



Highlights from the Hill

June 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](#).

National Advocacy

[Epilepsy Foundation Continues to Advocate for Preserving ACA Patient Protections](#)

As the Senate considers the House-passed *American Health Care Act* (AHCA), the Epilepsy Foundation continues to educate members of Congress about the critical need to maintain the patient protections created by the Affordable Care Act, including the [Essential Health Benefits](#) requirements and other protections that ensure people with pre-existing conditions can have meaningful coverage. On May 22, Epilepsy Foundation President & CEO, Phil Gattone sent a letter to the leaders of the Senate Health Care working group, expressing the Foundation's concerns with proposals included in the AHCA. Read the letter [here](#) and learn more about the AHCA by visiting advocacy.epilepsy.com/ACA.

Patient Groups Rally on Capitol Hill to Protect Medicaid



reducing quality of care.

More than 70 million Americans rely on Medicaid and the Children's Health Insurance Program (CHIP) for their health care needs - including more than one million people with epilepsy. The *American Health Care Act* (AHCA) would radically restructure Medicaid, instituting per-capita caps that would cut more than \$840 billion in Medicaid funding over the next 10 years. These caps would leave many states with a significant budget shortfall, forcing reductions in Medicaid benefits and

On June 6, Medicaid advocates, including Epilepsy Foundation Board Member and former Congressman, Tony Coelho, gathered on Capitol Hill for a "Don't Cap My Care" awareness rally to demonstrate the importance of the Medicaid program. To learn more about proposed changes to Medicaid and how they could affect people living with epilepsy, visit advocacy.epilepsy.com/ACA/Medicaid.

Prescription Drug User Fee Act Passes House Committee - Headed for Full Vote

On June 7, the House Energy and Commerce Committee voted unanimously to pass the *FDA Reauthorization Act of 2017*. The bill includes language that would reauthorize the FDA's user fee programs, which allow the FDA to collect fees from drug and device manufacturers to fund the new drug and device approval process. Now, the bill heads to the full House for a vote, where it is expected to pass. The bill also passed the Senate Health, Education, Labor and Pensions Committee earlier this spring, on May 11. It has yet to be voted on before the full Senate, and a floor debate on the bill is expected after the Senate has completed consideration of legislation related to health reform and ACA.

The Epilepsy Foundation strongly supports the FDA user fee agreements and has urged Congress to move judiciously through the process of passing the reauthorization bill. These agreements provide the funding that allows the FDA to stimulate biomedical innovation and efficiently approve innovative therapies to help people live well with epilepsy. If the user fee programs are not renewed, the FDA would be forced to lay off thousands of employees, adding significant delays to the new drug and device approval process. To learn more about the agreements, visit advocacy.epilepsy.com/FDA.

Tell Congress: Prioritize Epilepsy Funding in FY 2018 Budget

On May 23, the Trump Administration delivered its 2018 budget request to Congress, calling for significant cuts to government programs that help people live well with epilepsy. The President's budget requests an 18% reduction in funding for the National Institutes of Health (NIH), as well as a 17% funding cut to the Centers for Disease Control and Prevention (CDC).

The Epilepsy Foundation is strongly opposed to the proposed funding cuts and urges Congress to support funding levels for the CDC and NIH that would allow both agencies to continue their important work. CDC funding is critical to preserve programs that help communities better support people with epilepsy -- and NIH funding must continue to increase to ensure progress is made in biomedical innovation and efforts towards a cure for epilepsy are sustained. Ask your members of Congress to protect federal funding for epilepsy programs & research [here](#).

Tony Coelho, Epilepsy Foundation Board Member, Comments on Medicare Reform Discussions

On May 30, the Huffington Post published a [blog post](#) by Epilepsy Foundation board member and former Congressman, Tony Coelho, urging legislators and regulators to incorporate patient voices into discussions about the value of health care. Coelho highlighted the CHRONIC Care Act, a bill that would implement Medicare payment policies designed to improve the management of chronic disease, as an example of the kind of strong legislation that can result from patient engagement in policymaking.

For people living with epilepsy, there is no "one size fits all" treatment option. When policymakers fully engage with the epilepsy community, they understand that people with epilepsy need meaningful access to the full range of therapies available, and to the specialists who know how to prescribe them. As Congress considers the CHRONIC Care Act and other legislation, the Epilepsy Foundation continues to strongly support Medicare and the Six Protected Classes policy, which ensures greater protections for medications including anticonvulsants for epilepsy. Learn more about the Foundation's current Medicare efforts by visiting advocacy.epilepsy.com/Medicare.

Research Update: Cannabidiol Shows Promise for Treatment of Dravet Syndrome

On May 25, researchers from the Cannabidiol in Dravet Syndrome Study Group published a study in the *New England Journal of Medicine* showing promising results from the use of cannabidiol (CBD) to treat drug-resistant seizures in children with Dravet syndrome, a rare epilepsy. The researchers found that CBD treatment decreased seizures in trial participants by more than 50%, and caused 5% of participants to become entirely seizure-free. To read the study and learn more about the use of medical cannabis for epilepsy treatment, visit advocacy.epilepsy.com/medical-cannabis.

Epilepsy Foundation Comments on Proposed FDA Office of Patient Affairs

The Food and Drug Administration (FDA) recently proposed a new Office of Patient Affairs, which would expand the agency's efforts to engage patients and their unique perspectives in the drug and device development and review process. On June 12, the Epilepsy Foundation submitted a comment to the FDA in support of the establishment and goals of the Office of

Patient Affairs. We believe that this Office would serve as a helpful resource for patients and the FDA, both during the drug review process and after new drugs have gone to market. Patients can help to inform the work of the FDA by sharing with the agency what they find important in a treatment option. Read the Epilepsy Foundation's full comment to the FDA [here](#).

Epilepsy Foundation Research Quarterly

The Epilepsy Foundation is actively engaged in research initiatives to improve detection and prediction of seizures and SUDEP. In May, the Foundation hosted our annual Shark Tank competitions at the Antiepileptic Drug and Device Trial Conference in Miami. Inspired by the TV show *Shark Tank*, competition finalists present a five-minute pitch to judges about why the Epilepsy Foundation should invest in their idea to solve the challenges that people with epilepsy face every day. This and many other research initiatives are highlighted in the new Research Quarterly published by the Research Department of the Epilepsy Foundation. Read the recent Research Quarterly published in June [here](#).

State Advocacy

Illinois Epilepsy Advocacy Day

On May 17, the Epilepsy Foundations of Greater Chicago, Greater Southern Illinois, and North/Central Illinois gathered at the State Capitol in Springfield to meet with members of the state legislature. The day opened with a legislative declaration of May 17, 2017 as Illinois Epilepsy Advocacy Day. From there, more than 150 advocates spoke with their elected officials about the importance of legislation that directly impacts people with epilepsy, including a fully funded state health and human services budget and the Fair Prescription Coverage Act. Advocates were prepared to share their stories, and answer questions about epilepsy thanks to an advocacy seminar held the week before by the Epilepsy Foundation of Greater Chicago.

During Epilepsy Advocacy Day, the Illinois State Senate voted for a state budget that includes \$2 million for epilepsy services statewide. The budget will now move to the House, where Illinois epilepsy advocates will lobby for preserving epilepsy funding.

Virginia "Use a Helmet, Prevent Epilepsy" Award Ceremony at the State Capitol

On May 19, the Epilepsy Foundation of Virginia hosted its annual "Use a Helmet, Prevent Epilepsy" award ceremony at the State Capitol in Richmond. State Senator Jennifer McClellan and State Delegates John O'Brien and Betsy Carr presented the awards, and spoke to the audience about the importance of wearing a helmet when riding a bicycle or skateboard. Proper helmet use can prevent traumatic brain injuries, which are a leading cause of epilepsy. After the ceremony, the winners and their families had a guided tour of the Capitol.

The "Use a Helmet, Prevent Epilepsy" program is a statewide contest for fourth graders in all Virginia public schools. This year, nearly 500 students submitted drawings about helmet use, and

EFVA selected twelve winners. The winning drawings are featured in a calendar that EFVA sends to legislators, members of the media, and the Virginia epilepsy community.

Step Therapy Advocacy Update: Laws Signed in Colorado and Texas



During the 2017 state legislative sessions, the Epilepsy Foundation has closely monitored and advocated for legislation designed to reduce the burden of step therapy on people with epilepsy and other chronic conditions. Bills have been introduced this year in more than twenty states to provide protections against step therapy for patients with special medical needs.

On May 23, Texas Governor Greg Abbott signed Senate Bill 680 into law, requiring health insurers to consider the needs of special patient populations when establishing step therapy protocols. The bill also requires insurers to establish a user-friendly override process for step therapy requirements, allowing patients and doctors to override these requirements when medically necessary.

On June 2, Colorado Governor John Hickenlooper signed Senate Bill 203 into law, mandating that insurers provide a similar override process when step therapy requirements endanger the health of patients.

These efforts in the states have led to progress at the federal level as well. On April 6, 2017, Representatives Brad Wenstrup and Raul Ruiz introduced the *Restoring the Patient's Voice Act of 2017* (H.R. 2077), which would require employer-sponsored group health plans to provide a clear exception process for step therapy protocols and require that plans allow overrides in certain situations. The Epilepsy Foundation supports this legislation as it would help ensure people can more easily access the medications their physicians prescribe, which is especially critical for those living with epilepsy. On May 24, the Epilepsy Foundation and other patient groups sent a letter of support to Congressmen Wenstrup and Ruiz, thanking them for introducing H.R. 2077. Read the letter [here](#).

Learn more about step therapy at advocacy.epilepsy.com/StepTherapy

Nevada Gov. Brian Sandoval Vetoes Bill to Impose Innovation-Restricting Regulations

On June 2, Nevada Governor Brian Sandoval vetoed Senate Bill 264, a bill that could have constrained biomedical innovation and reduced participation by the patient community in the conversation on the value of health care in Nevada. If signed into law, the bill would have mandated nonprofit fundraising reporting requirements that would divert resources away from serving patient communities and perpetuate unfair assumptions about patient advocacy organizations. The bill would also have restricted the conversations between pharmaceutical companies and patient advocacy groups that currently ensure that new medications serve the needs of special populations. Additionally, while the bill was promoted as a way to address high drug prices, it would not have done so, especially because it failed to touch on the critical burden of high cost sharing (copays/coinsurance) that exists in many health plans. This high cost sharing

burden is a significant aspect of why so many people in Nevada and around the country are finding their medications unaffordable.

The Epilepsy Foundation sent letters to legislators and the Governor highlighting our concerns and urging them to instead pursue more thoughtful solutions with input from all stakeholders. Governor Sandoval's veto noted that the Epilepsy Foundation and other groups were concerned about the impact that Senate Bill 265 would have on Nevadans. To learn more about this bill, visit advocacy.epilepsy.com/Nevada.

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