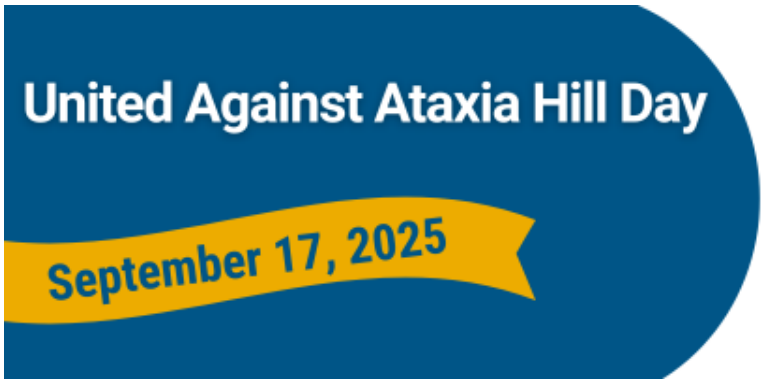
Advocacy Newsletter – August 2025

Join FARA for United Against Ataxia Hill Day!



On September 17, 2025, FARA and the National Ataxia Foundation (NAF) will host the 7th United Against Ataxia Hill Day!

United Against Ataxia Hill Day is a powerful opportunity for patients and families to meet with their legislators, raise awareness for FA, share their stories, and advocate for policies that will advance ataxia research! Your voice matters, and your story can help garner support for crucial policies that advance research and access to trials and approved therapies for patients.

In the past, participants in the United Against Ataxia Hill Day successfully advocated for:

- The continued inclusion of “Hereditary Ataxia” in the Congressionally Directed Medical Research Program (CDMRP), which has continued to provide millions in additional research funding for hereditary ataxias;

- A Senate Resolution recognizing September 25 as National Ataxia Awareness Day, and;
- Key accessibility reforms in the Federal Aviation Reauthorization Act, ensuring patients could access clinical trials!

Now, this progress is under threat. This year, CDMRP, which previously doubled the funding available for ataxia research, was cut by 57%, and thousands of NIH grants, totaling billions of dollars, have been terminated. Now, a proposed 40% FY26 NIH budget cut further endangers life-saving research and clinical trials. These choices will have impacts for years to come. The Congressional Budget Office (CBO) recently released a **report** that showed that just a 10% reduction in NIH funding would lead to 4.5% fewer drugs hitting the market each year. We need your voice now more than ever to make sure this projection doesn't become a reality!

Hill Day is an incredible opportunity for the FA community to educate lawmakers and serve as a catalyst for change, and you don't need to be a seasoned advocate to participate! FARA and NAF will coordinate all of the logistics and provide all of the information you need to feel prepared for your meetings. All you need to bring is your expertise in FA!

Help ensure that critical research continues and register for the 7th Annual United Against Ataxia Hill Day today! Act now because registration closes on August 20!

Capitol Hill Updates

The White House Releases New Executive Order Making Sweeping Changes to Federal Grants

On Thursday, August 7, President Donald Trump signed an Executive Order (EO) that makes dramatic changes to the federal grant award process. The EO, titled "**Improving Oversight of Federal Grantmaking,**" alters the peer review process that has historically been used to fund federal grants, temporarily halt grant awards until

new procedures are implemented, and ensure agencies prioritize grants that align with the President's policy priorities.

If you are not familiar with the typical federal grantmaking process prior to this EO, it follows the following structure:

1. **The agency awarding the grant issues a Request for Applications (RFA) or a Notice of Funding Opportunity (NOFO) Announcement asking for interested researchers to apply.**

2. **Interested researchers submit applications to the agency.**
   a. Applications must be completed to make it to the review process. Incomplete and noncompliant applications are removed by NIH staff and not reviewed.

3. **Complete and compliant grants move on to the first level of peer review.**
   a. The first level of peer review evaluates the scientific merit of grant applications. This review is completed by a Scientific Review Group (SRG) composed of non-federal scientists with expertise in a particular scientific discipline. SRG members can serve up to a six-year term and must be approved by the NIH Deputy Director.

4. **Then, grants move onto the second level of peer review.**
   a. This level of peer review is completed by Institute and Center (IC) National Advisory Committees or Boards. These committees/board consist of both scientific members and public representatives chosen for their experience, expertise, or interest in health/disease. Members of these advisory committees/boards typically serve four-year terms and must be approved by the Secretary of DHHS or sometimes the President.

These different steps eventually yield decisions on which grants to fund, which translates to research that may lead to treatments and cures.

So, what changes under the new EO?

The new EO fundamentally changes this grant review process. If implemented, instead of peer review, just one appointed person would have the final say as to grant awards. Advocates are concerned that this new process would leave out not only the input of scientific experts but also the voices of patients and patient advocacy organizations, which could lead to funding projects that may not be the most impactful or promising for the patient community.

In addition to the major changes to the peer review process, the EO also directs agencies like the NIH to stop funding grants until they are able to implement the new procedures. Moreover, the EO also instructs agencies to prioritize funding grants that align with the President's policy priorities and institutions with lower indirect cost rates, which would disadvantage larger research universities who are often at the forefront of medical discoveries.

The full impact of this EO will take time to develop and FARA will continue to monitor the effect on FA research. For more information, read this **article from *Nature*.**

Dr. Vinay Prasad Steps Down from FDA

In late July, Dr. Vinay Prasad stepped down as the Director of the Center for Biologics Evaluation and Research (CBER) after 3 months with the agency. However, less than two weeks after his departure, he returned to the agency to resume his role as Director of CBER at the direction of FDA Commissioner, Dr. Marty Makary.

For more information, you can read more **here.**

U.S. Representatives Write Letter Demanding Information About Newborn Screening Panel Dissolution

On July 29, 2025, over 20 U.S. Representatives sent a letter to Secretary Kennedy requesting information regarding the elimination of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), the panel of experts responsible for managing the Recommended Uniform Screening Panel (RUSP). The Representatives underscore the importance of federal newborn screening infrastructure to the health of patients and families across the country, and they urge HHS to ensure that critical newborn screening services aren't disrupted following the elimination of the ACHDNC. For more information, you can read the full letter **here.**

Susan Monarez Confirmed as New CDC Director

Susan Monarez, Ph.D., was confirmed by the U.S. Senate on July 29, 2025 as the new Director of the Centers for Disease Control and Prevention (CDC). She was narrowly confirmed by a 51-47 vote along party lines.

Dr. Monarez, a microbiologist and immunologist by training, has had a long career as a health scientist and civil servant. Prior to assuming this role, she served as the Acting CDC Director from January until March 2025, before stepping down as required when she was nominated for the role of Director. Before that, she served as the Deputy Director of ARPA-H. She is the first CDC director confirmed by the Senate under a 2023 law requiring confirmation, and she is the first non-physician leader of the agency in over 70 years.

You can read more about Dr. Monarez and her confirmation, **here.**

Senators Send Letter of Support for NIH Research Funding to Trump Administration Officials

On July 28, 2025, fourteen Republican Senators submitted a letter to Russel Vought, Director of the Office of Budget and Management (OMB), urging for the disbursement of funds appropriated to the NIH in the FY25 continuing resolution. The Senators expressed concerns that failure to do so would delay progress, jeopardize jobs, and hurt patients.

"…Suspension of these appropriated funds - whether formally withheld or functionally delayed — could threaten Americans' ability to access better treatments and limit our nation's leadership in biomedical science. It also risks inadvertently severing ongoing NIH-funded research prior to actionable results," the senators wrote.

If you're interested in learning more about the Senators who signed onto the letter and concerns they expressed, you can read the full text **here**.

Representatives DeGette, Raskin, Auchincloss Introduce Resolution on U.S. Leadership in Biomedical Research

Representatives Diana DeGette (D-CO), Jamie Raskin (D-MD), and Jake Auchincloss (D-MA) **introduced a congressional resolution on July 23** recognizing the importance of U.S. leadership in biomedical research. According to an **accompanying press release**, the "resolution emphasizes the indispensable role of the NIH, the world's largest public funder of biomedical research, and calls for a doubling of federal biomedical investment over the next decade. It also urges Congress to prioritize workforce development, scientific independence, and translational research that brings lab discoveries directly into patient care."

Update on FY26 Appropriations

On July 15, House Appropriations Committee Chair Tom Cole (R-OK) issued a press release sharing **updated fiscal year (FY) 2026 appropriations subcommittee allocations.** The subcommittee allocations provide funding ceilings that guide how much each House subcommittee can spend when crafting their FY26 appropriations bills.

According to the press release:

- The topline allocation for non-defense spending is nearly 6 percent less than that of FY25;
- And the allocation for the Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) appropriations subcommittee, which provides funding for the NIH, is $1.3 billion less than the appropriations included in the FY25 Labor-HHS bill.

So far, only the Defense Appropriations bill, which funds CDMRP, has passed the House. There are still 11 more House appropriations bills that need to be passed, including the Labor-HHS bill. These bills will not be heard or voted on again until September.

Meanwhile, the Senate Appropriations Committee has marked up and passed 8 of its 12 appropriations bills, including its Labor-HHS and Defense bills. In the most recent Senate report language, Hereditary Ataxia was included in the CDMRP once again, and CDMRP funding for the Peer Reviewed Medical Research Program (PRMRP) was restored to previous levels. Now, these bills await a final vote from the entire Senate when they return in September.

Scientists Stage a Science Fair in Congress to Highlight Grant Terminations

On July 8, a group of scientists who were impacted by grant cancellations held a “science fair” in the Rayburn House Office Building on Capitol Hill. This event, hosted by the minority Members of the House Science, Space, and Technology Committee, was organized to draw attention to the important research being halted due to grant terminations. During the event, over twenty scientists from across the country whose grants were terminated presented their research, covering numerous disciplines from neuroscience to astrophysics. To learn more about this event, click **here**.

U.S. Supreme Court Rules that Mass Layoffs for Federal Employees Can Continue

As you are likely aware, the Trump Administration has been conducting mass layoffs across the federal government since inauguration in January. These layoffs have

been met with significant legal challenges of varying levels of success. Recently, a lower court ordered the Administration to stop the layoffs. In response, the Department of Justice (DOJ) filed an emergency request with the Supreme Court, asking them to reverse the lower court's order. On Tuesday, July 8, the U.S. Supreme Court lifted that lower court's order, signaling that the Administration can continue with layoffs.

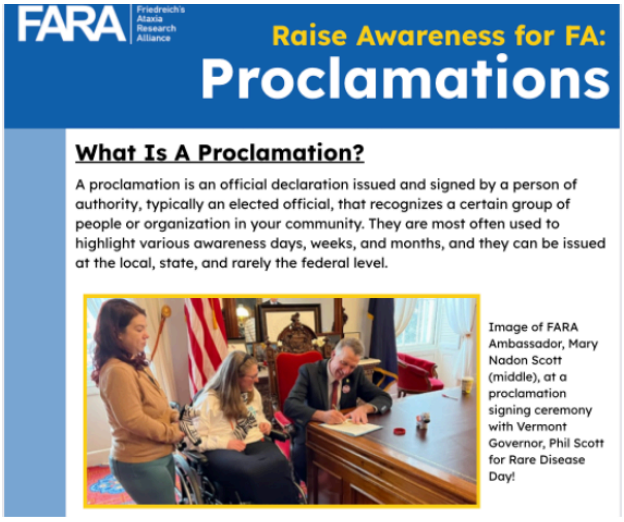
While this ruling doesn't decide the legality of the layoffs or reorganization plans, it paves the way for the Administration to continue laying off employees at agencies, which may implicate research, drug approvals, and other critical functions of the federal public health agencies. To learn more about this ruling, read this article from **CBS News**.

President Trump Signs the Big Beautiful Bill Into Law

On July 1, the U.S. House of Representatives passed the Senate-approved version of the One Big Beautiful Bill Act (**H.R. 1**). The legislation was passed through the budget reconciliation process, a special legislative process that allows Congress to fast-track spending-related bills. It is anticipated that the result of this action will be major cuts to Medicaid, which may impact access to care and treatments for FA patients and families. On July 4, President Donald Trump signed the bill into law. Although now officially law, many of its provisions, including a number of Medicaid-related provisions, will not go into effect for a couple of years.

If you would like to learn more about this legislation and its impact on the FA community, you can find a detailed explanation in FARA's **June Advocacy Newsletter**. Additionally, on July 10, the EveryLife Foundation hosted an emergency webinar on the impacts of H.R. 1 on the rare disease community, which you can watch **here**.

Upcoming Advocacy Events



Take Action to Raise Awareness for FA—Submit a Proclamation!

Remember when you first heard the words “Friedreich’s Ataxia?” It is likely you had no idea what that was or what that diagnosis fully meant. Legislators and the public are no different, they need to be educated on the condition and the implications for the patient and their family. One simple and meaningful way to raise awareness of FA is by submitting a **proclamation request** to your state or local government. A proclamation is an official declaration issued and signed by a person of authority—usually a governor, mayor, or other elected official—that recognizes a certain group of people or organization in your community. **And, the best part, anyone can submit a proclamation request!** That’s why proclamations are such a powerful advocacy tool.

FARA has created a **Proclamation Toolkit** that explains in detail what a proclamation is, how to submit one, your state’s rules and submission guidelines, draft language for your proclamation, and general advice. **International Ataxia Awareness day is on September 25, 2025 and provides a great opportunity to submit your first request.** Proclamation request deadlines are quickly approaching for that date, so check out the toolkit today!

South Carolina Advocates—Raise Your Voice with NORD!

On September 26, NORD’s South Carolina Rare Action Network (RAN) will host an in-person advocacy workshop as part of its Rare Action on the Road event series. During this workshop, NORD staff will provide:

- A look ahead to 2026 policy priorities for the rare disease community in South Carolina;
- Training on how to advocate and share your rare story when meeting with legislators and staff;
- An overview of NORD and how you can participate in raising awareness for the rare disease community!

The workshop will be held in-person from 10 AM to 2 PM ET at Segra Park in Columbia, SC. Refreshments will be provided in the morning and lunch will be provided in the afternoon. If you’re interested in attending, register **here**!

Announcements

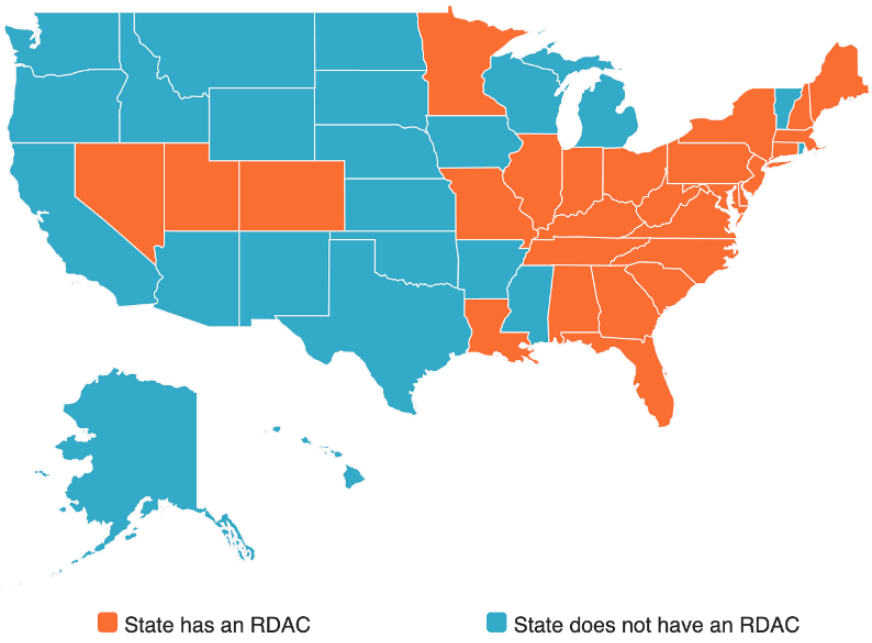
FARA Advocates for Research Funding and Patient Access on Capitol Hill

On July 22 and 23, FARA joined the Alliance for Regenerative Medicine (ARM) for their annual fly-in, convening leaders within the cell and gene therapy space to advocate for policies that would advance new therapies for patients. Advocates encouraged lawmakers to support for the Accelerating Kids' Access to Care Act (H.R. 1509/S. 752), reauthorization of the Rare Pediatric Disease Priority Review Voucher Program (PRV), and funding for critical public health agencies, like the FDA and NIH.

State News

Florida Enacts the Landmark Sunshine Genetics Act

On July 1, 2025, Florida officially enacted the Sunshine Genetics Act, a first-of-its-kind piece of legislation that created a five year pilot project which offers **free, voluntary whole genome sequencing (WGS) to all newborns** born in the state. In addition to creating an innovative WGS program for newborns, the act also creates a consortium of researchers, clinicians, and industry partners to support implementation of the act. This legislation now puts Florida at the forefront of genomic medicine.



Upcoming Rare Disease Advisory Council (RDAC) Meetings

- **Colorado:** The Colorado RDAC is meeting virtually on Monday, September 8 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**.

- **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**.

FARA Friedreich's Ataxia Research Alliance