



Highlights from the Hill

June 2018

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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](#).



PAME Attendees gathered on June 14, 2018 in Washington, D.C. to go up on Capitol Hill to advocate for SUDEP awareness and research.

National Advocacy

Epilepsy Foundation Participates in PAME Hill Day

On June 14, 2018, the Epilepsy Foundation assisted with and participated in a Hill Day for the Partners Against Mortality in Epilepsy (PAME) conference to advocate for awareness, prevention, and research on Sudden Unexpected Death in Epilepsy (SUDEP). Participants represented 9 states and met with almost 40 Congressional offices.

The PAME conference is a collaborative meeting convened by the American Epilepsy Society, Citizens United by Research in Epilepsy (CURE), the Danny Did Foundation, and the Epilepsy Foundation, which is devoted to increasing awareness and understanding of mortality in epilepsy—particularly Sudden Unexpected Death in Epilepsy (SUDEP). Attendees include parents and caretakers, adult patients, bereaved family members, advocates, medical professionals, government agencies, and industry leaders who join to advance progress. The conference is biennial and was held this year on June 14-16, 2018.

Learn more about SUDEP and the Epilepsy Foundation's SUDEP Institute [here](#).

Congress Pushes Markup of Labor-HHS-Education Appropriations Bill

Congress continues to move forward with the FY 2019 appropriations process. The Labor-HHS-Education bill, the largest nondefense discretionary spending bill, was released and passed out of subcommittee on June 15, 2018 by a voice vote. However, the House Appropriations Committee has pushed the markup of the bill from June 19, 2018 to June 26, 2018. This bill contains funding for the departments of Labor, Education, and Health and Human Services (HHS), which

houses the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

We urge Congress to support \$9.5 million in funding to invest in critical epilepsy public health programs at the CDC to improve the quality of life for individuals with epilepsy. Additionally, we advocate for \$175 million in funding for epilepsy research at the NIH.

The Epilepsy Foundation believes epilepsy should be a federal public health priority and supports investments in public health programs that help build safer communities, end stigma associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions and disabilities. The Epilepsy Foundation will continue to monitor the progress of the bill.

[Tell Congress to support federal funding for CDC epilepsy programs for FY 2019!](#)



Epilepsy Foundation of Iowa's Executive Director, Roxanne Cogil, and University of Iowa faculty and students, met with Senator Joni Ernst on June 14, 2018 for the PAME Hill Day.

[Administration Releases Association Health Plan Final Rule](#)

On June 19, 2018, the Administration released the final rule on Association Health Plans (AHPs), which will expand the definition of an employer, allowing more small businesses and self-employed individuals to join together for the sole purpose of offering health insurance through association health plans. The Epilepsy Foundation, along with 25 other patient advocacy organizations, **[released a statement regarding the final rule](#)** expressing concern over the repercussions the final rule will have on patients with pre-existing conditions or other serious and chronic health issues and the destabilization of the individual marketplace.

In the final rule, AHPs will not be able to deny individuals with pre-existing conditions coverage or charge them more, however these plans will not be required to cover Essential Health Benefits or comply with other patient protections created by the Affordable Care Act (ACA). Without comprehensive coverage, many who purchase these plans will be left underinsured.

Association Health Plans will be able to charge lower premiums because they do not have to cover all Essential Health Benefits or comply with patient protections created by the ACA. These

plans are expected to siphon healthier people out of the marketplace, leading to increased premiums for consumers, which will further destabilize the marketplace in which individuals with complex chronic conditions like epilepsy rely on for high-quality, affordable care.

The Epilepsy Foundation continues to advocate for access to high-quality, affordable, and comprehensive health care that meets the needs of individuals with serious and chronic health conditions and disabilities. We are dedicated to implementation, strengthening and enforcement of the patient protections created by the Patient Protection and Affordable Care Act (ACA).

Read the Epilepsy Foundation's comments and learn more about Association Health Plans at advocacy.epilepsy.com/ACA.

Rescissions Package Passes House, Fails to Pass Out of Senate Committee

On June 7, 2018, the House passed a rescissions package (HR 3), aligning with the Administration's proposed cuts, by a vote of 210-206, largely along party lines. The House-passed bill moved on to the Senate on June 11, 2018. However, on June 20, 2018, in a 48-50 vote, senators failed to discharge the measure from the Appropriations Committee. The Senate had until Friday, June 22, 2018, the deadline for considering the measure under privileged rules that would have protected it from a Senate filibuster. While it is unlikely another vote will occur by then, the Epilepsy Foundation will continue to monitor any actions on HR 3.

The proposed cuts would come from cutting about \$2 billion from the Child Enrollment Contingency Fund, which provides payments to states if they experience an unexpected surge in enrollment due to an economic recession or public health crisis, including natural disasters. The White House also proposes to rescind \$5 billion from the Children's Health Insurance Fund.

This proposal undermines the bipartisan CHIP agreement and removes reassurances states need that funding will be available to keep kids covered. Cuts to CHIP in the past have usually been reinvested to offset other vital health care programs, which is not the case for the most recent proposed rescissions.

Learn more about the Children's Health Insurance Program at advocacy.epilepsy.com/CHIP.

Epilepsy Foundation Monitors Plans Underway to Repeal the Affordable Care Act

The Health Policy Consensus Group, led by former Senator Rick Santorum, just released a new plan to repeal the Affordable Care Act (ACA). This plan was developed in consultation with Senate Republicans and the White House, which supports the plan. Some Senators are hoping to take legislative action on the plan by the end of August. The first step to repealing the ACA comes in the form of a budget resolution which would then open up the ability to pass a repeal bill.

The [Center for American Progress](http://CenterforAmericanProgress.org) has analyzed the proposal and concluded it would have an overall negative impact on health care in the U.S. It is projected that millions of Americans would lose health care coverage, and protections for pre-existing conditions would be largely

removed. Further, the plan could cut ACA funding for health coverage by 31 percent by 2028 and 26 percent from 2022 to 2028. The Epilepsy Foundation will continue to monitor any proposals that would impact the Affordable Care Act.

Learn more about the Affordable Care Act and the Epilepsy Foundation's efforts at advocacy.epilepsy.com/ACA.

Farm Bill Moves Forward, Opportunity to Deschedule Cannabidiol

Every five years, Congress authorizes an omnibus, multi-year law that governs an array of agriculture and food programs. The Agricultural Act of 2014 is set to expire soon and Congress is at work on authorizing new spending for the program. The Farm Bill, also known as the Agriculture Improvement Act of 2018, encompasses a number of agricultural and food programs across the U.S.

The Epilepsy Foundation has advocated on the Hemp Farming Act which is part of the overall Farm Bill package. This provision is sponsored by Senate Majority Leader Mitch McConnell and endorsed by 25 other senators, including Minority Leader Chuck Schumer. If passed, this bill would permanently remove hemp, including its derivatives like cannabidiol (CBD), from the Controlled Substances Act, making it an agricultural commodity rather than a Schedule I substance. The original version of this legislation would have removed Food and Drug Administration (FDA) authority over CBD and instead place oversight with the United States Department of Agriculture (USDA). The FDA regularly monitors CBD and other ingestible substances to ensure proper labeling, advertising, and that companies are not making false medical claims. The Epilepsy Foundation believes the USDA is not equipped to carry out this oversight authority. As such, we advocated for the addition of a provision that would preserve FDA oversight over CBD while still descheduling the substance. On June 12, 2018, the Hemp Farming Act was amended to include language preserving FDA's jurisdiction over CBD, and on June 13, 2018 the Senate Agriculture Committee overwhelmingly endorsed the full Farm Bill package by a vote of 20 to 1.

Learn more about medical cannabis and the Epilepsy Foundation's efforts at advocacy.epilepsy.com/medical-cannabis.

Epilepsy Foundation Named an *All of Us* Champion by the National Institutes of Health

The *All of Us* Research Program is an effort by the National Institutes of Health (NIH) to gather data from one million or more people living in the United States to accelerate research and improve health. The program will be open to people both healthy and sick, from all communities.

This is a long-term research effort that is expected to last for at least a decade. The long-term data may help researchers understand the impact of environmental factors on health, track the progression of a disease, or chart the effectiveness of a type of treatment for individuals over time. Data that the program would like to collect over time includes electronic health records, responses to questionnaires, information from wearable devices, and blood and urine samples.

The Epilepsy Foundation supports the *All of Us* research program efforts to leverage the rich diversity of America to ensure that historically underrepresented populations are included in research and to enhance research and science to identify new treatments for health issues. The program and its participants could change health and health care for generations to come.

Participants will be asked to complete questionnaires and share information about their health history, lifestyle habits, and environmental exposures. They may also be asked to provide access to their electronic health records and to go to a local enrollment center to have physical measurements taken and to provide blood and urine samples.

Visit https://www.epilepsy.com/clinical_trials/allus-research-program or <https://www.joinallofus.org/en> to learn more.

STATE ADVOCACY

Step Therapy Advocacy Update: Law Signed in Minnesota

On May 19, 2018, Governor Dayton of Minnesota signed House File 3196 into law, which will place limits on the use of step therapy protocols by insurers and expand access to physician-directed care for people with epilepsy and other chronic conditions.

Step therapy, or fail first, is a process that requires individuals who have been prescribed certain medications to try and fail one or more medications preferred by the insurer before receiving the originally prescribed drug.

Learn more about step therapy and the Epilepsy Foundation's efforts at advocacy.epilepsy.com/steptherapy.



Colorado constituents, Charles Anderson, left, and Mark Stevenson, right, met with Congressman Buck, middle, on June 14, 2018 for the PAME Hill Day.

Governor Hickenlooper Creates a Pathway for Therapies Derived from CBD

On June 4, 2018, Governor Hickenlooper signed HB 18-1187, which will allow therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration (FDA) to become available in Colorado, into law. During the 2018 state legislative session, New Mexico, Wyoming, and now Colorado, have made the necessary changes in their scheduling laws to allow a pathway for therapies derived from CBD.

The FDA is currently reviewing at least once CBD-derived therapy, Epidiolex, that shows promise for the treatment of Dravet and Lennox-Gastaut syndromes (LGS), tuberous sclerosis complex (TSC) and potentially other rare epilepsies. The FDA Peripheral Central Nervous System Drug Advisory Committee recently voted unanimously (13-0) in support of approving Epidiolex on April 19, 2018. An FDA decision is expected as soon as the last week of June, after which the Drug Enforcement Agency (DEA) must take action to schedule the medication.

Follow our advocacy efforts on FDA-approved Therapies Derived from CBD at advocacy.epilepsy.com/statefdapathway.

Update Your Contact Information for Speak Up, Speak Out Advocacy Network

We want to make sure you are well informed about what is happening right in your backyard so that you don't miss an opportunity to share your voice with state and local policymakers.

To ensure you don't miss out, please take a minute to update your contact information, including your home address, so that we can send targeted alerts based on your state and congressional district. Please do so by completing the form [here](#) - which is used only for our Speak Up, Speak Out advocacy network.

Email us at TSU@efa.org

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