FARA Friedreich's Ataxia Research Alliance

Medicaid Work Requirements

The Centers for Medicare & Medicaid Services (CMS) has released a new rule outlining how states will implement the Medicaid work/community service requirements from last year's H.R. 1. The rule requires many adults enrolled in Medicaid to complete at least 80 hours per month of work, education, job training, or community service to maintain their coverage. The rule takes effect July 31, 2026. States must implement the requirements by January 1, 2027, though many are already moving forward.

Importantly, the rule outlines exemptions from the work requirements for Medicaid recipients considered "medically frail." Encouragingly for the FA community, many states will use ICD-10 diagnostic codes to determine medical frailty. Because FA has an ICD-10 code, individuals with FA are likely to qualify for a medically frail exemption in many states. However, it is still important to review your state's specific criteria. In addition, caregivers of individuals deemed medically frail may also qualify for an exemption.

At the same time, there are concerns. Many people who technically meet the requirements—either by working the required hours or qualifying for an exemption—may still lose coverage due to complex reporting rules and administrative hurdles. Individuals may need to reverify their medical frailty status each year, including providing documentation from the past year to maintain their exemption.

For more information on how these changes may affect you, explore the resources below:

- NORD: Quick Reference Guide to CMS-2454-IFC Medicaid Community Engagement Requirements
- Center on Budget and Policy Priorities: How States Will Implement H.R. 1's Medicaid Policies, Including Those Taking Coverage Away for Not Meeting Work Requirements
- KFF: Key Issues to Watch for in Upcoming CMS Guidance

Capitol Hill Updates

Appropriations Update

The FY27 federal appropriations process continues to move forward, and recent developments underscore the impact of sustained advocacy efforts from our community. The House passed its FY27 Agriculture-FDA appropriations bill, which would provide approximately $7.1 billion for FDA, while the House Labor-HHS Appropriations Subcommittee advanced its FY2027 spending bill covering NIH, CMS, and other health agencies out of committee but has not been voted on by the full House. The Labor-HHS proposal includes a modest increase for NIH funding while making broader changes across HHS programs.

Excitingly, the draft report language accompanying the Labor-HHS bill encourages NIH to expand its funding of Friedreich's Ataxia research and accelerate its outreach and collaboration with other Federal agencies including the FDA to improve neurodegenerative disease research and treatment (Labor-HHS Appropriations Bill 2027 Draft Report Language p. 113). While report language is not legally binding like bill text, it serves as influential guidance to federal agencies on how Congress intends funds to be prioritized and allocated

The House Defense Appropriations Subcommittee approved its FY27 spending bill, proposing $916.5 million for the Congressionally Directed Medical Research Programs (CDMRP). While this is below the FY26 enacted level of $1.27 billion, it is significantly higher than last year's initial House proposal of $700 million. The bill is now in the full House for debate and passage and will then go to the Senate Appropriations Committee for consideration. We will continue to monitor, advocate, and provide updates as the appropriations process moves forward.

Bipartisan Letter on NIH Staffing Shortages

Reps. Sharice Davids (D-KS) and Brian Fitzpatrick (R-PA), joined by 37 bipartisan colleagues, sent a letter to HHS Secretary Robert F. Kennedy Jr. expressing concern that NIH staffing shortages are slowing the distribution of congressionally appropriated research funding. “These delays are not abstract,” wrote the Members. “They affect research into cancer treatments, Alzheimer’s and dementia, diabetes, and rare diseases that families across the country are living with every day. When grants stall, so does progress toward new therapies and potential cures.”

FDA Rare Disease Roundtable

FARA President Ron Bartek and CEO Jen Farmer were invited to participate in a closed roundtable discussion with FDA leadership on June 3. Ron shared opportunities and recommendations for how FDA can further meet the needs of the FA and rare disease community. FARA’s comments focused on the need to act with urgency, pediatric inclusion, use of regulatory flexibility and accelerated approval, and consistency.

FARA Public Comment to the FDA on Patient-Focused Drug Development

FARA submitted a public comment to the FDA on the impacts of patient-focused drug development (PFDD) meetings. FARA's 2017 externally-led PFDD meeting collected crucial feedback from FA patients and families that led to the approval of omaveloxolone, reshaped research priorities across the field, and has provided important data for ongoing research programs. Our public comment reaffirmed the success of this meeting and all the benefits that PFDD has for the medical research community.

Upcoming Advocacy Events

Registration Open for Rare Across America 2026

Registration is now open for Rare Disease Legislative Advocates' Rare Across America 2026. This advocacy initiative offers rare disease advocates the opportunity to meet virtually and in-district with Members of Congress from August 10–21 to discuss community policy priorities and share personal stories. Registration closes July 17.

Register Here

Rare Disease Congressional Caucus Briefing

On Wednesday, July 22, 2026, from 12:00 - 1:00 pm ET, Rare Disease Legislative Advocates, in cooperation with the Rare Disease Congressional Caucus, are holding a Rare Disease Congressional Caucus Briefing with a virtual option for listeners outside Washington, D.C. The briefing is titled Policy Solutions for Rare Diseases: Improving Access to Care, Treatment, and Community Supports.

Register Here

Announcements

Save the Date for United Against Ataxia Hill Day 2026

In partnership with the National Ataxia Foundation, FARA hosts an annual Hill Day to build relationships with Members of Congress, raise awareness for Hereditary Ataxia, and advocate for policies that would benefit the ataxia community. This year's United Againast Ataxia Hill Day will be held virtually on **Wednesday, September 23**. Save the date and stay tuned for registration information!

New Public Opinion Data on the Importance of Health Research

Research!America released their 26th annual poll data summary, America Speaks! The publication provides a look at the findings of recent research and public health-focused surveys. One of the many compelling results included in this resource is that 92% of Americans across the political spectrum say the federal government should support basic scientific research that advances the frontiers of knowledge even if there are no immediate benefits.

Study Highlights Potential of AI in Rare Disease Diagnosis

New research from Boston Children's Hospital found that AI tools helped identify or clarify diagnoses for children with rare diseases that had previously remained undiagnosed, including progressive neuromuscular diseases. The findings highlight growing interest in the potential role of AI to support genomic interpretation and rare disease diagnosis.

Read More

Disability Services Moving out of Department of Education

The Trump administration announced that it plans to move the Office of Special Education and Rehabilitative Services out of the Department of Education and into the Department of Health and Human Services. This office oversees $15 billion a year in funding for students with disabilities and enforces compliance with the Individuals With Disabilities Education Act.

This change will reduce services at the DOE and may make it harder for families to get the disability support they need. Eliminating the Education Department requires

an act of Congress, and disability groups have argued that so does moving the Office of Special Education and Rehabilitative Services. Legal and congressional challenges to the move are ongoing.

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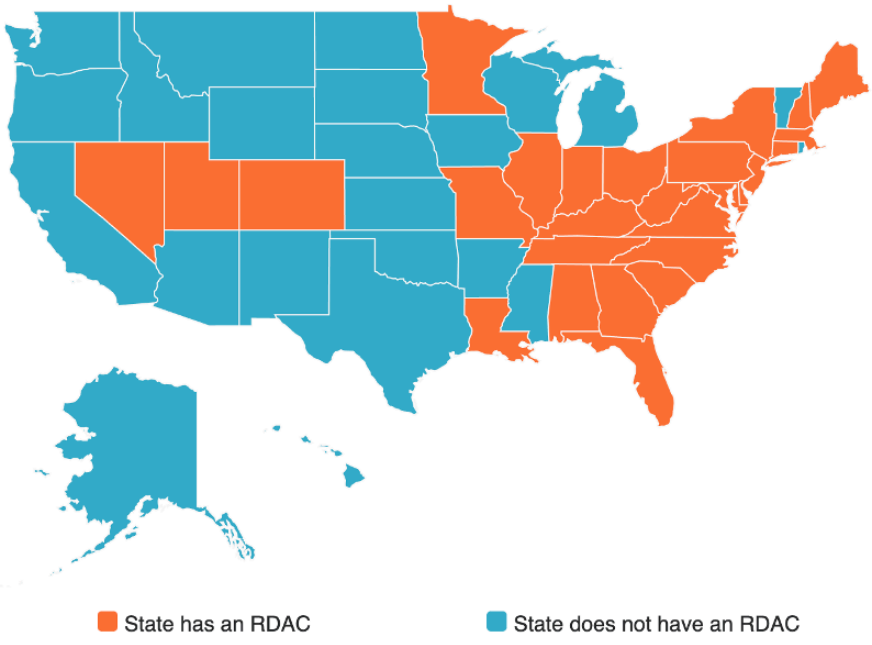
State News

There are six states still in session, with Alaska in special session. California and New Jersey are passing their budgets. Recent state activity includes prior authorization reform in Washington, enactment of Florida's genetic counseling education grant program, and continued legislative discussions related to telehealth, prescription drug coverage, and Medicaid administration.



Upcoming Rare Disease Advisory Council (RDAC) Meetings

- **Georgia:** The Georgia RDAC meets on the third Wednesday of each month at 12:00 PM. They will be meeting virtually on Wednesday, July 15. Additional meeting information can be found here.

- **Massachusetts:** The Massachusetts RDAC meets on the third or fourth Thursday of every other month from 9:00 am to 11:00 AM. They will be meeting virtually on Thursday, July 23. Additional meeting information can be found here.

- **Connecticut:** July 28 (virtual). 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.

- **Tennessee:** The Tennessee RDAC meets on the fourth Wednesday of every other month. They will be meeting on Wednesday, July 22. If you are interested in joining the meeting, please email info@tnrdac.org for instructions on attending. Additional meeting information can be found here.

- **Maryland:** The Maryland RDAC meets on the second Tuesday of every month from 4:00 p.m. to 5:00 p.m. They will be meeting on Tuesday, July 14. Additional meeting information can be found here.

- **Colorado:** The Colorado RDAC will be meeting virtually on July 13 from 9:00-11:00 AM. You can find additional meeting information here.

- **Michigan:** The Michigan RDAC will be meeting on July 22 at 10 AM. You can learn more about joining the meeting here.

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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