



2023

For Rare Disease Patient
Communities

GUIDE TO YOUTH, TEEN & KID HILL DAY



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Sati Cooper-McCann
young advocate

Our Why

By actively engaging in rare disease legislative advocacy, young people can contribute to meaningful and positive change, foster inclusivity, and ensure that the needs of those affected by rare diseases are recognized and prioritized by policymakers and decision makers.

Here are a few reasons to underscore the role that youth can play in patient advocacy hill days:

Amplify Youth Voices: By participating in legislative advocacy, young people can help amplify the voices of those affected by rare diseases, and draw attention to the challenges they experience while advocating for policies that address their needs.

Empower Youth to Be Involved in Patient Advocacy: Youth involvement empowers rare disease patients and their families to become more active and effective advocates for their own needs. By engaging in legislative initiatives, young people can learn about policy processes, participate in dialogue with lawmakers, and gain vital skills to navigate healthcare systems, ultimately becoming strong advocates for themselves and their communities.

Drive Policy Change: Legislative advocacy can lead to policy changes that have a direct impact on the lives of individuals with rare diseases. Young people bring fresh perspectives and energy to these initiatives, which can help drive innovation, foster collaboration among stakeholders, and shape policies that improve research, diagnosis, treatment, and support systems for rare diseases.

Youth perspectives offer significant value in rare disease advocacy, especially when working with and communicating needs to decision makers.



Lisa Facciolla
HAE Advocate
Community Engagement Specialist

Message From Our Contributors

It is estimated that more than 30 million Americans are living with one or more rare diseases, the majority of which are diagnosed in childhood. While scientific innovation offers much promise, still more than 93% of the estimated 10,000 known rare diseases have no FDA-approved therapy. Yet, improvements in diagnostics, clinical care, and therapeutic interventions are transforming pediatric rare diseases into 'pediatric-onset' rare diseases and young adults are thriving decades into adulthood.

However, significant gaps remain as resources to support the transition to adulthood is often overlooked, leaving individuals feeling alone or isolated. The rare disease community relies on the resources available to them to help navigate benefit eligibility, the healthcare system, securing and managing caregivers, mental and emotional support, advocacy opportunities, and the general day-to-day challenges that may arise.

Although many resources exist, opportunities for cross-collaboration are limited.

The Young Adult Rare Coalition serves as a platform for organization awareness, collaboration and problem-solving so that we can all better support young adults with rare diseases.

There are many organizations within the Coalition who support the advocacy efforts of the younger demographic have also hosted a Hill Day, specific for Youth, Teens & Kids. We have had other patient groups in the space ask for tips and best practices, so we collectively decided to create a guide in the hopes of sharing what we have already learned. Enjoy!

Sincerely,
YA Rare Coalition Members



Through the HAEA's Capitol Hill Day and Youth Advocacy Trainings I've learned that advocacy plays a vital role when you are diagnosed with an ultra-rare disease. When I look back at my past, I see this 14-year old girl who didn't want anyone to know about her disease. Now, I see myself as a person who wants to advocate on behalf of my community.



Jasmeen A.
HAEA Youth Advocacy Network
Regional Leader

Defining a Legislative Purpose

Establish what goals are most important to your rare disease community

Establishing a legislative purpose is key to a successful event and ensuring that you reach your goals in a measurable and attainable way.

Is the purpose of hosting a Hill Day to educate your younger community on how the legislative process works (**Educational**)? Is there a Bill that is impactful to your community that needs legislator support (**Legislative**)? Are you trying to raise awareness for your rare disease group and build relationships with Legislators (**Relationship**)?

It's important to keep in mind that younger groups tend to oversimplify and glorify what their dream goals are (i.e. save the world, make all sidewalks accessible, etc). Level-setting is important for the self worth of each participant.

Educational

- How a bill becomes a law
- Legislative chambers
- Federal versus State
- Senators, Representatives and Committees

Legislative

- Assess the impact of a policy issue for your specific community
- How to look up the status of a Bill
- Create a one-pager for your Legislative Ask

Relationship

- For advocates who want to focus on building a relationship with their Legislators
- Research your Legislator & Staffers
- Strategy for key Legislator meetings depending on committee

Budget & Establishing Partnerships

Getting started:

- Be realistic. What is your organization able to support?
- Is there a way to leverage any of your partnerships in a way that is financially beneficial for both parties?
- Are you able to outsource or apply for grants to cover some of the budgetary items?
- Are you able to provide travel stipends to community members in need?

Sample Budget

Youth & Teen Virtual Hill Day 2023

Advocacy Associates	\$15,000
Health Literacy	\$3,000
Graphic Design	\$1,500
Supplies	\$1,500
Printing	\$500
Social Ads	\$100

**Budgets will vary depending on the organization's financial resources.

Overview

60

Participants

\$21,600

Total Estimate

Ways to save on a limited budget

If taking more of a DIY approach, there are ways to get creative or do most of the heavy lifting yourself.

- **Scheduling meetings with legislative offices yourself** - it is highly recommended to outsource and hire a company like Advocacy Associates or the Health and Medicine Council of Washington, DC to schedule all your legislative meetings but if you are working with a limited budget, it is possible to schedule them on your own. Scheduling visits on your own is also a good option if you have a smaller group.
- **In-house graphics** - do you have a skilled staff member or volunteer that could create website banners, one-pagers, or marketing material?
- **Supplies** - consider including a small budget for give-aways, training materials, certificates of completion. These are nice to include but not must haves.

Other Budget Considerations

- Will your event be virtual or will you and your community be flying in?
- If you plan to bring young advocates to Washington, DC, it's important to consider whether you are able to include travel stipends in your budget. And remember, if your younger advocates are under 18, they may need to travel with an adult guardian, and that guardian may also need travel assistance.
- Are grants available to assist in funding your event? If so, prepare to apply for grants early in your planning process, as they can often take time to review and hear back.
- Are there sponsorships to help cover the cost? Are there stakeholders who will work with you on your initiatives in lieu of a financial contribution? What partnerships could help assist with bringing the cost down?
- Are there other rare disease groups you would like to collaborate with that have the same goals and could help to offset costs?



Pros & Cons of working with a company who schedules the meetings for you

Pros

- **Less logistics to handle** - alleviating the scheduling will save a ton of time and mental bandwidth. Companies not only handle the initial meeting scheduling, but all cancellations and rescheduling. Depending on your legislative asks, they are also able to provide templates for follow up communications and easy to follow guides to ensuring each office has the materials they need to support your bill.
- **Meeting Apps** - many companies offer an app that is included in their package. This creates an accessible line of communication for the day of and makes it easy to look up legislator information, such as what committees a member is on or what issues they care about.
- **Established relationships** - companies already have relationships with legislative offices, which can help with the scheduling process and other needs.
- **Assistance with training** - many companies will offer a presentation to your advocates in any preparatory trainings or webinars.

Cons

- Working with professional advocacy groups will add to your budget. This is important to consider.

Create an Agenda

Establish what goals are doable for the day of the event

- It's good to think about young people's attention span, and bandwidth for a full day on the Hill! It can be a long day.
- Do you want to host an educational component (in-person or virtual) leading up to the actual day or meetup on the day of your meetings?
- Will you be providing support with transportation or food?

Sample Agenda

Monday	8 a.m.	Check-In/Meet & Greet
	9 a.m. - 3 p.m.	Group Photo on Capitol Steps (Wear Your Shirts)
	9 a.m. - 3 p.m.	Training Begins • Meet your fellow delegates • How to effectively share your story • How to engage with legislative representatives • What is our ask • Schedule Review
	4 p.m.	Optional Activities • Washington Memorial • A walk around the Mall
	6 p.m.	Dinner on your own
	8 p.m.	Movie Night
Tuesday	8 a.m.	Group Photo on Capitol Steps
	9 a.m. - 3 p.m.	Legislative Meetings • Schedules vary based on state and districts • Arrive with your group 15 minutes early
	4 p.m.	Post Advocacy Meeting • How will you continue your advocacy when you get home?
	5 p.m.	Attendees Travel Home

Develop Educational Materials & Trainings



Three key steps to creating a meaningful educational experience:

- Provide basics of how legislation works
- Create engaging and supportive trainings
- Offer age-appropriate materials

CONSIDER THIS: How will you ensure that the materials are age appropriate and comprehensive to a younger age demographic?



Inspire

In your pre-event communications emphasize the importance of youth involvement in legislative advocacy. Discuss the value that young people bring to conversations during hill days to encourage participation.



Make it Simple

Develop age-appropriate materials and resources to help youth learn about government structure and legislative processes, how to structure effective communication, and the issues they will be advocating for.



Engage

Keep your attendees engaged by creating interactive learning activities that enhance their understanding of the issues and how individuals are impacted.



Support

Schedule training webinars to discuss current issues and what to expect during visits. Offer office hours or one on one catch ups for young people seeking to better understand how they can make an impact.

Develop Educational Materials & Trainings



Jordan Howard
YARR Leadership
Academy Graduate &
Hemophilia Advocate

CONSIDER THIS: How can you create opportunities and activities where learning about the legislative process is engaging and age appropriate?



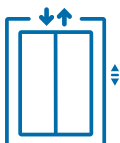
Fun Educational Activities

Mock meetings and role play anyone?



Accountability

Hold your attendees accountable by checking in with them to review progress on at home assignments and answer any questions that they might have.



Elevator Pitch

Offer a workshop or resource to help guide attendees in crafting a short, concise, and relevant personal story to share during their meetings. This is also known as a “elevator pitch”.



Practice

Consider offering time for them to practice with each other before their actual meetings on the Hill.

Planning for logistics

Taking care of the details - Things to consider

In addition to the traditional logistics (food and beverage, supplies, general event planning), it's important to understand the additional needs of holding an even for young people who may have never traveled before or need additional assistance.

Organizational

- Proper number of volunteers and staff chaperones
- Registration and Travel Booking Assistance
- Support assistance for accessibility needs

Liability

- Parental Permissions
- Alcohol policies
- Curfew and other policies depending on ages
- Photo release waivers

Experience

- Host training with hotel to discuss unique needs of your group
- Activities are easy to navigate to and from
- How should advocates dress and behave

Code of conduct

As the organizing organization, it is your responsibility to ensure the attendees are being safe and are also representing the community in the best way possible. Codes of conduct help establish expectations to the community members. These guidelines then need to be followed through with the logistical planning.



How do you want the community to best represent themselves and your organization?



What happens after hours if staying overnight in a hotel, especially with mixed ages.



What are the consequences and what will happen if rules are broken?

Promotion

How to inspire action

Advocacy can't happen if people don't know about it. It's crucial to plan for pre-event, during event and post event promotion to continue to engage your community.

Pre-Event

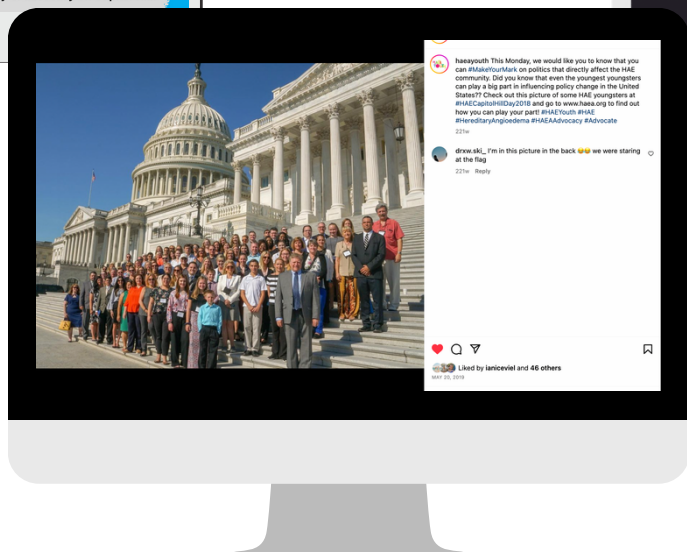
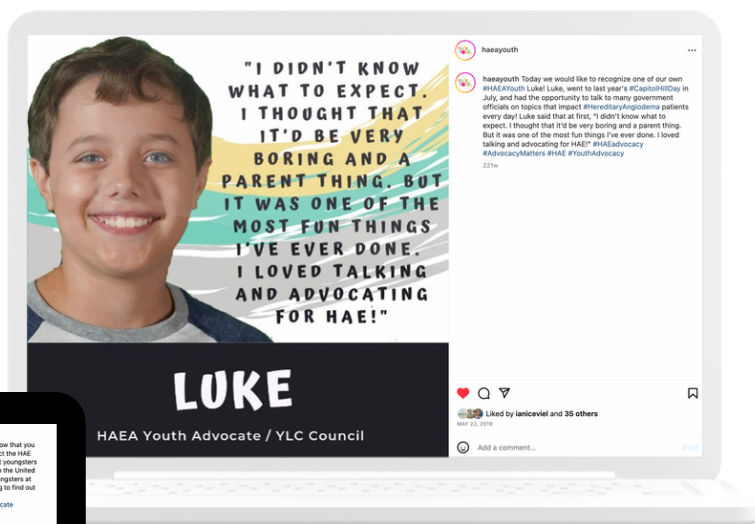
- Who are your target audiences? (youth, parents, sponsors, volunteers)
- How will messages differ based on audiences?
- How will you encourage involvement and registration?

During Event

- Professional group photo scheduled on Capitol steps
- Create challenges or contests to take photos throughout the day for a prize.
- Create a hashtag to help track online posts from advocates

Post Event

- Create an online photo album with all pictures
- Continually report or post about event successes
- Promote any future ways to get involved and advocate



Next Steps

How to Execute Your Hill Day



☐ 01

Follow the Agenda!

Keep on time and follow the schedule you have outlined for the community.

☐ 02

Remember your Goals

Stick to your goals and be sure to provide plenty of space for the kids/youth to ask questions.

☐ 03

Time Management

Be realistic about time needed to navigate to different meetings and other logistics that come up for rare disease patient community.

☐ 04

Buddy System

Consider creating buddy systems or touch points for adults to be with the advocates if they are on their own.

Next Steps

How to Execute Your Hill Day

Our voices as young adults living with chronic and rare diseases are invaluable as we are the next generation of advocates that will drive change and improvement in healthcare. There must be space made among stakeholders to allow for our perspectives and experiences to be heard and amplified.



Ella Balasa,
Meet-up Facilitator,
Our Odyssey

☐ 05

Leave Behinds

What to bring or ask attendees to bring? Printed information about their condition to leave the office, printed information about the legislative asks...etc. .

☐ 06

Self Care

Did your group eat breakfast? Does everyone know where to eat lunch? Are there rules about bringing water into Capitol Hill you should remind folks about? Do people have comfortable shoes?

☐ 07

Accessibility

Map out the accessible entrances and elevators. Ensure you have checked what the latest is with security on the Hill and prep folks what to say to security if a mobility modification is needed.

☐ 08

Emergency

Have a plan in place for if a health emergency or environment crisis takes place. Perhaps a general meeting place or who to notify if a health crisis occurs.

What comes after the Hill Day?

Hill Days don't end when attendees go home. To keep attendees engaged year-round and to continue momentum of their hard work, it's imperative for young people to understand what they can do after the event comes to a close. Encourage attendees to reach out to their local offices and schedule follow-up meetings in their hometown to discuss hot topics, send follow-up letters, host a celebration and recognition of achievement, and more!

- Will you be providing template emails or social media example posts after the event?
- How will you encourage the kids/youth to continue the conversation?
- Should they thank their members and build a relationship with their legislators after the meetings?



Provide follow-up opportunities

Social Media

- Legislators love to be recognized publically. Provide a format for public Thank you's.
- Provide instructions on how/when to ask for a photo or screenshot (hint, at the end)
- Ask for photo permission ahead of the event in your registration, so the organization can also post advocates on social media

Follow up on Bills

- Provide a template email
- If you hired a scheduling company, they can help with the template email and automatic email addresses
- Provide guidance on how they can all stay in touch with their local legislators.

Celebrate

- Will there be a post-meet up the day off?
- Consider an award show or a certificate of completion
- Not all bills will cross the finish line, so it's important to create another sense of positive completion

Seek Feedback

So how did we do?

You will most likely need feedback in order to gauge if goals were met, information was shared effectively. A feedback surgery can help to gather testimonials for promotion for future events or a communication recap, and provide insight into the patient experience to future donors.

- After the event takes place, how will you solicit feedback from the participants on their experiences? Survey? Focus group?
- Ask them to reflect via video or writing, so you can use it for future advocacy? You can use these to showcase the event success to key stakeholders.
- You can use these responses as a way to locate potential future leaders in your organization based on their answers.



FEEDBACK SURVEY

Thank you for participating in our advocacy day at the Capitol!
Please think about your experiences to help us improve this important initiative.

Tatiana, HDYO Ambassador
Lauren, HDYO Board Member
Anne Elizabeth, HDYO Ambassador

NO	STATEMENT	AGREE	DISAGREE
1	Pre-event training helped prepare you for your legislative meeting.		
2	Guidance for legislative ask was meaningful and easy to understand.		
3	The event schedule was the right amount of fun, education and advocacy.		
4	I would attend this event again.		

A message from us to you...

Young people's involvement in rare disease legislative advocacy is not just an act of compassion; it's a powerful force driving research, innovation, and policy change to create a world where hope conquers the rarest challenges, one voice at a time. Their dedication serves as a testament to the belief that together, we can transform the lives of those battling these often overlooked conditions, proving that no disease is too rare to merit our collective effort and support.

We hope that you found this guide useful in your advocacy journey. Remember that the Young Adult Rare Coalition is always available to offer support along the way.



Our vision for youth involvement in rare disease legislative advocacy is to inspire a generation of empathetic change-makers who lead the way in advancing policies that prioritize the needs of those facing rare diseases. Through their unwavering dedication, these young leaders have the power to light the path towards a society where no one is left behind due to the rarity of their disease, creating a legacy of compassion and progress for generations to come.”

-Young Adult Rare Coalition



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Megwyn Sanders-Andrews, Executive Director, Our Odyssey

We thank you for your continued support in our efforts to support the next generation of rare disease advocates.



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