FARA Friedreich's Ataxia Research Alliance

Advocacy News

Rare Disease Day 2026

Rare Disease Day, held this year on February 28, is a global movement to raise awareness of rare diseases and promote equity in health care—especially access to timely diagnosis and approved treatments. Events happen around the world and throughout the month, with a particularly exciting week of programming occurring in Washington, D.C.

From February 23 to 27, members of the rare disease community gathered in Washington, D.C. to celebrate progress, learn about emerging research, and urge lawmakers to continue investing in rare disease patients and scientists. The EveryLife Foundation hosted hundreds of advocates from across the country—including FARA

Ambassadors Shandra Trantham (FL), Bridget Downing (NC), Tony Brooke (NJ), Chris Meyer (CA), Kelly Barendt (OH), Hayden Howard (OH), Liam Kruesi (NJ), Jake Juip (MI), their families, and FARA leaders Ron Bartek, Brigid Brennan, and Berkley Bell—to share their stories on Capitol Hill.

The week kicked off with a virtual FDA Rare Disease Day webinar on Monday, followed by the EveryLife Foundation hosting a share-your-story workshop on Tuesday and a full-day legislative conference on Wednesday. Advocates met with fellow community members from their states, learned about policy issues affecting rare disease patients, and heard from experts on innovative research and policy solutions.

On Thursday, 700 advocates from 49 states and D.C. headed to Capitol Hill to participate in 357 meetings with their legislators and champion key legislation such as the Genomic Answers for Children's Health Act (H.R. 7118), the Credit for Caring Act (H.R. 2036/S. 925), and increased funding for NIH's Rare Disease Innovation Hub.

FARA Team Dinner

That day also featured a Senate Committee on Aging hearing focused on fostering innovative rare disease research at the FDA, and remarks from FARA co-founder Ron Bartek at a Rare Disease Congressional briefing on the Larimar journey. Thank you to all the advocates who came to Washington to ensure the FA community was heard!

The week concluded on Friday with Rare Disease Day at the NIH headquarters. FARA Ambassador Jake Juip delivered a powerful speech that moved the crowd to a standing ovation. (View Jake's speech here at

NCATS Director Jodi Rutter with the FARA/NAF advocacy team

about the 4 hours 7 minute mark.) After his speech, NCATS director Joni Rutter approached the FARA team to share that there had only been one other standing ovation in the event's history...when Skyclarys was approved on Rare Disease Day three years ago!

Outside of D.C., many others participated in Rare Disease Day initiatives such as Light Up for Rare, Show Your Stripes, global events, meetings with legislators, and social media campaigns. A special shout-out goes to Mary Nadon Scott for her exceptional advocacy work in Vermont during Rare Disease Week. Through her dedication, persistence, and leadership, she successfully secured a proclamation from Governor Phil Scott recognizing February 28 as Rare Disease Day in Vermont.

Mary also spoke at a Select Board meeting about Rare Disease Day and attended virtual rare disease events throughout the week. Mary is a tireless champion for the rare disease community—raising awareness, engaging leaders, and showing her stripes!

Rare Disease Day was an important opportunity to elevate awareness of FA, but the work continues. Sharing your story with lawmakers—whether through email, local meetings, or sponsored events—helps them understand the real-world impact of rare

disease research. Keep an eye out for future FARA action alerts and advocacy opportunities. Raise your voice with us to advocate for FA research!

Capitol Hill Updates

Help Ensure Crucial FA Research Funding Remains Available by Submitting CDMRP Appropriations Requests!

The Congressionally Directed Medical Research Program (CDMRP) is a crucial program that allows Congress to direct research funding on

conditions with significant unmet medical needs.

To be eligible for grants, Congress must list the condition as a topic area when developing the budget. Our advocates have successfully ensured a place on that list since the Fiscal Year 2022 budget, resulting in doubling the funding for ataxia research. This is a crucially important program for FA research!

FARA is currently working with community members to make similar requests for the Fiscal Year 2027 budget. Most members have an appropriation form on their website, and FARA has both a template to help you complete it and supporting documents to share with offices. While many of the offices have already closed their forms, there may still be a chance to submit requests to your members of Congress. If you would like to support this initiative, email berkley.bell@curefa.org.

Senate Passes Bill to Extend SBIR/STTR Programs

On March 18, the House passed a reauthorization bill (S.3971), the Small Business Innovation and Economic Security Act, to extend the Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) programs through 2031. The bill now heads to the president's desk for his signature.

The SBIR and STTR programs provide federal funding to small businesses and research institutions to support early-stage research and the development and commercialization of innovative technologies. The NIH is among several federal agencies that participate in these programs to support biomedical innovation and small business research partnerships by setting aside a portion of their research budget to support early-stage small businesses.

HSS Secretary Robert F Kennedy, Jr. Reduces Federal Research & Healthcare Agencies Workforce Significantly

Since Robert F. Kennedy Jr. took the helm of the Department of Health and Human Services last February, his department has shed more than 17,000 jobs, according to data from the U.S. Office of Personnel Management (OPM). As of this February, the reduction by sub-agency was:

- Food and Drug Administration (FDA): 4,332
- National Institutes of Health (NIH): 4,049
- Center for Disease Control (CDC): 2,889
- Centers for Medicaid & Medicare Services (CMS): 1,051

Read more about it here.

New RISE Workshop Announced: Data Sharing Across the Rare Disease Ecosystem

New RISE Workshop Announced: Data Sharing Across the Rare Disease Ecosystem: The third RISE workshop, hosted by the Food and Drug Administration in partnership with the Duke-Margolis Center for Health Policy, will focus on Data Sharing Across the Rare Disease Ecosystem on March 30, 2026, from 9:00am–4:30pm ET. The hybrid event will be held virtually and in person at the National Press Club.

Read More

FDA CBER Director Vinay Prasad Resigns Again

The FDA's Center for Biologics Evaluation and Research (CBER) announced that its director, Dr. Vinay Prasad, will depart the agency again at the end of April. Dr. Prasad previously resigned during a regulatory dispute on July 29, 2025, but returned two weeks later. As a reminder, CBER evaluates the safety and effectiveness of vaccines, gene and cell therapies, and other critically important medical advances.

NIH Advisory Council Appointments Needed

Each NIH Institute has an Advisory Council which plays a role in peer review for research grant applications and advises on priorities, policy, and program development and implementation.

Without a quorum of council members, the institute cannot approve pending grant applications or new programs. In the past year, only one member was added across 24 councils, and some institutes risk losing all members in 2026 due to their terms expiring. On March 5, a bipartisan group of 31 members of Congress sent a letter to HHS Secretary Robert F. Kennedy, Jr. expressing concerns about the nature and impact of these NIH advisory council vacancies. Read the full letter here.

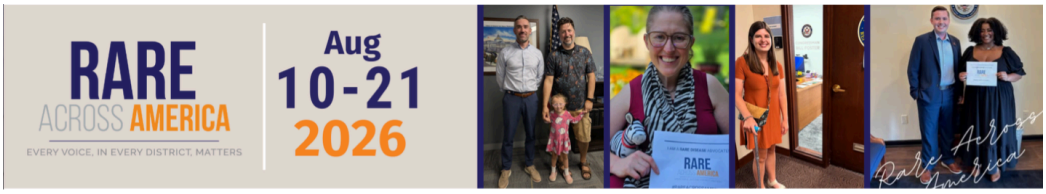
NIH Strategic Plan 2027–2031: Public Webinar Invitation

The NIH will host a webinar on **April 8** to introduce the Institute's strategic planning process and gather input regarding the agency's next five-year plan covering Fiscal Years 2027-2031. Learn more about the NIH-Wide Strategic Plan here, and register for the April 8 webinar here.

Announcements

Rare Disease Legislative Advocates (RDLA) invites members of the rare disease community between 10 and 18 years old to participate in our second Virtual Youth & Teen Advocacy Day.

Advocates will have the opportunity to virtually meet with their Members of Congress and share their rare disease story. Prior to meetings with Members of Congress, advocates will attend virtual trainings on how Congress creates laws, how to communicate with your Representatives and Senators, and how to understand key policies affecting the rare disease community, designed for youth and teens. Registration will open on April 27.



Rare Across America is the opportunity to meet with your Members of Congress at their in-district offices and educate them on the issues that are most important to the rare community by sharing your story. Registration opens on May 11.

The Everylife Foundation for Rare Diseases asks you to encourage your member of Congress to sign on to a letter requesting that the Rare Disease Innovation Hub receive $5 million in funding and to support report language that recognizes the importance of the Hub's work to transform rare disease therapy development. This initiative is being led by the House Rare Disease Congressional Caucus Co-chairs.

The Everylife Foundation for Rare Diseases asks you to encourage your member of Congress to Cosponsor H.R. 7118, supporting the Genomic Answers for Children's Health Act. This legislation clarifies Medicaid coverage of genomic sequencing, getting children needed care and preventing irreversible damage as the disease progresses during the search for diagnosis.

Announcements

New Survey Demonstrates Americans' Support for Research Investment

A new survey from Research!America reveals that nearly 7 in 10 Americans across the political spectrum say Congress should invest more taxpayer dollars to advance science and technology. Other findings include:

- Americans say medical progress should be among the top three of our nation's priorities over the next 50 years.
- 92% of Americans across the political spectrum support basic scientific research, an increase of seven points over last year's survey.
- Nearly 9 in 10 Americans across the political spectrum say it is important for candidates to champion faster medical progress, and 7 in 10 (including 70% of Republicans, a 10-point increase over 2024) say they would be more likely to support a candidate who favors increased spending on medical and health research.

Economic Impact of NIH

United for Medical Research released its 2026 update on the role of NIH in the U.S. economy. Key findings include:

- In 2025, NIH generated $94.15 billion in economic activity. That's a return on investment of more than 250%: every dollar invested in NIH-funded research resulted in $2.57 of economic activity;
- NIH research supported 390,863 jobs nationwide.

State News

Current State Sessions

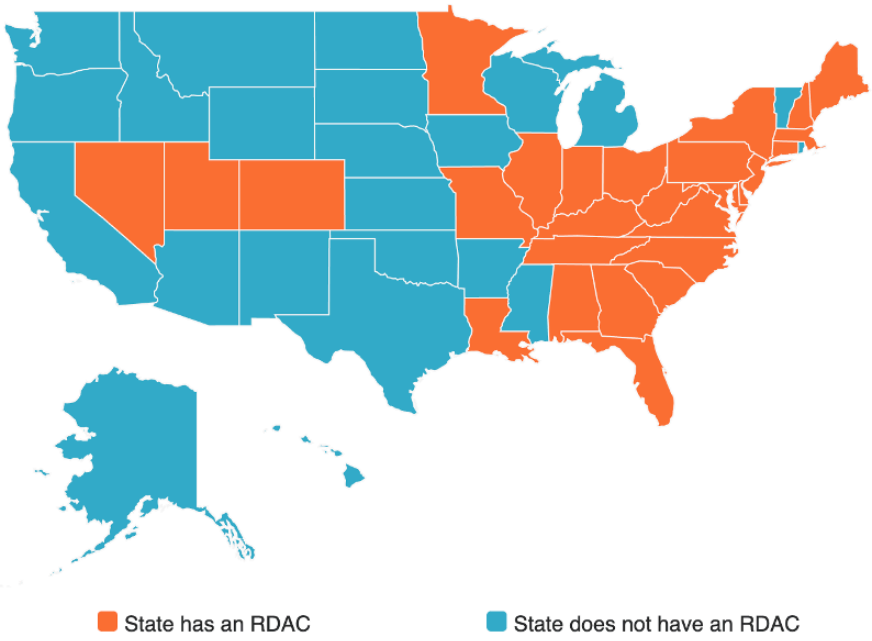
40 States are currently in regular session, in addition to Washington, D.C. and Puerto Rico. States like Louisiana, Arkansas, and Noth Carolina are scheduled to convene for the 2026 legislative session in March and April. Indiana adjourned its 2026 legislative session on February 27.

States continue to advance legislation across several areas relevant to the rare disease community, including newborn screening and RUSP alignment, Medicaid policy and implementation, prior authorization reforms, genetic non-discrimination, and the use of AI in healthcare decision-making. Contact your local legislators to learn more about rare disease policy advancements in your state.

Seattle Rare Disease Fair

The 8th Annual Seattle Rare Disease Fair will be held on March 27, 2026. The fair will feature an action-oriented discussion around the diagnostic odyssey, genetic testing, and AI.

Learn More and Register



Upcoming Rare Disease Advisory Council (RDAC) Meetings

- **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**.
- **Maryland:** The Maryland RDAC meets on the second Tuesday of every month from 4:00 p.m. to 5:00 p.m. Additional meeting information can be found **here**.
- **Nevada:** The Nevada RDAC meets on the first Friday of each even numbered month. They will be meeting on Friday, April 3 at 9:30 a.m. PT. You can join the meeting here.
- **Colorado:** The Colorado RDAC will meet virtually on Monday, April 13 from 9:00 a.m. to 11:00 a.m. MT. You can learn more about joining the meeting here.
- **Minnesota:** The Minnesota RDAC will host a full council meeting on Thursday, April 16 at Sprucetree Center, 1600 University Ave W #310, St Paul, MN 55104. For more information about joining please contact MNRDAC Operations Manager at paige-erin.wheeler@state.mn.us.

- **Michigan:** The Michigan RDAC will meet virtually on Tuesday, April 28 from 10:00 a.m. to 12:00 p.m. CT. You can learn more about joining the meeting here.

- **South Carolina:** The South Carolina RDAC's next quarterly meeting will be held on Friday, April 10 at 9:00 a.m. You can find the teams link here.

- **Massachusetts:** The MA RDAC is having a full council meeting on Thursday, March 26 from 9:00 a.m. to 11:00 a.m. on Zoom. Learn more here.

Newborn Screening Laws

The Virginia legislature passed a bill (H.B. 433) that directs the Department of Health to establish a process for adding new disorders to the state's newborn screening program. The bill has now passed both houses in the Virginia legislature and moves to the governor's desk for her signature.

Update Us on Your Advocacy!

Have you engaged in advocacy recently? Met with a federal, state or local lawmaker? Participated in a public meeting or wrote about FA or rare disease? FARA would love to share the amazing advocacy work our community members are doing. So, please let FARA know by sending updates to Berkley Bell, berkley.bell@curefa.org.

FARA Friedreich's Ataxia Research Alliance

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