



The **ALS Network**, then ALS Golden West, helped secure resources and support for ALS research and care through our advocacy efforts. Our important public policy initiatives at the federal, state, and local levels are aligned with the critical needs of people with ALS and their families and as part of our continued fight to ensure access to FDA approved treatments.



(CA AB 424) The ALS/ Neurodegenerative Disease Registry was signed into law by California Governor Gavin Newsom. The bill establishes a **statewide ALS registry and will direct the California Department of Public Health to collect data on ALS and require hospitals and healthcare professionals to report each case of ALS.**



(CA AB 511) The California ALS Research Network Voluntary Tax Contribution Fund was passed into law. Starting in 2025, Californians filing their state income taxes to donate an amount of their choice to fund ALS research. This will enable the establishment of a stable funding source to **support the work of our California ALS Research Network.**



The ALS Network **mobilized ALS advocates** who participated in several meetings with FDA officials and filed comments **in support of the approval of Qalsody (tofersen) for the treatment of ALS.** Qalsody was approved on April 25, 2023.



Advocated for the enactment of the **Justice for ALS Veterans Act.** This legislation would **extend benefits to surviving spouses of veterans who have died from ALS,** regardless of how long they lived with the disease.



ALS organizations and advocates, including the ALS Network, **sent letters to 43 of the largest insurance companies and healthcare payers** to make Relyvrio, an FDA approved ALS treatment **available and accessible for people living with ALS.**



In a letter shared with the Centers for Medicare and Medicaid Services and the Veterans Administration, ALS organizations and advocates, including the ALS Network, **formally objected to health insurer CIGNA for their decision to exclude Relyvrio from its formulary.**



The US House of Representatives passed the Elizabeth Dole Home Care Act, a key priority for people with ALS who have served in the military and their loved ones. This bill will **extend home care programs for veterans, benefiting families in our ALS community.**



ALS Network Leadership **submitted written comments for the FDA public advisory committee meeting for BrainStorm Cell Therapeutics' stem cell therapy, NurOwn,** for the treatment of ALS. We encouraged other ALS advocates to do the same.



The ALS Network presented a special ASK ME webinar titled **"Advocacy in ALS - Why Your Voice Matters,"** facilitated by notable legislative and public policy consultants and staff across the United States.



Representatives from the ALS Network and other advocates joined I AM ALS for **ALS Flag Day** in Washington DC, where **6,000 flags, with the names of people with ALS,** marked the number of people diagnosed with the disease every year in the US.

Your support makes a difference. It is only together that we will end ALS.