



# Highlights from the Hill

July 2017

## In this Issue:

### Federal Advocacy

- Senate Leaders Continue to Debate Health Care Reform
- Epilepsy Foundation Advocacy Team Blogs about Health Care Debate
- Share Your Story with the Epilepsy Foundation
- I Am Essential Coalition Responds to HHS Request for Information
- *FDA Reauthorization Act* Passes the House - Senate Vote to Follow
- Sen. Booker and Rep. Cohen introduce the *CARERS Act of 2017*

### State Advocacy

- Medication Synchronization Update: Senate Bill 800 Signed into Law in Florida
- PDMP Update: North Carolina PDMP Law Exempts Schedule V Epilepsy Medications
- Maryland Families Share Health Care Perspectives at Congressional Roundtable

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](#).

Since the beginning of 2017, the Epilepsy Foundation has been actively engaged on state and federal issues of importance to the epilepsy community. Learn about our work by reading the [Epilepsy Foundation Public Policy Engagement Review](#), which covers our advocacy initiatives from January - June 2017.

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## Federal Advocacy

[Senate Leaders Continue to Debate Health Care Reform](#)

Late last month, Senate leaders introduced the *Better Care Reconciliation Act* (BCRA), a health care bill to repeal and replace the Affordable Care Act. The BCRA is a slightly amended version of the *American Health Care Act* (AHCA), which passed the House of Representatives in May 2017.

The Epilepsy Foundation is deeply concerned about provisions in the AHCA and BCRA that threaten access to affordable, quality health care for people with epilepsy. Both the AHCA and the BCRA would make it possible for insurers to sell plans without coverage for basic services, including prescription drugs and preventive care. If insurers were permitted to sell these plans, the cost of coverage for comprehensive health insurance in the individual and small group markets would rise significantly, making access to health care unaffordable for many people with epilepsy.

The House and Senate bills also propose a radical restructuring of the Medicaid program. This restructuring could lead to over \$800 billion dollars in cuts to Medicaid. This proposal is exceptionally concerning to our community because more than one third of individuals living with epilepsy rely on Medicaid for their health care.

As the debate over health care reform continues, the Epilepsy Foundation is actively engaged with Congress and other patient advocacy groups. On June 22, 2017, we sent letters to key Senate leaders and GOP target members, emphasizing the importance of maintaining the Affordable Care Act's patient protections. On July 17, 2017, we visited 26 key Senate offices to hand-deliver the health care stories of people with epilepsy and urge the senators to protect access to care.

Read our June 22 letter [here](#) and learn more about our advocacy at [advocacy.epilepsy.com/ACA](http://advocacy.epilepsy.com/ACA).

### **Epilepsy Foundation Advocacy Team Blogs about Health Care Debate**

On June 20, 2017, the Epilepsy Foundation advocacy team blogged about the current health care debate. Read the blog to answer - [What's really at stake with ACA repeal?](#)

### **Share Your Story with the Epilepsy Foundation**

The Epilepsy Foundation is collecting the stories of those in our community who rely on Medicaid for their health care. We will share these stories with Congress as part of our continued advocacy in support of protecting access to care for people with epilepsy. Pending proposals will greatly impact Medicaid, so it's critically important that we show Congress why Medicaid matters! Read some of these stories and share your own: [advocacy.epilepsy.com/advocacymatters](http://advocacy.epilepsy.com/advocacymatters).

### **I Am Essential Coalition Responds to HHS Request for Information**

On June 12, 2017, the Epilepsy Foundation, our affiliates, and more than 100 additional patient and community advocacy groups joined an I Am Essential coalition letter to the Department of Health and Human Services, in response to their request for information (RFI) about how to

"change existing regulations in ways that put patients first, promote greater consumer choice, enhance affordability and return more control over healthcare to the States," The letter noted the importance of health coverage, Essential Health Benefits, and patient protections -- especially for individuals with pre-existing conditions like epilepsy. Read the letter [here](#).

The I Am Essential coalition is led by the Epilepsy Foundation, The AIDS Institute, and the National Alliance on Mental Illness, and unites diverse national and state patient and community organizations to advocate for access to high-quality, affordable health care.

Learn more about I Am Essential at [advocacy.epilepsy.com/IAMEssential](http://advocacy.epilepsy.com/IAMEssential).

### ***FDA Reauthorization Act Passes Congress - Senate Vote to Follow***

The U.S. House of Representatives passed the *FDA Reauthorization Act* on July 12, 2017 bringing Congress closer to reauthorizing the FDA's user fee agreements. These agreements provide the funding that allows the FDA to approve new medications and medical devices in a timely manner, advancing new treatments to market faster. The agreements must be reauthorized by the end of the summer, or the FDA would lose a significant revenue source, slowing the pace of medical innovation and the search for a cure for epilepsy.

Now that the House has passed the *FDA Reauthorization Act*, the Senate must take up legislation to reauthorize the user fee agreements. On July 14, 2017, the Epilepsy Foundation sent a [letter](#) to the House Energy and Commerce Committee, thanking legislators for supporting the user fees agreements. We will continue to encourage members of the Senate to be proactive in ensuring that the agreements are quickly reauthorized.

To learn more about the FDA user fee agreements, read about our advocacy work, and write to your senators in support of the bill, visit [advocacy.epilepsy.com/FDA](http://advocacy.epilepsy.com/FDA).

### ***Sen. Booker and Rep. Cohen introduce the CARERS Act of 2017***

On June 15, 2017, Senator Cory Booker and Representative Steve Cohen introduced the *Compassionate Access, Research Expansion, and Respect States Act* (CARERS), a bill that would protect patients and physicians in states with medical cannabis programs, and remove federal barriers to cannabis research. The Epilepsy Foundation supported the CARERS Act during the previous Congress and continues to support the 2017 bill.

Read our letter of support for CARERS [here](#) and learn more about medical cannabis and epilepsy at [advocacy.epilepsy.com/medical-cannabis](http://advocacy.epilepsy.com/medical-cannabis).

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## **State Advocacy**

### ***Medication Synchronization Update: Senate Bill 800 signed into law in Florida***

On June 14, 2017, Florida Governor Rick Scott signed Senate Bill 800 into law, making it easier for individuals living with epilepsy and other chronic conditions to refill multiple prescriptions on the same day each month, while ensuring that costs are appropriately pro-rated.

For people with epilepsy who take multiple medications for seizure control or to manage co-morbidities, having to make several visits to the pharmacy each month can present a barrier to care. The Epilepsy Foundation supports medication synchronization legislation, and wrote a letter in support of Senate Bill 800 on May 9, 2017.

Read the letter [here](#) and learn more about this issue at [advocacy.epilepsy.com/MedSync](http://advocacy.epilepsy.com/MedSync).

### **PDMP Update: North Carolina PDMP Law Exempts Schedule V Epilepsy Medications**

On June 29, 2017, North Carolina Governor Roy Cooper signed House Bill 243 into law, requiring state physicians to participate in North Carolina's prescription drug monitoring program. The final bill draft exempted Schedule V medications from the highest level of monitoring, ensuring that people with epilepsy who rely on Schedule V medications will not encounter additional barriers to accessing care. On March 10, 2017, the Epilepsy Foundation wrote to the sponsors of House Bill 243, requesting the exemption that was included in the final law.

Read our letter [here](#) and learn more about our policy priorities with prescription drug monitoring programs at [advocacy.epilepsy.com/PDMP](http://advocacy.epilepsy.com/PDMP).

### **Maryland Families Share Health Care Perspectives at Congressional Roundtable**

On July 5, 2017, epilepsy advocates from Maryland attended a community health care roundtable with a member of Congressional leadership to discuss the current health care debate. The attendees included Emma Denlinger, 17, who participated in the 2017 Teens Speak Up! conference. During the roundtable, advocates shared their experience with access to health care and encouraged Congress to preserve protections for people with pre-existing conditions and maintain the existing structure of the ACA marketplace.

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