



**Global Genes™**  
Allies in Rare Disease



help raise  
awareness  
for rare  
& genetic  
diseases  
with  
us!



# WHO WE ARE

Global Genes™ is a leading rare disease advocacy organization with global reach to the worldwide rare community of patients, caregivers, advocates, and clinical partners.

Each day, we promote the needs of our community under the unifying symbol of hope – the Blue Denim Genes Ribbon™

## OUR MISSION

To eliminate the challenges of rare disease. We build awareness, educate the global community, and provide critical connections and resources that equip advocates to become activists for their disease.



## RARE FACTS AND STATS



Rare diseases affect approximately **30 million Americans** or **1 in 10 people**.



It is estimated that **350 million people worldwide** suffer from rare diseases.



Approximately **30% of children** with these debilitating diseases **will not live** to see their 5th birthday.

**7000**

Over **7,000 distinct types of rare diseases** exist with more being discovered every day.



Approximately **80%** of rare diseases are genetic.



Rare diseases **impact more people** than AIDS and cancer combined.



**Only 5% of rare diseases** have an FDA approved drug treatment.

# WHAT WE DO

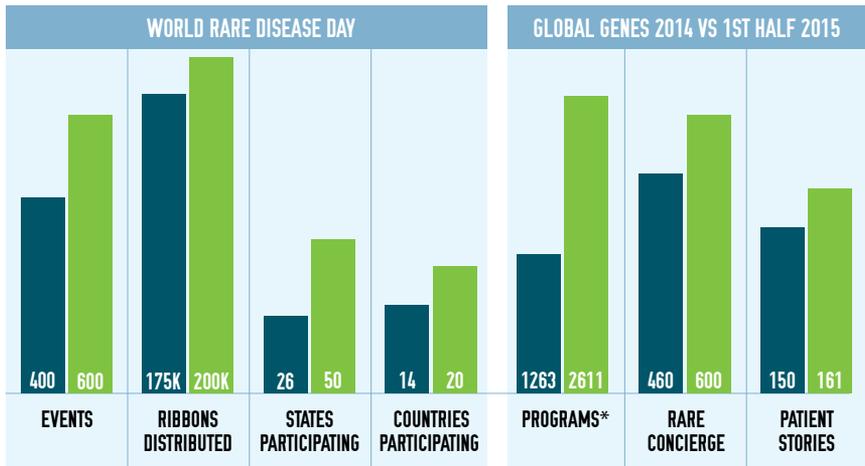
## WE EDUCATE & BUILD AWARENESS

- We develop tools to aid rare disease advocates .
- We equip patients to become successful disease activists.

## WE COLLABORATE AND EMPOWER

- We build bridges between patients, advocates, clinicians and corporate partners.

## DIRECT PATIENT IMPACT



■ 2014 Totals    ■ 2015 Totals (Jan – May)

\* Programs include: RARE Meetups, aHUS Tour, Cystinosis Teen Camp, RARE Patient Advocacy Summit, RARE Webinars, RARE Toolkits

## GET INVOLVED

### SUPPORT

Our Educational Resource Programs.

### HELP

Volunteer. Educate. Advocate.

### JOIN

The RARE Community and Our Awareness Campaigns.

# OUR PROGRAMS

Our programs are designed to build awareness about the prevalence of rare disease, build collaborations between the rare disease patient community and our partners in the biotech, pharmaceutical and medical fields, and provide education and support resources to rare disease patients, advocates and caregivers.

## AWARENESS & OUTREACH PROGRAMS

### World RARE Disease Day



### World RARE Disease Day

World Rare Disease Day is an internationally recognized day of advocacy to call attention to rare conditions both in the United States and around the world. This day is celebrated annually on the last day of February each year. Global Genes participates in a wide variety of awareness activities leading up to the event and has helped catalyze numerous events around the world.



### Blue Denim Genes Ribbon™ Campaign

Just as the pink ribbon symbolizes breast cancer awareness and the red dress symbolizes heart health, the Blue Denim Genes Ribbon™ has become the universal symbol for rare disease awareness. Hundreds of thousands of ribbons have been distributed since the ribbon was first introduced in 2009.



### Tribute to Champions of Hope

This inspiring event celebrates the pioneering achievements of individuals, corporations, and medical institutions in the fight against rare disease. More than 600 attendees at this annual sold-out event include business and rare community leaders, as well as over 250 patient advocates.

## OUR COLLABORATIVE PARTNERSHIP PROGRAMS



### RARE Corporate Alliance™

The mission of the RARE Corporate Alliance™ is to actively combine the resources and capabilities of industry leaders and patient communities to improve health and expedite access to effective therapies for all patients with rare diseases.

Specific initiatives of the Corporate Alliance include:

- Health Care Practitioner (HCP) Education
- Patient Education
- Patient Access



### RARE Meetups™

Patients, families and young adults fighting rare disease, connect in their local communities to learn, share experiences, knowledge, and gain support.



### RARE Foundation Alliance™

Brings together rare disease foundations with a shared commitment to advocacy in order to build a stronger collective voice for the rare disease community.



### RARE Concierge™

Assists patients and advocates faced with the challenges of locating resources and tools for reaching a rare disease diagnosis or potential treatments.

## COMMUNITY GROWTH

2011 5,000  
community members

2015 80,000+  
community members  
with reach to over 3 million

## JOIN THE MOVEMENT

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## OUR EDUCATIONAL PROGRAMS



### RARE Patient Advocacy Summit™

An educational and empowering event, which gives rare disease patient advocates an opportunity to engage, learn, and discuss topics that directly affect them. Annually more than 1400 patient advocates participate in the Summit by attending in-person or by livestream webcast.



### RARE Webinars

share resources for rare disease advocates and supporters. These 60 to 90 minute sessions bring together multidisciplinary expert panels that educate, inform and offer access to the latest information on a broad range of rare disease topics.

### Webinar Topics

- Navigating Health Insurance Issues
- Leveraging a Rare Disease Center of Excellence
- Understanding Rare Disease Registries
- How to Discuss Genetic Disease with Your Loved Ones
- Caregiver Support and Resources



### RARE Toolkits™

Print and online collaborative resources that educate rare disease advocates about issues critical to their journey. Each toolkit includes a resource section, FAQ section, video tutorials and patient advocate/expert testimonials.

### Toolkit Topics\*

- Using Storytelling to Raise Awareness for Your Rare Disease
- Becoming an Empowered Patient: A Toolkit for the Undiagnosed
- Genetic Testing: Is This My Path to a Diagnosis?
- Parenting a Child with a Life-Limiting Illness
- Gaining Independence as a Young Adult with a Rare Disease

\* More RARE Toolkit titles can be found on [www.globalgenes.org/toolkits](http://www.globalgenes.org/toolkits)



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