Global Genes™ is a leading rare disease advocacy organization with global reach to the worldwide rare community of patients, advocates, caregivers, and key rare disease stakeholders. Each day, Global Genes™ promotes the needs of the rare disease 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.
2015 CONTRIBUTIONS

REVENUE*

REVENUE GROWTH BY YEAR

$270K 2011
$735K 2012
$1.2M 2013
$2.2M 2014
$3.2M* 2015
$5.0M 2015

+45% increase in revenue, year-over-year 2014 to 2015 and continuing to grow.

ALLOCATIONS*

82% PROGRAM FUNDING

$0.82 of every $1.00 goes directly to programs that support the rare community.

12% ADMINISTRATION

6% OTHER

OTHER

* Projected 2015 revenue, non-audited estimate.

AWARENESS REACH

THOUSANDS HAVE READ AND LISTENED TO CONTENT DIRECTLY RELATED TO THE RARE DISEASE COMMUNITY.

SOCIAL COMMUNITY GROWTH*

2015

OVER 100,000 SOCIAL MEMBERS WITH A REACH OF OVER 88 MILLION*

DIRECT PATIENT IMPACT*

6000+
in 2015

2000+
in 2014

* 2015 Community number pulled from Facebook and Twitter—reach is combined non-unique users.

globalgenes.org
COMMUNITY EVENT HIGHLIGHTS

RARE PATIENT ADVOCACY SUMMIT™
• 400 in person attendees from over 40 states, and 6 countries, representing 120 rare diseases
• 1,000 livestream participants throughout the U.S. and 10 countries, 33,554 total minutes viewed
• 42 sessions convened with 56 guest speakers

RARE TRIBUTE TO CHAMPIONS OF HOPE™
• 15 individuals and organizations honored for efforts in rare disease
• 650 attendees supporting rare patients

WORLD RARE DISEASE DAY
• Over 200,000 Denim Gene Ribbons distributed
• 600 events supported in all 50 U.S. States and 20 countries

DENIM DASH 5K
• New program in 2015
• 674 Participants in 46 states and 7 countries
• $63,000 raised for Rare Patient Impact Grant Program

COLLABORATIVE PARTNERSHIP HIGHLIGHTS

CORPORATE ALLIANCE
• 65 partner organizations participating
• 20% growth from 2014

FOUNDATION ALLIANCE
• 330 participating organizations
• Added 74 new participating organizations in 2015
• 29% increase in year-over-year organizational participation 2014 - 2015

EDUCATION & RESOURCE PROGRAM HIGHLIGHTS

RARE CONCIERGE
Based on Salesforce.com:
• 101 inquiring cases were referred for specialized genetic counseling follow-up, of these:
  • 72 cases closed
  • 18 cases received further response
  • 11 cases opened for further action

• Over 450 patients served in four disease groups: aHUS, Cystinosis, LEMS, and Narcolepsy
• 19 Meetups were hosted, including two pediatric conferences

RARE MEETUPS
• Over 130 applicants in 6 weeks
• Over $1.3M in funding requests with an anticipated reach of over 1.1M patients, based on 100% funding
• 18 applicants were granted a total of $100K

RARE TOOLKITS
• 7 toolkits released
• About 3,000 toolkits distributed
• Top 3 titles:
  • Becoming An Empowered Patient: A Toolkit for the Undiagnosed
  • Using Storytelling to Raise Awareness for Your Rare Disease
  • How to Discuss Genetic Disease with Your Loved Ones

RARE WEBINARS
• 6 one-hour annual webinars
• 80% of participants shared information with their community
• Top 3 titles:
  • Optimizing Your Loved One’s Learning and Potential at School
  • Navigating Health Insurance Issues, Parts 1 & 2
  • Learning More About Informed Consent

RARE PATIENT IMPACT GRANT
• Over 130 applicants in 6 weeks
• Over $1.3M in funding requests with an anticipated reach of over 1.1M patients, based on 100% funding
• 18 applicants were granted a total of $100K
THIS IS WHY GLOBAL GENES WAS FOUNDED

7,000 RARE DISEASES IDENTIFIED
OVER
350 RARE DISEASE AFFECTS MORE THAN MILLION PEOPLE WORLDWIDE

APPROXIMATELY OF CHILDREN WITH THESE DEBILITATING DISEASES WILL NOT LIVE TO SEE THEIR 5TH BIRTHDAY.

50% OF PEOPLE AFFECTED BY RARE DISEASE ARE CHILDREN
30% APPROXIMATELY 80% OF RARE DISEASES ARE GENETIC.

5% OF RARE DISEASES HAVE AN FDA APPROVED DRUG

MEET THE TEAM

Nicole Boice
Founder & CEO
Angie Rowe
Chief Operating Officer
Monica Lee Copeland
Chief Development Officer
Kym Kilbourne
VP, Patient Advocacy
Tricia Mullins
VP, Strategic Alliances
Amanda Knitter
Director, Patient Advocacy
Amy Grover
Director, Operations

Alex Schlott
Director, Event Operations
Carrie Ostrea
Senior Manager, Advocacy
Kendall James-Davis
Senior Manager, Strategic Alliances
Jaymie Rodems
Manager, Marketing & Communications
Ashley Yee
Manager, Advocacy Programs
Kathy O’Connor
Manager, Strategic Alliances
Lisa James
Manager, Technology

Nikki Berry
Coordinator, Design
Ilana Jacqueline
Managing Editor, RARE DAILY
Brynn Dickson
Administrative Assistant

OUR BOARD

Nicole Boice
Founder & CEO of Global Genes
John F. Crowley
CEO of Amicus Therapeutics
Natalie Douglas
CEO of Healthcare at Home
Hugh Hempel
Founder of Solution Therapeutics
Caroline Loewy
BioTech Exec./Consultant, Co-Founder, KCNQ2 Cure Alliance

Brad Margus
Co-Founder & CEO, Exigence Neurosciences
Peter J. Pellizzon
Founder, Hollencrest Capital
Susan Stein
CEO/President, Connexion Healthcare
Wendy White
Senior VP, Dolmen Life Science Services, Parent Advocate
Matt Wilsey
President, Grace Wilsey Foundation

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