About Global Genes®

Guided by its mission to eliminate the challenges of rare disease, Global Genes is a leading patient advocacy organization with worldwide reach that serves and promotes the needs of patients and families touched by rare and genetic diseases. Global Genes has been building awareness, developing patient-focused education and advocacy tools, and funding patient care programs and early investigative research since 2009.

www.globalgenes.org

Join the Rare Conversation!
Follow @GlobalGenes on Social Media.
HOPE. It’s in our genes.

Under the Blue Denim Genes Ribbon®, the unifying symbol of HOPE, Global Genes has developed tools and resources that educate and empower patients and families touched by rare disease. Guided by our Mission to eliminate the challenges of rare disease, our work equips advocates to become activists - for their disease, and the community at large.

Your ongoing support has made possible Global Genes programs, events, and initiatives that build awareness, develop patient-focused education and advocacy tools, and fund patient care programs for families fighting rare. These include:

**Signature Events & Resources:**
- RARE Patient Advocacy Summit
- Tribute to Champions of Hope
- Virtual Denim Dash 5K
- RARE Toolkits
- RARE Patient Impact Grant Program
- RARE Daily
- RARE Webinars
- RARE Cast
- RARE Concierge

**Events & Resources in Partnership:**
- RARE Patient Advocacy Symposium
- RARE on the Road
- RARE Meetups
- RARE University
- UK Genetic Disorders Leadership Symposium

Thank you for your continued support throughout 2016, which has made all of this possible. You have helped strengthen our base, and inspired an expanded role for patients as partners, and the ultimate drivers of innovation. We look forward to continuing to develop a platform that promotes collaboration that accelerates patient-centered drug development and therapeutics.

Always in Hope,

Nicole Boice  
Founder & CEO of Global Genes

Wendy White  
Board Chair Principle, Wendy White Consulting, Parent Advocate

Natalie Douglas  
Board Vice Chair CEO, Healthcare at Home

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**THIS IS WHY GLOBAL GENES WAS FOUNDED**

- **7,000** OVER RARE DISEASES IDENTIFIED
- **350** RARE DISEASE AFFECTS MORE THAN 5 MILLION PEOPLE WORLDWIDE
- **50%** OF PEOPLE Affected BY RARE DISEASE ARE CHILDREN
- **30%** OF RARE DISEASES HAVE AN FDA APPROVED DRUG
- **80%** OF RARE DISEASES ARE GENETIC
- **5%** APPROXIMATELY OF CHILDREN WITH THESE DEBILITATING DISEASES WILL NOT LIVE TO SEE THEIR 5TH BIRTHDAY.
<table>
<thead>
<tr>
<th>Social Media</th>
<th>Website</th>
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<tbody>
<tr>
<td># of Followers</td>
<td>103,047</td>
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<tr>
<td># Impressions</td>
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<td># of Followers</td>
<td>4,199</td>
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<table>
<thead>
<tr>
<th>Rare Patient Impact Grant</th>
<th>Rare Daily</th>
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<tbody>
<tr>
<td>18 Awardees</td>
<td>RAREDaily by Global Genes</td>
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<tr>
<td>17,420 People Impacted (Estimated)</td>
<td>1,704,656 Total Page Views</td>
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<table>
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<tr>
<th>Education Awareness Events in Partnership</th>
<th>Rare Meetups</th>
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<tbody>
<tr>
<td>RareUniversity</td>
<td>427 Patients Served</td>
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<tr>
<td>3920 Page Visits</td>
<td>13 Meetups Serving 3 Rare Disease Groups: AHUS, LEMS, and Narcolepsy</td>
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EMPOWERING PATIENTS

RIBBONS DISTRIBUTED: 225,000
48 STATES 15 COUNTRIES

PATIENT RESOURCES

RARE TOOLKITS
10,015 DISTRIBUTED 11 RELEASED

GLOBAL GENES
RARE Cast
with Daniel Levine
4,289 LISTENERS

RARE WEBINARS
1393 REGISTERED
4 TOTAL WEBINARS

RARE CONCIERGE
274 GENETIC COUNSELING INQUIRIES

COLLABORATE AND ACTIVATE

FOUNDATION ALLIANCE
387 MEMBER ORGANIZATIONS
↑ +13%
FROM 2015

CORPORATE ALLIANCE
74 COMPANIES
↑ +17%
FROM 2015
The Summit gave me many tools and resources, ... which help patients get closer to a definitive diagnosis ...and soften the burden of those finding out they have a rare disease. Thank you GG.” - T. Voogel, GNE Myopathy International

97% Of attendees felt they received tools to support them and their Rare Disease Community

589 IN-PERSON ATTENDEES
1,600 LIVESTREAM PARTICIPANTS

“Every second of the Tribute to Champions of Hope was perfect...Helping and hoping to make life just a bit easier for some of the families is what we all hope to do.” - Nancy H., RARE Champion of Hope

670 ATTENDEES
27 HONOREES

“My family and I love to be a part of Denim Dash every year on behalf of my daughter Alanis who has a rare disease. A rare disease that in itself has been a race to find answers and cures.” - Perla P., Parent Advocate

1150 PARTICIPANTS
↑ +41% FROM 2015
2016 REVENUE AND EXPENSE SUMMARY

REVENUE GROWTH

86% PROGRAM FUNDING
$0.82 of every $1.00 supports the rare community.

11% ADMINISTRATION

3% OTHER

“I can’t begin to tell you what it all meant to me personally to meet other moms dealing with the same challenges. Thank you from the bottom of my heart!”
-Tammy Ruh

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globalgenes.org
@GlobalGenes

By helping Global Genes, you are helping to eliminate the challenges of rare disease globally. Thank you!

Global Genes® is a 501(c)(3) organization
Tax ID #26-3331487