FARA | Friedreich's Ataxia Research Alliance

Congress Needs to Hear From You!

In the last few months, there have been significant funding and staffing cuts across the federal government, the impacts of which are still unknown. FARA is in contact with all stakeholders including academic researchers, industry partners, fellow patient advocacy groups, regulators and legislators, and will continue to monitor these policy changes. FARA has always encouraged the FA community to develop relationships with their elected officials, but that action is vitally important right now. Congressional members and their staff are working to represent you and your interests. They want to know how FA families are doing. By sharing your story, you can help them understand the issues that are most important to you as well as how they could avoid any unintended consequences from their decisions.

Reaching out to your elected officials is incredibly easy. First, if you don't already know who your representatives are, you can look them up here by simply putting in your address. The website will also provide you with your members' websites and contact information. Next, you can either email or call them. You can typically email a Congressional office through the "Contact" page on their website. You can also call their office using the number for their Washington D.C. office, which you can either find using the link above or through their official website. If you cannot find their office's phone number, you can call the Capitol Switchboard at 202-224-3121 and ask to be connected to their office.

Now that you know how to contact them, what do you say? Your message does not have to include any particular information or even be very long. It is most important that you reach out and start the conversation. You are the expert on FA and if you speak from the heart, they will hear your concerns. Here are some general suggestions that may help you craft your message:

- Always open with where you live and a brief history of your family's journey with FA.
- Next, tell them about the issue that you are contacting them about and how it impacts you. There are many current topics to choose from, but the following items are discussed under Capitol Hill Updates below.
  - 57% cut to CDMRP in FY25 budget
  - Impact of Budget Reconciliation Process on research or Medicaid
  - Presidential proposed FY26 budget cuts and restructuring of HHS
  - 15% cap for indirect cost in NIH grants

- Wrap up with an “ask” — tell them what you want them to do.
- It is always good to end with a thank you, for their time and service.

Capitol Hill Updates

Contact Your Representatives to Protect CDMRP Funding!

On March 15, Congress enacted legislation that drastically reduced funding for the Department of Defense Congressionally Directed Medical Research Program (CDMRP). Funding was cut by 57%, from $1.5 billion to $650 million, impacting many critical research programs, including “Hereditary Ataxia.” CDMRP has been instrumental in advancing ataxia research by recommending seventeen grants for funding in the last three years.
This research program is designed to ensure the health and well-being of the men and women who serve in the Armed Services as well as the American public. Call on Congress to restore this vital funding! You can use this link and personalize to express how meaningful the CDMRP is to you and ataxia research!

Congress Begins the Budget Reconciliation Process

Earlier this month, the U.S. House of Representatives passed a Senate budget resolution, which allowed Congress to begin the budget reconciliation process. Budget reconciliation is a special process that allows Congress to expedite legislation that would change certain aspects of the budget and spending. This process begins with a resolution that directs funding for each appropriations committee. The resolution, however, does not direct how each committee should achieve these benchmarks. Additionally, budget reconciliation is not subject to the filibuster in the Senate, which is an avenue the minority party can use to delay or block a vote by preventing debate on it from ending. The resolution would only need a simple majority vote to pass.

A budget resolution was recently passed that directed the House Energy and Commerce Committee, the committee that oversees Medicaid, biomedical research, and other critical health programs, to cut $880 billion from its budget over the next ten years. Where those funds will come from still needs to be decided.

Proposed HHS Budget Reflects Significant Restructuring and Reductions

Recently, a draft proposal of the Trump administration's FY26 budget was publicly shared. In it, the President reduces the Department of Health and Human Services' budget by approximately one-third, from $121 billion to $80 billion, with proposed cuts affecting agencies such as NIH, CDC, and rural health programs. The proposal also outlines agency consolidations and program restructuring. Once finalized, the President will send his FY26 budget to Congress who will then determine appropriations. Click here to learn more.

Senators Baldwin and Welch Hold “Cures in Crisis” Forum

FA community members represented FARA at the event. From left (back row): Katrina Hood, Dr. Bertagnolli, Catie Juip, Maureen Juip, Ron Bartek. Front row (seated): Loren Hood, Claire Juip.

On March 26, Sen. Tammy Baldwin (D-WI), ranking member of the Senate Appropriations Labor, Health and Human Services, and Education Subcommittee, which has jurisdiction over funding for the NIH, and Sen. Peter Welch (D-VT) hosted forum titled “Cures in Crisis: What Gutting NIH Research Means for Americans with Cancer, Alzheimer’s, and Other Diseases.” Senators Baldwin and Welch were joined by many Democratic senators, and witnesses included former NIH Director Monica Bertagnolli, MD, and disease researchers and patients who have benefited from NIH clinical trials. Major themes of the forum included the impacts of recent executive and agency actions on NIHsupported research. You can watch the livestream recording here.

Federal Newborn Screening Advisory Committee Disbanded

Early in April, the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) was terminated as a part of the restructuring effort at the U.S. Department of Health and Human Services (HHS). The ACHDNC is an advisory committee responsible for providing guidance to the Secretary for Health and Human Services on various aspects of the newborn screening program, including making recommendations on what conditions should be added to the Recommended Universal Screening Panel (RUSP).

In response, the EveryLife Foundation and the National Organization for Rare Diseases organized a community letter to reinstate the ACHDNC. FARA has signed onto this letter and will continue to monitor all future developments.

Federal Judge Blocks LDT Ruling

A federal judge in Texas has blocked the FDA's plan to regulate laboratory-developed tests (LDTs) like other medical devices, ruling that the agency overstepped its authority. The decision, favoring the American Clinical Laboratory Association and the Association for Molecular Pathology, vacates the FDA's rule entirely, maintaining LDT oversight fell under a separate certification framework called CLIA instead. Click here for more information.

NIH Grants and Indirect Costs

On February 7, 2025, the NIH capped indirect costs for all grants at 15% through a notice titled "Supplemental Guidance to the 2024 NIH Grants Policy Statement: Indirect Cost Rates." Previously, indirect costs were negotiated, with an average of 27%. **Direct costs** include things specific to the study, such as faculty and postdoctoral salaries and equipment bought for that specific study, while **indirect costs** include all of the other important things that keep labs running (i.e. administrative and clerical staff salaries, equipment shared with other labs, building upkeep and utilities, etc.). Without the anticipated funding for indirect costs, labs are left financially insecure.

NIH grants are a significant source of funding for FA research and ensuring that indirect costs are adequately funded is critical to ensuring that this important research continues. To date, NIH grants have led to 2,856 research projects, 1,567 peer-reviewed articles, and 9 clinical studies on Hereditary Ataxia. By typing "hereditary ataxia" into the search box on this website, you can show legislators the impact of NIH funding on the FA community!

Upcoming Advocacy Events

New Jersey State Advocacy Day

Join the EveryLife Foundation in Trenton, New Jersey on **Monday, June 2** to advocate for rare disease issues at the state level! This event will consist of a brief training session, where you'll get to hear about a number of state-level policies impacting the rare disease communities, followed by meetings with your state legislators.

If you're interested in attending this event, visit the EveryLife Foundation website for more information and to register.

Register Now

Join EveryLife for Their Virtual Youth & Teen Advocacy Day!

Are you between 10 and 18 years old? Want to speak up for kids with rare diseases and meet others like you? Learn how to tell your story, connect with new friends, and become a voice for change. This is your chance to make a difference right from home! Don't miss out, sign up today!

The RDLA Virtual Youth & Teen Advocacy Day is your chance to connect directly with your U.S. Representative and Senators, share your story, make an impact, and get the tools you need during our prep sessions. You'll learn effective communication strategies with lawmakers and learn essential policies that affect the rare disease community. Invite your friends and start making a difference today!

Registration closes on May 23! Click here to register or learn more!

Register Now

Register to Participate in Rare Across America!

Rare Across America 2025 is an opportunity to meet with your Members of Congress in their district offices and educate them on the issues that are most important to the rare community. During Rare Across America, advocates have the opportunity to meet with their Representatives in-person at their district office and meet with their Senators virtually via Zoom. The event is flexible. So, you're welcome to attend just the virtual meetings, just the in-person meeting, or all of the meetings. Additionally, no prior advocacy experience is necessary. There will be training webinars beforehand to help you get familiar with the legislative asks, and you will have a team lead to help organize meetings and guide you through the process.

Registration opens on May 12! If you're interested in participating, you can find more information on the EveryLife Foundation website.

Announcements

FARA Hosts Advocacy Webinar

On Thursday, April 3 the FARA Advocacy team hosted a webinar titled "Let's Talk About the Power of Advocacy for FA Research" as part of the Community Conversations series. The webinar, featuring a number of FARA staff members and guest speakers, provided updates on FARA's advocacy initiatives as well as highlighted what other patient organizations across the globe are doing to advance FA research.

If you missed it, don't worry! You can find the recording of the webinar on the FARA YouTube and a helpful resource on policy issues the FARA team is tracking here.

FARA President speaks at World Orphan Drug Congress

FARA President and co-founder Ron Bartek spoke on a panel at the World Orphan Drug Congress USA in Boston. He shared his insights in a panel discussion about 'Priorities, Policies and Impact on Patients Living with Rare Disease' along with panelists Christoph Glaetzer, Chief Global Value and Access Officer at Johnson & Johnson Innovative Medicine, and Victoria Gemme, Director of Policy and Regulatory Affairs at National Organization for Rare Disorders (NORD). The panel was moderated by Jayson Slotnik, Partner at Health Policy Strategies, LLC.

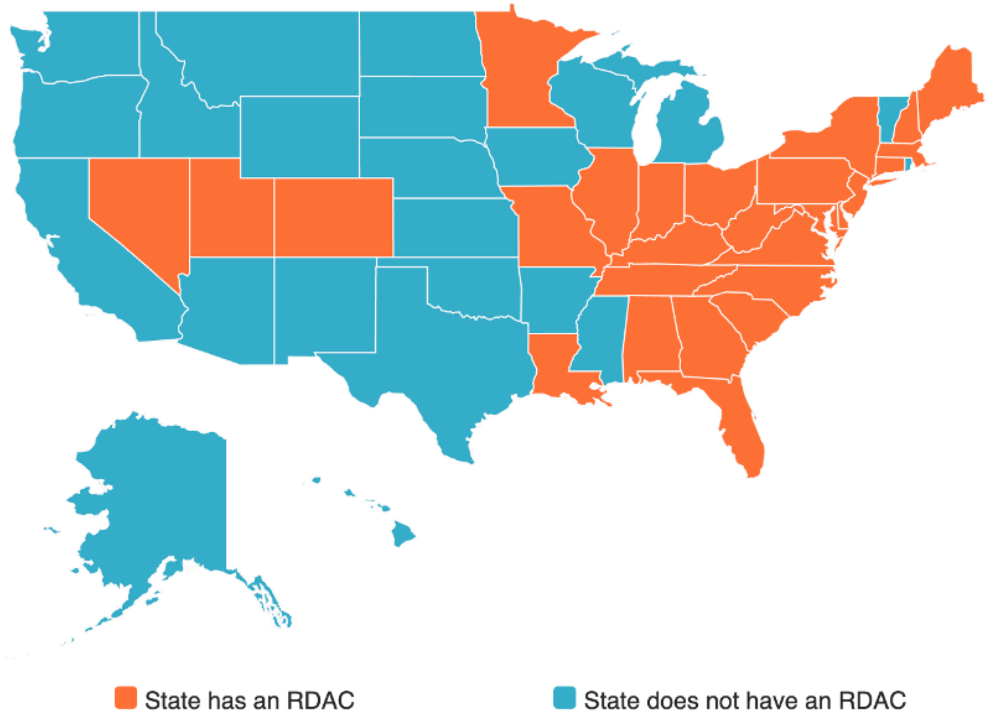
The World Orphan Drug Congress USA fosters key collaborations for rare disease patients and orphan drug developers — a defining event for the rare disease and orphan drug space globally.

State News

Genetic Discrimination Bill Reintroduced in New York

New York Assembly Bill A3229, which prevents insurance companies from discriminating based on genetic conditions, has been introduced by Assemblyman Jeffery Dinotwitz. This bill is a reintroduction of Assembly Bill A2083, one of the legislative asks from last year's New York Rare Disease State Advocacy Day.

If you would like to contact your state legislators and ask them to support A3229, you can click here to find your state legislators and their contact information.



Upcoming Rare Disease Advisory Council (RDAC) Meetings

- **Colorado:** The Colorado RDAC is meeting virtually on Monday, May 12 from 9:00 a.m. - 12:00 p.m. Additional meeting information can be found here.
- **Nevada:** The Nevada RDAC meets on the first Friday of even-numbered months at 9:30 a.m. For more information, click here.
- **Tennessee:** The Tennessee RDAC meets on the fourth Wednesday of every other month 8:00 a.m. to 9:30 a.m. CST. If you are interested in joining the meeting, please email info@tnrdac.org for instructions on attending. Additional meeting information can be found here.
- **Massachusetts:** The Massachusetts RDAC is meeting on Thursday, May 22 from 9:00 a.m. to 11:00 a.m. ET. Smaller committee meetings are also held throughout the month. You can find more information on meetings here.
- **Minnesota:** The Minnesota RDAC is meeting on Friday, May 9 from 10:00 a.m. to 11:00 a.m. CST. Smaller committee meetings are also held throughout the month. You can find more information on meetings here.
- **Connecticut:** The Connecticut RDAC meets on the fourth Tuesday of every month from 2:00 p.m. to 3:00 p.m. ET, unless otherwise noted. To join the monthly meeting or see other events held by the Connecticut RDAC, click here.
- **Ohio:** The Ohio RDAC holds quarterly public meetings. The next meeting is scheduled for Thursday, May 1 from 2:00 p.m. to 4:00 p.m. ET. You can find more information on upcoming meetings here.