



Highlights from the Hill

February 2017

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As the state and federal legislative sessions progress, 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 epilepsy throughout the year. Growing our advocacy network is critical to achieving our public policy goals as we head into 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 Urges Federal Government to Prioritize NIH Funding

On February 7, 2017, the Epilepsy Foundation joined 260 member organizations of the Ad Hoc Group for Medical Research in a letter urging President Trump and Congressional leaders to approve a Senate Appropriations Committee-approved \$34.1 billion in Fiscal Year (FY) 2017

funding for the National Institutes of Health (NIH). The letter also emphasized the importance of ensuring that funding for NIH remains a top priority in FY 2018 and beyond.

The Epilepsy Foundation supports funding increases for epilepsy research at the National Institutes of Health that bring us closer to better treatments for epilepsy and a cure. Read our coalition letter [here](#).

Epilepsy Foundation and I Am Essential Ask HHS to Maintain Non-Discrimination & Patient Protection Provisions in Health Care Law

The Epilepsy Foundation, as a leader of the I Am Essential coalition, joined 200 patient groups, including all Epilepsy Foundation chapters and affiliates, in a February 10, 2017 letter to recently-confirmed Secretary of Health and Human Services Dr. Tom Price. The letter urged Secretary Price to maintain patient protections in the Affordable Care Act that limit discriminatory benefit designs and high cost-sharing and improve transparency.

It is especially important to advocate for patient protections like the Essential Health Benefits that ensure access and coverage for quality care as Congress and the Administration consider changes to current health care laws and regulations. We will continue to engage Secretary Price and other agencies as other agency heads are nominated and confirmed.

Read the I Am Essential letter [here](#).

Epilepsy Foundation Board Member and Former Congressman Tony Coelho Pens Op-Ed in *The Hill*

The February 3, 2017 op-ed encouraged President Trump to choose an FDA commissioner with the experience and education necessary to pave the way for future innovation at the FDA. Coelho wrote:

"Having epilepsy myself, I know the U.S. Food and Drug Administration (FDA) plays a critical role in the life and well-being of all Americans. Since serving in the House of Representatives, I have served for many years on the Epilepsy Foundation's Board of Directors and have always been sensitive to the need for innovative treatments that are both safe and effective.

Therefore, I recognize the significance of the administration's choice to nominate for commissioner of FDA, and urge it be someone whose experience will allow for a deep understanding of the community of patients and people with disabilities that rely on the FDA heavily for their health and well-being."

Read the full op-ed [here](#).

Urge Your Senators to Support House-Passed Protecting Patient Access to Emergency Medications Act of 2017

The United State Senate is considering a bill (H.R. 304) which would amend the Controlled Substances Act (CSA) to ensure that Emergency Medical Services (EMS) personnel can continue to administer controlled substances, including emergency seizure medications, in a timely manner. On January 9, 2017, H.R. 304 was passed by the House of Representatives with strong bipartisan support (404-0), and it is currently pending in the Senate Committee on Health, Education, Labor and Pensions.

This bill would directly benefit many people in the epilepsy community. There is a demonstrated clinical need for administering controlled substance medications, such as those to treat active seizures, during an emergency. Delaying immediate treatment by first responders with a readily available emergency medication can be life-threatening.

Help us pass H.R. 304 in order to ensure the best emergency care possible for those with epilepsy. Write your senators to show your support and let them know you stand with the epilepsy community in this matter - [here](#).

State Advocacy

Keep Track of Advocacy Efforts in your State

Remember to keep track of state-specific legislative issues on your state page, which can be accessed [here](#). We continually update these pages, especially during the current legislative sessions.

Creating State Pathways for FDA Approved Therapies Derived from CBD

The Epilepsy Foundation is bringing together the epilepsy community in every state around the country to advocate for changes to state scheduling laws in order to allow therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration (FDA) to become available in a timely manner. This is an issue of prescription drug access and it is a time sensitive priority for the epilepsy community as there is currently a product in the FDA pipeline, which could be approved as soon as early 2018. Even after FDA approval and subsequent rescheduling on the federal level by the Drug Enforcement Administration (DEA), individuals would not have access to this medication without state action. Each state has its own laws and processes for scheduling drugs separate from the federal system and we will continue to work with our affiliates and chapters in the states to determine steps forward to accomplishing this goal.

Follow the effort here: advocacy.epilepsy.com/statefdapathway.

Bills to Limit Step Therapy Protocols Make Progress in at Least 13 States

During the 2017 state legislative sessions, the Epilepsy Foundation is focusing special attention on ensuring the success of bills intended to limit step therapy requirements that make it harder for individuals to get the medications their doctors prescribe. [Step therapy](#), or "fail first" is a

process used by insurance companies to require individuals who have been prescribed certain medications by their physicians to try and fail other medications preferred by their insurers before receiving coverage for the medication their physician originally prescribed. During the current legislative session thus far, bills requiring a clear appeals process and providing certain circumstances when a health care provider and patient can override the step therapy protocols have been introduced in the following states: Florida, Hawaii, Iowa, Kansas, Massachusetts, New Mexico, Ohio, Oregon, Texas, Virginia, Utah, Washington and West Virginia. We expect more to be introduced in the coming weeks.

Follow our advocacy related to step therapy here: advocacy.epilepsy.com/StepTherapy.

Epilepsy Foundation Opposes Plans to Limit or Ban Copayment Reimbursements

On January 23, 2017, the Epilepsy Foundation and the Epilepsy Foundation New England wrote to members of the New Hampshire House of Representatives urging them to oppose a bill prohibiting drug manufacturers from offering copayment reimbursement to patients. Copayment assistance programs play a vital role in ensuring the affordability of epilepsy medications, and help individuals avoid medication switching or delays. We expect similar bills in other states and will continue to monitor this issue.

Access to CBD Hemp Oil for Children with Epilepsy Gains Traction in Indiana

In January 2017, Indiana State Senator Jim Tomes introduced SB 15, a bill that would improve access to hemp oil as a potential treatment option for Indiana children living with epilepsy and uncontrolled seizures. This bill would align Indiana with the majority of states which already allow some level of legal access to CBD. The bill passed through the Indiana Senate Committee on Corrections and Criminal Law on February 9, 2017, and passed the full Indiana Senate on February 14, 2017. The Epilepsy Foundation will continue to support SB 15 as it passes into the House. Thank you to the more than 80 epilepsy advocates who wrote letters to the Indiana Senate in support of SB 15 - your voices were heard!

The Epilepsy Foundation is committed to supporting physician-directed care, and to exploring and advocating for all potential treatment options for epilepsy, including hemp or CBD oil and medical cannabis. In states where medical use of hemp or CBD oil and/or cannabis is legal as a treatment for epilepsy, a number of people living with epilepsy report beneficial effects, including a decrease in seizure activity.

Read more about this issue here: advocacy.epilepsy.com/medical-cannabis.

Removing Barriers to Epilepsy Medications in State Drug Monitoring Programs

In Pennsylvania and Arizona, the Epilepsy Foundation and our local affiliates are urging legislators to exempt Schedule V epilepsy medications from state prescription drug monitoring programs to ensure meaningful access to epilepsy medication. While we understand the need to curb abuses of certain scheduled prescription drugs, including Schedule V non-opioid drugs (which are epilepsy medications) in state prescription drug monitoring programs can limit or

delay access to lifesaving medications. Scheduled epilepsy medications do not pose the risk for abuse associated with other scheduled medications, and individuals living with epilepsy who experience a delay in accessing their medication due to onerous drug monitoring requirements are at a high risk for developing breakthrough seizures and related complications.

Learn more about this issue here: advocacy.epilepsy.com/PDMP.

Preserving Open Access to Epilepsy Medications in State Medicaid Programs

Protections for epilepsy medications in state Medicaid programs are constantly under threat as the states and insurers look for ways to cut costs by limiting access to medications. The Epilepsy Foundation strongly supports preserving open access to epilepsy medications in state Medicaid programs, and is committed to ensuring that those who rely on Medicaid for their health care and medication needs can get appropriate care without administrative barriers like step therapy and prior authorization, which can lead to a loss of seizure control, more hospitalizations, and injury or even death. We are currently supporting legislation in Indiana, Massachusetts, and Texas that would restore, improve, or preserve protections for epilepsy drugs.

Follow these efforts here: advocacy.epilepsy.com/Medicaid.

Email us at TSU@efa.org

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