# ELC POLICY AGENDA-2025-2026

The Epilepsy Leadership Council (ELC) is a coalition of more than 60 professional societies, patient advocacy organizations, and governmental agencies working together to improve the lives of all people living with the epilepsies, seizures and related disorders (epilepsy). The ELC was created in response to the 2012 Institute of Medicine Report, *Epilepsy Across the Spectrum: Promoting Health and Understanding.*

The nonprofit members of the ELC support the policies outlined below that will:

- Increase awareness and reduce stigma and discrimination;
- Fuel research and innovation leading to better treatments and ultimately, a cure;
- Improve surveillance, data collection and prevention activities; and
- Improve access to care.

In all areas, ELC supports policies that will reduce health disparities and promote health equity in the epilepsy community.

As expressed in this April 2025 statement, many ELC nonprofit members oppose actions to cut vital federal epilepsy programs including but not limited to the Epilepsy Program at the Center for Disease Control and Prevention (CDC), various epilepsy-related programs within the Congressionally Directed Medical Research Programs, and the National Institutes of Health (NIH). Since 40% of adults with epilepsy and more than one-third of children and youth with special health care needs rely on Medicaid, many ELC nonprofit organizations are also concerned with the changes and cuts to Medicaid contained in H.R. 1. ELC nonprofit organizations stand united in this policy agenda-to both protect current epilepsy programs and funding and to advance new initiatives that improve the lives of people with epilepsy, their families, and the broader epilepsy community.

ELC's policy agenda is federally focused but recognizing that some programs have federal and state implications, ELC and its nonprofit members are able to engage in state issues in line with this policy agenda when they are related to and/or impacted by federal programs.

## Increasing Awareness of the Epilepsies and Reducing Stigma and Discrimination

Despite it being estimated that nearly 3.4 million Americans and 50 million people worldwide live with epilepsies, epilepsy is relatively unknown. The lack of awareness has resulted in a disproportionately small percentage of funds being allocated to the epilepsies-which, as noted above, are under current threat. There is also significant stigma associated with epilepsy and people with the epilepsies unfortunately face discrimination in many aspects of life including employment, education and access to healthcare.

ELC advocates for:

- Education and awareness of the epilepsies to reduce the stigma associated with epilepsy;
- Increasing membership in the Congressional Epilepsy Caucus;
- Passing the National Plan for Epilepsy Act to develop a comprehensive strategy to prevent, diagnose, treat, and cure epilepsy and improve the wellbeing of people with epilepsy and their families;
- Preserving funding for, reinstating staff of, and protecting the work done by the Center for Disease Control and Prevention's (CDC's) Epilepsy Program, which has surveillance and data collection efforts and implements public health research and programs and activities to improve the health and well-being of people with epilepsy;
- Protection and enforcement of rights for people with the epilepsies, including through the American Disabilities Act, the Rehabilitation Act, education laws including the Individuals with Disabilities Education Act (IDEA), Section 1557 of the Affordable Care Act and other civil rights laws related to accessibility, education, employment, transportation and non-discrimination in health care;

- Preservation of the U.S. Department of Education to ensure that the rights of students with disabilities are enforced and protected;
- Passing the Seizure Awareness and Preparedness Act to authorize federal funding to train school personnel on seizure awareness and preparedness and individualized health care plans; and
- Improving public awareness about the prevalence of epilepsy mortality including Sudden Unexpected Death in Epilepsy (SUDEP) and methods to reduce risk.

**Access to Care**

People with the epilepsies need access to affordable and comprehensive health insurance coverage and medical care in a timely manner. Accordingly, the ELC opposes all barriers that impede access to care to epileptologists, epilepsy centers, other specialists, and the diagnostic tools, drugs, devices, surgeries and other treatments they recommend for epilepsy and its co-morbidities.

ELC advocates for:

- Protecting and improving access to high-quality, comprehensive health coverage and protecting private and government health programs vital to people with epilepsy including but not limited to Medicaid, the Children's Health Insurance Program (CHIP), Medicare, TRICARE, the VA and the patient protections required by the Affordable Care Act;
- Opposing cuts and changes to Medicaid that would impede access to care, long-term services and supports, and early intervention for children and adults with epilepsy including per capita caps and block grants, work and community engagement requirements, required cost sharing, and more frequent eligibility checks;
- Protecting and increasing funding for the VA Epilepsy Centers of Excellence (ECoE), a national network of treatment centers that provides specialty care and state-of-the-art diagnostic and therapeutic services to our nation's veterans with epilepsy and seizure disorders, as well as outreach, education, and research;
- Removing insurance barriers in public and private insurance related to step therapy, quantity limits, burdensome prior authorization requirements, narrow networks, and other barriers that delay or impede access to the services and treatments necessary to diagnose and treat epilepsy and its co-morbidities;
- Supporting care models that address geographic barriers to care, including maintaining expanded access to care and treatments via telehealth and non-emergency medical transportation;
- Passing the Accelerating Kids' Access to Care Act which would streamline the process for out-of-state medical providers to enroll in a state's Medicaid program, which will make it easier for kids with epilepsy covered by Medicaid or the Children's Health Insurance Program (CHIP) to travel to another state for medical care;
- Access to the full range of FDA-approved treatments used for epilepsy including by maintaining Medicare's Six Protected Classes Policy;
- Reinstating the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC); and
- Coverage of and affordable access to seizure detection devices.

**Research and Innovation in Epilepsy**

Given its prevalence and significant impact on their daily lives, children and adults with epilepsy and their caregivers deserve epilepsy research to be prioritized by the federal government. ELC advocates for more research and innovation in epilepsy to advance basic science, translational, and clinical research that fuels many important areas including but not limited to: expediting diagnosis; preventing epilepsy and its progression; improving treatment options-particularly for those with few or no effective treatments; understanding and preventing adverse effects of epilepsy including Sudden Unexpected Death in Epilepsy (SUDEP) and other epilepsy-related mortalities; understanding and treating common comorbidities of epilepsy such as mental health challenges; improving quality of life for affected individuals and their caregivers; and advancing toward a cure for the epilepsies. In general, ELC advocates for funding for research that aligns with the research benchmarks discussed during the NINDS Curing the Epilepsies meeting.

ELC advocates for:

- Protecting and increasing funding for epilepsy-related research at federal agencies and programs, including but not limited to programs at the National Institutes of Health (NIH), the Brain Research Through Advancing Innovative Neurotechnologies (BRAIN) Initiative, Department of Defense Congressionally-Directed Medical Research Programs (CDMRP), and the Department of Veterans Affairs (VA);

- Protecting a structure for the NIH-particularly the NINDS-and other aspects of NIH such as indirect costs so that epilepsy research is not impeded;
- Continued activities of ICARE, the Interagency Collaborative to Advance Research in Epilepsy, which seeks to coordinate research activities at the NIH, other federal agencies, and the research and patient advocacy communities;
- Research to support and develop well-designed, scientifically rigorous, controlled research trials on any cannabis-based products that have potential to have positive benefits in the treatment of resistant epilepsy;
- Protecting and increasing funding for-as well as preserving authority of-the Food and Drug Administration to continue to fuel innovation and increase approved treatment and device options for people with the epilepsies;
- Protecting the Orphan Drug Act to facilitate innovation and development of treatments and potential cures for the rare epilepsies.
- Reauthorizing the Rare Pediatric Disease Priority Review Voucher;
- Policies that support coordination and clinical trials that use patient-important outcomes and endpoints as well as increase the diversity of participants in clinical trials so that trial participants reflect the population of individuals who will receive the treatment;
- Quality improvement programs and activities that enable people with epilepsy to receive high-quality care from their providers; and
- Funding for the National Institutes of Health to establish a Pediatric-onset Epilepsies Network-creating a collaborative, multidisciplinary research model to enroll patients from many hospitals in the same system to enable cooperative research studies, accelerate the development of knowledge about the epilepsies, and rapidly advance therapeutic options and their implementation to improve treatments and healthcare outcomes and ultimately cures.

**Surveillance, Data Collection, and Prevention Activities**

Restored and expanded surveillance and prevention activities will improve the health and well-being of people with the epilepsies and their families. ELC encourages all stakeholders – federal and state governments, non-profit epilepsy provider data collection efforts including learning health systems, and patient advocacy organizations – to work together to achieve better understanding of the incidence and prevalence of the epilepsies, and the causes of and effective treatments for the epilepsies and their co-morbidities.

ELC advocates for:

- Protecting and increasing funding for the CDC's Prevention Research Center (PRC) program, which supports the Managing Epilepsy Well (MEW) Network, which conducts and promotes research on epilepsy self-management;
- Restored and expanded national surveillance of the epilepsies, such as data collection through the Behavioral Risk Factor Surveillance System (BRFSS), the National Health Interview survey, the National Survey of Children's Health and the National Neurological Conditions Surveillance System;
- Funding for data modernization efforts at the CDC to improve our nation's public health data infrastructure; and
- Funding for the Safe Motherhood and Infant Health Program to continue and expand the Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry.