



Changing Policy, Saving Lives

#EveryLifeMatters



# The Power of Patient Advocacy



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# 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.



YEARS OF  
CHANGING POLICY,  
SAVING LIVES

## EVERYLIFE MILESTONES



The EveryLife Foundation established by Dr. Emil Kakkis



Foundation helped establish Rare Disease Congressional Caucus



First Lobby Day held in Washington, D.C.

Food and Drug Administration Safety and Innovation Act (FDASIA) signed into law



First RDLA Rare Disease Week on Capitol Hill in Washington, D.C.



The OPEN ACT introduced by Congress



COMMUNITY CONGRESS  
Community Congress program created

California unanimously passed newborn screening legislation SB1095



21st Century Cures Act signed into law



Rare on the Road launched in partnership with Global Genes

Florida unanimously passed newborn screening legislation SB1124

The Rare Disease California Caucus established

Mark Dant elected EveryLife Foundation Board Chair

FDA announced restructuring plan for the way its Office of New Drugs evaluates new medicines

Young Adult Representatives of RDLA (YARR) launched



New headquarters and shared office space opened at the RareHub in Washington, D.C.

Newborn Screening Bootcamp in partnership with Baby's First Test held in Chicago, IL

2019

*No Disease Is Too Rare to Deserve Treatment*

# 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*





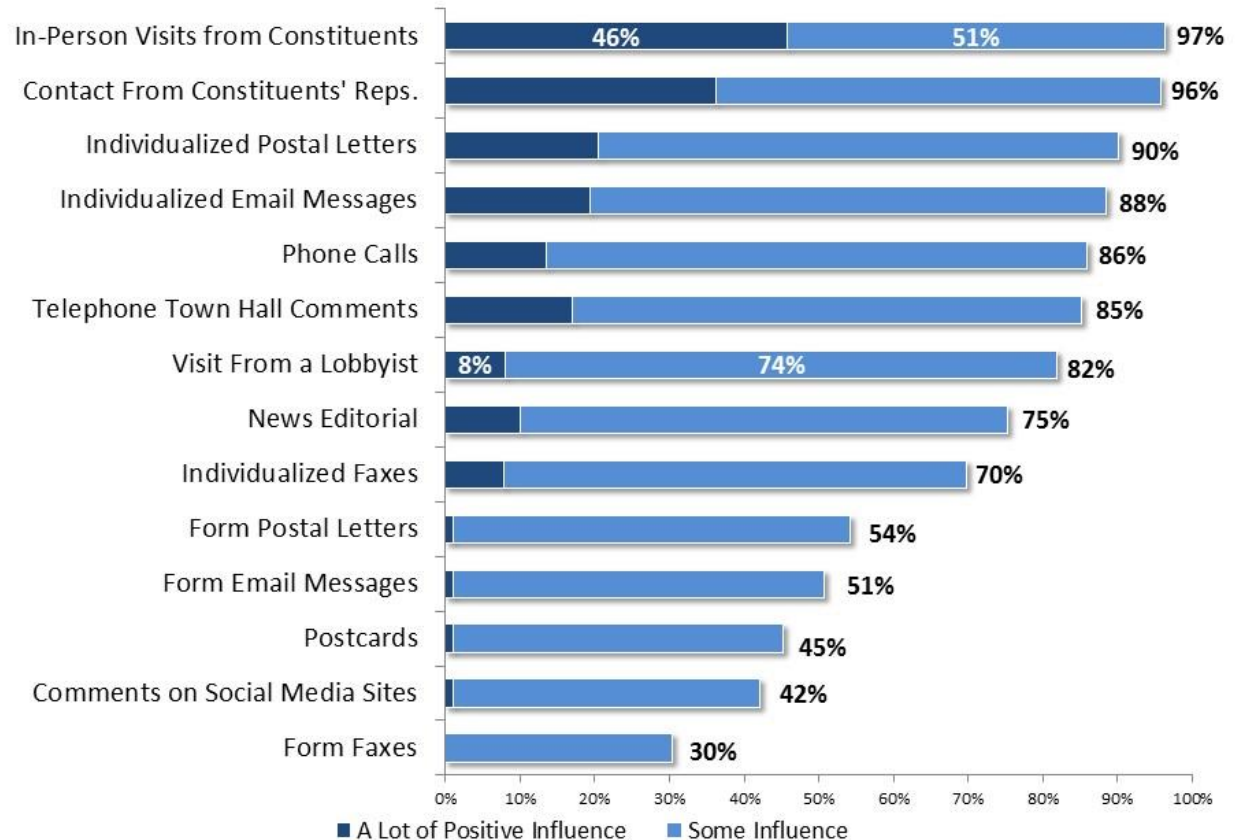
# Your Advocacy Matters!

Your legislators want to hear from you!

- ❑ You are the constituent
- ❑ You are the expert!

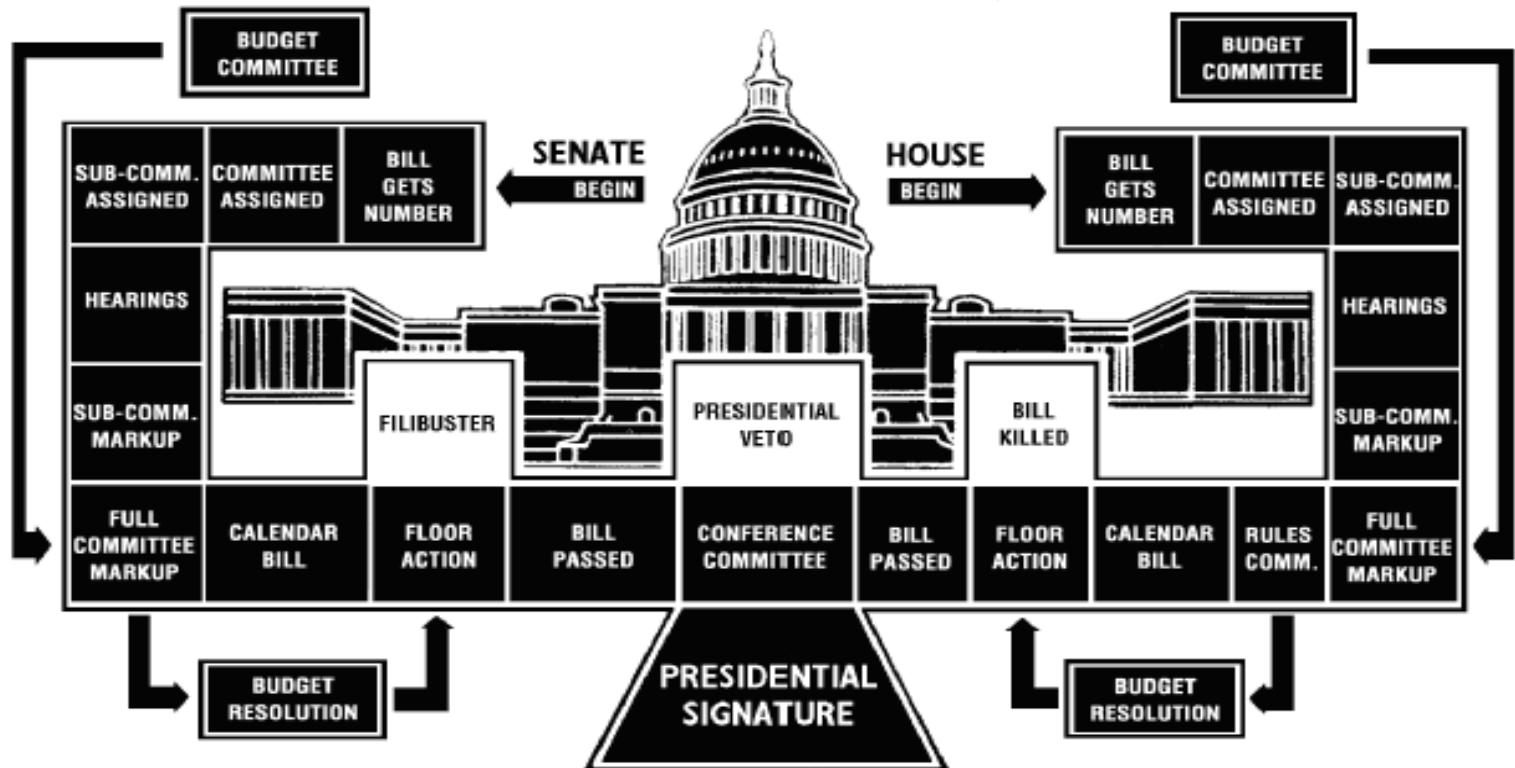


# Why Relationships Matter



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

# 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



*No Disease Is Too Rare to Deserve Treatment*





# 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

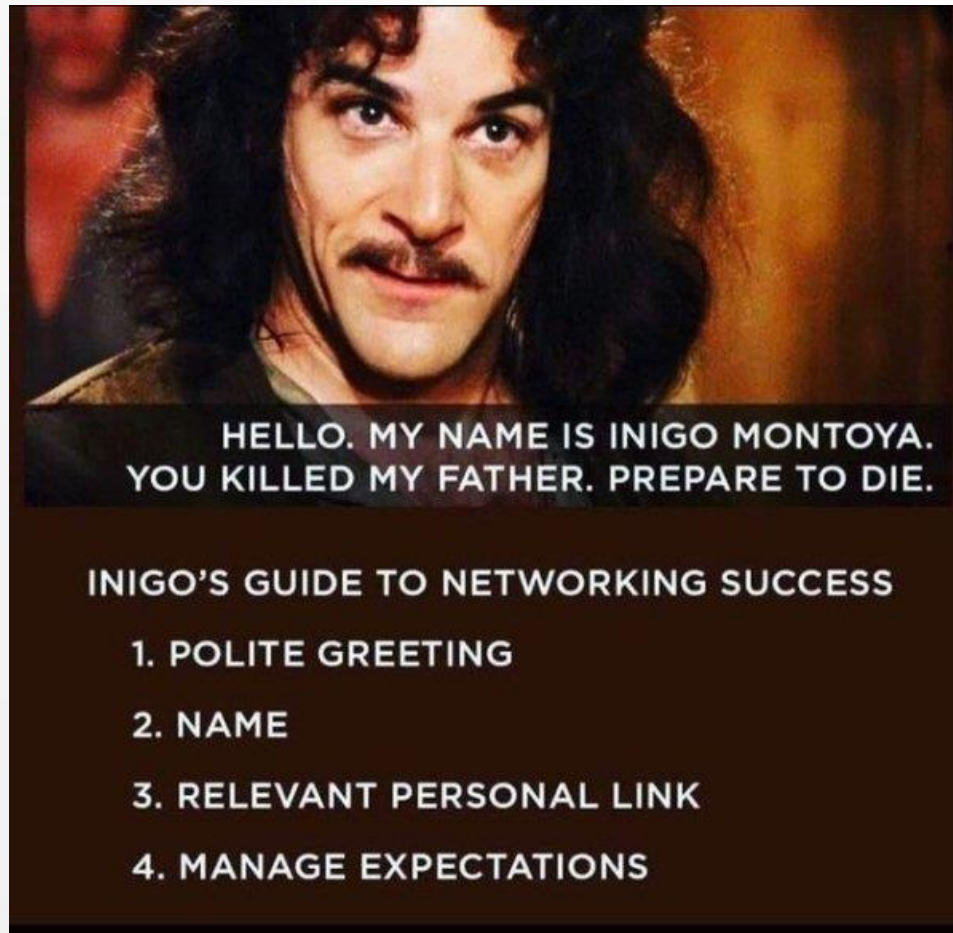


## Three Parts:

- Introductions
- Share Your Story
- Make the “Ask”



# Telling Your Story: Practice Makes Perfect



# 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?

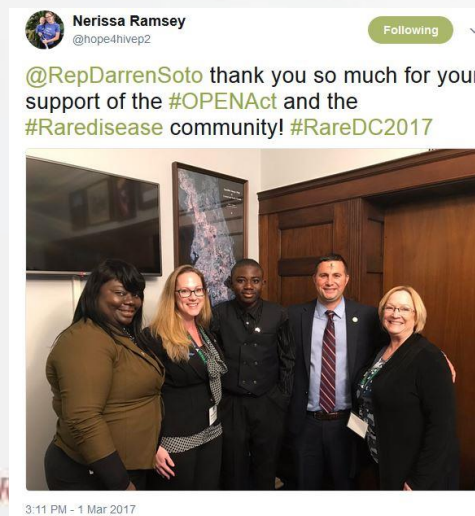


- The goal is to get your Member of Congress/legislator to take action on your priority
- Make sure that your request is clearly articulated and actionable by the legislator
- Be specific: e.g. “Please co-sponsor Senate bill 2158”

# 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 I 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



**RARE**  
ACROSS AMERICA

**RARE**  
DISEASE WEEK  
ON CAPITOL HILL

# 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](http://RareAdvocates.org).

A screenshot of the RDLA website's "TAKE ACTION" page. The page has a dark blue header with the RDLA logo and navigation links: ABOUT, TAKE ACTION, NEWS, CAUCUS, EVENTS, RESOURCES. The main content area is titled "TAKE ACTION" and features three white cards on a background of raised hands. The first card is titled "Energy and Commerce Committee Chairman's Open Letter to Advocates on #CuresNow" with a date of August 30, 2016. The second card is titled "Take Part in the Rally for Medical Research!" with a date of August 16, 2016. The third card is titled "Ask Congress to Fund More Childhood Cancer Research" with a date of July 29, 2016. Each card includes a "Read more" link with a right-pointing arrow.



**FOLLOW US**

Enter your email address below to receive news, action alerts, and invitations.

Join

*No Disease Is Too Rare to Deserve Treatment*

# 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

**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!**

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# Rare Disease Week on Capitol Hill 2020

**RARE**  
DISEASE WEEK  
ON CAPITOL HILL

**When:** February 25<sup>th</sup> through February 28<sup>th</sup>

**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.



*No Disease Is Too Rare to Deserve Treatment*

# Goals of Rare Across America

**RARE**  
ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS



- 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](#)

Patient Programs: Lindsey Cundiff  
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