

2012

Global Genes | RARE Project Year In Review

The Global Genes | RARE Project is a leading rare and genetic disease patient advocacy organization.

We work tirelessly to meet goals set forth by our mission: to build and unify a worldwide rare and genetic disease community and positively impact patients in their lifetime. Each day, we promote the needs of our community under the unifying symbol of hope – the Blue Denim Genes Ribbon™.



Global Genes™
RARE PROJECT™



LETTER FROM NICOLE BOICE

As 2012 comes to a close and we reflect on what we have accomplished this year, it is important for us to think about the impact that our efforts will have on setting the stage for a meaningful 2013 and beyond.

We had a tremendous year that was filled with many firsts, including our 1st annual RARE Tribute to Champions of Hope Gala and Patient Advocacy Summit. We also launched our RARE Corporate Alliance™, RARE Meetups™ and RARE Disease Detective™ programs.

In our effort to build awareness and create a connected global community, we have developed important strategic collaborations within the rare disease patient community and with our partners in the biotech and the pharmaceutical industry. We also successfully grew our social media channels and launched a new website, all while distributing over 100,000 of Blue Denim Genes Ribbons™ worldwide.

In 2013, we will continue to expand what we have started, ensuring that we are enhancing community engagement programs, while directly impacting the lives of rare patients, advocates and caregivers. We will continue to expand our Board of Directors, with an emphasis on bringing together leaders in business, philanthropy, and life sciences to help us further this cause and our efforts.

We thank you for your continued support.



Nicole Boice
President & Founder



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FINANCIALS

What is 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.

- Community Building
- World Rare Disease Day
- RARE Meetups™
- RARE Disease Detective™
- RARE Corporate Alliance™
- Tribute To Champions Gala
- RARE Blog
- Social Media Outreach
- Patient Advocacy Summit
- Webcasts
- Scholarships

65%
PROGRAMS

RARE FACTS AND STATS



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



It is estimated that **300 million people worldwide** suffer from rare and genetic 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 and genetic diseases** exist with more being discovered every day.



Approximately **80 percent** 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.

ANNUAL EVENTS



RARE Tribute to Champions of Hope™ Gala

Our uplifting and inspiring event celebrates the pioneering achievements of individuals and corporations who have worked tirelessly in support of patients affected by rare and genetic diseases. In 2012, we had over 400 attendees at our Gala, including 100 patient advocates representing over 80 disease groups. Guests enjoyed musical performances by recording artists Chris Mann and Katrina Parker ("The Voice"), Elliot Yamin ("American Idol"), and Gracie Van Brundt (a young rare disease patient fighting Shwachman-Diamond Syndrome).





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AWARENESS EFFORTS

Blue Denim
Genes
Ribbon™



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 sign for rare and genetic disease awareness. Hundreds of thousands of ribbons have been distributed since the ribbon was first introduced in 2009.

WEAR THAT
YOU CARE™

Genes and Jeans – a natural fit! All across the world, people participate in our Wear That You Care™ campaign and support the rare and genetic disease movement by wearing the Blue Denim Genes Ribbon™ and their favorite pair of jeans.

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 and genetic diseases.



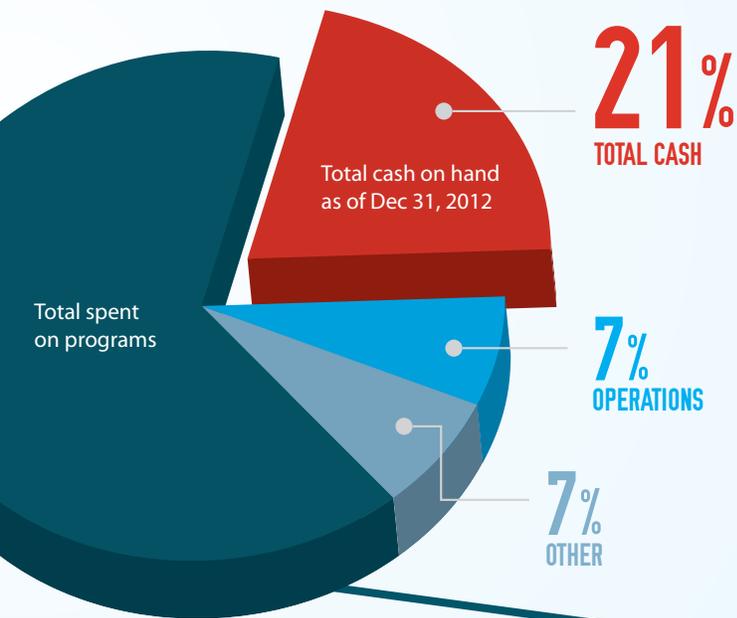
RARE Meetups™

Patients and families fighting different rare and genetic diseases connect in their local communities to share experiences, knowledge, and gain support.



RARE Disease Detective Program™

In partnership with the EveryLife Foundation, the RARE Disease Detective Program™ assists patients and advocates faced with the challenge of locating resources and tools for reaching a rare disease diagnosis or potential treatments.



Feb 28, 2013

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 | RARE Project participates in a wide variety of awareness activities leading up to the event and has helped catalyze numerous events around the world.



Sept 20, 2013

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. In 2012,

over 145 patient advocates participated in our Summit with more than 200 people tuning in via webcast.



SOCIAL GROWTH



2012 3,000 fans



2013 35,000+ fans

JOIN THE MOVEMENT



Global Genes Project



@GlobalGenes

#hope
#genes
#wearthatyoucare
#careaboutrare

MEET THE TEAM AND BOARD

TEAM



Nicole Boice
President & Founder



Amy Grover
Director, Community Development



Jason Omenn
Director, Development



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Director, Marketing



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Katie Mastro
Program Manager



Kathy O'Connor
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Lisa James
Manager, Community Development



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