STATISTICS
50 Ben's Friends Support Communities
80,000+ Ben's Friends Community Members
17,000+ Ben's Friends Unique Monthly Visitors
7,000+ Rare Diseases
400M+ Rare Disease Patients Around the World

Contact Info: info@bensfriends.org

Connect: Facebook, Twitter, Instagram, LinkedIn

SOME BEST PRACTICES FOR OUR COMMUNITIES
Involve - get members involved early
Tailor - change to adapt to member's needs
Recognize - feature most helpful members
Enable - easy tools to post content and refer friends
Incentives - give people reason to take action

FOR PATIENTS, BY PATIENTS.

WAYS TO GET INVOLVED
• Invite a director from Ben's Friends to give a presentation
• Host an event - materials and support will be provided
• Visit the website to join a community
• Inquire about partnership opportunities - joint marketing, email
• Dedicate a gift www.bensfriends.org/donate

Inquire About Partnerships

DO YOU KNOW SOMEONE WITH A RARE DISEASE?

WE BUILD PATIENT COMMUNITIES FOR PEOPLE WITH RARE DISEASES.

Please refer them to us at www.BensFriends.org
Changing Lives Every Day

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VALUES:

Impact - Make a positive impact on patients’ lives.

Integrity - Maintain the integrity of our communities.

Action - To get support, community members are encouraged to give support.

Grassroots - Our communities are by patients, for patients.

Openness - Accept all patients where they are at, and keep in mind where they can be.

Positivity - Hope is always the focus of a Ben’s Friends Community.

Safety - Both online for our members and accuracy of information presented.

Focus - Patients’ voices is a paramount in all we do.

MISSION
To ensure that everyone in the world with a rare disease has a safe and supportive place to connect with others like them.

YOU ARE NOT ALONE

Our Patient Communities:
- Acute Disseminated Encephalomyelitis (ADEM)
- Addison's Disease
- ADHD/ADD
- Adrenoleukodystrophy (ALD)
- Amyloidosis
- Arteriovenous Malformation (AVM)
- Ataxia (International)
- Atrial Septal Defect
- Brain Aneurysms
- Caregiver Support Community
- Charcot Marie Tooth (CMT)
- Chiari Malformation
- Congenital Heart Defects
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
- Crohn's Disease
- Central Pain Syndrome
- Chronic Pelvic Pain
- Dysautonomia
- Eagle Syndrome
- Ehlers-Danlos Syndrome
- Epidermolysis Bullosa (EB)
- Erythromelalgia
- Fabry
- Fibromyalgia
- Chronic Facial Pain
- Glossopharyngeal Neuralgia (GPN)
- Graves' Disease
- Guillain-Barre Syndrome (GBS)
- Lupus
- Lyme Disease
- Mast Cell Disorder
- Multiple Myeloma
- Myasthenia Gravis
- Myositis
- Narcolepsy
- Oculopharyngeal Muscular Dystrophy (OPMD)
- Polyneuropathy
- Psoriatic Arthritis (PsA)
- Primary Sclerosing Cholangitis (PSC)
- Raynaud's Disease (RD)
- Sarcoidosis
- Sjogren's Syndrome
- Sleep Disorders
- Synovial Sarcoma
- Traumatic Brain Injury (TBI)
- Ulcerative Colitis (IBD)
- Von Willebrand's Disease (VWD)

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