



# Highlights from the Hill

August 2017

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We encourage you to invite others to join our [Speak Up, Speak Out!](#) advocacy network. Members receive the monthly Highlights from the Hill newsletter and alerts about opportunities to advocate for the epilepsy community throughout the year. Growing our advocacy network is critical to achieving our public policy goals as we move through busy state and federal legislative sessions. Make a difference today by sharing our Speak Up, Speak Out! Network on [Facebook](#) and [Twitter](#).

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## National Advocacy

### Senate Rejects Plan to Unravel Affordable Care Act and Cut Medicaid Funding

In the early morning hours of July 28, 2017, members of the U.S. Senate ended debate and voted 51–49 against the *Health Care Freedom Act* (HCFA), a bill that would have left millions of Americans without access to affordable health care. Prior to the vote, more than 2,000 members of the epilepsy community wrote to Congress in opposition to the legislation and other related proposals that endangered access to care for people with epilepsy.

The Epilepsy Foundation advocates for access to high-quality health care that is affordable and comprehensive. We look forward to a bipartisan effort in Congress to implement health care reforms that will lower the cost of medical care while preserving patient protections created by the *Affordable Care Act* (ACA). Health care reforms must be designed to ensure people with

epilepsy and other chronic conditions and disabilities have insurance coverage options equal to individuals without immediate health care needs or pre-existing conditions, and plan options should not require prohibitively high cost-sharing.

To learn more about health care reform, visit [advocacy.epilepsy.com/ACA](http://advocacy.epilepsy.com/ACA).

### **Congress Reauthorizes Food and Drug Administration User Fee Programs**

On August 3, 2017, the Senate passed the *FDA Reauthorization Act of 2017* with an overwhelming majority, clearing the way for the bill to be signed by the president. The bill previously passed the House of Representatives with a voice vote on July 12, 2017.

The Epilepsy Foundation applauds Congress for passing the *FDA Reauthorization Act* with bipartisan consensus. The user fee agreements accelerate the pace of biomedical innovation by allowing the Food and Drug Administration (FDA) to collect fees from drug and medical device manufacturers to fund the new drug and device approval process. Without speedy reauthorization, the current agreements would have expired on September 30, 2017, forcing the FDA to lay off thousands of workers and halting their important work. The reauthorization also includes many provisions to improve FDA's work – ensuring an effective and efficient FDA that is responsive to scientific innovation and the needs of the patient community.

Promoting biomedical innovation and bringing promising therapies to market sooner is exceptionally important to the epilepsy community because no cure currently exists for epilepsy. At least one-third of people with epilepsy live with drug-resistant or intractable seizures, and many more live with debilitating side-effects from medications. Despite the development of many innovative medications, medical devices, and surgical options over the last decade, the number of people with epilepsy who are experiencing uncontrolled seizures has not changed.

The FDA user fee agreements play a key role in advancing medical innovation, and they are the result of years of discussions with all relevant stakeholders, including the FDA, industry, and the patient community. The policies and goals included in the agreements reflect what these stakeholders value and will help ensure advancements and improvements within the FDA and ultimately in health care more broadly.

To learn more about the agreements and thank your representatives for voting to support biomedical innovation, visit [advocacy.epilepsy.com/FDA](http://advocacy.epilepsy.com/FDA).

### **Congress Considers CHIP Reauthorization**

For twenty years, the Children's Health Insurance Program (CHIP) has provided health care coverage to American children with family incomes too high to qualify for traditional Medicaid, but too low to afford private insurance. Today, CHIP provides coverage to 8.9 million children across the United States, including many with epilepsy.

Funding for CHIP is set to expire on September 30, 2017. Without reauthorization, 30 states and the District of Columbia will run out of CHIP funding by March 2018. The Epilepsy Foundation

strongly supports CHIP reauthorization, and joined a [coalition letter](#) on June 12, 2017 in support of the CHIP program. Ask your representatives to promptly support the reauthorization [here](#).

To learn more about CHIP, visit [advocacy.epilepsy.com/CHIP](http://advocacy.epilepsy.com/CHIP).

## Epilepsy Foundation Board Member Tony Coelho Discusses Value-Based Care Delivery



On Friday, July 21, 2017, Epilepsy Foundation Board Member and former Congressman, Tony Coelho joined a discussion panel hosted by the Partnership to Improve Patient Care (PIPC). The Epilepsy Foundation is a member of PIPC’s steering committee. The coalition is dedicated to bringing the patient experience to discussions about the value of health care. The panel, entitled “Uses and Misuses of the QALY: Ethical Issues and Alternative Measures of Value,” focused on the use of quality-adjusted-life-years (QALY), a measure used in the health care industry to assess the effect of medical intervention on patient quality of life.

Speakers cautioned about use of the QALY measure by insurers to determine what types of care should be covered. The QALY can lead to the undervaluing of quality-of-life improvements, especially for people with disabilities, and it can justify limits on access to care. Medical value determinations must consider the social and personal benefits of medical treatment. To read more about the July PIPC panel, visit [pipcpatients.org/qaly-panel.html](http://pipcpatients.org/qaly-panel.html).

The Epilepsy Foundation will continue to advocate for the patient voice to be included in the dialog around value as policymakers consider reforms intended to improve the delivery of quality health care and bend the ever-growing health care cost curve.

## CDC Update: Epilepsy Population at an All-Time High

On August 10, 2017, the Centers for Disease Control and Prevention (CDC) released new data about epilepsy prevalence, estimating that at least 3.4 million Americans are currently living with epilepsy, including 470,000 children. For the first time, the new data also show the state-by-state prevalence of epilepsy, providing definitive reporting on epilepsy populations in each state.

The number of Americans reported living with epilepsy has risen 1.1 million since 2010, demonstrating the need for improved access to appropriate epilepsy care. To learn more about the new CDC numbers, read the Epilepsy Foundation’s press release [here](#).

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## State Advocacy

### Epilepsy Foundation Attends National Conference of State Legislatures Annual Summit



In early August, the Epilepsy Foundation Public Policy team joined thousands of legislators, legislative staff, and representatives from advocacy groups at the National Conference of State Legislatures -

Legislative Summit in Boston, MA. Our local affiliate, the Epilepsy Foundation of New England, was also in attendance. Over the course of the four-day conference, Foundation staff talked to hundreds of lawmakers and legislative staff about our policy priorities, with a special emphasis on reducing the burden of step therapy on people living with epilepsy and other chronic conditions.

To learn more about the public policy priorities of the Epilepsy Foundation visit [advocacy.epilepsy.com/policy-priorities](https://advocacy.epilepsy.com/policy-priorities).

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