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**National Advocacy**

**Teens from Around the Country Joined the Epilepsy Foundation on Capitol Hill to Urge Congress for Funding for Epilepsy Research & Programs**

The Epilepsy Foundation hosted its annual Teens Speak Up! & Public Policy Institute program April 28-30, 2019 in Washington, D.C. More than 175 advocates representing 40 states, including 52 teens and ambassadors living with epilepsy, took part in more than 180 Congressional meetings on Capitol Hill to raise awareness and advocate for policies that are of importance to the epilepsy community. These efforts were part of the Foundation’s signature advocacy event which provides an opportunity for teens living with epilepsy and their parents to visit the nation’s capital to get educated on federal legislative issues, learn effective advocacy techniques and share their personal stories with members of Congress and their staff.

During congressional meetings, advocates asked their members of Congress to: appropriate $11.5 million within the Centers for Disease Control and Prevention’s (CDC) National Center for Chronic Disease Prevention and Health Promotion’s Epilepsy Program; support step therapy protocol reform; [preserve Medicare Part D’s Six Protected Classes](#)
policy, and create a safe and legal federal pathway for access to, and medical research of, medical cannabis and cannabidiol (CBD).

Upon their return home, Teens Speak Up! participants complete a year of service focused on raising awareness, educating about epilepsy in their communities, and continuing to advocate with state and federal lawmakers.

Now it’s your turn to participate and take action! The U.S. House of Representatives Appropriations Committee has recommended a $3 million increase for the CDC’s Epilepsy program and now, we need to urge the Senate to recommend the same increase. The Senate is expected to start working on its bill in June, so now is the perfect time to tell your Senators to support this $3 million increase for the CDC’s Epilepsy program—for a total of $11.5 million.

Learn more about the Teens Speak Up! & Public Policy Institute program at advocacy.epilepsy.com/TSU-PPI.

Epilepsy Foundation Endorses the Safe Step Act

In April, Representatives Raul Ruiz, M.D. (CA-36) and Brad Wenstrup, D.P.M. (OH-02) introduced the Safe Step Act (H.R. 2279), a bipartisan bill to improve step therapy protocols and ensure patients are able to safely and efficiently access the best treatment for them. The Foundation joins over 20 patient and consumer groups in supporting this legislation.

Step therapy, or fail first, is a process that requires individuals who have been prescribed a medication by their healthcare provider to try and fail one or more medication(s) preferred by the insurer before receiving the originally prescribed drug. The Safe Step Act does not ban the use of step therapy but amends the Employee Retirement Income Security Act of 1974 (ERISA) to streamline step therapy protocols and require exceptions to step therapy requirements so that people, especially those with chronic conditions such as epilepsy, can access the most effective medications in a timely manner. For example, the bill makes exemptions from step therapy protocols for people who are currently stable on their medication regime, who have already failed or had an adverse reaction to the treatment, or for whom the step is contraindicated. The legislation will also give healthcare providers and people with epilepsy a transparent and standardized process to appeal step therapy requirements when a particular treatment is needed.

Learn more about step therapy at advocacy.epilepsy.com/StepTherapy.
Pictured above: Teens Speak Up! and Public Policy Institute's Tennessee delegation, which includes the TSU teens Kaylee Smith (Epilepsy Foundation of East Tennessee) and Emma Whitaker (Epilepsy Foundation of Middle and West Tennessee), their families, and Executive Directors Pam Hughes (East Tennessee) and Elisa Hertzan (Middle and West Tennessee).

**Foundation Weighs in on the Administration's Proposed Rules on Drug Rebate Reform and Purchasing Insurance Across State Lines**

Since its blueprint to lower drug prices and out-of-pocket costs was released one year ago, the Administration continues to issue proposed rules aimed at achieving these goals. On April 8, 2019, the [Foundation submitted comments to the Department of Health and Human Services on a proposed rule amending the safe harbor regulations to the Federal anti-kickback statute regarding rebates in Medicare and Medicaid](https://example.com). The Foundation supports the Administration’s efforts to reduce out-of-pocket costs by making changes to the anti-kickback statute as they pertain to Medicare, to reduce cost sharing and ensure all discounts are passed on to the beneficiary at the point of sale. However, we oppose the changes to the safe harbor provision as they relate to Medicaid and believe that changes to Medicaid should not be in the final rule. Medicaid beneficiaries face little or no cost sharing, so they have no way to benefit from the change. Additionally, the Foundation signed on to comments with our coalition partners, the [Consortium for Citizens with Disabilities](https://example.com) and [MAPRx](https://example.com), highlighting similar areas of support and areas of concern.
On May 6, 2019, the Foundation joined with 19 national patient and consumer coalition partners, as well as with the Consortium for Citizens with Disabilities, in submitting comments on a proposed rule from the Centers for Medicare & Medicaid Services (CMS) on the sale of individual health insurance coverage across state lines. Both comments outline concerns that the proposed approach to facilitating the sale of insurance across state lines could erode consumer protections and leave policyholders with inadequate coverage leading to higher healthcare costs.

17 Patient Groups Urge Appeals Court to Uphold Health Care Law

On April 1, 2019, the Foundation and 16 other patient groups filed an amicus curiae ("friend-of-the-court") brief urging the United States Court of Appeals for the Fifth Circuit to uphold the Affordable Care Act (ACA) and its critical protections for millions of individuals with pre-existing conditions and access to health care. This is the next level of appeal, after a federal judge ruled in December 2018 that because the penalty associated with the individual mandate was repealed as part of the tax law, the rest of the Affordable Care Act must also be invalidated. While there is no impact on health insurance coverage as the case goes through the appeals process, in jeopardy are popular and effective provisions including a prohibition on pre-existing condition exclusions, cost-sharing limits and a prohibition on annual and lifetime limits. The amicus brief focuses on the importance of these protections for people with pre-existing conditions including epilepsy.

Read the full amicus brief here.

Learn more about the Foundation’s efforts to protect individuals with pre-existing conditions at advocacy.epilepsy.com/ACA.

The Challenges of High-Deductible Plans for Individuals with Chronic Conditions

High-deductible health plans (HDHPs) are on the rise in the health insurance Marketplace. Nearly 70 percent of mid to large employers offer HDHPs to employees and for 13 percent, an HDHP is the only option offered. However, for the 60 percent of Americans living with at least one chronic condition, high deductibles present a precarious financial burden that recur every January 1. Laura Weidner, Vice President of Government Relations & Advocacy at the Foundation contributed to an article highlighting concerns of HDHPs and how it affects those living with epilepsy. Read the full article here.
Pictured above: Senator Mike Braun of Indiana with Indiana’s TSU teens, James Franklin to the left of the Senator and Breanna Jaffe on the right.

STATE ADVOCACY

Indiana Becomes Second State in the Nation to Enact Seizure Safe Schools Legislation

On May 5, 2019, Governor Eric Holcomb signed HEA 1089 into law making Indiana the second state in the nation, after Kentucky, to enact Seizure Safe Schools legislation. The bill includes the Foundation’s Seizure Safe Schools language, which will help improve the care of the 10,600 students living in Indiana with epilepsy and seizure disorders. Under the law, public schools in the state will mandate training of school personnel on seizure detection and first aid; require that Seizure Action Plans be on file for every student diagnosed with epilepsy or a seizure disorder and available to all personnel responsible for the student; and ensure the administration of seizure rescue medication, approved by the U.S. Food & Drug Administration, or medication prescribed by the student’s health care provider.

Seizure Safe/Seizure Smart Schools legislation has been introduced during this year’s state legislative session in nine states, most recently in North Carolina. Bills in Illinois and Texas continue to make progress and move forward in their respective legislatures.

Learn more about Seizure Safe Schools legislation at advocacy.epilepsy.com/seizuresafeschools.
New York Introduces Legislation Requiring Health Care Practitioners to Provide Information on SUDEP

On April 29, 2019, Senate Bill 5397 was introduced in the New York State Senate. The bill would require any health care practitioner who is treating a person with epilepsy to provide current and evidence-based information about Sudden Unexpected Death in Epilepsy (SUDEP) risk factors and conditions and contact information for nonprofit organizations that provide information and support services for epilepsy syndromes. The Foundation and the local Epilepsy Foundation’s in New York will continue to monitor its progress.

For more information on SUDEP legislation, please visit advocacy.epilepsy.com/SUDEP.

Step Therapy Reform Sweeps Across the United States

During the 2019 state legislative session, multiple states have passed step therapy reform legislation! The Foundation and its local offices worked behind the scenes in several of these states to help pass this crucial legislation. Virginia became the first state to pass step therapy reform this year in March when Governor Northam signed House Bill 2126 into law. Quickly following Virginia, Oklahoma’s Governor Kevin Stitt signed Senate Bill 509 into law on April 16. Georgia’s House Bill 63 was signed into law on April 25 by Governor Brian Kemp and in Washington, House Bill 1879 was signed into law on April 29 by Governor Jay Inslee. The bills passed in Virginia, Oklahoma, and Georgia and will go into effect in 2020. However, the bill passed in Washington won’t go into effect until 2021.

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

Stay up to date with the legislation in your state by visiting advocacy.epilepsy.com/states.

We encourage you to invite others to join our Speak Up, Speak Out! advocacy network. Members receive the monthly Capitol Circuit 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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