

Virtual Rare Care Package

Hosted by



Raretour.org

[#RAREontheRoad](https://twitter.com/RAREontheRoad)

Thank you to our Sponsors

PLATINUM



GOLD



SILVER

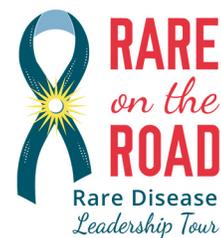


BRONZE



PARTNERS





Dear RARE on the Road friend,

Thank you so much for your interest in our two-part, RARE on the Road virtual event.

We thoroughly enjoyed connecting with so many rare disease friends and hope you feel more empowered to engage in advocacy and will continue to network with others in your local rare disease community.

To help you take the next steps in your rare disease journey, we have provided you with this Digital Rare Care Package. Thanks to the generous support from our sponsors, you'll find various resources that can help you with these next steps.

As a reminder, Part 1: Interactive Webinar was recorded. If for any reason you were unable to attend this portion of the event, or would simply like to view the presentations again, you can find the recording on www.raretour.org.

Thank you for being a part of this unique virtual experience. We hope to see you again, somewhere on the road!

Sincerely,



info@everylifefoundation.org
202-697-RARE(7273)



globalgenes@globalgenes.org
949-248-RARE(7273)



CHANGING POLICY, SAVING LIVES



We do not speak for patients. We provide the training, education, resources and opportunities to make their voices heard. By activating the patient advocate, we can change public policy and save lives.

Join Us.

EVERYLIFEFOUNDATION.ORG



Thirty million Americans suffer from a rare disease, making it a public health crisis.



In the United States, a disease is defined as rare when it affects fewer than 200,000 people.



Rare disease patients must wait an average of six years after symptoms present before receiving a proper diagnosis.



50% of rare disease patients are children, 30% of children with a rare disease will not live to see their fifth birthdays.



93% of the 7,000 known rare diseases have no U.S. Food and Drug Administration-approved therapies.

The EveryLife Foundation is working to:

- ☀ Improve the regulatory process
- ☀ Close the innovation gap
- ☀ Ensure patients receive earliest access to diagnostic and treatment opportunities
- ☀ Enhance the patient voice



1012 14th St, NW, Suite 500, Washington, D.C. 20005
(202) 697-RARE (7273)

@EVERYLIFEORG

Join the Movement

The contest is open to anyone whose life is touched by rare disease – patients, family members, friends, caregivers, researchers and medical professionals. Artists four and older are welcome.

For more information, contact
Lindsey Cundiff, lcundiff@everylifefoundation.org



RAREARTIST

POWERED BY THE EVERYLIFE FOUNDATION



SHARE YOUR RARE THROUGH ART



More than \$3,000 awarded in prizes



Awardees invited to speak on Capitol Hill



Artwork displayed around the country



To become a Rare Artist sponsor, contact
Ted Brasfield, tbrasfield@everylifefoundation.org

2020 CONTEST OPENS JUNE 16TH

RAREARTIST.ORG

FOLLOW US ON  @RAREARTISTCONTEST


EVERYLIFE
FOUNDATION
FOR RARE DISEASES

1012 14th St. NW, Suite 500, Washington, DC 20005
(202) 697- RARE (7273)



POWERED BY THE EVERYLIFE FOUNDATION

EVERY VOICE MATTERS

WHY Advocacy Matters?

You, yes, YOU!

You have heard it before, but it's true: many voices are louder than one single voice. This is the power of advocacy.

Using your voice, sharing your rare disease story and joining with others to amplify the message, brings the needs of the rare disease community to the attention of local, state, and federal government officials.

If you do not participate in advocacy, then your unique voice and rare disease story will not be heard.

The rare disease community needs advocates like YOU to ensure that policymakers and legislators are aware of the challenges facing rare disease patients and caregivers from getting a diagnosis to accessing treatments and cures. Without your story, legislators can't effectively support policies that help you, your families, or others with rare diseases.



For more information, contact: Shannon von Felden (RDLA Program Director) at svonfelden@everylifefoundation.org

rareadvocates.org    

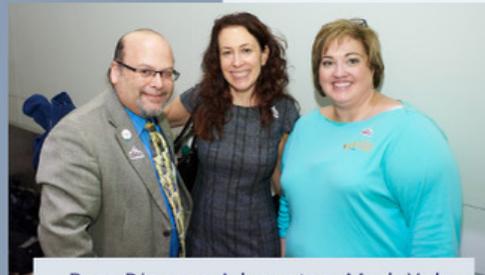
HOW To Get Started

- ✓ Sign up to receive communications from RDLA at www.rareadvocates.org.
- ✓ Participate in Rare Across America meetings with legislators in August 2020. Register at www.RareAcrossAmerica.org.
- ✓ Come to Washington, DC for Rare Disease Week on Capitol Hill 2021. Find out more, including how to apply for a travel stipend, at www.rareadvocates.org/rdw.
- ✓ Schedule a meeting with your Member in their district office or on Capitol Hill.
- ✓ Invite your Member of Congress or their staff to events held in your community.
- ✓ Attend events like townhalls that your Member of Congress holds in the district and state.
- ✓ Participate in meetings about research and therapy development for your disease area at NIH or the FDA. Learn more, including how to apply for travel stipends at: raregiving.org.
- ✓ Engage with legislators on social media.
- ✓ Write letters or emails to your legislators.
- ✓ Write op-eds for your local newspapers.



As a rare disease patient, it's important to make our voices heard so we are considered in this climate of healthcare reform, especially considering our preexisting conditions may not be protected in future regimes.

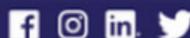
- Rebecca Strong. (Rare Disease Advocate)



Rare Disease Advocates: Mark Yale, Stephanie Fischer, Rebecca Strong.

For more information, contact: Shannon von Felden (RDLA Program Director) at svonfelden@everylifefoundation.org

rareadvocates.org





Patient Programs

Rare Disease Legislative Advocates, is designed to support the advocacy of all rare disease patients and organizations. By growing the patient advocacy community and working collectively, we can amplify our many voices to ensure that rare disease patients are heard in local, state and federal government.



RDLA Advocacy Resources:

- ▲ Monthly Action Alerts
- ▲ Congressional Scorecards
- ▲ Online Advocacy Tools
- ▲ Consulting on Legislative Strategies
- ▲ Monthly Conference Calls/Webinars

Rare Disease Week on Capitol Hill brings rare disease advocates from across the country together to learn about federal legislative issues, meet other advocates, and share their unique stories with legislators. We offer free events throughout the week to all patients, caregivers and family members. It is a chance to meet the community, join forces and drive change.



In-District Lobby Days is another opportunity build a relationship with your elected officials. RDLA will schedule meetings for you with your Congressional Representative offices during their summer recess. This event is ideal for advocates who are unable to travel to Washington DC or want to continue to build relationships with their legislators.



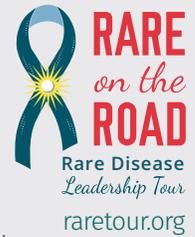


We are a nonprofit, nonpartisan organization dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science-driven public policy.

EveryLife Foundation Programs

- ▲ Rare Disease Legislative Advocates (RDLA)
- ▲ Rare Giving
- ▲ Rare on the Road
(in partnership with Global Genes)
- ▲ Rare Artist
- ▲ Community Congress
- ▲ Young Adult Representatives

The EveryLife Foundation and Global Genes are excited to partner for **RARE on the Road, a Rare Disease Leadership Tour** to bring critical education and insights to rare disease patients, caregivers and other advocates. We are uniting to build and activate the rare disease community at the local level. Whether you're new to the rare disease community or a "seasoned veteran" this workshop will benefit you!



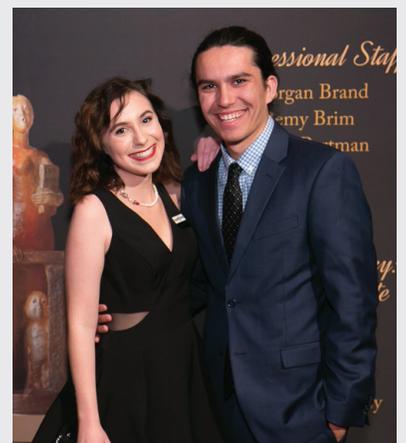
The Community Congress

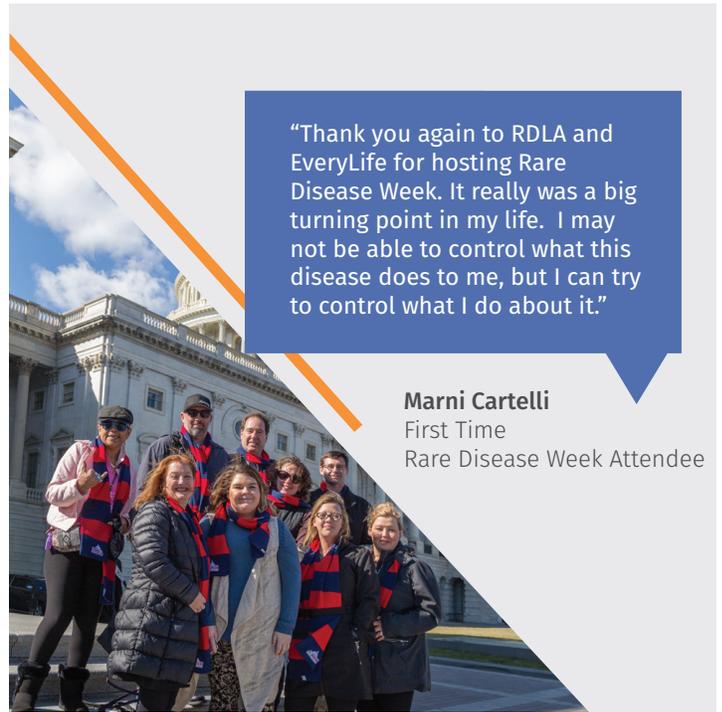
is a membership-based program dedicated to bringing patient organizations, industry leaders, and other rare disease stakeholders together. The Congress acts as a strategic advisory council, providing advice and insight on urgent policy issues and Foundation programs and initiatives. The Congress is comprised of three working groups that focus on self-selected projects to advance policy for rare disease patients. Membership is free for all patient organizations.



Young Adult Representatives of RDLA

is a group of 16-30 year-olds from the rare disease community, who focus on building advocacy skills in the rare space. The group is relatively new and looking for more young adult champions, including representation in each state. The primary goal is to ensure young adults have a growing impact on public policy and legislation.





“Thank you again to RDLA and EveryLife for hosting Rare Disease Week. It really was a big turning point in my life. I may not be able to control what this disease does to me, but I can try to control what I do about it.”

Marni Cartelli
First Time
Rare Disease Week Attendee

Rare Giving is designed to support individual rare disease patients as well as organizations that engage patients, caregivers and others in the community in public policy. We believe it is critical for policymakers and regulators to hear directly from rare disease patients and caregivers.



- ▲ **Travel Stipends:** Each year, we provided more than \$80,000 in travel stipends for advocates from around the United States to enable them to participate in meetings with Congress, FDA and NIH.
- ▲ **Event Sponsorships:** We provide funding to support patient organization events that engage rare disease patients and caregivers in public policy.



Rare Artist was established to exhibit the unique gifts of individuals affected by rare diseases and to promote the expression of their stories through art. We host an online gallery dedicated to artists affected by rare disease. RareArtist.org creates a permanent, free, virtual space where “rare artists” can express themselves and submit their work for public viewing. The winners of the Rare Artist contest gather together annually for a reception during Rare Disease Week on Capitol Hill to showcase their works of art.



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(202) 697-RARE (7273)

info@EveryLifeFoundation.org • EveryLifeFoundation.org
501(c)(3) nonprofit organization (Tax ID 26-4614274)





The RARE Foundation Alliance

is a coalition of more than 500 rare disease organizations that exchange best practices and share lessons learned to drive better outcomes for the entire rare disease community. We encourage you to join if you are a rare disease support group, U.S. foundation with 501(c)(3) status or an international foundation.*

Not a member yet? Join Today!
GlobalGenes.org/Foundation-Alliance/



Global Genes[®]
Allies in Rare Disease

Advocacy Is *Storytelling*

Reflect, map, and strategize how you will deliver your message and make an impact.

Mapping the Story

What do I want people to know?

1. _____
2. _____
3. _____

What do I want people to feel?

1. _____
2. _____
3. _____

What actions do I want to inspire?

1. _____
2. _____
3. _____

The Subject of the Story

Who: _____

What: _____

Where: _____

When: _____

Why: _____

How: _____

Audience

Who needs to take action?

- Audience 1: _____
- Audience 2: _____

Who is the story intended for?

- Audience 1: _____
- Audience 2: _____

How will the audience be reached?

- Audience 1: _____
- Audience 2: _____

Method

How am I going to inspire change?

Methods

Results



RARE TOOLKITS

Global Genes' RARE Toolkits are collaborative resources that provide critical information on topics important to the rare disease community that aim to educate and share best practices.

Over 30 toolkits available on a variety of subjects including:

- Advocacy
- Psychosocial
- Genetics
- Drug Development, Research, and Access
- Organization Development
- Clinical Care

To order toolkits in bulk for meetings, events, and your community: shop.rarehouse.org
To access the online version of toolkits: www.globalgenes.org/toolkits



Global Genes RARE Toolkits

RARE Toolkit: Bringing Rare Disease to Capitol Hill: Advocating for Your Cause

RARE Toolkit: Using Storytelling to Raise Awareness for Your Rare Disease

RARE Toolkit: Building Relationships with Your Representatives

RARE Toolkit: Speak Easy: A Guide to Public Speaking

RARE Toolkit: The ABC's of Advocating in the Classroom

RARE Toolkit: How to Promote Your Rare Disease Story Through Social Media

RARE Toolkit: Becoming an Empowered Patient: A Toolkit for the Undiagnosed