Caroline Arnette
Youth Ambassador and Rare Disease Advocate

Stephanie Fischer
Member, Rare Advocacy Movement

Tori Williams
Youth Ambassador
OPPORTUNITIES FROM CAROLINE’S DOCTOR

• MoreThanTired.com information videos - The Burden of Pediatric Narcolepsy

“If she laughed, she looked exactly like a marionette with the strings cut.”
Watch Caroline and her mom explain how intrusive cataplexy can be.
Not all patients with cataplexy experience complete collapse.

“I couldn’t move, and I would start to hyperventilate.”
Watch Caroline describe her sleep paralysis and hypnopompic hallucinations.
• The goal is to raise awareness and help people seek diagnosis, not promote specific treatments

• Facebook Live event for World Narcolepsy Day viewed by 11,000 people
WHY DOES PUBLIC POLICY MATTER?

Public policy through LEGISLATION and REGULATION can help address some of the challenges faced by patients and their families as well as with the development and accessibility of new treatments.
ESTABLISH A RELATIONSHIP WITH YOUR ELECTED OFFICIALS AND THEIR STAFF

- Call, email, and meet with your U.S. Representative and Senators on a regular basis.
  - Let them know rare disease issues are important to you, and why.
  - Thank them for cosponsoring and/or voting for legislation you support.
  - Attend their town halls and other events.
- Developing a relationship with their staff is equally important.
- There are rare disease organizations to help you with this effort!
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, DC
Cost: **FREE** for advocates to attend and travel stipends are available
RARE DISEASE WEEK ON CAPITOL HILL

• **Tuesday, February 25th**
  - Rare Disease Caucus Briefing
  - Documentary Screening and Cocktail Reception

• **Wednesday, February 26th**
  - Legislative Conference
  - Young Adult Meet-Up

• **Thursday, February 27th**
  - Hill Day Breakfast
  - Hill Day on Capitol Hill
  - Rare Artist Reception

• **Friday, February 28th**
  - Rare Disease Day at the National Institutes of Health (NIH)
RARE DISEASE WEEK ON CAPITOL HILL
RARE ACROSS AMERICA
YOUNG ADULT REPRESENTATIVES OF RDLA (YARR)

• The Young Adult Representatives of Rare Disease Legislative Advocates (RDLA) are highly motivated individuals aged **16 to 30 years** from the rare disease community.

• YARR aims **to instill confidence** in the next generation of rare disease advocates and **facilitate peer support** in the transition to adult advocacy.

• **YARR is diverse** in geography and relationship to the community, as members hail from all over the United States and represent all aspects of rare disease, from patient to caregiver to sibling.

• YARR does not discriminate by race, gender, disability, religion, cognitive level, or political party.
YOUNG ADULT REPRESENTATIVES OF RDLA (YARR)

Learn more at https://everylifefoundation.org/young-adult-representatives/
Instagram: https://www.instagram.com/hearusyarr/
LinkedIn: https://www.linkedin.com/company/yarr
Facebook: https://www.facebook.com/groups/hearusyarr/
Global Genes has free RARE Toolkits on a variety of topics including:

- **Building Relationships with Your Representatives**
- **Bringing Rare Disease to Capitol Hill: Advocating for Your Cause**
- **Speak Easy: A Guide to Public Speaking** (which includes tips on media outreach and crafting an elevator speech)
- **Using Storytelling to Raise Awareness of Your Rare Disease**

https://globalgenes.org/resource-hub/
MORE RESOURCES

• Rare Disease Legislative Advocates (RDLA)
  • http://rareadvocates.org/
  • https://rareadvocates.org/rdw/
  • https://everylifefoundation.org/young-adult-representatives/
  • @RareAdvocates

• National Organization for Rare Disorders (NORD)
  • https://rarediseases.org/
  • http://rareaction.org/get-involved/join-rare-action/
  • @RareDiseases
SOCIAL MEDIA

Caroline
Advocacy for rare diseases, sleep disorder awareness, and invisible disabilities. One in ten suffer from a rare disease. You are not alone.

Followed by:
- abby_barfoot
- _hltdhun3r
- project_sleep
- 22 more
USING SOCIAL MEDIA FOR ADVOCACY

Encourage your legislators to support or oppose specific legislation, and thank them when they do. Use their official social media handles so their offices receive a notification.

Thank legislators (or their staff) for meeting with you, especially if they agree to something you requested such as supporting legislation. Take a photo to include in your post, if possible.
USING SOCIAL MEDIA FOR ADVOCACY

Use your Twitter & Facebook accounts to ask your followers to take action.

Share action alerts from organizations that you support to expand the number of people who see it and participate.
FIRST STEPS TO USE SOCIAL MEDIA FOR ADVOCACY

• Find and follow your Senators on Twitter: https://twitter.com/cspan/lists/senators/members?lang=en

• Find and follow your Representative on Twitter: https://twitter.com/cspan/lists/u-s-representatives/members?lang=en

• Check out the tips in this RDLA blogpost on using social media to engage policymakers: http://rareadvocates.org/utilizing-facebook-twitter engages-policymakers-key-part-advocacy/
QUESTIONS?