The Capitol Circuit
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National Advocacy

Epilepsy Advocates Spread Awareness and Advance Key Policies During Virtual Capitol Hill Week

The Epilepsy Foundation kicked off its annual signature advocacy event, the Teens Speak Up! & Public Policy Institute (TSU-PPI)’s Virtual Hill Week on March 22. Given the COVID-19 pandemic, TSU-PPI participants received advocacy training and met virtually with their members of Congress and staff thru March 26, 2021. At this event, more than 160 advocates representing 38 states, including 54 teen representatives and ambassadors living with the epilepsies held more than 150 meetings with congressional offices. Advocates shared their experiences of living with epilepsy and asked their members of
Congress to provide $13 million for the CDC’s Epilepsy program in Fiscal Year 2022, as well as to help ensure safe and legal access to medical cannabis and cannabidiol (CBD) and to promote research in order to better understand its potential benefits and risks through passage of legislation, such as the Medical Marijuana Research Act and the Cannabidiol and Marihuana Research Expansion Act (S. 253).

During the virtual event, the Foundation awarded the inaugural Tony Coelho Impact Award to Representative Ed Perlmutter (CO-07) for his leadership in Congress to improve the lives of people with the epilepsies including helping secure a nearly $4 million increase for the Veterans Affairs Epilepsy Centers of Excellence (ECoE) in FY 2021, which provide critical care to the nation’s veterans with epilepsy and seizure disorders. The Sara Stubblefield Advocacy Award was presented to Shari Dudo of Troup, Texas for her instrumental role in passing Sam’s Law in Texas, part of the Foundation’s Seizure Safe Schools initiative, as well as her work to include seizure education to the health curriculum for more than 4 million students in the state.

Learn more about this year’s event here.

Medicare Six Protected Classes Victory for Epilepsy Community

On Tuesday, March 16, the Centers for Medicare and Medicaid Services (CMS) announced the rescission of a Six Protected Classes proposal that would have restricted access to epilepsy medications in Medicare. Under the proposal, which was released in January, Medicare plans could have chosen to no longer cover all or substantially all anticonvulsants (anti-seizure medications) and instead, cover only one drug per therapeutic class—which is even less than Part D’s standard for non-Protected Class medications of two drugs per class.

The epilepsy community responded with vigor and passion, sending nearly 1,700 emails to the administration about the importance of physician-directed and person-centered care and access to the full range of medications for people with epilepsy. In their announcement, the administration specifically said that that stakeholder feedback was a large reason behind their decision. The Foundation is grateful for everyone who took action and helped protect access to anti-seizure medications for the 1.1 million Medicare beneficiaries who live with the epilepsies.

Congress Passes Comprehensive COVID-19 Package Including Provisions Helpful to the Epilepsy Community

In mid-March, Congress passed and President Biden signed the American Rescue Plan Act (H.R. 1319), the latest COVID-19 relief package, into law. The
final package included several provisions that the Foundation advocated for including: additional direct payments to Americans and for the first time, inclusion of adult dependents in Economic Impact Payments; dedicated funding for Medicaid home and community-based services; extension of emergency paid leave tax credits; and extension and expansion of unemployment benefits. The comprehensive package also takes several steps to improve the affordability of health care coverage, including subsidizing premium costs for those on COBRA, and increasing subsidies to purchase coverage through the Affordable Care Act (ACA), as well as expanded eligibility for those subsidies. The bill also included incentives for states that have not yet expanded Medicaid to expand coverage.

Survey Opportunity: How Has COVID-19 Impacted People with Epilepsy?

Be part of an exciting and interesting opportunity, as researchers at the University of Oxford and SUDEP Action in collaboration with other key partners are inviting people living with or affected by epilepsy around the world to share how COVID-19 has changed and created challenges in their lives. To participate, you must be over 18 years old and either a person with epilepsy, someone who cares for a person with epilepsy (who may be a child or adult with epilepsy), or a healthcare professional who helps in the management of people with epilepsy. The online survey takes 10-20 minutes to complete. The information collected will be anonymous. To complete the survey, click here.

Becerra Confirmed as Secretary of Health and Human Services

On March 18, the U.S. Senate confirmed Xavier Becerra as the Secretary of the Department of Health and Human Services (HHS). Most recently, Becerra served as California’s Attorney General and is a former California congressman. He becomes the first Latino to hold the Cabinet position. The Department of Health and Human Services houses many important agencies pertaining to health services that can impact the epilepsy community, such as the Centers for Medicare & Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), and the National Institutes of Health (NIH). The Biden administration has nominated Chiquita Brooks-LaSure to serve as the CMS Administrator and an FDA Commissioner nominee has not yet been named – both cabinet positions must be confirmed by the Senate.

Special Enrollment Period for Marketplace Plans

In response to the COVID-19 pandemic, President Biden issued an Executive Order on January 28th calling for a Special Enrollment Period (SEP) for individuals and families to enroll in Marketplace health insurance plans. Due to
the pandemic, many Americans may be facing new health challenges and/or have lost coverage as a result from the economic fallout – millions remain uninsured or underinsured.

Now through **August 15, 2021**, individuals and families can enroll in a new Marketplace plan or change plans. This SEP will be available to consumers in the 36 states served by Marketplaces that use the [HealthCare.gov](http://HealthCare.gov) platform. Consumers who are uninsured will be able to look for coverage that would start prospectively the first of the month after plan selection and learn whether they qualify for financial assistance to help pay for health insurance. Currently, 9 out of 10 consumers enrolled in coverage through Healthcare.gov receive financial help and 75% of consumers can purchase a plan for $50 or less per month after financial assistance. Additionally, consumers will not need to provide any documentation of a qualifying event (e.g., loss of a job or birth of a child), which is typically required for SEP eligibility. Starting April 1, consumers may be able to get more savings and lower costs on Marketplace health insurance coverage due to provisions included in the **American Rescue Plan Act**, which was signed into law in mid-March.

Visit [HealthCare.gov](http://HealthCare.gov) or [CuidadoDeSalud.gov](http://CuidadoDeSalud.gov) to learn more and enroll or see if you qualify for Medicaid or CHIP. Consumers can also call the Marketplace Call Center at 1-800-318-2596 which provides assistance in over 150 languages. TTY callers should use 1-855-889-4325.

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**State Advocacy**

**Virginia Becomes 6th State to Enact Seizure Safe Schools Legislation**

In late February, the *Jamie and Brie Strong Act* (SB 1322) – Virginia’s Seizure Safe Schools legislation – passed through the General Assembly and made its way to Governor Ralph Northam’s desk. The bill automatically became law on March 31st at 11:59 p.m. ET, making Virginia the sixth state to enact Seizure Safe Schools legislation, following Kentucky, Indiana, Texas, Illinois, and New Jersey.

During the 2021 state legislative session, this critical bill has been introduced thus far in Alabama, Arizona, Colorado, Iowa, Maryland, Michigan, Minnesota, Missouri, Nebraska, Oklahoma, Rhode Island, South Carolina, and Washington.

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