

## 2017 GOVERNMENT AFFAIRS STATEMENT

**1 in 26 Americans** will develop epilepsy at some point in their lifetime. More than 3 million children and adults in the United States have epilepsy and children and the elderly are particularly affected. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions and can develop at any stage of life. Epilepsy can result from a variety of causes including head trauma; brain tumor; stroke; infection; neurodegenerative disorders, including Alzheimer's disease; genetic predisposition; and poisoning. Often no cause is identified. The effects of epilepsy vary widely from individual to individual, and often create medical, economic, and social hardship. Epilepsy and seizures can affect anyone from any age, ethnic background, or gender – everyone is at risk of developing seizures or epilepsy.

The Epilepsy Foundation is committed on behalf of people with epilepsy and their family members and caregivers to an effective advocacy program. Our goal is to ensure access to and coverage of quality care and essential services; the protection of the rights of individuals with disabilities; and the promotion of research into treatments, better understanding of causes, consequences, and outcomes, and, ultimately, cures for all the epilepsies. These broad goals guide our federal and state advocacy, and we dedicate ourselves to a government advocacy program that includes the following legislative and regulatory issues.

### **Epilepsy Research & Programs**

- Advocate for federal funding for epilepsy research and public health education programs within the Centers for Disease Control and Prevention (CDC).
- Support increased funding levels and expanded research efforts for epilepsy at the National Institutes of Health (NIH), the Department of Defense (DoD), the Veterans Administration (VA), the Department of Labor, and all agencies that may impact the cure and treatment of epilepsy and seizures.
- Advocate for removing federal barriers to research on the connection between cannabis and epilepsy, including supporting the rescheduling of cannabis to increase access to cannabis for research.
- Support increased funding for the Food and Drug Administration (FDA) and other relevant agencies to promote research studies on the safety and efficacy of anti-epilepsy drugs (AEDs), including continued research into bioequivalence.
- Promote research on traumatic brain injury and epilepsy conducted through grants from the NIH, VA Epilepsy Centers of Excellence, and DoD.
- Promote epilepsy research in psychosocial, mental health, behavioral, cost of care, prevention, women's health, aging, and other underserved populations.
- Support government policies that ensure the adequate protection of people in clinical trials and work to require that all clinical trials be posted on [www.clinicaltrials.gov](http://www.clinicaltrials.gov), including those whose outcomes may be adverse.
- Promote open access to research information produced with funding from the federal government.
- Support sound fiscal policies that maintain critically needed benefits for people with disabilities and chronic health conditions, including epilepsy.

## **Epilepsy Treatment & Access to Care**

- Support policies that promote a health care delivery system that ensures availability, portability, and access to appropriate and affordable health care for all children and adults with epilepsy, including easy access to specialty care and all available treatments.
- Ensure that people with epilepsy are protected by all state and federal laws designed to ensure nondiscriminatory access to insurance and health benefits.
- Promote, support, and improve upon provisions contained in the Affordable Care Act that benefit people living with epilepsy.
- Advocate relevant federal agencies for policies that protect access to all epilepsy medications and treatments.
- Support policies consistent with the Epilepsy Foundation's policies on drug formularies and medication substitution.
- Oppose efforts to reform Medicaid in ways that limit adequate coverage for patient services or restrict the scope of services.
- Support policies that exempt epilepsy medications with no evidence of abuse, like Schedule V non-narcotic anti-epilepsy drugs (AEDs), from prescription drug monitoring programs (PDMP) to ensure timely access to physician directed care.
- Support the creation of safe, legal medical cannabis programs for individuals living with epilepsy that will allow for in-state cultivation, production, and dispensing while encouraging further in-state research and ensuring that products are safe and consistent.
- Advocate for improved patient care and treatment by increasing the number and availability of specialists in the field.
- Support policies encouraging pediatric studies of new drugs and the inclusion of women in clinical trials.
- Support efforts to modernize the drug and diagnostics evaluation and regulatory network, and encourage the development of new and more targeted treatments.
- Encourage the federal agencies that oversee access to medication and treatment for epilepsy to continue to research and analyze the issue of bioequivalence among different manufacturers' versions of the same therapeutic product, and to ensure such medications are safely interchangeable for the individual with chronic, hard-to-manage seizures.
- Support efforts to create electronic medical information systems that protect individual privacy, allow for individual access, and promote the portability of records and information.
- Work with other national agencies and professional organizations providing psychiatric care to promote comprehensive care of people with epilepsy and co-morbid psychiatric disorders.

## **Civil Rights**

- Support implementation of the Americans with Disabilities Act (ADA) and the ADA Amendments Act of 2008.
- Promote civil rights laws that ensure protections for people with epilepsy, including those contained in the ADA, the Family Medical Leave Act, and the Rehabilitation Act of 1973.
- Support efforts to educate first responders about seizures and epilepsy and legislation directed at local, state, and federal programs to protect individuals from unnecessary restraints or other measures that endanger an individual's health or safety.
- Support legislation that opposes the use of restraints and seclusion for children in school. Educate teachers and first responders about the dangers of using restraints, seclusion, and other forms of abuse against people with epilepsy.

- Protect the voting rights of people with disabilities by ensuring accessibility to voting places and machines, and addressing concerns surrounding photo ID requirements for those who do not have driver licenses.
- Support nominees to the federal courts who understand disability rights, and support legislation that improves the effectiveness of our federal courts.

### **Transportation & Driving Laws**

- Support legislative and regulatory proposals that align with the consensus model law related to driver licensing and epilepsy developed by the Epilepsy Foundation, the American Epilepsy Society, and the American Academy of Neurology.
- Advocate for improvements to the United States Department of Transportation regulations on commercial driving.
- Support funding for local and state transportation services and programs that include resources for people with disabilities and epilepsy.

### **Social Security Disability Insurance Program**

- Promote Social Security policies that remove barriers to returning to work, improve the disability determination process, and preserve entitlements and benefits.
- Support the recognition of epilepsy as a related consequence of military service brain injury, and protect access for military veterans with service connected epilepsy and seizures to disability benefits and services for their condition.

### **Education**

- Support the rights of children with epilepsy and seizures to full inclusion in all educational activities and programs whether or not they need auxiliary services, such as access to medication and treatment, in order to safely participate in such educational activities.
- Support parents in their right to be members of their children’s Individual Education Plan (IEP) team.
- Support inclusion of epilepsy education in the United States Department of Education national teacher certification standards.

### **Employment**

- Support increased funding for and reauthorization of programs affecting people with epilepsy, including those authorized by the following laws: the Workforce Investment Act Amendments of 1998; the Social Security Act; the Rehabilitation Act Amendments of 1998; the Individuals with Disabilities Education Act; the Developmental Disabilities Act; the Lifespan Respite Care Act; the Mental Health Parity Act; and the Children’s Health Act of 2000.
- Support employment policies that implement the goals of the ADA and the ADA Amendments Act.
- Promote the use of the federal government’s purchasing power to increase the employment of people with disabilities in the private sector.
- Increase the number of people with disabilities employed by the federal government.
- Support federal policies that improve the ability of people with disabilities to gain full employment.

**Public Awareness**

- Promote and encourage public awareness campaigns about epilepsy and seizures through federal and state agencies.

**Injury Prevention**

- Support laws, regulations, and programs that promote use of helmets, sports safety equipment, seatbelts, and speed limits to prevent head injury.

**Family and Community Support**

- Support legislative and regulatory efforts to promote respite care programs, family support programs, and caregivers programs.
- Support legislation that increases wages and benefits for direct support professionals.

**Nonprofit Advocacy**

- Encourage government policies that strengthen the ability of voluntary, nonprofit organizations to provide essential services. This includes the continued preferential treatment for nonprofit postal rates, tax policies that encourage charitable giving, and fair policies overseeing lobbying activities.
- Support government policies that promote the transparency and accountability of voluntary organizations, without adding undue burdens to or violating individual constitutional rights.
- Oppose efforts to limit nonprofit advocacy.