



Ben's Friends
Patient Support Communities

BEN'S FRIENDS

BENSFRIENDS.ORG



MEDIA KIT

Media Kit (February 2017)
www.bensfriends.org

Contact: press@bensfriends.org





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Thank you for reading our Media Kit. Please email us at press@bensfriends.org with media inquiries. We look forward to working with you and helping people get support for their rare diseases!

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BENSFRIENDS.ORG BOILERPLATES

(Overview in 50 Words)

BensFriends.org is a mission-driven 501(c)(3) nonprofit dedicated to providing safe, supportive online communities for people affected by rare diseases. Founded in 2007 by Ben Munoz after a stroke at age 29, BensFriends.org has a network of patient-to-patient communities helping tens of thousands of people worldwide. For more information, visit www.bensfriends.org.

(Overview in 100 Words)

BensFriends.org is a mission-driven 501(c)(3) nonprofit with a network of online communities that provide support for people affected by rare diseases. It was founded in 2007 by Ben Munoz after he suffered a serious stroke at age 29 caused by a rare condition called an AVM. During his ordeal, Ben realized how online communities could help support those suffering alone. Since then, Ben and his friends have started dozens of communities helping tens of thousands around the world.

More details:

- Website: <http://www.bensfriends.org/>
- Videos: <http://www.youtube.com/BensFriendsVideos>
- Blog: <http://blog.bensfriends.org/>
- Facebook: <http://www.facebook.com/bensfriendsorg>
- Twitter: <https://twitter.com/bensfriends>
- Pinterest: <http://www.pinterest.com/bensfriends/>

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BENSFRIENDS.ORG MISSION, VALUE, AND MODEL

Mission

To ensure that everyone with a rare disease has a safe place to go and connect with others like them.

Core Value

Positively impact our members' lives everyday.

Model

BensFriends.org is bootstrapped and fully supported by donors, sponsors, and advertisers. An army of volunteers help out, no one profits, and all donations go directly to funding the networks.

A MESSAGE FROM BEN

Ben created our first patient community so that he could find someone to connect with while recovering from a stroke. He and Scott realized what an impact a compassionate community could make in the life of a patient and began creating more patient communities for people with other rare diseases. Ben was formerly a software developer at eToys and IVT. Ben is a graduate of Stanford University and Kellogg School of Management, and currently on leave from Baylor Medical School (to become a brain surgeon).

"I'm forever thankful to the neurosurgeon for saving my life. However, each time I left the doctor's office or the hospital during my treatment and recovery from the brain hemorrhage, I felt lost and lonely. How am I supposed to know what to do next? The first few months after my brain surgery was an emotional roller coaster.

The turning point came when I was put in touch with a friend of a friend who had been through a brain hemorrhage like mine and knew what it was like. We spoke for a long time and he answered the million questions that I had about treatment and recovery. I wanted desperately to connect with others who also had an AVM brain hemorrhage & talk more about the emotional aspects of this life-changing experience.

I was able to put together a good enough web site to invite a few people from a mailing list to come join me in an open discussion of what we were going through. I was so thankful to connect with others who knew what I was going through and members who joined felt the exact same way. It became apparent as the community doubled in size, again, and again, that we had created something special.

We wanted to share that emotional connection with patients of other rare diseases, so we created Ben's Friends."

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-Ben Munoz

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BENSFRIENDS.ORG STORIES & TESTIMONIALS

Race car - AVMSurvivors.org member, Michael Hunt, painted his racecar with our logo!



Tattoos - We've had at least 2 members get tattoos with one of our logos! How's that for loving a brand and what we do!?

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Fundraising - John Stamler, moderator of ASDSurvivors.org and LivingWithVWD.org, raised over \$7,000 for BensFriends.org while running the NYC marathon 6 months after open heart surgery.



Saving a life - Anna (from Sweden) reached out to/for her friend in across the globe preventing her from committing suicide (livingwithtn.org).

And these are just a few of the amazing stories we hear about nearly every single day.

Testimonials

I have to say I received so much love from you guys just in the first day I found this site. –Evet

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This site is incredible. I can see how many lives have been touched. Being able to connect to people all over the world who suffer from AVM is so important. It reaffirms that while it can be agonizing to battle AVM, we don't have to do it alone. Hope is out there. Thank you so much! –Melanie

Thank you for setting this wonderful site up. I truly feel a part of a wonderful family. –Chris

I felt so alone when I was going through my major surgeries. This is a wonderful place you have created to bring people together with this rare condition. Thanks again and wishing you the best. –Sandi

Thanks Ben. You and your friends created a WONDERFUL website. Friendly, caring folks who want to help each other - that's what a support group is all about! –Patti

We are proud to say in the past year and a half, our community, which is free to all members, has grown to 2,000 members. With deep gratitude, we want to thank Ben for his vision, which has allowed the creation of many other support communities for those affected by rare conditions. –The Brain Aneurysm Foundation Support Community

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BENSFRIENDS.ORG FACT SHEET & TIMELINE

What is a rare disease?

A disease or disorder is defined as rare in Europe when it affects less than 1 in 2,000 citizens and in the USA when it affects fewer than 200,000 people. Rare diseases may affect more than 350 million people worldwide.

Stats

- 29 Support Group Communities (14 communities with more than 1000 members)
- 153 Moderators from around the globe volunteer their time to support and help out
- 64,624 members (more than 100% growth from 2013 to 2017)
- 51,263 uniques/month (Google Analytics)
- 218,585 page views/month (Google Analytics)
- Still 6,000+ rare diseases out there
- Still 300 million people around the world affected by rare diseases (Nearly 1 in 20 people!)

Timeline

- 2006
 - Ben Munoz suffers serious stroke caused by rare condition called an AVM.
 - During recovery he's alone & unable to find a support group of AVM stroke survivors.
- 2007
 - So Ben creates avmsurvivors.org to ensure others with an AVM don't suffer alone.
 - Dozens of people join in the first 2 months to find care, support, and friends.
- 2008
 - Hundreds more join and express gratitude.
 - Ben's grad school classmate and good friend Scott Orn sees power of Ben's online support community and they create #2: livingwithtn.org and #3: livingwithataxia.org
 - BensFriends.org is formed encompassing all of the rare disease communities.
- 2009
 - AVMSurvivors.org passes 1,000 members.
 - Ben and Scott launch #4: www.aldsupport.org/
- 2010
 - New friends join team to help Ben achieve his mission, launch new communities, raise \$.
 - Blog launched (blog.bensfriends.org) with amazing thank yous, stories, and updates.
 - BensFriends.org passes 20 communities & 7,000 total members.
- 2011
 - BensFriends.org featured in or partners with Seth Godin's book Tales of the Revolution, NPR, Extol, Pay It Forward, Brown Alumni Mag, Disability Digest, and more.
 - BensFriends.org reaches 25 communities & passes 14,000 members.





- 2012
 - Partnered with Advocacy for Patients with Chronic Illness (free legal), Friends of Treasure (patient financial assistance), RareDiseaseDay.org (global awareness).
 - BensFriends.org passed 30 communities and 25,000 members.
- 2013
 - Launched mobile app & e-book; featured in TechCrunch, Houston Chron, Harvard BR.
 - Partnered with 2nd.MD (2nd opinions), Rare Disease UK, Rare Genomics, Patient Power...
 - More than 37,500 members across 35 communities (plus many more groups).
- 2014
 - Nearly 46,000 members
 - Ben Featured in Forbes Magazine
 - Receives "LinkedIn for Good and Nonprofit Innovation Grant"
- 2015
 - More than 54,000, with 11 communities having more than 1k members each
 - Ben's Friends was awarded with Yahoo Employee Foundation grant for Project Platform
- 2016
 - Ben's Friends is fully migrated off of Ning and the communities are humming on Discourse

COMMUNITIES (GLOSSARY)

BensFriends.org Communities (with what system it affects) - and a description

Acute Disseminated Encephalomyelitis (ADEM, Immunological System) - An immune mediated disease of the brain that usually occurs following a viral infection but may appear following vaccination, bacterial or parasitic infection, or even appear spontaneously.

ADHD - Attention deficit hyperactivity disorder (ADHD, or AD/HD or ADD) is a developmental disorder. It is primarily characterized by "the co-existence of attentional problems and hyperactivity, with each behavior occurring infrequently alone" and symptoms starting before seven years of age.

Adrenoleukodystrophy (ALD; Nervous System, Endocrine System) - Adrenoleukodystrophy describes several closely related inherited disorders that disrupt the breakdown (metabolism) of certain fats (very-long-chain fatty acids).

Amyloidosis - Amyloidosis is a disease that occurs when substances called amyloid proteins build up in





your organs. Amyloid is an abnormal protein usually produced by cells in your bone marrow that can be deposited in any tissue or organ. Amyloidosis is rare, and the exact cause is often unknown. Treatments are available to help you manage your symptoms of amyloidosis.

Arteriovenous Malformation (AVM; Circulatory System) - AVMs are defects of the circulatory system that are generally believed to arise during embryonic or fetal development or soon after birth. Although AVMs can develop in many different sites, those located in the brain or spinal cord can have especially widespread effects on the body.

Ataxia (Nervous System) - People with ataxia have problems with coordination because parts of the nervous system that control movement and balance are affected. Ataxia may affect the fingers, hands, arms, legs, body, speech, and eye movements. The word ataxia is often used to describe a symptom of uncoordination which can be associated with infections, injuries, other diseases, or degenerative changes in the central nervous system. Ataxia is also used to denote a group of specific degenerative diseases of the nervous system called the hereditary and sporadic ataxias which are the National Ataxia Foundation's primary emphases.

Atrial Septal Defect (ASD; Circulatory System) - Atrial septal defect (ASD) is a congenital heart defect in which the wall that separates the upper heart chambers (atria) does not close completely. Congenital means the defect is present at birth.

Brain Aneurysms (Nervous System) - A brain aneurysm (AN-u-rizm) is a bulge or ballooning in a blood vessel in the brain. It often looks like a berry hanging on a stem.

Charcot Marie Tooth (Nervous System) - Charcot-Marie-Tooth disease is a group of inherited disorders that affect the peripheral nerves (those outside the brain and spine).

Chiari Malformation (Nervous System) - Chiari malformations (CMs) are structural defects in the cerebellum, the part of the brain that controls balance.

Crohn's Disease (Digestive System, Endocrine System) - Crohn's disease is a form of inflammatory bowel disease (IBD). It usually affects the intestines, but may occur anywhere from the mouth to the end of the rectum (anus).

Chronic inflammatory demyelinating polyneuropathy (Nervous System) - CIDP is a neurological disorder characterized by progressive weakness and impaired sensory function in the legs and arms.

Disabilities - An umbrella term covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by





an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body & features of the society in which he/she lives.

Eagle Syndrome (Musculo-Skeletal) - Eagle Syndrome is a condition where elongated facial bone (temporal styloid process) (more than 30mm) is in conflict with the adjacent anatomical structures.

Erythromelalgia (also known as Mitchell's disease, acromelalgia, red neuralgia, or erythermalgia) - Erythromelalgia is a rare neurovascular peripheral pain disorder in which blood vessels, usually in the lower extremities (or hands), are episodically blocked (frequently on and off daily), then become hyperemic and inflamed.

Fibromyalgia (Nervous, Immunological, Endocrine) - Fibromyalgia is a syndrome in which people experience long-term, body-wide pain and tender points in joints, muscles, tendons, and other soft tissues.

Glossopharyngeal Neuralgia (GPN; Nervous System) - Glossopharyngeal neuralgia is a condition in which there are repeated episodes of severe pain in the tongue, throat, ear, and tonsils, which can last from a few seconds to a few minutes.

Guillain-Barré syndrome (GBS) is a rapid-onset muscle weakness caused by the immune system damaging the peripheral nervous system. The initial symptoms are typically changes in sensation or pain along with muscle weakness, beginning in the feet and hands.

Lupus (Immunological) - Systemic lupus erythematosus (SLE) is a chronic autoimmune disorder. SLE may affect the skin, joints, kidneys, and other organs.

Mast Cell Disorder - Systemic mastocytosis (mas-to-sy-TOE-sis) is a disorder caused by a genetic mutation that results in an excessive number of mast cells in your body. Mast cells normally help protect you from disease and aid in wound healing by releasing substances such as histamine and leukotrienes. But if you have systemic mastocytosis, excess mast cells can build up in your skin, around blood vessels, in your respiratory, gastrointestinal and urinary tracts, or in reproductive organs. When triggered, these mast cells release substances that can overwhelm your body and result in symptoms such as facial flushing, itching, a rapid heartbeat, abdominal cramps, lightheadedness or even loss of consciousness. Common triggers include alcohol, temperature changes, spicy foods and certain medications.

Myeloma (Blood) - Multiple myeloma is a cancer that begins in plasma cells, a type of white blood cell. These cells are part of your immune system, which helps protect the body from germs and other harmful substances. In time, myeloma cells collect in the bone marrow and in the solid parts of bone.

Myositis (Immunological, Musculoskeletal) - Myositis is inflammation of your skeletal muscles, which are also called the voluntary muscles. These are the muscles you consciously control that help you move





your body. An injury, infection or autoimmune disease can cause myositis.

Narcolepsy (Neurological) - Narcolepsy is a chronic sleep disorder, or dyssomnia, characterized by excessive sleepiness and sleep attacks at inappropriate times, such as while at work. People with narcolepsy often experience disturbed nocturnal sleep and an abnormal daytime sleep pattern, which often is confused with insomnia. Narcoleptics, when falling asleep, generally experience the REM stage of sleep within 5 minutes; whereas most people do not experience REM sleep until an hour or so later.

Oculopharyngeal muscular dystrophy (OPMD) - is a rare genetic muscle disorder with onset during adulthood most often between 40 and 60 years of age. OPMD is characterized by slowly progressive muscle disease (myopathy) affecting the muscles of the upper eyelids and the throat. Affected individuals may develop drooping of the eyelids (ptosis), trouble moving their eyes (ophthalmoplegia) and/or difficulty swallowing (dysphagia). Double vision (diplopia) is uncommon. Eventually, additional muscles may become involved including those of the upper legs and arms (proximal limb weakness). In some cases, muscle weakness of the legs may eventually cause difficulty walking. OPMD may be inherited as an autosomal dominant or recessive trait.

Primary Sclerosing Cholangitis (PSC; Digestive System, Immunological System) - Sclerosing cholangitis refers to swelling (inflammation), scarring, and destruction of the bile ducts inside and outside of the liver.

Psoriatic Arthritis (PsA; Immunological) - Psoriatic arthritis is an arthritis that is often associated with psoriasis of the skin.

Sjögren's Syndrome (Immunological) - is an autoimmune disease characterized by dryness of the mouth and eyes. Autoimmune diseases feature the abnormal production of extra antibodies in the blood that are directed against various tissues of the body. The misdirected immune system in autoimmunity tends to lead to inflammation of tissues.

Synovial Sarcoma (Immunological, Musculoskeletal) - Synovial sarcoma is a type of soft tissue sarcoma. Soft tissue sarcomas are cancers of the muscle, fat, fibrous tissue, blood vessels, or other supporting tissue of the body, including synovial tissue. Synovial tissue lines the cavities of joints, such as the knee or elbow, tendons (tissues that connect muscle to bone), and bursae (fluid-filled, cushioning sacs in the spaces between tendons, ligaments, and bones). Although synovial sarcoma does not have a clearly defined cause, genetic factors are believed to influence the development of this disease.

Trigeminal Neuralgia (Nervous System, Musculo-Skeletal) - Trigeminal neuralgia is a nerve disorder that causes a stabbing or electric-shock-like pain in parts of the face.

Traumatic brain injury (TBI) - a form of acquired brain injury, occurs when a sudden trauma causes





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damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue.

Von Willebrand's Disease (Blood) – Von Willebrand's Disease is the most common hereditary bleeding disorder.

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