



Didn't Sign Up for Hill Day? You Can Still Make Your Voice Heard

Here at FARA, we are getting excited for the 8th Annual United Against Ataxia Hill Day on September 23! We want to thank all the advocates who have been preparing to connect with congressional offices and champion the issues that matter most to our community.

If you missed the registration deadline, don't worry, there are still plenty of ways to get involved and make an impact.



You can contact your lawmakers by email or phone using the contact information available on their official websites and share our [Hill Day asks](#). Personal stories and direct outreach are powerful tools for helping policymakers understand the importance of continued investment in ataxia research and support programs.

You can also show your support for ataxia advocacy by sharing your story on social media and highlighting what ataxia research means to you. With International Ataxia Awareness Day coming up on September 25, it's a great opportunity to raise awareness and amplify our message. Every email, phone call, and social media post demonstrates the strong support behind our advocacy priorities and reinforces the message we're delivering on Capitol Hill.



Congress Passes Continuing Resolution, Delays Proposed OMB Grant Rule

Congress passed a continuing resolution to fund the federal government through December 11, 2026, avoiding a government shutdown. The legislation also temporarily delays implementation of the Office of Management and Budget's proposed revisions to federal grant regulations, allowing additional time for consideration of changes that could affect federal grant administration.

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FDA Names New CDER and CBER Directors

The FDA announced that it has tapped Michael Davis, M.D., Ph.D., and Karim Mikhail—who've been serving as acting directors of the Centers for Drugs Evaluation and Research (CDER) and the Centers for Biologics Evaluation and Research (CBER),

respectively—to occupy their posts on a permanent basis. Rather than just filling vacancies, the selections “signal the direction we are heading,” acting FDA commissioner Kyle Diamantas said in a Sept. 8 statement. “These leaders will help us attract and retain best-in-class talent while building the workforce and infrastructure needed to accelerate innovative across all FDA centers.”

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President Trump Nominates Heidi Overton to Lead FDA

President Trump has nominated Dr. Heidi Overton, currently a deputy director of the White House Domestic Policy Council, to serve as FDA Commissioner. Overton would succeed former Commissioner Marty Makary and must be confirmed by the Senate before assuming the role.



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HRSA Modernizes National Newborn Screening Review Process

A National Newborn Screening Workgroup was announced by the Health Resources and Services Administration (HRSA) in August. The Association for Public Health Laboratories (APHL) received a grant from HRSA to re-establish a pathway for conditions to be considered and recommended for inclusion on the Recommended Uniform Screening Panel (RUSP), and to discuss nationwide issues impacting newborn screening. HRSA announced funding for the creation of a stakeholder workgroup to evaluate a new evidence review pathway for the RUSP and to address emerging newborn screening issues.

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FDA Releases Assessment on the Use of Patient Experience Data

FDA has released its 2026 assessment on how patient experience data is incorporated into regulatory decision-making. The report finds continued growth in the use of patient experience data, including in rare disease and orphan drug applications, and highlights opportunities to strengthen early sponsor engagement, improve data quality, and enhance transparency around how patient perspectives inform regulatory review.

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Physicians Urge CMS to Change Medicaid Work Requirements

The American Medical Association and other physician organizations are urging CMS to revise its implementation of Medicaid work requirements. They argue that the current rule could place people with serious, permanent, or progressive medical conditions at risk of losing coverage.

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Upcoming Advocacy Events



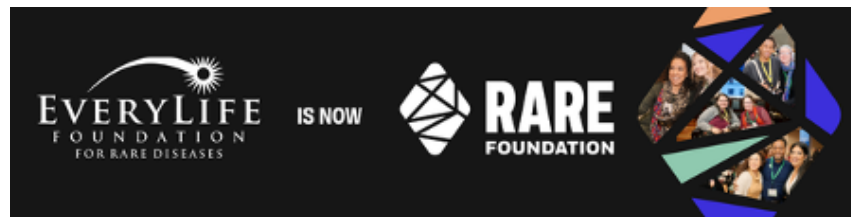
New England Rare Disease Advocacy Day

Registration for Rare Disease legislative Advocates' (RDLA) New England Rare Disease Advocacy Day is open through Friday, September 11! The event is a virtual day of action for New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont) residents impacted by rare disease to meet your state legislators, share your stories, and help advance the policy priorities of the rare disease community.

Virtual meetings will be held on October 6 and 7, with mandatory attendance at the virtual legislative conference and webinar trainings the week of September 28.

[Register Here](#)

Announcements



The EveryLife Foundation for Rare Diseases is now The RARE Foundation

The RARE Foundation's new name stands for Relentless Advocates. Robust Evidence. It reflects the voices of patients, caregivers, advocates, researchers, industry leaders, and policymakers coming together to drive science-based policy change. While the look has changed, RARE Foundation's mission has only grown stronger. The organization remains committed to accelerating diagnosis, improving access to treatments, advancing equitable healthcare, and strengthening the rare disease community.

[Explore the New Website and Updated Programs](#)

FARA Joins Mitochondrial Disease Advocacy Coalition

We're proud to announce that FARA has joined 16 other mito-focused organizations to launch the Mitochondrial Disease Advocacy Coalition, a unified body formed to speak with one voice on Capitol Hill. For years, we've each fought hard for this community – separately. Today, that changes as we work together toward more federally funded research, supporting mito friendly legislation, and fostering a regulatory environment that can meet the urgent need for therapies.



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State News

Prescription Drug Coverage for Rare Diseases in California



[CAAB 1887](#) passed both chambers of the legislature and is now on the Governor's desk. The bill requires health insurers to complete prior authorization within 30 days of a drug being prescribed to treat rare diseases.

CMS Finalizes Changes to Medicaid State Directed Payments



CMS has finalized new limits on Medicaid state directed payments, reducing the maximum payment levels available to states under managed care. States are now evaluating how the changes may affect Medicaid financing, provider reimbursement, and access to care as implementation moves forward.

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Utah: The Utah RDAC will meet on September 15 from 11:00 a.m. to 1:00 p.m. You can attend in-person at HELIX Complex, 30 Mario Capecchi Dr, Salt Lake City, UT 84112. You can attend virtually by filling out [this form](#).

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.

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