

## 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](mailto:info@bensfriends.org)

Connect:    

## 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](http://www.bensfriends.org/donate)

***Inquire About Partnerships***

# DO YOU KNOW SOMEONE WITH A RARE DISEASE?

Please refer them to us at  
[www.BensFriends.org](http://www.BensFriends.org)  
Changing Lives Every Day

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WE BUILD  
PATIENT  
COMMUNITIES  
FOR PEOPLE WITH  
RARE DISEASES.



## 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

## 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.

## 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 (FB)
- Von Willebrand's Disease (VWD)

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