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# 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
- How to Start
- Ways to Get More Involved in Advocacy



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# EveryLife Foundation for Rare Diseases

## Because Every Life Matters

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.



*“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.”*

— Julia Jenkins, Executive Director



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# What we believe

- No disease is too rare to deserve treatment.
- Rare disease therapies should be safe and effective.
- We could do more with the science we already have.



# Foundation Policy Goals



- Close the innovation gap for the 93% of rare diseases that have no FDA-approved treatment.
- Eliminate the diagnostic odyssey for rare disease patients.
- Improve the regulatory process and advance regulatory science for rare disease therapies.
- Ensure equitable patient access to safe and efficacious therapies and cures at the earliest moment possible.
- Empower patient to develop an impactful voice in policymaking, drug development, and regulatory decision-making.



# 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.

# *Rare Disease isn't so rare after all*



**7,000+**  
rare diseases

**30+**  
million  
affected

Estimated  
prevalence of 379 RDs  
**15.5 million**

**6.3**  
**YEARS**

Navigating without  
RD diagnosis  
(mean)

**16.9**

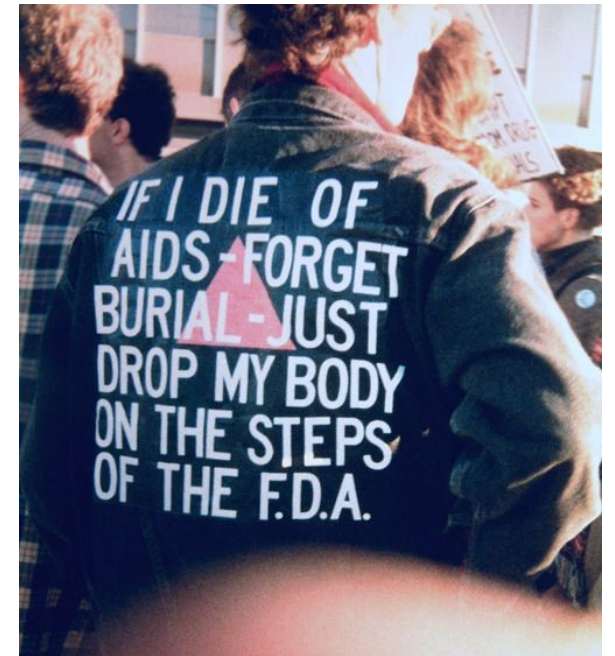
Average number of  
specialists seen since  
first RD symptom

Based on final analysis sample of 1,360 completed survey responses

*The National Economic  
Burden of Rare Disease Study*



# What we can learn from the AIDS movement



# What we can learn from the AIDS movement

- HIV drug development example
- AIDS activists stormed FDA in late 80's
- 1992: FDA forced to create “Accelerated Approval”
  - New regulations allow use of a surrogate or biomarker to determine if the drug is effective
  - If the surrogate is “reasonably likely to predict clinical benefit”
  - Reduces the time and cost of development
- Biggest surge ever in innovation
  - 25 drugs in 15 years period after regulation change in 1992
  - All approved under Subpart H Accelerated Approval





# Why do you advocate?

- **Advocate** for yourself, a loved one, a community, etc.
- **Advocate** to educate lawmakers and/or to solve a problem.
- **Advocate** because legislation & public policy impact healthcare for you and your loved ones.
  - Close the gap for the 93% of rare diseases with no FDA approved treatment.
  - Eliminate the diagnostic odyssey.
  - Improve the regulatory process and advance regulatory science for treatments.
  - Access to safe and efficacious therapies as soon as possible.



# The Power of Grassroots Advocacy

You have the **POWER** to effect change!

- Take an active role in the political process
- Influence legislation & policy
- Speak up
- Tell your story
- You are your best advocate



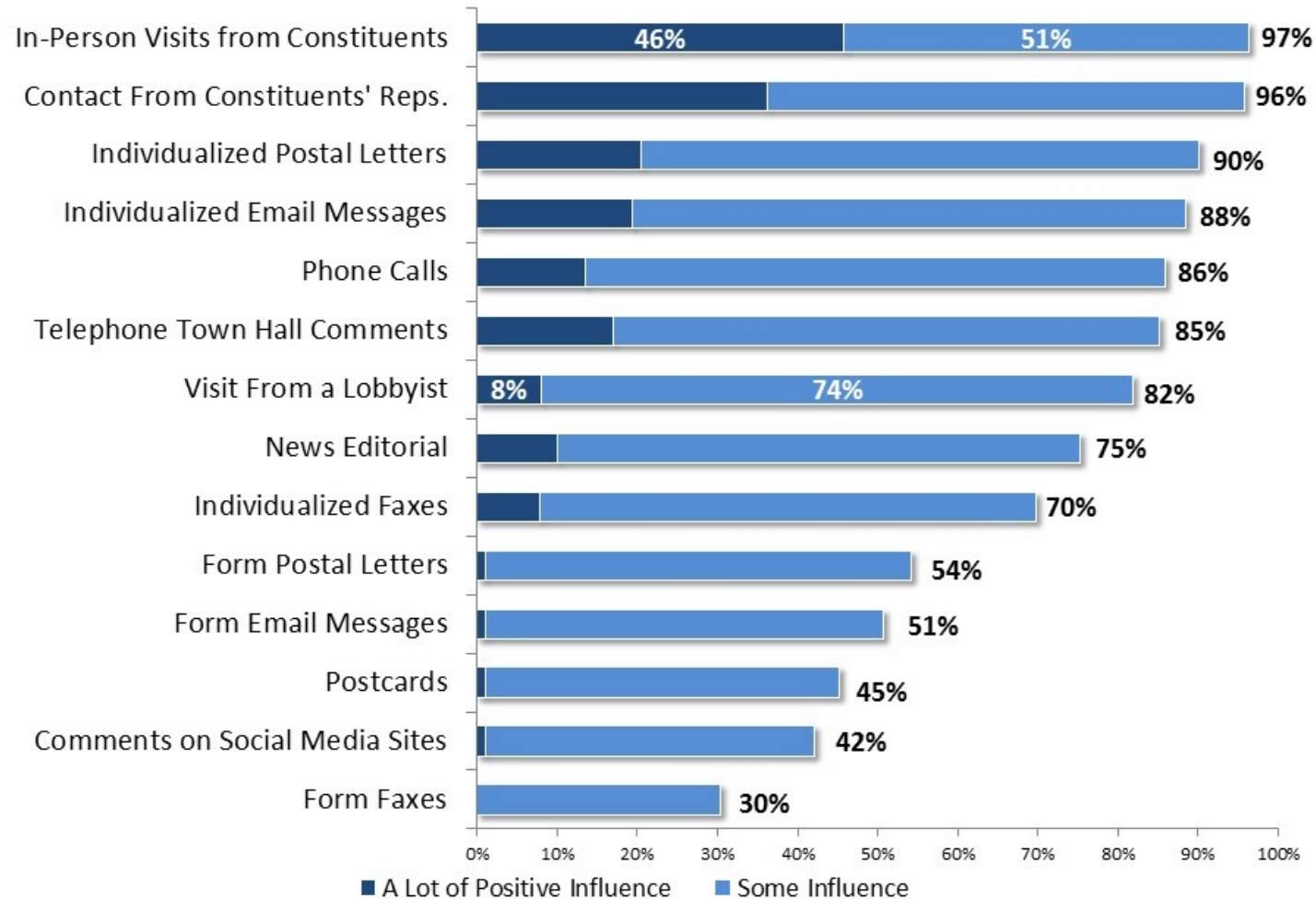


# Your legislators want to hear from YOU!

- YOU are the constituent
- YOU are the expert on your rare disease and experience

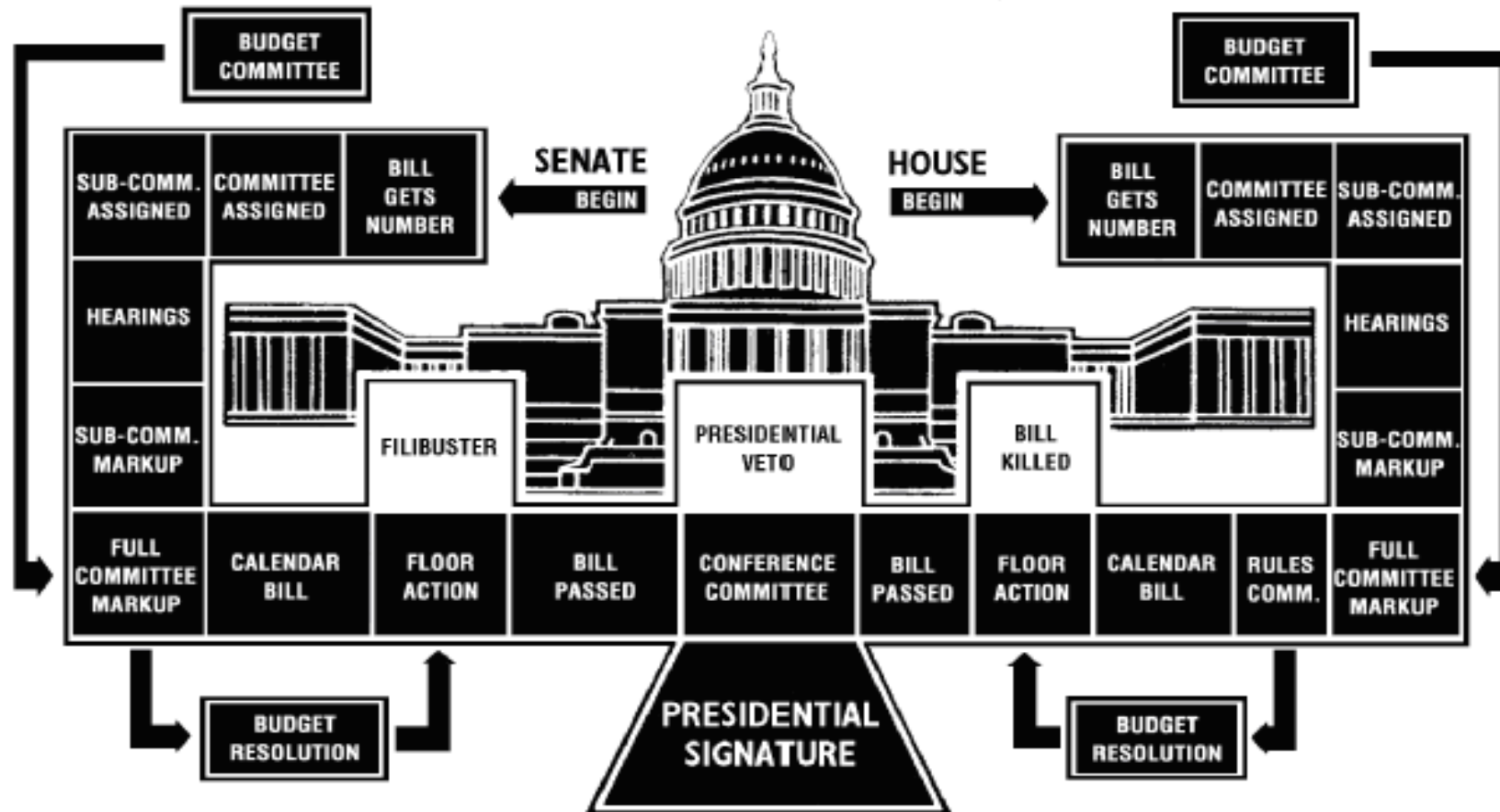


# Why Relationships Matter



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

# Your Roadmap to Change



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# How do you advocate?



- Create relationships with your state and federal legislators
- Share your story with a policy ask
- Ask questions
- Engage with organizations to support you
- Support others with their policy goals when they align
- Activate your own network! You have one!

# How to get started: What is your goal?

Determine your goal for advocacy.

- Is there a problem you need solved?
  - Insurance coverage of a treatment, needing an FDA-approved treatment, needing a diagnosis, funding for research, etc.
- Awareness for your rare disease
- Education about your rare disease



# How to get started: Engage with your legislators

- Governor and state legislators
- Your federal Representatives and Senators
- Members of the Committee of Jurisdiction
- Leadership (Majority/Minority leaders)
- Government Agencies
- State and Local Representatives



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

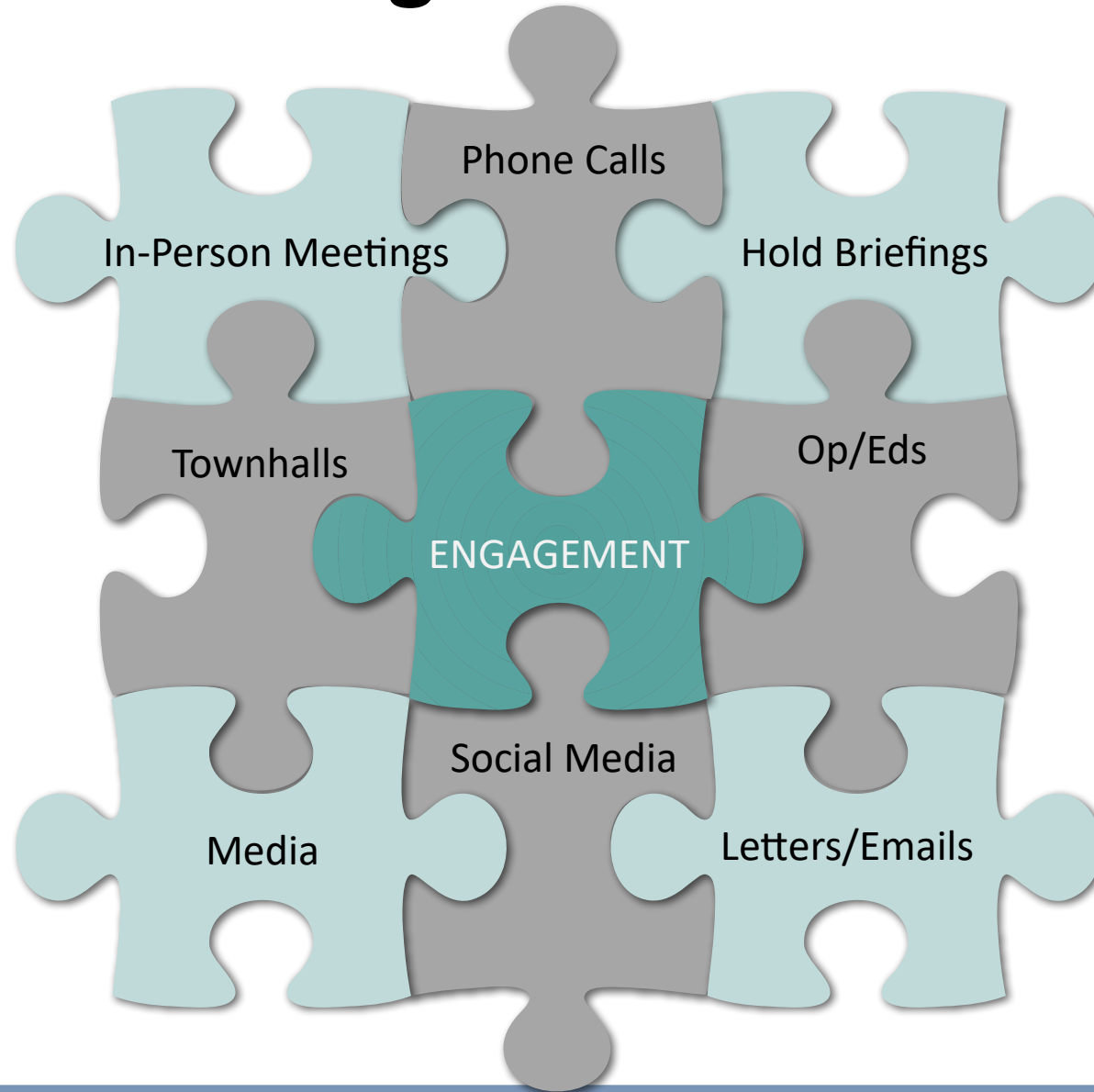


# How to get started: When to Engage

- Build relationships with your legislators.
- **ANYTIME and 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's too late. Be vocal early about the issues you care about



# How to get started: Tactics



No matter how  
you engage,  
**make it  
personal!**

“



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# 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 at the meeting





# Follow Up and Grow Relationships with your Legislators

## Effective Advocacy = PERSISTENCE

- **Thank** the Member and staffer after a meeting.
- **Follow up** after a meeting.
- **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.**

# Want to Advocate?

Sign up for monthly newsletters, action alerts, and invitations to the monthly webinars and other FREE events at  
**RareAdvocates.org**



**Foster a Relationship with Your Member of Congress**

**TIP SHEET**

Building relationships with your Members of Congress is important to ensuring that rare disease patients are heard on Capitol Hill and policymakers are working to improve the lives of patients with rare diseases.

Members of Congress are more responsive to their constituents and more likely to support a policy proposal when they hear directly from people who live in their district.

To build a relationship with your Member of Congress, you can:

- Schedule a meeting with your Member in the District office or on Capitol Hill.
- Get to know the key staff who handle health care policy in the district and in Washington, DC.
- 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.
- Volunteer for a candidate's campaign activities.
- Engage with legislators on social media.
- Write letters or emails to your legislators.
- Write op-eds for your local newspapers, and
- Send "thank you" messages (call, email, letter, social media) when your legislators support rare disease issues.

**When should I engage with my Representative and Senators?**

Anytime and all the time! Start out slowly, with one or two different activities. As issues arise, engage with your legislators on those issues. Pay attention to the issues you care about most.

As a bill progresses through Congress (committee, House vote, Senate vote, conference committee, etc.), let your legislators know about your position on the issue. Don't wait until it's too late to voice your support or concerns on legislation you care about.

**How do I connect with my legislator?**

- Find personal connections you have in common? As a constituent, you are from the same state and area as your legislator. You may live in the same neighborhood, go to the same school, etc.
- Research the issues that are important to your legislator (check out their website and press releases).
- Research the legislation that the legislator has supported (check out their website and press releases).

**TIP** > Staff are an amazing resource and Members of Congress rely on them to advise them on issues that affect their district and constituents.

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, broadly, and openly for the patient voice to be heard by local, state and federal policy makers. For additional assistance with creating a state rare disease council, contact Shannon van Patten, RDLA Program Director, at [vanpatten@everylifefoundation.org](mailto:vanpatten@everylifefoundation.org).

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**THE RDLA IS YOUR ADVOCACY PARTNER!**

We provide free resources, tools and events for patients, caregivers and organizations.



**#EveryVoiceMatters**

**Every Voice Matters.**

Welcome! Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDLA believes that every voice matters and that patients are the key to changing public policy.

**TAKE ACTION**

About



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# Next Steps in Your Advocacy Journey







- Create relationships with your state and federal legislators
- Share your story with a policy ask
- Ask questions
- Engage in resourceful organizations to support you
- Support others with their policy goals when they align
- Activate your own network! You have one!

Register at [www.rareadvocates.org/rdw](http://www.rareadvocates.org/rdw)



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# Rare Disease Week on Capitol Hill 2021

*New dates, new format...same life-changing experience!*

**July 14<sup>th</sup>-July 22<sup>nd</sup>**

**Registration OPEN at [rareadvocates.org/rdw](https://rareadvocates.org/rdw)**



# Rare Disease Week on Capitol Hill 2021

## *Learning, Networking, Advocating*



July 14<sup>th</sup>

Rare Disease Caucus Briefing  
Documentary Screening

July 15<sup>th</sup> -

Legislative Conference Day 1  
Rare Artist Gallery Opens

July 16<sup>th</sup> -

Legislative Conference Day 2  
YARR Leadership Academy  
Graduation  
YARR Meet up

July 20<sup>th</sup>

Virtual Meetings with Representatives

July 21<sup>st</sup>

Virtual Meetings with Senators

July 22<sup>nd</sup> -

Diversity Roundtables

# Rare Disease Week on Capitol Hill 2021

## Advocacy + Fun= \$100,000

Advocates will have the chance to win up to \$5,000 for their favorite rare disease organization during Rare Disease Week!

- Advocates will earn points for attending events, virtual Hill meetings, and other activities.
- The **top 50 point-earners** will win between \$1,000 to \$5,000 for their organization of choice and the donation will be made by the EveryLife Foundation in their name.





# RARE ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS



## Meetings in August 2022

RareAcrossAmerica.org



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# Young Adults Advocacy

HearusYARR.org

@hearusyarr



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# RAREARTIST

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SHARE YOUR RARE THROUGH ART  
Enter now through July 16, 2021  
Visit [RareArtist.org](https://RareArtist.org)

*Finalists are awarded with individualized advocacy coaching. Awardees receive coaching, a cash prize of \$500, and an opportunity to come to Washington, DC to display their artwork at the Rare Artist Reception during Rare Disease Week on Capitol Hill 2022.*

*Email [rareartist@everylifefoundation.org](mailto:rareartist@everylifefoundation.org) for more information.*





# Keep in Touch

Sign-up for our newsletter, action alerts, and event invitations at **[www.rareadvocates.org](http://www.rareadvocates.org)**

Follow us on Social Media

Facebook & Twitter: **@EveryLifeOrg** and **@RareAdvocates**

Instagram: **Rare\_advocates**

LinkedIn: **EveryLife Foundation**

Policy: Annie Kennedy (**[akennedy@everylifefoundation.org](mailto:akennedy@everylifefoundation.org)**)

RDLA: Shannon von Felden (**[svonfelden@everylifefoundation.org](mailto:svonfelden@everylifefoundation.org)**)

State Advocacy: Swapna Kakani (**[skakani@everylifefoundation.org](mailto:skakani@everylifefoundation.org)**)

Patient Engagement: Lindsey Cundiff (**[lcundiff@everylifefoundation.org](mailto:lcundiff@everylifefoundation.org)**)

