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National Advocacy

Congress Begins Working on 2021 Spending Bills

In early July, the U.S. House Appropriations Committee began working on several 2021 spending bills. The budgets for many agencies and programs that are vitally important to the epilepsy community including the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) are included in these bills. The CDC's National Center for Chronic Disease Prevention and Health Promotion's Epilepsy Program is the only public health program specifically related to epilepsy that offers a national scope and community programs. This funding is critical in helping to promote
awareness, collect data, and support programs that improve the quality of life and care for people with the epilepsies.

On Monday, July 13, the House committee advanced its Labor-HHS-Education bill spending bill, which includes $10.5 million for the CDC’s Epilepsy Program—a $1 million increase from the previous year. We are deeply grateful for the support from the community—both during the 2020 Teens Speak Up! Capitol Hill Day in March and for our grassroots sending over 1,200 letters to the U.S. House—that helped achieve this recommended increase! We are now awaiting the Senate Appropriations Committee to begin taking up spending bills and we will continue to advocate for $11.5 million for the CDC’s Epilepsy Program to be included in the final bill.

Epilepsy Foundation Urges Congress to Include Epilepsy Community Priorities in the next COVID-19 Package

The House passed its next COVID-19 package entitled the HEROES Act (H.R. 6800) in mid-May and the U.S. Senate is now starting to work on its package. On July 6, the Foundation sent a letter to Senate leadership and committees of jurisdiction urging Congress to ensure the needs of Americans living with chronic conditions and disabilities, like epilepsy, are adequately addressed in the next package. Specifically, the Foundation urged provisions that would re-open the enrollment period in the health insurance marketplace nationwide; expand paid leave; ensure all adults with disabilities are eligible for economic impact payments, suspend step therapy protocols; and increase funding for state Medicaid programs and target additional support for home and community-based services. The Foundation also sent a letter to House leadership thanking them for including several of the above-mentioned provisions in the HEROES Act.

In line with our own letter, the Foundation joined more than 100 organizations, representing health care providers and state and local governments, on a letter to congressional leadership urging for an enhanced federal medical assistance percentage (FMAP) for the Medicaid program in the next bipartisan pandemic relief bill. Through the Consortium for Citizens with Disabilities (CCD), the Foundation endorsed the Coronavirus Medicaid Response Act (S. 4108), which would both improve the nation’s response to the current pandemic and help prepare for future public health emergencies and economic downturns by building in automatic support to state Medicaid programs.

Stay up to date by reading the Foundation’s COVID-19 and Epilepsy resources, which will be updated as information becomes available and watch out for action alerts as the COVID-19 packages start to advance.
Read more about the Foundation’s COVID-19 pandemic advocacy engagement and the full list of the COVID-19 related letters at advocacy.epilepsy.com/covid-19.

19 National Patient Organizations Applaud Critical Healthcare Reforms

In late June, 19 national patient and consumer organizations, including the Foundation, released a statement praising critical reforms included in the U.S. House’s Patient Protection and Affordable Care Enhancement Act (H.R. 1425). This legislation includes additional protections for individuals living with pre-existing conditions which, if passed, would help more people access and afford health care coverage and services especially during the public health emergency in which many have lost their health insurance. The bill expands eligibility for tax credits to afford health insurance for middle class families, includes increased federal funding to expand Medicaid, and reverses the Administration’s expansion of short-term limited duration health plans, which can charge more or deny coverage if a patient has a pre-existing condition.

340 Organizations Send Letter to Congress Urging Action on Telehealth

At the onset of the pandemic, Congress and the Administration quickly waived statutory barriers to allow for easier access to care through telehealth. This provides great benefits to many people with epilepsy who, for instance, have transportation challenges and/or may have to travel far distances to access specialty care. On June 29, the Foundation joined with 340 organizations in a letter to congressional leadership urging Congress to make permanent reforms that will allow Medicare beneficiaries to continue accessing health care through telehealth after the public health emergency ends. As telehealth issues continue to evolve, the Foundation will be looking more deeply into this area and monitoring the ever-changing landscape to ensure the epilepsy community is represented.

Foundation Celebrates 30th Anniversary of the Americans with Disabilities Act (ADA)

The Foundation is excited to join other organizations and individuals across the nation to celebrate the 30th anniversary of the Americans with Disabilities Act (ADA), which was signed into law by President George H.W. Bush on July 26, 1990. The ADA prohibits discrimination and guarantees the civil rights of people with disabilities. In 2008, President George W. Bush signed the ADA Amendments Act that restored the original intent of Congress and clarified the definition of “disability” to encompass episodic conditions like epilepsy. The Foundation is proud to have served in such a critical advocacy role in helping to pass the ADA and the ADA Amendments Act alongside the
collaborative efforts of the disability community, local offices, business leaders, and Congress – including former Congressman Tony Coelho, a person living with epilepsy, a member of the Foundation’s National Board of Directors and lead sponsor of the ADA while in Congress.

The Foundation will be hosting an ADA 30th Celebration virtual event on Thursday, July 23 at 2 p.m. ET. Registration and more details to follow!

State Advocacy

Oklahoma Block Grant Cuts Jeopardizes Access to Care

After back and forth amongst state leadership over Medicaid expansion, Oklahomans narrowly approved a ballot measure at the beginning of July that would expand Medicaid to eligible adults. However, with the Administration now allowing states to block grant their state Medicaid programs, Oklahoma has submitted its SoonerCare 2.0 proposal which would greatly reduce the benefits of expansion and jeopardize beneficiaries’ access to care by shifting the program to a capped funding structure, reducing patients’ access to critical benefits and services, and adding multiple eligibility restrictions, such as work requirements, premiums, and the elimination of retroactive coverage. The Foundation strongly opposes the proposal and submitted a joint comment with the Epilepsy Foundation Oklahoma to Secretary Azar during the federal public comment period expressing our concerns.

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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