



Highlights from the Hill

December 2016

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Thank you

Dear Friend,

This year has been full of successes for the epilepsy advocacy community. With the help of our dedicated grassroots supporters, we've been able to expand access to lifesaving epilepsy treatments, fight back against discrimination and stigma, and secure commitments for increases in funding for medical research across the country.

We're excited to continue our work in 2017. One of our main goals is to expand our network and amplify the voices of the epilepsy community - and we need your help! As the year comes to an end, please take a moment to encourage your friends and family to join our [Speak Up, Speak Out](#) network. The greater our numbers, the louder our voices will be.

Thank you,

Epilepsy Foundation Public Policy Team

Wrap-Up of Key 2016 Initiatives

National Successes

21st Century Cures Act Signed into Law - Includes Epilepsy Priority Neurodata Registry!

In December, Congress overwhelmingly passed the 21st Century Cures Act, a bipartisan bill that increases funding for medical research at the National Institutes of Health (NIH) and innovation at the Food and Drug Administration (FDA), creates incentives for developing therapies for rare conditions, and strengthens the patient voice in the regulatory environment. On December 13, 2016, President Obama signed the 21st Century Cures Act into law.

Thank you to the nearly 1,500 members of the epilepsy advocacy network who recently wrote letters to Congress in support of the bill!

This is a great legislative victory for medical research and an example of removing barriers and helping the government foster innovation. The new law will require the Centers for Disease Control and Prevention (CDC) to set up a surveillance system for neurological diseases. This registry may include epilepsy, and we will continue to watch and help our community voice our support for including epilepsy in the registry launch. Thank you to all who joined us in advocating for the neurodata surveillance legislation - this was a key priority of the Epilepsy Foundation, and we are so pleased to see it included in the final package.

The 21st Century Cures Act will help bring the innovative treatments and therapies that patients want and need to the market faster. It will allow the FDA to use real-world data from patients that can significantly improve how drugs are evaluated throughout the lifecycle of a product, from development to post-approval monitoring.

Further, important provisions were included in the bill to support the Precision Medicine Initiative and the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, which set the goal of helping researchers find new ways to treat, cure, and prevent brain disorders, including epilepsy.

Epilepsy Foundation and I Am Essential Coalition

The Epilepsy Foundation, as a leader of the I Am Essential coalition, has advocated for improved access to quality and affordable health care in ACA Marketplace Plans throughout the year by sending several letters to the Administration.

For further details on these efforts see: <http://bit.ly/EF-ACA>.

Epilepsy Foundation Encouraged Congress to Finalize New Fiscal Year Spending

In November, the Epilepsy Foundation joined a coalition letter with over 50 other organizations urging Congressional leadership to complete the fiscal year 2017 appropriations process and not revert to using continuing resolutions. Continuing resolutions can cause uncertainty or reduced funding that can be devastating for medical research - including epilepsy research at the National Institutes of Health (NIH).

Throughout the year, you have joined us in advocating for increased funding for the NIH. We will continue to advocate for the completion of the funding process for fiscal year 2017 as Congress passed and the President signed another continuing resolution on December 10. This continuing resolution funds most federal agencies, including NIH and other health programs, until April 28, 2017 at a rate of operations that is 0.1901 percent below last year's budget!

Fortunately, there was some positive action from Congress regarding funding. The December continuing resolution did enable NIH to immediately access the full \$352 million in funding made available for 2017 under the recently-passed 21st Century Cures Act.

State Successes

Arizona Reinstated KidsCare

In May, Arizona reinstated KidsCare, a health insurance program providing coverage for more than 30,000 low-income children, including many with epilepsy. KidsCare reinstatement was one of the Epilepsy Foundation's top priorities in Arizona. In March, we sent a [letter](#) to Arizona Senate President Andy Biggs explaining that "for persons living with complex chronic conditions, like epilepsy, health insurance is incredibly important."

Connecticut Improved Timely Access to Epilepsy Medications

In May, Connecticut passed HB 5053, a bill that lessened reporting requirements for some medications, including epilepsy treatments. The bill requires prescribers to check the prescription drug monitoring program when writing an initial prescription, and then annually after that, instead of every 90 days. While we strongly support exempting Schedule V non-opioid drugs, which are epilepsy medications, from the state's drug monitoring program, we believe HB 5053 was a step in the right direction. Read our letter to Connecticut Governor Dan Malloy in support of HB 5053 [here](#).

Several States Created Medical Cannabis Programs

Through legislative efforts and direct ballot initiatives, six states (**Pennsylvania, Ohio, North Dakota, Florida, Montana, and Arkansas**) passed legislation to create or expand medical cannabis programs. These programs will expand access to life-changing treatment for people living with intractable epilepsy. The Epilepsy Foundation supports the creation of safe, legal medical cannabis programs for individuals living with epilepsy - read more about our advocacy efforts here: <http://bit.ly/EFmedicalcannabis>.

Looking Ahead to 2017

Morning Consult Op-ed by Angela Ostrom: *A Unique Opportunity to Focus on Epilepsy Patients and Innovation*, November 11, 2016

This op-ed was an opportunity to spread awareness about epilepsy and the challenges that the epilepsy community faces. It anticipated the important debates to come related to the reauthorization of the Prescription Drug User Fee Act (PDUFA) and underscored the significance of this legislation.

"We cannot afford to be complacent when it comes to making new discoveries for patients with epilepsy, especially those who cannot control seizures. Ensuring reauthorization of PDUFA VI in a timely manner is an important step forward. Lawmakers from both parties agree that we're on the cusp of major advancements across the biosciences."

The full op-ed can be read here: <http://bit.ly/EFMorningConsult>.

Epilepsy Foundation Joins over 60 National Organizations to Caution Congress Against Repealing the ACA

The letter was sent to members of Congress on Monday, December 12 and it expressed strong opposition to repealing key provisions of the Affordable Care Act, especially without an adequate, comprehensive replacement plan in place. The letter encouraged efforts to improve access to health care and move forward to advance affordability and access. It highlighted the improvements that those with disabilities and chronic conditions have already experienced due to aspects of the ACA, including consumer protections that aim to limit discrimination against people with pre-existing conditions and the expansion of Medicaid in most states.

We will continue to closely monitor Congressional and Administrative actions as they relate to health care access and health insurance in 2017.

Continued Advocacy for Epilepsy Foundation Priorities on National and State Stages

The Epilepsy Foundation advocacy priorities revolve around three core principles:

1. Increasing funding for epilepsy program, research, and a cure
2. Ensuring access to care
3. Spreading awareness and ending discrimination

These principles will continue to shape our priorities going into the 2017 legislative sessions.

There is still a great deal of uncertainty around what is in the pipeline for 2017, especially in the federal government. We look forward to continued discussion as we learn more once the new Administration and Congress are installed.

Epilepsy Foundation and I Am Essential Coalition Urge Enrollment in Health Insurance

As a leader of the I Am Essential coalition, the Epilepsy Foundation encourages our community to enroll in health care coverage through the 2017 marketplaces. With the new presidential administration in 2017, there is apprehension around the future of the Affordable Care Act. Now, more than ever, members of the epilepsy community need to be educated about their options for coverage. No one living with epilepsy should go without health insurance.

Remember: When shopping for health insurance, look #BeyondPremiums to understand the hidden costs of health insurance that could affect your budget and your treatment.

This email went out to advocates in the I Am Essential coalition and can be viewed here: <http://bit.ly/IAEemail>.

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