. Three years, several cycles of chemotherapy and radiation, one autologus stem cell transplant, one bout of remission, a pair of boxing gloves to "knock out cancer," and one replaced hip later, Dad was gone. It rocked my world to watch my father battle that terrible disease; so much so that I made a career move into cancer research. Today I manage a program dedicated to inflammatory breast cancer, the rarest and most deadly form of breast cancer.

So given my personal experience and my position with access to resources and information, when Ben, someone I've known and respected since Kindergarten, began building these communities, I jumped at the opportunity to support him. Most of my support is through sharing of information from first-hand experience and from knowledge of research breakthroughs and resources. My heart is with every member of every community in the network. And while I may not be able to be as active as I would like, I immediately turn to the community when I find something that may benefit them.

Dad holding Lia: My father holding my daughter. He would pass away one week after her 1st birthday.

Andy-June: Dad and his dog after his hip replacement.

D: Me in the office working on IBC Program stuff.

State Resolution: With IBC Delegates and supporters from Komen, American Airlines, and New Mexico State Senator Tim Jennings at the Texas Capitol to declare October 2011 Inflammatory Breast Cancer Awareness Month.

Best wishes,
Danielle

Danielle
Multiple Myeloma
Life With Multiple Myeloma
(www.LifeWithMultipleMyeloma.org)
Family member & now breast cancer program manager
Tomball, TX

I have Lupus, but Lupus does not have me… This is a fairly simple statement, but the concept is complicated! (I don't actually prescribe to this concept, personally) I have heard others say this multiple times. However, it took quite some time to sink in. Anyone with this disorder has felt overwhelmed, and has lived under the label of, "I have Lupus"; which is multi-faceted, just as each one of us are.

So far I have not met/been in contact with any two people that are exactly alike or "their" Lupus manifests in the same way. The "textbook" definition of Lupus has more than 30 different criteria, the "non text-box" definitions have even more. But the bottom line is pain and suffering.

It is test of anyone's fortitude on their best day…don't get me started on the worst day(s). We all know that there is a new "normal" (not one we would choose), and that "normal" is ever changing. With Lupus you learn to be flexible, hopefully to cope, and so much more. Each of us has or will go through the grief process, multiple times.

My personal theory is that 50% of solving any problem is identifying the problem itself. Below you will find the 5 stages of grief, and as I have said each of us will go thru the process in our own unique way…at our own pace, and more than once.

Whether you are a religious or spiritual soul or not, once you have actually gotten through the work of mourning, you'll look back on it all with wonder. Right now, you won't understand this, but in retrospect, you'll be forced to admit it is a miraculously designed process. There is a good reason for each step or stage of the grief process.

Grief doesn't actually follow a neat little progression of stages or cycles. It's much messier than that. It's a very complicated and personal thing. There will be a lot of regression, or backtracking to earlier "stages" or "tasks." And that's okay. It just means you weren't yet finished, and are fully working it through in your own way.

The stages of grief...

Here is a brief overview of the "grief stages" so you will understand better what is happening to you, and what to expect in the future. There are several "theories" about how grief works.

It is suggested you read about them all, as they make for interesting reading, and each one adds a little bit more insight. As well, knowledge/education is invaluable. Please remember, the following are just models, just scholars trying to get their minds around one of the most complicated emotional processes of the human experience. And keep these points in mind as you read:

See, you're really not going crazy!

Many others have had to travel this hard road before you. You are not alone.

Grief is a long-term process, and you will have good days and bad.

There is hope—brighter days lie ahead for you.

You will never return to your pre-grief state, but you will eventually find joy in life in new ways that you invent.

There really are no true "stages of grief" *and no time frame for mourning.*

Although the Kubler Ross model of grief has also been called "The 5 stages of grief," this is another working model, or staging of grief that we will discuss. It introduces some additional, useful concepts on the process of bereavement.

There is no set timetable to grief, of course, and all of these staging models are meant solely to help you understand some of the commonly experienced emotions and changes you may encounter. The danger in any "staging" of grief is that it may give people a way to "buttonhole" you into a convenient little category, and predict how you should progress next. And grief just doesn't work that neatly.

The 5 stages of grief:

NUMBNESS & DENIAL—The first reaction to a loss, numbness or shock can help cushion the blow and can help you get through the initial mourning rituals with the family and the funeral. This stage can last a few hours, days, or even a few weeks.

YEARNING & ANGER—The numbness wears off, and the painful realization of the loss hits full-force; you will yearn deeply for your lost loved one. You may be angry and have regrets of things left unsaid or dreams never realized.

EMOTIONAL DESPAIR, SADNESS & WITHDRAWAL—The storm of intense emotions of the second stage gives way to a period of heavy sadness, silence and withdrawal from family and friends.

REORGANIZATION—Reorganization and the beginning of positive emotions. Over time, the sadness stage will start to lessen, and you will begin to see a lightening of your emotions. You will start to perceive your life in a more positive

light, although bouts of grief and sadness will persist, probably for the rest of your life.

LETTING GO & MOVING ON—The final phase of this model is to let go of your need for the loss and to move on with your life. Sadness will lessen greatly, and new interests will gradually occupy your thoughts more and more, crowding out the misery and desolation. The final stage is when you "pull your life back together."

All of the grief models stress that you will never fully "get over" or forget your loss. The grief process allows you to integrate the memory of your loss into a more manageable place in your psyche and heart so that you can resume a more functional and bearable existence. The process works.

Clearly, this will be an ongoing cycle as Lupus is a progressive disorder. My greatest hope is that this information is helpful in your understanding of what you are feeling and going through.

As well, hopefully find peace, harmony and balance in your life. Be Blessed…

Melissa

P.S. All this is something I post on LifewithLupus.Org. But it is the best I can do right now as I am dealing with a flare.

Ms M D
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient

After beginning my day getting out of bed, taking a couple of steps and falling on my face, I finally listened to my husband and made an appointment to see my physician. Lately I had been bumping into the furniture more than usual and was having difficulty climbing stairs. Just the other day, when gardening, I had to crawl over to the fence in order to pull myself up, since my legs would not cooperate.

After blood work and a spinal MRI ruled out the usual suspects, my neurologist suggested I might have some form of a genetic peripheral neuropathy. Researching online, my symptoms seemed to indicate I might have Charcot-Marie-Tooth disorder. Athena diagnostics genetic testing confirmed I have CMT1A, a progressive neuromuscular disorder, affecting approximately 1 of 2,500 people.

I had to give up my career as a pharmacist, since I cannot stand for long hours, and frequently lose my balance, trip and fall. Also, I have lost function in my weakened hands, leaving me unable to open containers, frequently dropping things. Buttons and zippers are a challenge.

I started a support group to let others know how helpful physical therapy has been for me and to give others hope about the encouraging research that is being done with the CMTA. We share information, resources and friendship with others affected by CMT. This year I have been fortunate to work with the CMTA on the national CMT Awareness Month campaign, September and am chair of the Global CMT Awareness Day, Sept 24."

Melinda
Charcot-Marie-Tooth
Charcot Marie Tooth Support
(www.CharcotMarieToothSupport.org)
Patient

After researching all I could find on SLE (systemic lupus erythematosus), I religiously followed my doctor's advice and medication regimen and otherwise dealt with my SLE on my own for about four years. In spite of my knowledge about the disease, good healthcare, and some of my worst symptoms had improved. However, as previously mentioned, I still suffered from extreme fatigue and other debilitating symptoms. As a result, I began to feel increasingly isolated, lonely and sorry for myself sitting at home with my husband away working for months and my motley crew of three spoiled, stir-crazy dogs giving me way too much attitude about my inability to get them out for the long walks and dog park visits they took for granted when my health was better.

I finally got to the point where I couldn't imagine going on with my life as it was and yet couldn't imagine anything but an all-out cure changing it. The only thing I could think to do was to sincerely ask whatever God there may be for help. My prayer was answered one morning when I came to the realization that I needed a support group, an idea I had poohpoohed for years. But simply having this unpleasant thought convinced me that it must be a message from God. Certainly on my own, I had better sense, didn't I?

So I only reluctantly tiptoed into a support group, bringing a long-time lack of respect for what I always thought was the unseemly neediness that must be characteristic of the people who joined them. This prejudice also fed my fear of sharing anything too personal, which rationalization had turned into a virtue and allowed me to be smug about it. I mean no one is immune to being dealt a few bad cards in life, right? But the key difference was that we normal people, (Now there's a fellowship in which I firmly believed I was

in good standing, despite many obvious clues that said otherwise), just dealt with them better and moved on with our lives. Never mind that I was doing a pretty crappy job of moving on to anything except more crazy rationalizations about not needing any help.

Since then, my husband is still away working and my dogs still drive me crazy in spite of trips to the dog park almost every day now. But at least my attitude has vastly improved and I can only attribute that to the magnanimously shared experience, wisdom and support from my group members. What I value most, however, are the dear friends I have made with several group members in only a few weeks after sharing a little about myself and welcoming newcomers. All of this virtual good done has also allowed me to be easier on myself, better understand and manage my condition, and feel a lot less lonely and isolated.

Patricia
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Boynton Beach, FL

Hi, my name is Joanne and I have been battling these conditions for the past 7-8 years. As far as my Major Depression and Anxiety, it all began in 1991 when I lost my Mom to pancreatic cancer. I watched her battle this fatal disease for almost 5 years before it completely devastated her body and she no longer had the strength or ability to survive it. My Mom was always my go-to person, very wise and the most supportive person I knew. She could read me like a book without my having to say anything that was stressing me out. That was in 1991 and the pain of her loss is still as overwhelming to this day as the day she passed.

I worked in the dental field, the front office manager for an orthodontist. I had undergone two jaw operations (1981 & 1997) to correct my bite which we thought was the reason for my having chronic migraines since I was 13-15 years old. About 6-7 years ago I went in for a routine cleaning and my dentist found that I had severe decay in between every tooth. This was a shock because after all I had been through and how well I took care of my dental hygiene was unimaginable. I always had a traveling toothbrush and paste in my purse and even after eating out, I'd go and brush my teeth in the restroom. I was hyper-conscious about all of this.

From there I went on to undergo 10 root canals and three crowns. Finally my M.D. sent me for a bone density x-ray. They found that I had severe osteoporosis and severe fibromyalgia for at least 2 years. I was put on Lyrica for the fibromyalgia and it seemed to help for a bit but the specialist I was referred to kept upping the dose to 225 mgs. and I began to gain weight steadily. I was also prescribed Boniva to rebuild my bone density. I'm 5'1" and my normal weight was around 110-115. I ballooned up to over 160 lbs., a side effect

of this medication along with Lexapro for my depression and Clonazapam for my anxiety. This only made the pain in all my joints worse so I finally, with the help and supervision of my M.D., [began] to wean myself off of the Lyrica. All the medications I was prescribed had the side effect of Dry Mouth Syndrome, which was actually one of the main reasons for my teeth deteriorating.

I began to lose all the calcium I required and all my teeth began to thin, chip and break when I ate. As my Mom always did when trying to find any medical answers or information, I began my own research. After everything I had been through with my teeth, there was so much damage that I had to have them all removed in March of this year. I had posts (two on top and two on the bottom) and was fitted for dentures. What frustrated me the most was that as you all know, when you see a new Doctor, they require you to fill out a health history and list any or all the medications you have been prescribed. None of them put it all together as to why between these meds, it was a combination of the above conditions with the side effect of Dry Mouth Syndrome.

At this point, I am still at a state of recovery as I required a great deal of bone grafting on my lower left canine. The post is so far down that my gum tissue has grown over the post and safety cap. I'm on a predominately liquid diet, smoothies with protein powder, eggs, oatmeal and supplemental Slimfast shakes as a source of any or all of the nutrients that I'm unable to get otherwise. Now my weight has steadily been dropping which is a concern because after my Mom passed and over the last 10 years, I got down to 99 lbs. Then I found out that my son was an addict. From the age of 2, he's always been overly curious and rebellious. We were

your average white picket fence family, always had an open door policy and had discussed many times the pitfalls of sex at too young of an age and the dangers of "experimenting" with drugs. We found out that from the age of 13 to 19 (when it became obviously apparent something was up with our son) he'd been smoking weed, was drinking and did about every dangerous drug from E, cocaine, oxycontin and heroin. We put him through 3 rehabs and it was an absolutely devastating period of time.

I had a complete nervous breakdown and the pain was so bad that I began to self-medicate which only made things worse. I went through my own intervention and have been in therapy ever since. Battling all of the above has been devastating to me, the person I once was, outgoing, self-confident, a hard worker—everything to give my kids a great childhood. Something neither my husband nor I had ever had.

My son hates me now because for some reason, I believe he blames me for not "catching on" sooner but he was so sneaky while always appearing to be on the up and up with his father and me. My daughter has issues (deservedly so) as to my self-medicating and the scares I put her though and she refuses to talk about it to me even though I have apologized up and down and tried to explain as a parent how all of the above affected me. Everything seems to have become so overwhelming, dealing with my own health issues, etc. I'm ashamed to say that I have attempted suicide several times when I was at such a loss of self, of faith and in such physical/mental pain. I consider myself still a work in progress at the age of 52 and am so blessed to have the husband I do. He's stuck in the middle of being there for my son who gives me a severe panic attack even at the sound of his voice.

Everything feels like such a mess.

I've had two serious slip and falls (I was perfectly clean at the time) in my kitchen. The first one was trying to reach the top shelf in my refrigerator. I broke the metatarsal bone and all the little bones in my left foot and required surgery. When I was finally out of a wheelchair and cast, the Dr. said I could begin putting some weight on my foot. I was making myself a sandwich for lunch, bare foot in the kitchen on a tile floor and didn't see that my dishwasher was leaking. The next memory I have is of being on my back on the floor and wondering what happened. I got up and slipped again, feet in the air and I cracked my head in three places. When I came around, I had no idea how long I'd been unconscious and laid there wondering what the heck happened. Then I began to feel that back of my head stinging and put my hand back to hold it and found a pool of blood. I was in shock but managed to get to my cell phone and call my husband who came racing back home. I broke my wrist, had a concussion and also broke my baby toe on the foot I'd just been healing from.

This is definitely not the life my husband and I had both worked long and hard to have and after all of the above, I have lost my self. I'm miserable, grouchy (have horrible insomnia too) and angry at the world. I can't do much, I'm at home alone all the time and I hate how things have turned out. I feel that I'm only here by the grace of God, the support of my husband and my best childhood friend whom I've known since I was 9 yrs. old. Unfortunately, she lives in Florida and I'm in California. We both have had to go through bankruptcy and the amount of stress seems insurmountable at times. My Mom instilled a great sense of humor in me and my husband is a very funny, entertaining

and loving man—those are the things I rely on now as well as my excellent therapist.

With the illnesses I have now, I never know day to day how I'm going to be feeling, mentally and physically and it's a frustration that is beyond words. I do the best I can, keeping up the house but it's not enough. Three of my saving graces are what I refer to as my three hairy grandchildren....

I have 3 golden retrievers who give me such solace and unconditional love. The oldest, a male (Buddy) is hypersensitive to my emotions and I've trained him to help me get up when I've fallen. All three are great therapy.

In closing just as a point of interest, I met my husband when I was 15 and he was 17. He was a good friend of my older brother. We dated for five years and got married when I was 20. My daughter, who from age 15 is still with her boyfriend, whom I love as if he were my own, is now 24. Isn't that odd? lol

I hope my story helps or comforts any of you and I also hope that anyone dealing with similar circumstances can share any advice with me. This appears to be a great site for engaging with other people going through all kinds of physical and emotional problems. And a special thanks to Ben for giving me a place to share my story. From your video, you sound like such a heartfelt, sincere and caring person who is using his trials to help others. So admirable and I thank you sincerely.

Joanne
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient

I am a 51-year-old female that lives in the most Western part of Maryland... Yes, in the Mountains. I was diagnosed with LUPUS when I was 16. For the first three years I took twenty aspirin a day for inflammation; only to destroy the lining of my stomach. Later I was prescribed steroids for long term use which resulted in me developing Avascular Necrosis (AVN); which has caused me to have both knees grafted. AVN is very painful and grafting requires a long recovery and many, many hours of physical therapy.

I suffered two miscarriages and was told I would never have a child, but my attitude has always been to do what they tell me I can't do. So in 1992 I gave birth to an absolutely gorgeous baby girl; who gave me the strength to continue on this Lupus adventure, which has been less than exciting for the most part. I am now into my 36th year of living with LUPUS and it has been quite an experience. Always keep your chin up and keep smiling… there is always someone worse off than yourself.

-anonymous

Here is a great video from moderator JC with the transcript below (but it's better in video form!):

http://www.youtube.com/watch?v=AVY_QLMw04Q&feature=plcp

Hi, my name is… JC. I'm 49 and have been diagnosed with cerebellar ataxia, which affects my balance, coordination, and speech. I've been a member of Ben's Friends since March 2010. I joined the Ataxia support site and have become a moderator of that site and the Life with Lupus site, which is very close to me because my mother passed from Lupus and my sister is struggling with symptoms of it. The thing I've learned is the mental aspect of having a rare disease is more important to get over than the disease itself. Asking for help is a sign of courage not weakness. The medical community I admire and respect, but the true power is within the patients themselves. To connect and share and inspire each other through Ben's Friends is one of the most important things we can do. I see the growth and see it is accepted and appreciated. We don't have all the answers but not feeling alone is a huge step. I'm proud of BensFriends… To inspire others and help those who feel alone in their struggles.

[Ben's Friends is] Something I look forward to for the rest of my life. Thank you.

JC
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Life With Lupus (www.LifeWithLupus.org)
Living With Erythromelalgia
(www.LivingWithErythromelalgia.org)
Life With ADD (www.LifeWithADD.org)
Patient

BENSFRIENDS.ORG

SECTION 3 – BensFriends.org

One of the main benefits for the many volunteers helping with BensFriends.org is reading the amazing stories and thank you testimonials that come in from our members. It's great to see how we've helped and what BensFriends.org*—and its rare disease communities—mean to someone who's directly impacted. The thank you testimonials that follow are directly from members, answering the questions:*

- *What does BensFriends.org mean to you?*
- *How has BensFriends.org helped you?*

For more testimonials—please visit blog.bensfriends.org *and to submit a testimonial of your own—please email us at* testimonials@bensfriends.org

We encourage people affected by rare disease to join a support group in person and online to connect with others like them. If you are affected by one of our rare diseases, please join us. If your rare disease is not currently covered, please send us an email to info@bensfriends.org *with your condition and we can discuss getting a community started. Please remember that you are not alone in this and we are here for your support.*

If you are looking for more information, feel free to check out bensfriends.org

Section 3A - How has Bens-Friends.org Helped You?

I am a very new member, but have read so very much. Learned of others' stories, struggles, and achievements. It is so inspiring.

Kelly
Traumatic Brain Injury
Traumatic Brain Injury Support
(www.TraumaticBrainInjurySupport.org)
Patient
Ashland, OR

It gave me a place to share my feelings, doubts, worries, and concerns without being judged. And a place to get support from people that are dealing with some of the same things you are whenever you need it.

Jenny
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient

Given me a platform to encourage others.

Kene
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Atlanta, GA

BensFriends.org, has helped me come a long way!!! When I was told "LUPUS was going to be in my LIFE to the end and that my health was up to me; that I was to make adjustments to live longer," well it seemed like the world was going to end. There were things that I really didn't want to do!! Honestly, I tried to make myself understand that the pain of stress would and could play a major role in this, so I had to limit myself around things, people, and places, which had an impact on that.

BensFriends.org gave me back things that I, in a sense, had let go of. Since August 2011, I've met people from around the world that share something in common with me—they all have LUPUS! It's good that this network lives. It has helped me understand myself a little more than I've ever been able to and communicate with others. Thanks to my online family for being supportive and being there to give me advice when I didn't have anyone else to turn to. Thanks, my friends and those to come.

Lupus
Life With Lupus (www.LifeWithLupus.org)

Helped me??? No they saved me! From the AVM Survivors Network, I have learned so much and made many wonderful friends.

Louisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Rhode Island

LifeWithLupus.org has truly given me peace of mind, knowing that I am not alone fighting Lupus. It has given me a chance to meet people in far-away places who I can relate to with my symptoms and who have true concerns about me and my health on a daily basis, when my family and personal friends cannot. I don't have to explain to my LifeWithLupus.org family about the chronic pains and how I am feeling.

Beverly
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Stone Mountain, GA

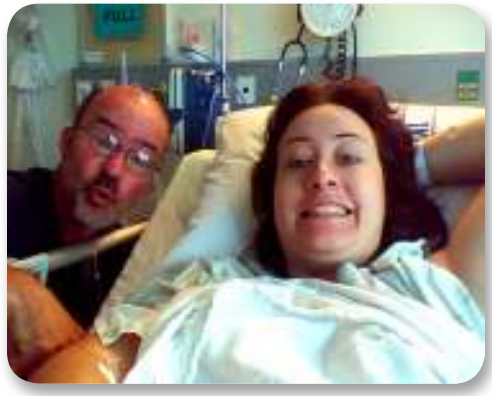
It has helped me find people in my situation. I love my family and thankfully they have never been through what I have been through and even though they are there for me every step of the way, it is nice talking to people who can relate. It has also given me the confidence to start a foundation called No Strain on the Vein.

Melissa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Ben's Friends have been wonderful. While I wasn't always connected, some people were interested in my story. I've also got a lot of people interested in knowing more about opiate-induced pain. I am grateful for the help that I got from BensFriends.org.

Julianne
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Durham, NC

When I was first diagnosed with an AVM, I must have thought "What the heck did I do to deserve this!!!" But then I found Ben's Friends and the AVM Support group. And although there may not be many of us from where I actually live that I can meet up with for support, this online network of friends has almost been my lifeline!! Your doctor can give you all the facts and your family/friends can say, "oh, I am so sorry and I understand," but I personally don't think they can understand unless they experience it for themselves. But with Ben's networks of amazing support groups there are people who understand and know exactly what you have been going through and are always there to talk to when needed.



Kat
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Auckland, New Zealand

Helps me cope and helps pay it forward.

Jamie
Adrenoleukodystrophy
Adrenoleukodystrophy Support
(www.AdrenoleukodystrophySupport.org)
Patient, parent
Lancaster, California

There isn't any word to describe how wonderful Ben's Friends are. They are truly your friends....

Rachel
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Warren, MI

Just knowing I can go there and see how many others suffer from the same problems is a blessing. If I needed anyone to talk to or need help, there are people there for me and they have so much information and helpful tips it's amazing. Everyone is friendly and supportive.

Allison
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Albany, NY

It helped me to talk to people my age and older with my condition. I learned more about it and it gives me a release while having an attack to be able to talk to other people who may also be suffering one that day.

Mica
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Liverpool, UK

BensFriends.org has helped me tremendously by connecting me to others like myself that I can identify with, compare notes, find help, support, and sometimes cry or vent or laugh with. I AM NOT ALONE... this does wonders for your PEACE OF MIND. When I run across someone, whether on the street or on the Internet that I feel may need the help of Ben's Friends, I send them that way for answers.

Debbie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Algonac, Michigan

Recovery suggestions

Support

Companionship for the homebound

Knowledge about my condition

Attempt to help others

Nicole
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Pittsburgh, Pennsylvania

Support

Kim
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Tempe, AZ

It's helped me see that I am not alone with my condition and I can reach out to others who are experiencing the same thing.

Kellie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Skokie, IL

BensFriends.org has helped me a lot. It made me reach out to people/parents who are/were in the same boat as me/us. I am so glad I found this website. It made me have hope that after the incident our lives have a chance to be as normal as we can hope for.

Thank you so much, Ben, for the support and all the people who I have talked to and still talk to on this website.

May God Bless all of you as He had Blessed my family.

Alexander
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Parents of AVM survivor
Friend/Family/Caregiver
Toronto, Canada

Helping others helps me. I just wish I had the strength to post more.

Tessa
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Raleigh, NC

Any support is helpful!!

Sally
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Van Horne, IA USA

By facing my condition and not being in denial—there is something wrong with me!

Dianne
Von Willebrand's Disease
Living With VWD (www.LivingWithVWD.org)
Patient
Washington, DC, USA

Finding others who are walking the same uncertain path is so helpful. The initial diagnosis is so alarming, but then you realize that you are not alone.

Beth
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Grand Rapids, MI

To be able to look up other people's experiences is a must for me. To know that I feel the same way as many other sufferers is a comfort and to read how others cope with various situations
is great.

Jeanette
Psoriatic Arthritis
Living With Psoriatic Arthritis (www.LivingWithPsoriaticArthritis.org)
Patient
Bedford United Kingdom

Just having someone who understands what I'm going through and experiencing is wonderful. I've also gotten advice on picking out a cane and walker.

Community is SO important. I had felt so isolated. I knew no one with Gluten Ataxia before
Bensfriends.org

Julie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
American Ataxia Networking
(www.AmericanAtaxiaNetworking.ning.com)
Patient
Colorado Springs, CO, USA

Ben's Friends has helped me in so many ways. Just knowing there is a group of people out there who do understand what I am going on a daily basis. I can take so much comfort from knowing that I am not alone in this.

Gwen
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
St Louis, MO

BensFriends.org—there are so many people out there to try and help you, as well as the fact that those who have ailments really appreciate speaking with those who can give them a positive outlook on life. You feel as though you know the person you are talking/typing to. Always so helpful with their feedback. This is something that can certainly give you a boost.

I am thankful that I found this site. So many others are suffering as well as yourself so there is no negativity on the site. I honestly hope that this site will be around for some time. There is always a "positive-ness" after talking/typing with someone who is either helping you or you are helping them.

-anonymous

Excellent site!!

Rita
Fibromyalgia, Psoriatic Arthritis
Living With Fibro (www.LivingwithFibro.org)
Living With Psoriatic Arthritis
(www.LivingWithPsoriaticArthritis.org)
Friend/Family/Caregiver
Canada Ontario

Yes I got familiarized with AVM

Rajasri
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
India

It has afforded me a support group of people who have had a similar health issue as mine.

Carolina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Homestead, FL

I can always log on to avmsurvivors.org and post any questions I have and hear from real people who have faced what I have faced and know they can help me. Even if it's just support online, some days I need that more than anything! I also love that I can go on and help someone with things I have gone through.

Andrea
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Tonawanda, NY

I am newly diagnosed with Trigeminal Neuralgia so this particular website has given me a new place to get support and get good information.

Anastasia
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient, Friend/Family/Caregiver
Eunice, LA

Reassured me that I'm not alone, and that people really do care.

Katrina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

It has helped my family realize we are not alone and that even though no one else has heard of this condition, others are out there. It's amazing really that this small group of affected people have come together.

Nan
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Friend/Family/Caregiver
Nebraska/Colorado

Connecting with all the beautiful people in the world who are trying to make a difference by raising awareness. Ben's Friends are the best people in the world.

Joanne
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Glendale, AZ

Finding others like me and hearing their stories is useful. I found people who had same symptoms as me even though the doctors said they weren't from GPN.

Chrisa
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Pittsburgh, PA

Knowing that I wasn't alone, and helped with research of specialists.

Emmanuelle
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Bellingham, WA

It has given me a place to read and reflect info contained and stories of others.

Scott
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Creston, Washington

When I was diagnosed with TN, I was extremely upset and scared of what the future held for me. As soon as I joined LWTN (LivingWithTN.org) the members welcomed me and helped me to come to terms with the diagnosis and answered the many questions I had. They also helped me compile a list of questions to take to my first Neurologist's appointment.

Jo
Trigeminal Neuralgia, Arteriovenous Malformation
Living with TN (www.LivingWithTN.org)
AVM Survivors (www.AVMSurvivors.org)
Patient
Hemel Hempstead, United Kingdom

By providing me with an amazing support network of wonderful people who truly know what it's like to go through this. They understand the need to vent occasionally and are always there with positive energy and support, no matter what.

Kylie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
New Zealand

AVMSurvivors is helping me with a lot of issues:

- Support (I am not feeling alone)
- I can get opinions.
- Most important, AVMSurvivors gave me the knowledge to realize that I am dealing with a condition and a progressive disease, not only with a complicated tumor.

Rosario
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Fort Lauderdale, FL

When something comes up with my disease, I know I can log on and ask a question and get answers.

Millie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Billerica, MA

Joining a support group has helped me see other people that are going through the same thing and have answers to questions I ask. Even suggestions for medication that my doctor can try to make things better.

Sandra
Erythromelalgia
Living With Erythromelalgia
(www.LivingWithErythromelalgia.org)
Patient
Edmonton, Alberta, Canada

BensFriends.org has given me the opportunity to stay connected to fellow sufferers.

Anthony
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Rock Ferry, Merseyside, United Kingdom

BensFriends.org has helped me to better deal with my disease just knowing that I am not alone in my fight, and it gives me strength when I am able to pass strength on to someone else to help them continue their fight.

Sarah
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Houston, Texas

I read the postings, I learn so much from reading and listening to what others are going through. Belonging to a support group is the best thing. It offers a world of information and gives you others to talk to that truly understand what you are going through. No one knows better than someone who has been there.

Brenda
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Osage Beach, Missouri

It's nice to know you're not alone cuz you sure do feel like you are most days. Family is there but they just don't understand.

Laura
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Apache Junction, AZ

Information and knowledge, and education! Seven days post-op I feel as if I did the right thing, because there was another twisted surprise they found regarding my brain stem. I researched doctors from all over—because the best was nowhere near my state or even my section of the country. I have a Master's in Social Work... I will let others know of Ben's Friends.

Kimberly
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Lee's Summit, MO

Have met so many AVM survivors with similar stories, and some who needed support. This is a great organization!

Caryn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lufkin, Texas

I was thrilled when I found the avmsurvivor.org website and have enjoyed making friends with other AVM survivors. It is good to know that we are not alone.

cd
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

I wasn't looking for a support group when I found Ben's Friends but when I did, I was overcome with gratitude. I literally had tears in my eyes. That sounds terribly cheesy, I know, but it is authentic. I felt so alone and felt that no one knew what I was going through. Joining a group like this has opened up a world where I can feel free to discuss my condition without feeling like I was saying, "Look at me, I have a really rare disease." I could discuss the ups and downs of TN without drawing attention to how different I am and having to explain what it is like, which feels self-absorbed.

Melissa
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Bradenton, Florida

Some of us find out about an AVM after a stroke, and it's a profound shock to deal with something no one else "gets" and which has literally turned your world upside down. I was long past that hurdle when I found the site, but am glad to help others cope with such intense challenges. You are all alone even when you are surrounded by people. For me personally, I am so glad Ben built this oasis of support and friendship, and am proud to contribute. The world is truly a little bit better from the work of Ben and the many other moderators that build and with love and friendship maintain and grow.

Sharyn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Manchester, CT

They have helped me by hearing other peoples' stories and ongoing problems with their condition. It is a great resource to find out more information on my condition.

Alicia
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
North Bay, ON, Canada

I've been able to speak to people, who are going through the same as me, prepare for side effects and read other people's stories who have suffered a lot worse than Ethan. I've realized rare conditions can affect anyone.

Lauren
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
UK

Not only has it helped me know for myself that I'm not alone with TN, but also that my mom's diseases are valid. Hearing that she is not the only one suffering helps validate your disease.

Julie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Friend/Family/Caregiver
Huntington Beach, CA

From the AVM Survivors Network, I have learned so much and made many wonderful friends.

Louisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

Ben's Friends has helped me to connect with others who have CMT to share information, resources and friendship.

Melinda
Charcot-Marie-Tooth
Charcot Marie Tooth Support
(www.CharcotMarieToothSupport.org)
Patient

During my own my journey I visited the AVM site often and whether it was emails sent to me or postings on the boards, I not only become less afraid, but more knowledgeable & definitely more empowered. Hopefully, my mini-story will offer someone encouragement & show proof positive that there's a magnificent outcome possible on the other side. I would be honored if my letter would be included in the e-book!

Hope you had a great wk/end :-)
Deborah

Deborah
Proud AVM Survivor and Warrior :-)
Fox Point, WI

How has BensFriends.org helped you? What does BensFriends.org mean to you?

- Ben's Friends is near and dear to my heart for so many reasons. I am blown away by the current and new members that I come into contact with each and every day.
- Some might say my story is inspirational but I would beg to differ. I am just one of the 11,000 plus and growing inspirational stories on Ben's Friends. *(editor: now 30,000 + members)*
- I am beyond grateful to have been given the opportunity to start and moderate two sites (ASDsurivors.org and LivingwithVWD.org) and become very involved with the running of Ben's Friends.
- I ran the NYC Marathon in November 2010 less than six months after open heart surgery in May 2010 to ensure people living with a rare disease have a safe place to go for support. As a result of that race, we raised a significant amount of money and awareness for Ben's Friends.

I plan on running the Amsterdam Marathon in October 2011 and Prague Marathon 2012 to raise additional awareness and money for Ben's Friends and the Cleveland Clinic.

John
Atrial Septal Defect, Von Willebrand's Disease
Atrial Septal Defect Support
(www.AtrialSeptalDefectSupport.org)
Living With VWD (www.LivingWithVWD.org)
Patient
BensFriends.org, Partner
London, England, UK

Section 3B - What Does BensFriends.org Mean To You?

It means not feeling alone. Being connected to others who struggle with life in the same way. It's so very important to know that we are not alone. Everyone has a different story, but we all have one thing in common. That is, we all have a chronic illness that affects our daily lives. BensFriends.org is the only place that I am aware of where we can meet to share our grief, happiness and find a coping mechanism.

Julianne
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Durham, NC

That we are not alone. That we all have the opportunity to assist our compatriots in struggle and to congratulate achievement.

Kelly
Traumatic Brain Injury
Traumatic Brain Injury Support
(www.TraumaticBrainInjurySupport.org)
Patient
Ashland, OR

Survival!

Mica
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Liverpool, UK

It means that even when I think I'm alone, I never am. I always have a place to go where people will always listen and care even when they don't know you.

Jenny
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient

A place I can talk with people that have dealt with AVM.

Kene
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Atlanta, GA

I also have 30 years' experience battling clinical depression that at times was so severe it caused a few serious suicide attempts that necessitated lengthy hospital stays and many different medications and treatment options (including electro-convulsive therapy which turned out to be a last-straw and long-term blessing in my case). Consequently, I am convinced that had I not, in doubt and desperation, eventually found my way into my support group, LifeWithLupus, there is a better-than-odds chance that I wouldn't be here to write about it today. When I claim that the right support group was a lifesaver for me it is no exaggeration and that fact came as big a surprise to me as it may sound to you only if you haven't availed yourself of a good one of your own.

My earnest hope for you is that you may find the kind of valuable information, honest and humble support, and cherished new friendships that have marked my unlikely experience with the right support group.

Patricia
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Boynton Beach, FL

In a word... fellowship.

Melissa
Lupus
Life With Lupus (www.LifeWithLupus.org)

BensFriends.org gives you a chance to view another person's attitude towards things that you really don't want to discuss with even your own family. Security is the feeling that I've gotten from this online family. I can be me and live with Lupus with an ease. I look forward to talking online daily to people or just reading their profiles and sending out friendship requests. I give this site 10 thumbs up!!!!

-anonymous
Lupus
Life With Lupus (www.LifeWithLupus.org)

It means that I will always have AVM friends that understand and care about me. My goal in life is to help other people with AVMs to have a peaceful life regardless!

Louisa
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Rhode Island

Find your inner spirit and have faith and belief that you will conquer Lupus—keep it moving.

Beverly
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Stone Mountain, GA

It's my haven, a place where I can really feel like I am myself and my AVM doesn't make me that weird kid with the stupid genetic malformation that may not be life-threatening. But that doesn't make it any less scary. I really don't know where I would be without it!

THANKS, BEN!!!

Kat
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Auckland, New Zealand

It is a corner for strength.

Jamie
Adrenoleukodystrophy
Adrenoleukodystrophy Support
(www.AdrenoleukodystrophySupport.org)
Patient, parent
Lancaster, California

A way to spread the word and help others.

Jerrod
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lubbock, TX, USA

It means a great deal to me because without this community I would still feel alone on this issue.

Kellie
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Skokie, IL

It made me open up my eyes to a new world and has given me the chance to support the other people here in the group and people outside the group. It has made our family more human and wanting to help others in what they are going through right now.

Alexander
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Parents of AVM survivor Friend/Family/Caregiver
Toronto, Canada

Ben's Friends means that I am a person, not a misfit. I have meaning, I have friends, and I have support to help me through these difficult times.

Rachel
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Warren, MI

I am thankful to be a part of this site. It means a lot to me that there is such a supportive group of people out there that understand what I am going through. Thank you!

Allison
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Albany, NY

Understanding, direction, a future of listening, friendship, questions, answers, and most of all HOPE. I thank you.

Debbie
Ben's Friends
Patient
Algonac, Michigan

The one place I can talk every day to friends going through the same life traumas and find comfort and suggestions.

Nicole
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Pittsburgh, Pennsylvania

Ben's Friends means that I was able to find a sense of peace knowing that there are so many friends out there waiting to help with information and encouragement. Even when I have spurts of not logging on faithfully, when I do return, they are right there waiting with open arms and hearts.

Beth
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Grand Rapids, MI

It means no more worries about my symptoms as most of the time I can see that others are suffering in the same way. Half the battle is knowing that you are not on your own...x

Jeanette
Psoriatic Arthritis
Living With Psoriatic Arthritis
(www.LivingWithPsoriaticArthritis.org)
Patient
Bedford United Kingdom

Community and support.

Julie
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
American Ataxia Networking
(www.AmericanAtaxiaNetworking.ning.com)
Patient
Colorado Springs, CO, USA

It means a longer rope to hang on to in really bad times. It means friends who really understand me. It means hope.

Gwen
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
St Louis, MO

BensFriends.org to me means those who are also on this Website are so willing to help. They give advice as in who to seek for Medical Attention. They truly are people who care and are there for you, it is my hope as well that I have been there for others as well.

I would recommend this site to so many.

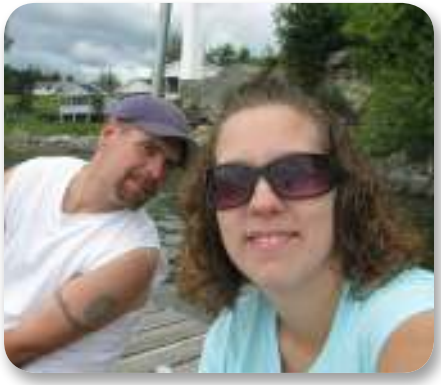
Thanks to all of you on BensFriends.org—a wonderful bunch of people looking for answers as well as giving advice of what they themselves have gone through. Keep BensFriends going, so many love to hear from others, myself included. With the hope that I myself can give some positive feedback to others on this site and make them feel better about themselves.

Rita
Fibromyalgia, Psoriatic Arthritis
Living With Fibro (www.LivingwithFibro.org)
Living With Psoriatic Arthritis
(http://www.LivingWithPsoriaticArthritis.org)
Friend/Family/Caregiver
Canada Ontario

A lot.

Rajasri
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
India

It means the world to me! I don't know how to completely describe what it means to me and to my husband. It's like there is ALWAYS someone to talk to and that you really know them. Even though you will never personally meet them you feel like you know them personally. They know what you are actually dealing with. They understand you BETTER than anyone in your life can. We all get everything we are talking about without you having to say many words. It's simply amazing how much we understand each other.



Andrea
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Tonawanda, NY

It means that I do not have to be all alone in the world with the worst pain in the world at the worst possible time in my world (which is any time that pain strikes!). I wish your chat room was more lively but I understand why it is not... too PAINFUL! Okay, I am sorry but I try to laugh whenever possible because it releases the stuff to make pain go away! Yeppers, old Tegretol will not let me think what that stuff is called right now! But I digress...

Anastasia
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient, Friend/Family/Caregiver
Eunice, LA

Support from people who genuinely care.

Katrina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient

A life line.

Nan
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Friend/Family/Caregiver
Nebraska/Colorado

Life and a future to all with AVM's. Together we are going to get answers and end this horrible disease.

Joanne
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
Glendale, AZ

Hope.

Chrisa
Glossopharyngeal Neuralgia
Living With GPN (www.LivingWithGPN.org)
Patient
Pittsburgh, PA

It is the only place where people understand what I have been through.

Emmanuelle
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Bellingham, WA

People who listen and reading others stories really do help you out. Knowing that others have what you have, feel what you feel and see what you see is the best comfort in the world.

Tanya
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Spotsylvania, VA

Just what the name says—a friend that understands and doesn't question or judge my thoughts.

Scott
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Creston, Washington

BensFriends.org will always mean a great deal to me. I will always be thankful for the wonderful people I have met and now have many friends worldwide who are only a mouse click away.

Jo
Trigeminal Neuralgia, Arteriovenous Malformation
Living with TN (www.LivingWithTN.org)
AVM Survivors (www.AVMSurvivors.org)
Patient
Hemel Hempstead, United Kingdom

It means everything to know that there are others out there who truly understand. It's meant that I can vent without always worrying my family if I'm feeling a bit down and has helped me find peace with myself. It has also helped me to reach out to others and provide them with support, too.

Kylie Sadlier
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
New Zealand

AVMSurvivors means knowledge (an important tool to succeed with any treatment or decision about your medical situation).

Also, it means support—everyone so far answers all my questions with a personal concern.

And of course it means responsibility. I feel that is extremely important for me to share my experience—as a woman, as a survivor, and as a mother to every single AVM survivor. But I would like to do it after my first appointment (in Miami), because I need to know the status of my condition. I don't want to give fake hopes to those who are starting their lives, and maybe want to take the risk of being a mom... However, now I know, I understand... I must talk about it, and I will.

Rosario
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Fort Lauderdale, FL

Friendship.

Millie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Billerica, MA

It means a place I can go to talk to other people that know exactly what I am going through
and understand.

Sandra
Erythromelalgia
Living With Erythromelalgia
(www.LivingWithErythromelalgia.org)
Patient
Edmonton, Alberta, Canada

This site is an important means for my communication.

Anthony
Ataxia
Living With Ataxia (www.LivingWithAtaxia.org)
Patient
Rock Ferry, Merseyside, United Kingdom

BensFriends.org is my safe haven. I know that I can get someone to listen to me about anything, anytime, day or night, and that is very important to me, because sometimes even the strongest fighter gets down and depressed some days. It means having another family, a special family, one that understands, listens, and offers unconditional help and love, and I don't even have to ask for it; for free, no strings attached. THAT'S GENUINE LOVE SENT FROM ABOVE. I hope Heaven is this sweet.

Sarah
Lupus
Life With Lupus (www.LifeWithLupus.org)
Patient
Houston, Texas

It is a great resource for people living with a chronic disease. It's people helping people ... Sharing and learning together.

Brenda
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Osage Beach, Missouri

Support is important!!!

Laura
Chiari
Chiari Support (www.ChiariSupport.org)
Patient
Apache Junction, AZ

A great place to connect with other CMTers!

Laura
Charcot-Marie-Tooth
Charcot Marie Tooth Support
(www.CharcotMarieToothSupport.org)
Patient
New York, NY

Lifeline from the solitary island called TN.

Kimberly
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Lee's Summit, MO

That I can reach out to others who are coping with an AVM.

Caryn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Lufkin, Texas

Ben's Friends is a place that has been created for people like me who, due to the isolating nature of having a rare disease, would otherwise have no outlet for discussing their illness.

Ben's Friends has helped me realize that I am not alone and I know now that there is a place I can go to share where people will understand. That means a lot to me.

Melissa
Trigeminal Neuralgia
Living with TN (www.LivingWithTN.org)
Patient
Bradenton, Florida

I'm analytical, so I know that studies show how important support and a positive attitude are for any health challenges. A site like Ben's Friends can change lives and make lives better. You cope better when you know you feel "understood" and supported. You can learn about new studies, new treatments, and new vitamins, whatever. You learn, you grow. You see what works for people, and you feel good that others can gain from your experiences and insight, even when the experience shattered them at the time.

Sharyn
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org*)*
Patient
Manchester, CT

It means support from other people and being able to see what other people are going through. Before this website I had found very little on AVM.

Alicia
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
North Bay, ON, Canada

It's helped me through this testing time. I will always do what I can to help Ben's Friends.

Lauren
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Friend/Family/Caregiver
UK

It's a place to share & encourage each other. Most of all VALIDATION!

Julie
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Friend/Family/Caregiver
Huntington Beach, CA

Ben's Friends is a great community. We are family!

Tessa
Fibromyalgia
Living With Fibro (www.LivingwithFibro.org)
Patient
Raleigh, NC

A place where I can share with others.

Carolina
Arteriovenous Malformation
AVM Survivors (www.AVMSurvivors.org)
Patient
Homestead, FL

BensFriends.org provides valuable patient support by creating and running compassionate, responsive communities. BensFriends.org maintains dozens of patient communities and has changed thousands of lives.

Melinda
Charcot-Marie-Tooth
Charcot Marie Tooth Support
(www.CharcotMarieToothSupport.org)
Patient

FINAL WORDS

Special Thanks

Before we wrap up, we want to thank everyone who contributed to this project. You've helped provide support to those with rare diseases who need it. Together, we're positively changing patients' lives every day.

THANK YOU!!!!!

Final Words

This may be the end of our initial e-book, but our work is never done. The mission of BensFriends.org is to ensure that everyone in the world with a rare disease has a safe place to go and connect with others like them.

What started as one guy all alone with his rare disease has turned into dozens of support groups helping tens of thousands of people around the world.

But we're not done… not even close.

There are more than 6,000 rare diseases out there and more than 300 million people affected. Many of those people are alone.

No one should be alone.

Thank you for reading. If you need support or want to help in any way, please visit us at BensFriends.org

If you want to:

- **get more info** or **help in any way**, email us at info@bensfriends.org
- **contribute a story** to a future e-book or the website, email us at stories@bensfriends.org (please write STORY FOR FUTURE E-BOOK in subject)
- **share a helpful tip**, you can post it in a specific community (list can be found on the left side of bensfriends.org), or you can email us at tips@bensfriends.org (please write TIP FOR FUTURE E-BOOK in subject)
- **let us know what you think of** bensfriends.org, email us at testimonials@bensfriends.org