



# Highlights from the Hill

April 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**

**Epilepsy Foundation Hosts Teens Speak Up! and Public Policy Institute Conference in Washington, DC**



The annual Teens Speak Up! (TSU) and Public Policy Institute (PPI) conference - the Foundation's signature advocacy initiative - was held Sunday, March 26 through Tuesday, March 28 in the Washington, DC area.

This year's conference brought together more than 150 teens, parents, affiliate staff, and volunteers from 37 chapters and affiliates in 35 states. A day and a half of learning and advocacy training culminated with a successful day on Capitol Hill,

where families and state advocacy leaders shared their personal stories and advocated in support of the Epilepsy Foundation's policy priorities in more than 180 Congressional meetings.

We were thrilled to welcome so many members of the epilepsy community for the 2017 TSU/PPI conference. Thank you to all participants for joining us in DC and for your commitment to be advocates back home. To learn more about this year's conference and to follow participants' advocacy efforts in their communities

visit: [advocacy.epilepsy.com/TSU2017](http://advocacy.epilepsy.com/TSU2017).

### **ACT NOW - Encourage Congress to Support Access to Quality Health Care & CDC Programs for People with Epilepsy**

**[Ask your legislators to stand by the epilepsy community by preserving access to quality health care and programs that build safer communities >>](#)**

Current language in the American Health Care Act (AHCA) would cut Medicaid funding by \$880 billion over the next ten years, by instituting per-capita caps on federal support to the states for the program. Other health reform proposals Congress is considering include eliminating Essential Health Benefits requirements for plans offered in the ACA Marketplaces, which ensure plans cover prescription drugs, hospitalization, and emergency services, among other basic benefits. Learn more about Essential Health Benefits and our advocacy in support of meaningful access to care in the ACA Marketplace at [advocacy.epilepsy.com/ACA](http://advocacy.epilepsy.com/ACA)

When Congress returns from recess next week, they will continue discussions regarding appropriations and funding for the remainder of Fiscal Year (FY) 2017 and for next year (FY 2018). Congress needs to hear from you about the importance of the epilepsy programs at the Centers for Disease Control & Prevention (CDC), which help build safer communities for people living with epilepsy. We have joined our friends at the CDC Coalition -- more than 180 state and national organizations -- in support of at least a 7.8 billion funding level for CDC in FY 2018. You can view the letter [here](#).

## **Share Your Story on Social Media to #SaveEHBs and show that #MedicaidMatters**

During the Congressional recess, we have been raising awareness about the important role Medicaid and Essential Health Benefits (EHBs) in ACA Marketplace plans play for the epilepsy community. More than one third of people living with epilepsy rely on Medicaid, and EHBs ensure meaningful access to quality health care. Join us by sharing your story using the hashtags #SaveEHBs and #MedicaidMatters.

FOLLOW us on Twitter @ [EpilepsyFdn](#) & LIKE us on Facebook at [Epilepsy Foundation of America](#) to stay up-to-date with our efforts and share our posts to strengthen the voice of the epilepsy community.

## **I Am Essential Coalition Featured in News Stories Highlighting Reaction to CMS Announcement it Will Delegate ACA Formulary Review to the States**

On April 13, 2017, the Centers for Medicare and Medicaid Services (CMS) issued [guidance](#) to the states that announced it will review fewer health plans offered in the ACA Marketplace for drug coverage. These reviews are intended to ensure that plan design does not discriminate against patients with chronic conditions. Instead, the CMS Center for Consumer Information & Insurance Oversight will mainly rely on states to conduct these complicated reviews.

The Epilepsy Foundation was quoted in several news stories that highlight the I Am Essential coalition's response to the announcement. Enforcing patient protections is critical so people can access the medications they need and to guard against ACA plan's discriminatory benefit design. Many states simply do not have the tools and expertise needed to handle complex formulary reviews.

Read I Am Essential's press release and the news stories at [advocacy.epilepsy.com/IAMEssential](http://advocacy.epilepsy.com/IAMEssential).

## **The Value of Research Funding for Epilepsy at NIH**

The National Institutes of Health (NIH) is the world leader in biomedical research and one of the largest funders of epilepsy research in the United States. Funding for research at NIH enjoys longstanding, strong bipartisan Congressional support. Learn more about epilepsy research at NIH by reading a [recent blog post](#) authored by Epilepsy Foundation Director of the Epilepsy Innovation Institute (Ei2) Sonya B. Dumanis, PhD.

As the new Administration begins to discuss the federal budget and potential cuts to funding at NIH and other programs, we must raise awareness with all stakeholders about the critical role federal investments in biomedical research play for epilepsy research priorities and the overall research enterprise. The research supported by NIH is an essential component that can be complemented, but not matched or replaced, by the nonprofit community's investments in research.

Read the blog post and learn more about the Epilepsy Foundation's research initiatives at: [advocacy.epilepsy.com/federal-funding-for-epilepsy](http://advocacy.epilepsy.com/federal-funding-for-epilepsy)

## Congress Begins to Weigh in on FDA User Fee Agreements

The Food and Drug Administration (FDA) user fee acts and agreements, which establish a structure for pharmaceutical and device manufacturers to fund specific aspects of the FDA drug and device approval processes, must be reauthorized this year. Timely reauthorization will ensure that the FDA can sustain its important work and continue to develop and refine its processes to get much needed new therapies and devices to the market in a timely manner.

During the last few years, all relevant stakeholders, including the FDA, industry, and the patient community, have negotiated these user fee agreements that now must be enacted into law by Congress. 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 health care more broadly.

Over the past few weeks, committees in both the Senate and the House of Representatives held hearing to discuss these agreements. The Epilepsy Foundation sent a [letter](#) to the chairman and ranking member of the House Energy and Commerce Committee's Subcommittee on Health expressing support for the user fee programs and the agreements. The Epilepsy Foundation urges Congress to move judiciously through the process of reauthorizing the user fee programs and to honor the negotiations that led to the agreements.

Keep track of this issue here: [advocacy.epilepsy.com/FDA](https://advocacy.epilepsy.com/FDA)

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## State Advocacy

### Keep Track of Advocacy Efforts in your State

Remember to keep track of state-specific advocacy activities on your state page, which can be accessed [here](#).

### Epilepsy Foundation Affiliates Around the Country Host State Legislative Days

The epilepsy community comes together at state legislative days to advocate for state priorities, which often revolve around access to care issues and state funding for epilepsy program. This year, we supported several initiatives aimed at improving access to physician-directed care and prescription medications, including bills to limit step therapy or "fail first" requirements imposed by insurance companies on people with epilepsy and other conditions; bills that would make it easier for pharmacists to help people synchronize their medication refills; and bills that would prevent insurers from making mid-year changes to the list of prescription medications covered by a health plans. We also supported initiatives specific to the epilepsy community, like preserving epilepsy protections in state Medicaid programs; removing barriers for scheduled epilepsy medications created by drug monitoring programs; and safe, legal access to medical cannabis and cannabidiol (CBD) at the state level. In support of these legislative priorities, several states have held legislative days this year. Learn more about a few of these days below.

### **Iowa Epilepsy Advocacy Day in Des Moines - March 16, 2017**



On March 16, the Epilepsy Foundation of North/Central Illinois, Iowa & Nebraska held Iowa Epilepsy Advocacy Day at the state capitol in Des Moines. Nearly 100 Iowa epilepsy advocates met with their state legislators to discuss priority issues, including funding for epilepsy programs and services, and access to medical cannabis and cannabidiol (CBD). As part of the advocacy day, Governor Terry Branstad declared March 26 "Global Purple Day for Epilepsy Awareness."

Learn more about Iowa Epilepsy Advocacy Day and Iowa's participation in the 2017 Teens Speak Up! Conference [here](#).

### **Minnesota Epilepsy Advocacy Day in St. Paul - March 7, 2017**



On March 7, the Epilepsy Foundation of Minnesota partnered with the Minnesota Consortium for Citizens with Disabilities to host an advocacy day at the state capitol in St. Paul. During advocacy day, 37 advocates held 32 meetings with their state legislators to discuss access to medication challenges and adequate state support for home and community based services for people living with disabilities.

### **Taco Thursday at the Texas Capitol - March 2, 2017**



On March 2, representatives from the Epilepsy Foundations of Texas were the featured speakers at a "Taco Thursday" lunch event to educate lawmakers about epilepsy issues and policy priorities. President and CEO of the Epilepsy Foundation of Central & South Texas, Sindi Rosales, shared this year's legislative priorities for the Texas epilepsy community with legislative staff and other attendees. These priorities include: preserving the protection for epilepsy medications in the Texas Medicaid program; limiting step therapy protocols that require individuals to fail on less costly medications before receiving the therapies prescribed by their physicians; and allowing individuals to synchronize their medication refills to improve medication adherence.

## Kentucky Advocacy Day in Frankfort - February 23, 2017



On February 23, the Epilepsy Foundation of Kentuckiana held a Speak Up, Speak Out! Kentucky Advocacy Day at the state capitol in Frankfort. Kentucky's Teens Speak Up! representative Charles Wilson served as a Senate page for the day, and he was recognized on the Senate floor for his epilepsy advocacy. Read more about Charles in the *Lexington Herald Leader* [here](#).

## Florida Legislative Reception and Advocacy Days - February 22-23, 2017



On February 22, the Epilepsy Foundation of Florida hosted a reception in Tallahassee to honor four Florida lawmakers for their extraordinary support of the epilepsy community. Epilepsy Foundation of Florida CEO Karen Basha Egozi said, "These legislators have worked tirelessly to ensure that the 400,000 Floridians living with epilepsy have the support they need to deal with this serious condition. On behalf of those

with epilepsy and related seizure disorders, it is our distinct pleasure to celebrate the accomplishments of these stellar individuals."

Also on February 22 and 23, members of the Epilepsy Foundation of Florida board met with more than 20 legislators throughout the day to discuss epilepsy issues. The affiliate also had a table with educational materials set up at the entrance to the capitol.

## Delaware Legislative Lunch in Dover - January 26, 2017



On January 26, the Epilepsy Foundation of Delaware hosted state legislators for lunch and epilepsy advocacy at the state capitol in Dover. Epilepsy Foundation of Delaware Executive Director Val Budischak gave a presentation on epilepsy programs and services in Delaware, and met with numerous state legislators - including the Delaware Speaker of the House!

If you live in [Connecticut](#), [Rhode Island](#), [Pennsylvania](#), or [Illinois](#), mark your calendars -- the Epilepsy Foundations in these regions will be hosting state advocacy days and public policy conferences over the next month. Visit your state page (linked above) to learn more about these events.

## Jim Ross of Connecticut Receives 2017 Sara Stubblefield Advocacy Award



The Epilepsy Foundation was pleased to present the 2017 Sara Stubblefield Advocacy Award to Jim Ross. Jim and his wife Victoria launched a successful campaign in Connecticut to allow trained, non-medical school personnel to administer emergency seizure medications. Their four-year effort was inspired by their son, Emmett, who lives with frequent seizures, and by the 3,000 Connecticut children who live with epilepsy. The Ross family was supported throughout the process by the Epilepsy Foundation Connecticut and the national office for the Epilepsy Foundation. Read more about their story [here](#).

The annual Advocacy Award honors the late Sara Stubblefield, who passed away in 2011 at the age of 36. Sara was diagnosed with epilepsy when she was in high school. She was known for accepting her condition with grace and for never letting it define her. A dedicated advocate for epilepsy education and research, she served for 10 years as epilepsy services coordinator for the Epilepsy Foundation of Greater Southern Illinois.

## Advocacy Update: State Pathways for FDA Approved Therapies Derived from CBD

In 2017, one of the Epilepsy Foundation's major advocacy priorities has been ensuring the creation of state pathways to allow therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration (FDA) to become available at the state level in a timely manner.

The past month has been full of success for the epilepsy community on this issue. On March 25, Utah Governor Gary Herbert signed Senate Bill 219 into law, creating a pathway in Utah for FDA-approved therapies derived from CBD. Less than a month later, on April 10, Kentucky Governor Matt Bevin signed HB 333 into law, expanding access to this potential treatment option to Kentuckians with epilepsy. Earlier this year, the Arkansas Governor signed similar legislation. The Epilepsy Foundation is expecting several other state victories on this issue, especially in Arizona, where the State House and Senate recently passed legislation that is now headed to the Governor for signature. Stay up to date on state pathways for FDA-approved therapies derived from CBD at [advocacy.epilepsy.com/stateFDApathway](http://advocacy.epilepsy.com/stateFDApathway).

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