



Ben's Friends
Patient Support Communities

**Patient Support Communities
for People with Rare Diseases**

BensFriends.org

March 7, 2015

Rare Disease Statistics



7,000+

Rare diseases

30,000,000

Americans affected

350,000,000

People affected worldwide

Our Mission



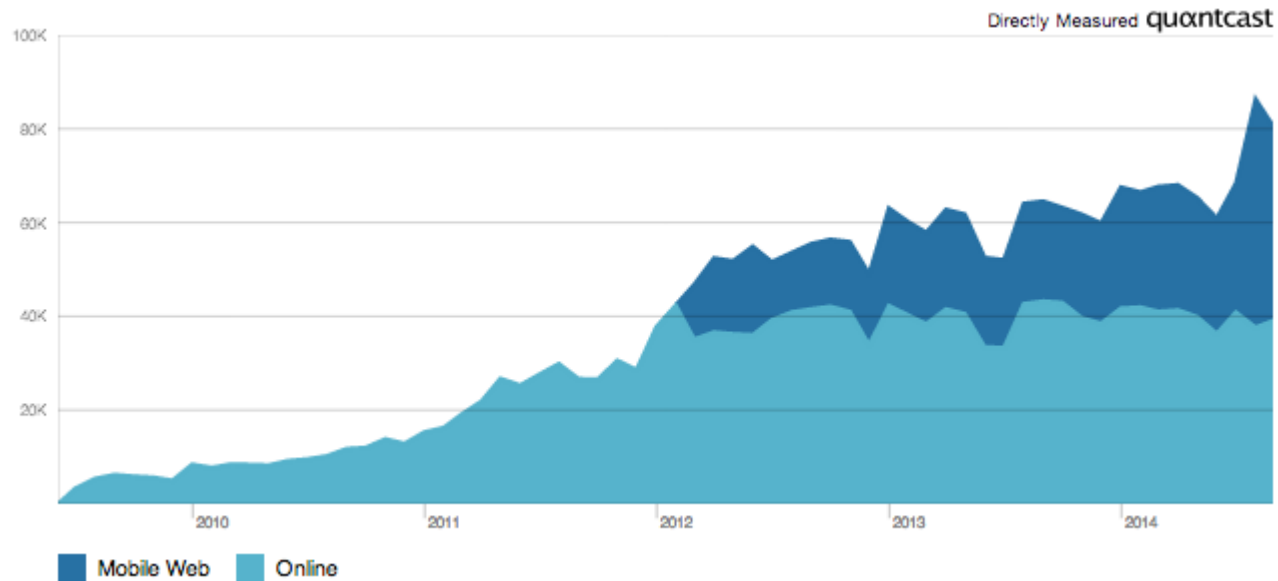
**To ensure that everyone
affected by a rare disease
has a safe place to connect
with people like them.**

Traffic Growth Since 2007



Today:
**40k+ members &
~100k+ visitors/mo**

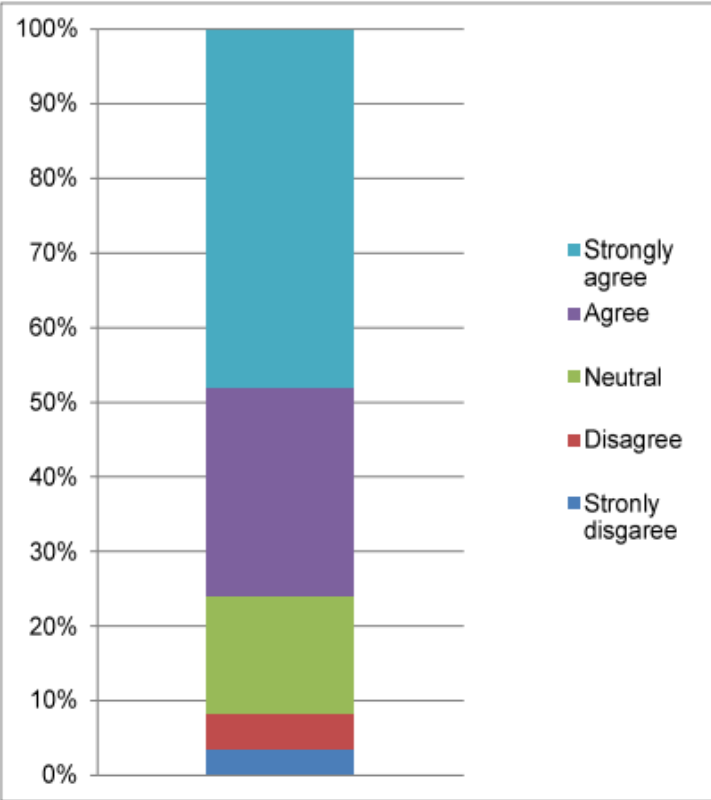
40,000+ lives changed...and counting.



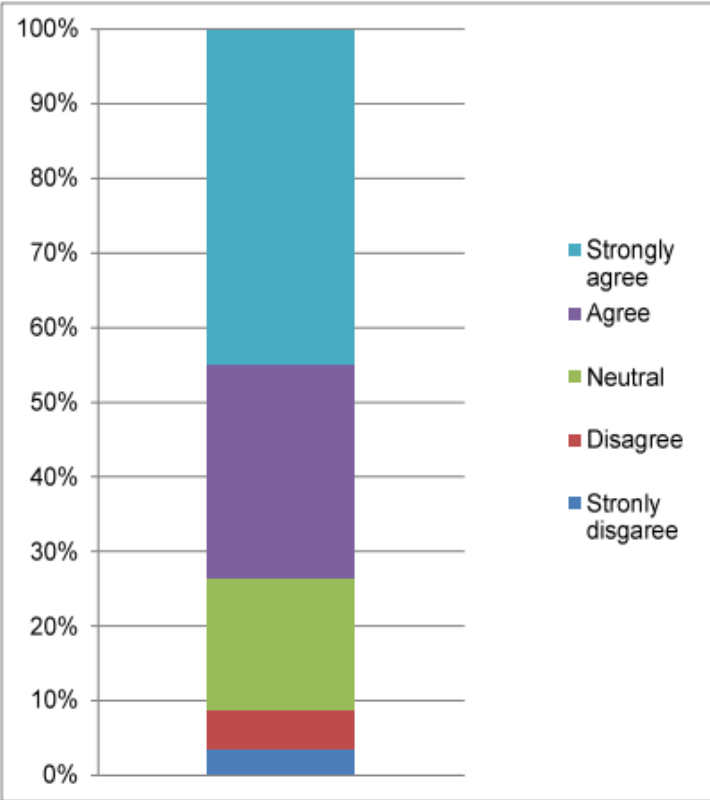
Patients Recognize Positive Impact



76% of Patients Say That Ben's Friends Has a Positive Influence on How They Approach Treatment for Their Condition (N = 1,273)



74% of Patients Say That Ben's Friends Has a Positive Impact on Their Health (N = 1,275)



From Ben's Friends & Bridgespan Consulting Survey (March 2014)

What Patients are Saying (Testimonials)



Testimonials (cont'd)



How BensFriends.org is Run



Board

(5 Members)
Organization &
Fundraising

Moderators

(200+)

Virtual Admins

(Working behind the
scenes)

Members

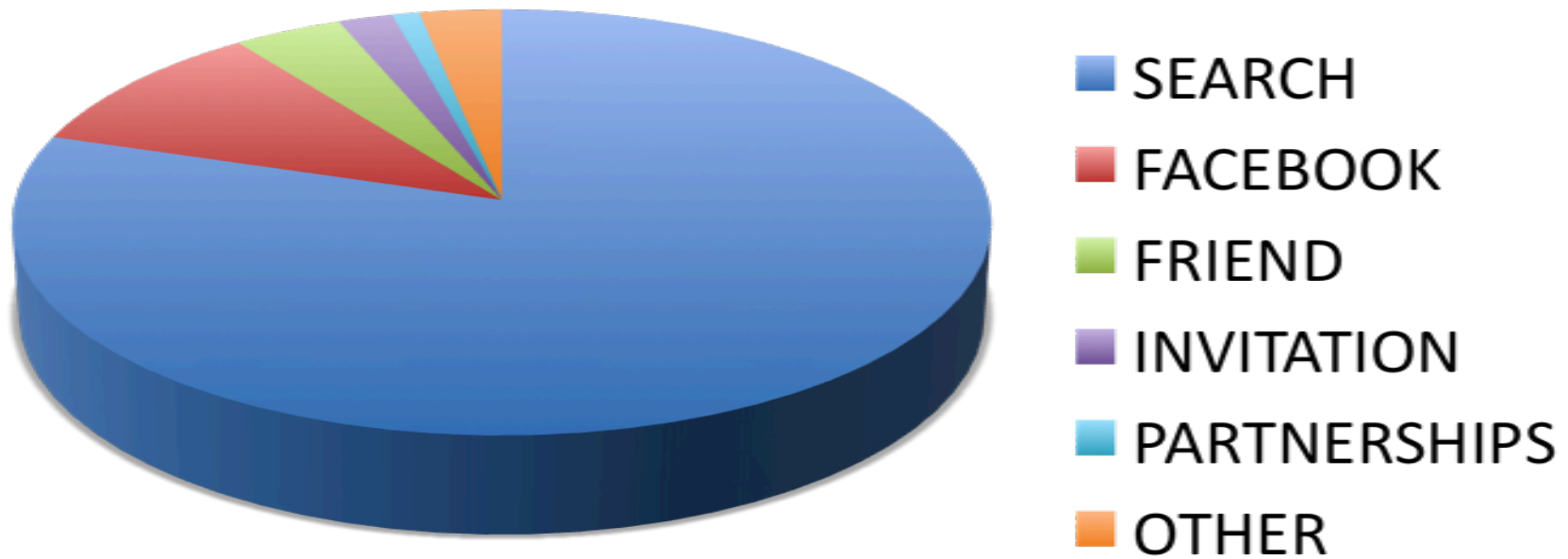
(40,000+)



Power of BF Volunteer Moderators

- 200 plus moderators across our rare disease communities
- Moderators either have condition or touched by person living with one
- Moderators get their own support site:
 - Great resource for sharing of information across all of moderators and communities
 - Sharing of best practices
 - Supporting all of the moderators especially the newer ones as they venture on the journey of building a community from ground zero
 - Broadcasting updates to all of our moderators

How Members Find Us



Member Benefits



- Emotional support by patients for patients
- Knowledge sharing between rare disease patients
- Recommendations for rare disease specialists
- Financial/legal assistance through 3rd parties
- E-book of inspiration patient stories “We’re In This Together”



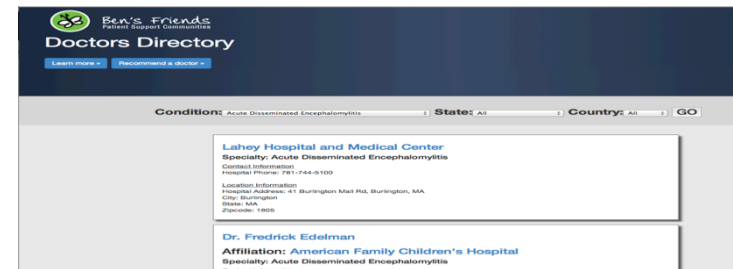
Ben's Friends Doctor Database



40% of all patients with rare diseases are misdiagnosed

- Ben's Friends members crowdsource a database of rare diseases specialists.
- Some hospital systems have sparse lists.
- Searches on Yelp or Angie's List return poor results for rare disease specialists.
- Beta version is live. Already crowdsourced 1,500 doctor listings.

Beta Version of Doctor Database Up but Needs Improvement



The screenshot shows the Ben's Friends Doctors Directory interface. At the top, there's a search bar with filters for 'Condition' (Acute Disseminated Encephalomyelitis), 'State' (All), and 'Country' (All). Below the search bar, there are two doctor listings. The first listing is for 'Lahey Hospital and Medical Center' with a specialty in 'Acute Disseminated Encephalomyelitis'. The second listing is for 'Dr. Fredrick Edelman' with an affiliation to 'American Family Children's Hospital' and a specialty in 'Acute Disseminated Encephalomyelitis'.

Ben's Friends Mobile Growing Fast - Patients Want Mobile Doc Database

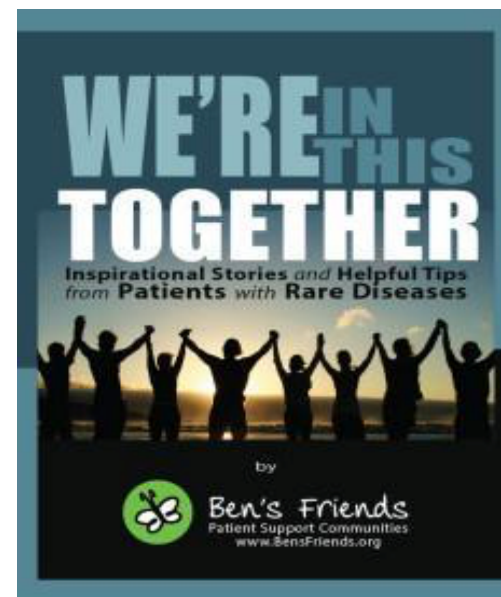


E-book



We're in This Together

- Ben's Friends first ebook launched in December 2013 and listed on Amazon
- Our first ebook is a compilation of patient tips and inspirational stories
- These personal stories show the true courage of patients and their families; along with what they all go through when dealt a devastating diagnosis
- It is a very powerful tool for folks with rare diseases, their family and their caregivers as well as doctors, hospitals, pharmaceutical companies and nurses



Media Mentions



“Community Is The Best Medicine’: How An Aneurysm Survivor Leveraged Indiegogo To Fight Back” - Forbes.com

“Big Impact On A Small Budget: Ben’s Friends Wants To Build A Web & Mobile Support Network For Every Rare Disease” - TechCrunch

Social Media



40k members

1k+ members/community



4k followers

Rated #1 influencer (2013)
#rarediseases by Symplur



48k fans

40+ pages



40+ YouTube Videos
(~20k views)



Won LinkedIn Grant

Tech Trends



Power of Crowds

User-gen, Crowdfunding
40k Support & Crowdfunding



Connected & Real-Time

Any Device, Anytime
Mobile Site



Personalized

Everyone is unique
Personal Profiles



Global

Anywhere
Global Groups/Meetups

BensFriends.org Summary & To Do's



- **Add to 30+ rare disease patient support communities**
- **Support 200+ volunteer moderators**
- **Find more members (& visitors)**
- **Partner with new like-minded organizations**
- **Keep lean & scrappy (low cost\$, win grants)**
- **Fulfill mission & help people affected by rare diseases**

Thank You & Please Keep In Touch!



https://www.youtube.com/watch?v=TeqTzOVWY74&list=UULE_Y7T0acMX48mSDm8dZpg



www.bensfriends.org



facebook.com/bensfriendsorg



[@bensfriends](https://twitter.com/bensfriends)



info@bensfriends.org



UK GENETIC DISORDERS

LEADERSHIP SYMPOSIUM

March 6-7, 2015

Presented by Genetic Disorders UK
in partnership with Global Genes – Allies in Rare Disease

[#GDLS2015](#)