Global Genes is a leading rare disease advocacy organization with global reach to the worldwide rare community of patients, caregivers, 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 is 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.
EDUCATIONAL PROGRAMS

RARE WEBINARS

Webinar Topics
- Newborn Screening
- Essential Health Benefits
- Understanding Rare Disease Registries
- Caregiver Resources (In association with National Caregivers Month)
- World Rare Disease Day
- Navigating Health Insurance Issues
- Using Successful Online Fundraising Strategies

RARE Toolkits

Toolkit Topics
- Starting A Nonprofit: The First Steps
- Bringing Rare Disease to Capitol Hill
- Parenting A Child With A Life-Limiting Illness
- Genetic Testing
- Access to Unapproved Medications
- Becoming an Empowered Patient
- Exploring Treatment Options for Rare 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.
- 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.
- 95% of rare diseases do not have a single FDA approved drug treatment.

FINANCIALS

Even more important to our organization than the funds we raise, is how we utilize them. We are extremely conscientious with the donations you have entrusted to our care.

In addition to our programs and annual events, funds raised help maintain the RARE Daily, RAREcast Podcast Series, scholarships and stipends, social media awareness and marketing & communications efforts for the rare community.

ANNUAL EVENTS

TRIBUTE TO CHAMPIONS OF HOPE

Tribute of Champions of Hope™

Each year, Global Genes hosts its annual Tribute to Champions of Hope Gala, where we have the good fortune of hearing from rare disease champions from around the globe who are proving that great things can be accomplished by dreaming, planning, taking action, and believing. The results of which, are quite inspiring.

In 2014, the 3rd Annual Tribute to Champions of Hope was hosted to over 500 attendees at the Hyatt Regency in Huntington Beach, California. Guests enjoyed performances from LA dance crew Culture Shock, up and coming singer/songwriter Jessi Malay, and platinum recording artist Kris Allen.
**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. In 2014, membership to the RARE Corporate Alliance increased 30%.

Specific initiatives of the Corporate Alliance include:
- Health Care Practitioner (HCP) Education
- Patient Education
- Patient Access

**RARE Meetups™**
Patients and families fighting different rare diseases connect in their local communities to share experiences, knowledge, and gain support. In 2014, five aHUS Meetups and one Cystinosis Camp were hosted. Plans for 2015 include at least fifteen aHUS Meetups, one aHUS Pediatric Conference, one Narcolepsy Meetup, and one Cystinosis Camp.

**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. In 2014, the RARE Foundation Alliance multiplied from 130 rare disease foundations to 241, which is an increase of 85%.

**Undiagnosed Patient Program**
Supports the start of the rare disease journey for undiagnosed patients through connections, resources and direct funding for complex diagnostics. In 2014, a pilot program to fund exome sequencing for 30+ patients was launched in partnership with clinical sequencing providers UCLA Clinical Genomics Center and Parabase Genomics.

**RARE Concierge™**
Assists patients and advocates faced with the challenges of locating resources and tools for reaching a rare disease diagnosis or potential treatments. In 2014, the RARE Concierge program provided information and support to over 500 inquiring members of the rare community.

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**RARE Patient Advocacy Summit™**
The goal of the Summit is to have patient advocates and other rare disease stakeholders, become inspired, as well as walk away with new information and new connections. The world of rare disease is always changing, providing the community with new opportunities and new challenges; this is why empowering patient advocates to become successful activists is so important. In 2014, the 3rd Annual RARE Patient Advocacy Summit was host to over 350 in person attendees and over 1,000 who participated via LiveStream.

**World RARE Disease Day**
World RARE Disease Day is the last day in February, and 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.