



## 2018 EPILEPSY CAPITOL HILL MESSAGE

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1. The Epilepsy Foundation believes epilepsy should be a federal public health priority, and supports investments in public health programs that help build safer communities, end stigma associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions and disabilities. **We urge Congress to continue to invest in critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC) by supporting a funding level of \$9.5 million to ensure the safety and health of people with epilepsy.**
2. The Epilepsy Foundation supports \$175 million in funding for epilepsy research at the National Institutes of Health (NIH) and \$38.4 billion in overall funding for NIH. We urge Congress to continue to invest in research initiatives that have been partially funded at NIH, and to support funding for a cure and better treatments for epilepsy. **We urge Congress to continue to support the following initiatives at National Institute of Neurological Disorders and Stroke (NINDS):**
  - **NINDS Centers without Walls.** The initiative promotes key opportunities for collaborative research.
  - **BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Initiative.** The initiative calls upon the private and scientific communities to form partnerships to advance research on mapping the human brain.
  - **ICARE (Interagency Collaborative to Advance Research in Epilepsy).** Led by NINDS, this initiative coordinates the research efforts of federal agencies and voluntary organizations to identify areas for collaboration.
3. The Epilepsy Foundation strongly opposes efforts to undermine the stability of the Affordable Care Act (ACA) Marketplace for individual and small group insurance created by the Patient Protection and Affordable Care Act (ACA). **We support access to quality health care that is affordable and comprehensive, and that meets the needs of individuals with serious and chronic health conditions.** The ACA allowed millions of individuals – many who had been unable to access health insurance in the past because of denials and exclusions for pre-existing conditions, as well as unaffordable premiums – to gain meaningful access to quality and affordable care.
  - **Stabilizing the ACA Marketplace:** People living with epilepsy and other complex chronic conditions need access to quality health care to lead productive lives. We urge Congress to oppose policies that destabilize the ACA Marketplace, including the *Improving Choice in Health Care Coverage Act* (S. 2507), which would allow short-term limited duration plans - intended to bridge gaps in coverage – to become a substitute for comprehensive annual plans. We urge Congress to instead support policies that would help stabilize the ACA Marketplace, such as the *Fair Care Act* (S. 2494), which would create protections for short-term limited durations plans, and the *Bipartisan Health Care Stabilization Act of 2017*, which would improve affordability by limiting enrollees' cost-sharing burden.

4. The Epilepsy Foundation supports the *Restoring the Patient's Voice Act (H.R. 2077)*, which would streamline step therapy protocols for health plans governed by the Employee Retirement Income Security Act of 1974 (ERISA). Onerous step therapy requirements or “fail first” policies that require individuals to try and fail one or more medications preferred by the insurer before receiving the originally prescribed medication prolong ineffective treatment. **H.R. 2077 would reform step therapy protocols to improve access to physician-directed care and provide exceptions to step therapy protocols in specified cases.**
5. The Epilepsy Foundation is committed to ensuring that state Medicaid programs meet the needs of people living with epilepsy and other complex chronic conditions and disabilities. More than a third of people living with epilepsy rely on Medicaid for their health care needs. We actively support formularies that meet the needs of beneficiaries and strongly opposes onerous administrative barriers, such as work requirements intended to limit access to care for the most vulnerable Americans. **The Epilepsy Foundation strongly opposes proposals to weaken the safety net provided by state Medicaid programs for children and adults living with epilepsy.**
6. The Epilepsy Foundation supports the Orphan Drug Act, which provides incentives for biopharmaceutical companies to develop products for rare diseases. More than one third of people living with epilepsy are not able to reach seizure control with current FDA-approved therapies, including those with rare forms of epilepsy. **We urge Congress to oppose proposals that would weaken the Orphan Drug Tax Credit, which has been extremely successful in incentivizing innovation in the rare disease space.**
7. The Epilepsy Foundation is committed to supporting physician-directed care and to exploring and advocating for all potential treatment options, including medical cannabis and cannabidiol (CBD). **We support lifting federal barriers to research on cannabis and CBD and support access to these potential therapies, through state-regulated programs, for individuals when other treatment options have failed them.** If a patient and their health care team feel that the potential benefits of medical cannabis for uncontrolled epilepsy outweigh the risks, then the patient should have safe, legal access to medical cannabis.
8. The Epilepsy Foundation opposes the *ADA Education and Reform Act (H.R. 620)* and any similar efforts to modify the Americans with Disabilities Act (ADA) to limit the rights of people with disabilities. **We urge Congress to encourage full implementation of the ADA and other civil rights laws that protect the rights of people with disabilities, and oppose H.R. 620 and other attempts to reduce the disability community's right to access public accommodations**

**If you have any questions or concerns, please contact Beatriz Duque Long, Interim Vice President Public Policy and Advocacy at [bduquelong@efa.org](mailto:bduquelong@efa.org) or 301-918-3764.**