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National Advocacy

Epilepsy Advocates Bring Awareness and Advance Key Policies in the Nation’s Capital

The Epilepsy Foundation welcomed members of the epilepsy community to Washington, D.C., on March 1-3, 2020, for its annual signature advocacy event, Teens Speak Up! and Public Policy Institute. Teens Speak Up! and Public Policy Institute provides an opportunity for teens living with epilepsy and their parents to visit the nation’s capital, receive advocacy training, meet
with legislators, and tell their personal stories to make a difference in the lives of 3.4 million people in the U.S. living with epilepsy. The event brought together more than 175 advocates representing 38 states, including 53 teen representatives and ambassadors living with epilepsy.

Families and state advocacy leaders shared their personal stories to raise awareness and advocate for important policies in more than 180 Congressional meetings. Advocates asked their members of Congress to provide $11.5 million for the Centers for Disease Control and Prevention’s (CDC) Epilepsy Program; pass the Safe Step Act (H.R. 2279/S. 2546) so people with epilepsy have timely access to needed medications; and pass H.R. 2093/S. 1028 and H.R. 4322/S. 2400 to ensure access to safe and legal medical cannabis and CBD.

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

>>>Now it’s your turn to take action! Ask your lawmakers to support and co-sponsor the Safe Step Act or thank them if they are already a co-sponsor!

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

**Foundation Joins Patient and Disability Communities in Urging Lawmakers to Take Action to Protect Those Most Vulnerable to COVID-19**

Congress is working on an economic stimulus package — the Families First Coronavirus Response Act (H.R. 6201) — given the COVID-19 pandemic. The Epilepsy Foundation has been advocating in coordination with the patient and disability communities for provisions to be included that help ensure access to health care and medications and other critical support like meaningful paid leave during these challenging times.

On March 14th, the Foundation joined the Consortium for Citizens with Disabilities in a letter that was sent to Senate leadership outlining critical support needed for people with disabilities and the programs they rely on. On March 16th, 29 national patient and consumer organizations, including the Foundation, released a statement urging the U.S. Senate to immediately pass H.R. 6201 and sent an accompanying letter to Senate leadership.

Congress passed and the president signed H.R. 6201 into law on March 18. Further economic stimulus packages are already under discussion, which will provide further opportunity to include provisions that support the epilepsy
community. The Foundation continues to advocate for policies that will ensure people with epilepsy can follow CDC guidelines on social distancing, including access to extra supplies of medications, ensuring that people with disabilities have the services and supports they need in the community, and paid leave.

>>>Take action to thank Congress for passing H.R. 6201 and urge them to take additional steps for the epilepsy community to access medications during this time!

Stay up to date by reading the Foundation’s FAQ on COVID-19 (Coronavirus) and Epilepsy, which will be updated as information becomes available.

Patient and Disability Groups Respond to Administration’s Medicaid Block Grant Announcement & Proposed Notice of Benefit and Payment Parameters Rule

On January 30, the Centers for Medicare and Medicaid Services (CMS) released guidance encouraging states to adopt Medicaid Block Grants, now called the “Healthy Adult Opportunity” program. The guidance will allow states to reduce Medicaid benefits – including adopting closed formularies and other restrictions on prescription drug coverage – in exchange for capped federal funding. The Foundation joined with 25 national patient groups and over 40 disability organizations to express concern about the announcement. We will continue to engage at the federal and state level to protect access to health care for people with epilepsy on Medicaid.

On January 31, CMS announced the proposed rule on the Notice of Benefit and Payment Parameters for 2021. The proposed rule makes changes to policies implemented through the Affordable Care Act (ACA). In early March, the Foundation joined with 21 other national patient and consumer groups, as well as through the Consortium for Citizens with Disabilities (CCD), in submitting comments expressing concern over proposals to amend the automatic re-enrollment process as well as allowing issuers to implement Accrual Parameters in any circumstances.

Congressional Action on Surprise Medical Billing

Surprise medical billing also known as “balance billing” has become an increasingly popular topic in Congress and refers to charges arising when an insured individual inadvertently receives care from an out-of-network provider. Often, surprise bills are related to emergency care – urgent and sometimes life-threatening situations where individuals are not able to decide which facility or physician provides their care. In late 2019, the Senate Health,
Education, Labor and Pensions (HELP) Committee and House Energy & Commerce Committee reached a bipartisan bicameral agreement in regard to surprise medical billing legislation (S. 1895). In early 2020, the House Ways & Means and Education & Labor Committees also took action on this issue by passing H.R. 5826 and H.R. 5800 out of committee, respectively. Twenty-five national patient and consumer advocacy organizations, including the Foundation, have signed on to a set of principles to protect consumers from surprise medical bills and guide congressional efforts.

We Want to Hear from You: Share Your Story with the Foundation

Congress and state legislatures are constantly considering and putting in place policies that can affect the epilepsy community. The best way to make sure that your needs are considered in these decisions is by sharing your story and explaining how these policies would affect you. You know first-hand the challenges that come from living with epilepsy. Your experiences help inform your story. Without speaking up and telling your story, elected officials may never know what epilepsy is, what living with epilepsy is like or even know that an issue is important to you. If you are willing to share your story with the Epilepsy Foundation, we can share it with elected officials to advance important policies for you and the epilepsy community.

Share your story with us by filling out the form at advocacy.epilepsy.com/advocacymatters.

State Advocacy

Seizure Safe Schools Legislative Activity

During the 2020 state legislative session, one of the Foundation’s top legislative priorities—Seizure Safe Schools legislation—has been introduced in more than 15 states and many bills have made significant progress by advancing to committee hearings or full chamber votes. However, due to COVID-19, many state legislatures will be shutting down early to protect the health and safety of the public. We will continue to monitor how this unique situation will affect state-level legislation, including seizure safe schools bills.

Learn more about the legislation and this nationwide initiative at advocacy.epilepsy.com/seizuresafeschools.
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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