



ALS Network 2025 Impact: National ALS Advocacy

The ALS Network advanced ALS advocacy at the federal, state, and local levels. Our public policy efforts are powered by people with ALS and their families and focus on protecting access to care, research, and FDA-approved treatments.



The ALS Network **engaged in 20+ Congressional meetings with 15 Senate and House offices** to advance priorities focused on ALS research funding, access to care, and caregiver support.



Through targeted advocacy alerts and grassroots engagement, the ALS Network activated **more than 4,200 advocates nationwide, resulting in over 1,200 documented actions** supporting federal priorities, including funding and protections for the ALS research ecosystem.



The ALS Network launched its first **Advocate Committee**, creating a community-led forum for people living with ALS and caregivers to engage directly in advocacy. The committee has taken action to support ALS Caucus growth and shape caregiver-focused education and policy priorities grounded in lived experience.



The ALS Network joined ALS organizations nationwide in coordinated sign-on letters and joint advocacy to **defend funding for the National ALS Registry and Biorepository**, oppose proposals limiting access to Medicaid and community-based services, and urge Congress to fully fund ALS programs across NIH, the Department of Defense, and CDC.



Alongside advocacy partners, the ALS Network helped pass California Senate Bill 590, expanding **Paid Family Leave to include chosen and extended families**, ensuring caregivers supporting people living with ALS can take paid, job-protected leave that reflects real caregiving relationships.



In Hawaii, the ALS Network held nine meetings with state policymakers to increase ALS awareness and build momentum for future policy advocacy for families. The ALS Network also supported House Bill 701 (HD1), legislation aimed at **strengthening financial support for family caregivers**.



The ALS Network helped lead national strategy and education efforts to **advance the reauthorization of the ACT for ALS Act**, aligning partners, engaging congressional offices, and elevating community stories to reinforce the law's impact and the need for sustained federal investment.



In honor of **ALS Awareness Month**, the ALS Network, alongside local advocates and community partners, facilitated the adoption of official proclamations recognizing ALS awareness across **the Island of Hawaii, the State of Hawaii, Fresno County, the County of Maui, and Thousand Oaks**.



In California, the ALS Network, alongside advocacy partners, engaged L.A. Care and submitted formal opposition that resulted in protecting key CalAIM Community Supports in Los Angeles County, **preserving access to care for people living with ALS and their caregivers**.



Advocates and representatives from the ALS Network joined I AM ALS in Washington, D.C., for the **ALS Community Summit and 4th annual ALS Flag Display**. ALS Network advocates held 10+ meetings with congressional offices while joining thousands on the National Mall to honor people living with ALS.

Your support makes a difference. Let's cure ALS together.