FARA | Friedreich's Ataxia Research Alliance

The Impact of Recent Changes at NIH on Research

The U.S. has long led the world in scientific research and innovation, and the NIH—the world's largest funder of biomedical research—is a critical tool to continue to advance science, maintain our leadership, and find cures for diseases like FA. However, in the last few months alone, the Administration has terminated over $3 billion in grants from the NIH, which amounts to approximately 2,282 grants in total. These deep cuts to the NIH not only threaten promising science, critical research infrastructure, and the scientists responsible for bringing lifesaving treatments to patients, but they also jeopardize state economies, hospitals, medical schools, and other academic institutions that support critical research.

On June 16, a federal district court in Massachusetts struck down the termination of NIH grants and ordered their restoration in a case called *APHA v. NIH.* However, the Administration is actively appealing this decision and trying to pause the judge's decision from taking effect. So, legal battles regarding grant terminations are likely to continue over the coming months and years.

Despite the major win in *APHA v. NIH*, advocacy is needed to ensure that the NIH is robustly funded for fiscal year 2026 (FY26) and beyond. At the end of May, the President submitted his proposed FY26 budget to Congress which recommended a 40% cut in NIH funding, as well as cuts to other public health agencies. It also maintained a 15% cap on indirect costs for all grants. If enacted, this would be the lowest level of NIH funding in decades, after adjusting for inflation. In addition to funding cuts, it also suggests a major restructuring of federal public health agencies, including the NIH. Currently, the NIH consists of 27 Institutes and Centers, each with a different clinical and/or research focus. However, the proposed restructuring would consolidate the 27 existing Institutes and Centers into just 8. This proposal, combined with the present funding challenges, further jeopardize research and fundamentally change the U.S.'s biomedical research infrastructure for the foreseeable future.

sure your Members of Congress are aware of how important NIH funding is to you!

Reaching out to your elected officials is incredibly easy. First, if you don't know who your representatives are, you can look them up here. The website will provide you with your members' websites and contact information. You can then either email them through their "Contact" page or call them at their Washington D.C. office. 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? FARA has created this advocacy toolkit that includes a template for reaching out to your Members, relevant statistics about NIH funding, and additional resources that you can use in your outreach. To make your message even more compelling, add details about your own personal experience and what NIH funding means to you!

Capitol Hill Updates

Budget Reconciliation Updates

There is a lot of buzz currently in DC about the Big Beautiful Bill, but what is it, and how does it impact the FA community? Congress is not currently voting on the FY26 budget, but rather on a budget reconciliation proposal. Read on to understand the difference and how this legislation may affect you.

Q: What is budget reconciliation?
A: Budget reconciliation is a special legislative process that allows for accelerated consideration of specific tax, spending, and debt ceiling legislation, so long as the

Q: What changes can be made during budget reconciliation?
A: Budget reconciliation can only be used to make changes to fiscal policy—changes to how the government spends money and taxes constituents. It cannot be used to pass policies that don't have a significant impact on the federal budget and/or the deficit.

Q: What kind of spending changes can be made through budget reconciliation?
A: Typically, reconciliation bills only make changes to "mandatory" spending—funding for programs that are mandated by existing laws (i.e. Medicare, Medicaid, and food assistance programs). It is more difficult to include "discretionary" funding—money appropriated during the annual appropriations process (i.e. NIH research funding, defense spending, and funding for schools).

Q: How is budget reconciliation different from the typical legislative process?
A: There are a few major differences between budget reconciliation and the normal legislative process. The two most important are:

1. <u>No Filibuster in the Senate:</u>
    - During the normal legislative process, a 60-vote majority is usually required to pass legislation.
    - In budget reconciliation, a simple majority (51 votes) is required.
2. <u>The Byrd Rule:</u>
    - During the normal legislative process, there are no requirements for what can and can't be included in legislation.
    - In budget reconciliation, "the Byrd Rule" sets limits on what can be included in proposed legislation. It is comprised of six tests that are intended to keep the reconciliation process focused on budgetary changes and protect the jurisdiction of Senate Committees. The Byrd Rule only applies in the Senate, and there is no equivalent in the House. This rule is enforced by the Senate Parliamentarian.

Q: How does the Byrd Rule work, and what happens if a provision violates it?
A: The Senate Parliamentarian, a nonpartisan advisor who provides guidance regarding Senate rules and procedures, decides whether or not a provision violates the Byrd Rule. If a provision does violate the Byrd Rule, it will usually be removed from the bill. If it doesn't violate the Byrd Rule, it can stay in the bill. Sometimes, the Byrd Rule can be waived, but that requires a 60-vote majority, which is unlikely to occur.

considered and made changes to the bill, and their version of the bill passed on July 1. Now that it has passed the Senate, the House and Senate will have to decide how to reconcile some major differences between the two bills. If they are able to pass a unified bill, the President will then sign it into law.

Q: One area impacted by this bill is Medicaid. What are the changes?
A: The changes impacted by this bill are:

1. **Implementing an 80-hour per month work and/or community engagement requirement to maintain eligibility, with some exclusions.**

   How this may impact the FA community: While people with disabilities, caregivers, those under 19 years old, and full-time students are technically exempted from this provision, evidence from states that have previously implemented work requirements for Medicaid suggests that they increase administrative burden and may lead to clerical errors.

   December 31, 2026 is the deadline for states to implement this provision, but states can elect to use work requirements earlier if they want.

2. **Requiring states to implement cost-sharing requirements for expansion adults (those making between 100-138% of the federal poverty level and not eligible under other eligibility pathways) covered by Medicaid.**

   How this may impact the FA community: If you or a family member are eligible for Medicaid under Medicaid expansion (meaning you make between 100-138% FPL and do not meet the requirements for any of the other eligibility pathways in your state), then you may have to pay more for your care than you did previously. There will be a maximum cap on copays at $35 per service, and some services are exempt.

   This provision will not take effect until **October 1, 2028.**

3. **Requiring Medicaid redetermination every 6 months rather than annually.**
   How this may impact the FA community: Currently, if you are eligible for Medicaid, you are covered for a full year. Under the new bill, your state would

greater opportunities to lose coverage.

This provision will not take effect until **December 31, 2026.**

4. **Limiting retroactive coverage to 1 month for expansion enrollees and 2 months for traditional enrollees, which is less time than the original 3 months of retroactive coverage.**

How this may impact the FA community: Retroactive coverage means that Medicaid will pay for some of your medical bills for a period of time before you were formally enrolled. This is particularly important for patients and families that had medical emergencies or a new diagnosis that coincided with or led to them becoming eligible for Medicaid. Shortening this retroactive coverage period will put more burden on families to pay for these bills.

This provision doesn't go into effect until **December 31, 2026.**

5. **Limiting states' ability to change provider taxes, which help fund their state Medicaid programs.**

How this may impact the FA community: Medicaid is paid for by both states and the federal government. States issue taxes on medical providers to help pay for their share of Medicaid costs. Limiting states' ability to tax providers will lead to less funding for their state Medicaid programs. Therefore, states will either need to find another way to pay for Medicaid, or they will need to cut benefits or eligibility for people on Medicaid.

This provision will be effective immediately, but states have a 3-year grace period to comply.

6. **Limiting state flexibilities to supplement provider reimbursement under Medicaid, called state directed payments (SDP).**

How this may impact the FA community: To encourage greater access, state directed payments (SDP) allow states to choose to reimburse certain providers more for seeing Medicaid patients. By capping states' ability to pay providers more for these patients, providers may be less likely to see Medicaid

This provision will be effective immediately after the bill is signed into law.

Overall, the nonpartisan Congressional Budget Office (CBO) estimates that these changes cut a total of around $1 trillion from Medicaid and will lead to around 7.8 million people losing health coverage between 2025-2034.

President’s FY26 Recommends Deep Cuts to Health Agencies

As discussed above, the U.S. Department of Health and Human Services (HHS) released the President’s FY26 Budget on Friday, May 30, which details the President’s funding recommendations to Congress for the upcoming fiscal year. The released budget suggests steep cuts to numerous federal public health agencies, including a $271 million (3.8%) cut to the FDA, a $17.9 billion (39.5%) cut to the NIH, and an almost $4 billion (50.7%) cut to the CDC. The proposal also maintains the current 15% cap on indirect costs for NIH grant funding. In addition to cuts, the budget also proposes widespread changes to the structure of federal health agencies, including absorbing the Health Resources & Services Administration (HRSA) into the new Administration for a Healthier America and consolidating the NIH’s 27 institutes and centers into just 8. To learn more about this budget proposal, click here.

House Energy & Commerce Committee Holds Hearing on FY26 HHS Budget

The House Energy & Commerce Committee, which oversees the majority of public health legislation and funding, held a hearing on Tuesday, June 24, regarding FY26 funding for HHS and related public health agencies, like the NIH. The Committee called HHS Secretary Robert F. Kennedy Jr. as a witness and allowed for Q&A from Members of the Committee. During the hearing, Committee Members discussed impacts of the proposed budget on medical research funding, clinical trials, and other critical public health programs. You can watch the hearing here.

Newborn Screening

On May 20, the Rare Disease Congressional Caucus held a briefing detailing the lifesaving impact of the newborn screening program and calling for new federal action to strengthen and modernize the program. You can watch a recording of the briefing here.

FDA Announces New Voucher Program

On June 17 , the FDA announced the Commissioner's National Priority Voucher (CNPV) program with the goal of shortening the drug review process from 10-12 months to 1-2 months.

Vouchers will be issued to companies that are addressing a US health crisis, delivering more innovative cures for the American people, addressing unmet public health needs, and increase domestic drug manufacturing. FDA Commissioner Marty Makary, M.D., M.P.H., stated that "the ultimate goal is to bring more cures and meaningful treatments to the American public." How this program will be implemented is still unknown. You can find the FDA's press release on the CNPV here.

Upcoming Advocacy Events

Rare Artist 2025 is now Open for Submissions

Enter through July 9 at RareArtist.org

The Rare Artist program, powered by the EveryLife Foundation for Rare Diseases, was established in 2010 to showcase the talents of those impacted by rare diseases. The annual contest provides a national platform for artists to advocate through music, poetry, and visual artwork.

This year EveryLife is introducing a **new medium: MUSIC!** Music has the power to move hearts and activate change. Now, it's another way to raise your voice for rare

The contest is open to anyone in the U.S. who has a rare disease or is connected to someone who does. **For a full list of guidelines visit *RareArtist.org***

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 issues, and you will have a team lead to help organize meetings and guide you through the process.

Registration closes on July 11! If you're interested in participating, you can find more information on the EveryLife Foundation website.

Announcements

FARA Ambassador Mary Nadon Scott is Named as a NORD Rare Impact Award Honoree

Congratulations to FARA Ambassador, Mary Nadon Scott, for being named as a 2025 NORD Rare Impact Award Honoree! NORD's Rare Impact Awards are granted to individuals or groups who are driving change and making a difference on behalf of the millions of Americans with rare diseases.
The awards are split into multiple categories, including: Youth Leaders, Policy Changemakers,

Champion category, which honors patient advocates who have made a meaningful impact by improving access to care, accelerating research, or driving policy.

Mary was recognized for her advocacy in Vermont and the wider U.S., including her work advocating to establish a Rare Disease Advisory Council (RDAC) in Vermont and getting several proclamations issued to raise awareness for FA and rare disease as a whole!

Apply Now: State Medicaid Beneficiary Advisory Councils Seeking Patient Members

Several states have open applications for their Medicaid Beneficiary Advisory Councils, which provide patients a voice in shaping Medicaid policy and program operations within their home state. State Medicaid leaders are especially encouraging applications from rural residents, working-aged adults, and men. Click here to learn more on Medicaid Beneficiary Councils.

Upcoming deadlines:

- Alabama : 7/9
- Indiana: 7/15
- Ohio: newly opened, no firm deadline

For questions or if you can't find information on your state's application, contact bmcgowan@everylifefoundation.org with the EveryLife Foundation who is spearheading this effort.

State News

Ohio's Senate budget bill is poised to eliminate the state's Rare Disease Advisory Council (RDAC). RDACs provide critical infrastructure for connecting providers, patients, and policymakers, and they operate on negligible administrative funds. This bill is still in committee so there is time for advocates to make their voices heard!

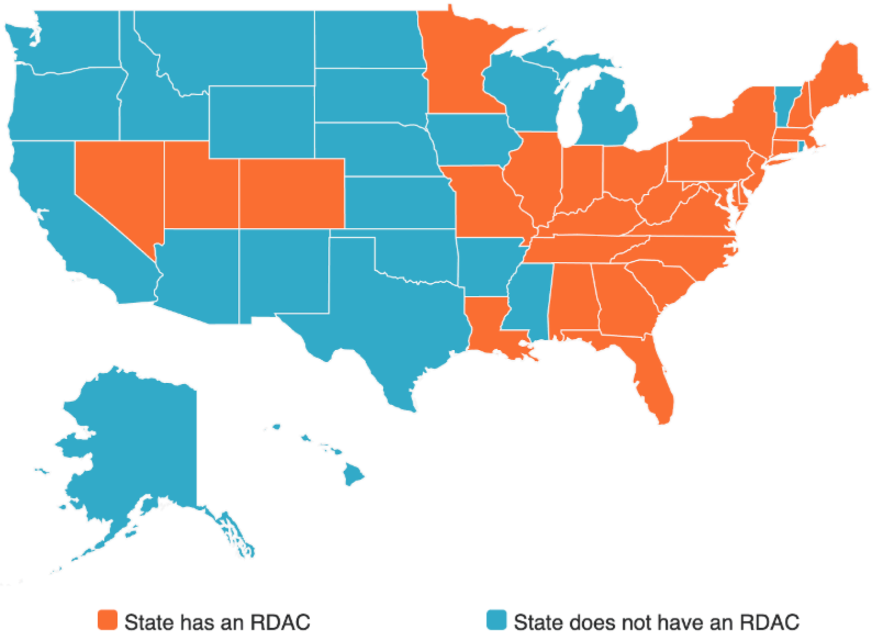
If you live in Ohio, NORD has an action alert where you can contact your elected representatives and ask them to remove this provision and maintain funding for the RDAC! If you would like to get involved in other advocacy efforts within Ohio, contact NORD's State Policy Manager, Carolyn Sheridan, at csheridan@rarediseases.org.

RDAC Bill Passes the Oklahoma State Legislature

At the end of May, the Oklahoma legislature passed SB207, a bill that would establish a RDAC in the state of Oklahoma. On May 28, the bill was sent to the governor's desk for signature. If you live in Oklahoma, you can send a message to Governor Stitt asking him to sign SB207 into law on NORD's website!

Rhode Island RDAC Bill Signed Into Law

At the end of June, the Rhode Island state legislature passed SB474, which would establish a RDAC in Rhode Island. On June 27, Governor McKee **officially signed the bill into law**, making Rhode Island the 33rd state to establish a RDAC! This is a huge win for the rare disease community in Rhode Island, and rare disease advocates made it happen!



Upcoming Rare Disease Advisory Council (RDAC) Meetings

- **Colorado:** The Colorado RDAC is meeting virtually on Monday, July 7 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.

- **Michigan:** The Michigan RDAC holds quarterly public meetings. The next meeting is scheduled for Wednesday, July 23 from 10:00 a.m. to 12:00 p.m. ET. If you are interested in joining the meeting, please email MDHHS-RareDiseases@michigan.gov. For information on future meetings, click here.

View this email in your browser

FARA Friedreich's Ataxia Research Alliance

Our mailing address is: