Changing Policy, Saving Lives

#EveryLifeMatters
The Power of Patient Advocacy
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Rare Disease Legislative Advocates
Agenda

• About the EveryLife Foundation for Rare Diseases
• About the Rare Disease Legislative Advocates
• The Power of Patient Advocacy
• Where to Start
• Ways to Get More Involved in Advocacy
The EveryLife Foundation for Rare Diseases

A nonprofit, nonpartisan organization dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through public policy.
Rare Disease Legislative Advocates

• Educate patients advocates about how legislation and policy impact the availability and access to treatments and provide them resources.

• Build awareness on Capitol Hill and ensure Congress hears directly from patients and caregivers.

• Connect every Member of Congress with a rare disease advocate, so when they consider legislation, it’s not just about treating a disease it’s about saving a person they know.
The Power of Grassroots Advocacy

Legislation & Public Policy impact science, the drug development process and access to treatments

- You have the **POWER** to effect change
- Take an active role in the political process
- Influence legislation & policy
You Have the Power

“I am only one, but still I am one. I cannot do everything, but still I can do something; and because I cannot do everything, I will not refuse to do something that I can do.”

-Helen Keller

No Disease Is Too Rare to Deserve Treatment
Your Advocacy Matters!

Your legislators want to hear from you!

- You are the constituent
- You are the expert!

WE WANT TO HEAR FROM YOU
Why Relationships Matter

In-Person Visits from Constituents: 46% (A Lot of Positive Influence) + 51% (Some Influence) = 97%
Contact From Constituents' Reps.: 96%
Individualized Postal Letters: 90%
Individualized Email Messages: 88%
Phone Calls: 86%
Telephone Town Hall Comments: 85%
Visit From a Lobbyist: 8% (A Lot of Positive Influence) + 74% (Some Influence) = 82%
News Editorial: 75%
Individualized Faxes: 70%
Form Postal Letters: 54%
Form Email Messages: 51%
Postcards: 45%
Comments on Social Media Sites: 42%
Form Faxes: 30%

Copyright – Congressional Management Foundation
Source – 2015 Perceptions of Citizen Advocacy

No Disease Is Too Rare to Deserve Treatment
Your Roadmap to Change
Where to Start?

Create a plan!

- Resources
- Community support
- Strategy
- Tactics
What do YOU do as an advocate?

- Educate
- Provide Guidance
- Persuade
- Pressure
Who to Engage

- The Governor
- Your hometown Member/Legislators
- Members of the Committee of Jurisdiction
- Leadership (Majority/Minority leaders)
- Government Agencies
- State & Local Representatives

Tip: Staff are an amazing resource, and in-district meetings are often easier to schedule and more beneficial
When to Engage

- Build relationships with your legislators
- ANYTIME & All The Time!!
- Schedule in-district meetings during district work periods.
- Pay attention to a bill’s progress through the House/Senate and schedule meetings around key events in this cycle.
- Don’t wait until it is too late. Be vocal early about the issue you care about.
How to Engage

Tactics:

- In-person meetings
- Hold briefings
- Letters/Emails
- Media
- Op-Eds
- Town Halls
- Phone Calls
- Social Media

Make it personal
Know Your Decision-Makers: Find ways to connect!

- Research your decision-makers
- What issues are they interested in?
- What legislation have they supported?
- What do YOU personally have in common with them?

Remember: Rare disease issues are bipartisan!

We are the RARE Party!
Meet with your Legislator

Three Parts:

• Introductions
• Share Your Story
• Make the “Ask”
Telling Your Story: Practice Makes Perfect

HELLO. MY NAME IS INIGO MONTOYA. YOU KILLED MY FATHER. PREPARE TO DIE.

INIGO’S GUIDE TO NETWORKING SUCCESS

1. POLITE GREETING
2. NAME
3. RELEVANT PERSONAL LINK
4. MANAGE EXPECTATIONS

No Disease Is Too Rare to Deserve Treatment
Making the Ask

Three ingredients:

- What is the problem?
- What is the solution?
- Call to Action: What do you want them to do to help?
The Ask: How can they help you?

- The goal is to get your Member of Congress/legislator to take action on your priority
- Make sure that your request is clearly articulated and actionable by the legislator
- Be specific: e.g. “Please co-sponsor Senate bill 2158”
Social Media as an Advocacy Tool

Use Social Media for your advocacy!

- Make them aware of the problems you face
- Thank them for actions they take
- Thank them for meeting with you
- Tag the Member with photos you took in the meeting
Grow Relationships with your Legislators

- Sign-up for the Member’s newsletters and follow him/her on social media.
- Look for opportunities to engage the Member in person such as town halls.
- Call the Member’s office for relevant action alerts on legislation.
- Thank the Member for cosponsoring or voting for legislation you asked him/her to support.
- Stay in touch with staff.
Follow up!!!

- Thank your Members on social media
- Email the staffer to thank them and ask for an update on your request
- Share relevant news and updates
- Meet with the Member and district staff in the local, district office
- Stay in touch!
Use Social Media to Reach Policymakers

• Thank legislators by using their official Twitter handle for a vote, meeting or even a thoughtful response to an inquiry. Include a photo of the meeting!

• Engage in discussions about legislative initiatives.
Want to be active in Rare Disease Advocacy?

- RDLA’s Advocacy Tools
- Rare Across America
- Rare Disease Week on Capitol Hill 2020
So, You Want to Be an Advocate?

Sign up for monthly newsletters, action alerts and invitations to the monthly webinars and other FREE events at RareAdvocates.org.
Stay Informed on Key Policy Issues

- Monthly interactive webinars highlight urgent state & federal legislation
- RareAdvocates.org serves as a legislative clearinghouse
- Monthly e-blast shares latest policy news, action alerts & events
- Online Calendar lists policy events and legislative deadlines
- Facebook & Twitter accounts feature breaking news & action alerts
Rare Disease Week on Capitol Hill

2019 was our eighth and most successful year!

800+ patients, caregivers, researchers and other advocates joined us for at least one event during the week!
Rare Disease Week on Capitol Hill 2020

**When:** February 25th through February 28th

**Who:** Rare disease patients, caregivers and other advocates including physicians

**What:** Series of events aimed at empowering patients

**Where:** Washington, D.C.

**Cost:** FREE for advocates to attend

*No Disease Is Too Rare to Deserve Treatment*
Rare Disease Week on Capitol Hill

Why should YOU attend?

• Learn about key legislative initiatives with the potential to benefit rare disease patients.
• Educate legislators on the unmet needs of rare disease community and build (or strengthen) your relationship with them.
• Raise awareness of your specific rare disease and rare diseases in general.
• Network with other rare disease advocates, Members of Congress and staff, leaders at FDA and NIH, and representatives of biopharmaceutical companies.
Rare Across America

During August recess, rare disease advocates from across the country will meet with Members of Congress in their local offices to advocate for legislation benefiting the rare disease community.

Registration will open in May 4, 2020.

Like all of our programs, it is free for patients, caregivers and other rare advocates.
Goals of Rare Across America

- Strengthen your relationships with Members of Congress and staff
- Advance legislation that would benefit the rare disease community

A best-practice of effective advocacy is to make your friends before you need them! We NEED to gain allies in both parties who will champion rare disease causes.
Keep in Touch!

Sign-up for our newsletters, action alerts and event invitations

Follow us on Social Media

Facebook and Twitter: @EveryLifeOrg and @RareAdvocates

Instagram: Rare_advocates

Linkedin: EveryLife Foundation

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