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National Advocacy

House Appropriations Committee Advances Spending Bills Including Proposed Increase for CDC Epilepsy Program

Last week, members of the House Appropriations Committee marked up and voted on all 12 annual spending bills, where they will next advance to the House floor. The Labor, Health and Human Services, Education and Related Agencies (LHHS) spending bill includes funding for many important agencies including, the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH). The House Appropriations Committee
approved $13 million for the CDC’s National Center for Chronic Disease Prevention and Health Promotion’s Epilepsy Program, which would be a $2.5 million increase over the current year. The CDC’s Epilepsy Program is the only public health program specifically related to epilepsy that offers a national scope and community programs. It helps promote awareness, collect data, and support programs that improve the quality of life and care for people with the epilepsies. The bill also includes language directing the Centers for Medicare and Medicaid Services to write a report on alternatives to the quality-adjusted life year, an economic measure sometimes used in health care that discriminates against people with disabilities.

The Epilepsy Foundation is ecstatic to see this level of funding moving forward and wants to thank our grassroots advocates who have been advocating for this increased funding through virtual meetings with members of Congress and sending emails to targeted committee members. The House Committee's recommended funding is a great first step, though the Senate still needs to take action and there are several more steps until the funding levels are finalized. The House Appropriations Committee Chair Rosa DeLauro (CT-03) will be pushing for the full House to take up all 12 spending bills before August Recess. As of now, the Senate Appropriations Committee is not expected to take action on these bills until fall or potentially late summer. As the spending bills progress, the Foundation will reach out to our grassroots advocates for future action opportunities.

Disability Community Urges Congress to Provide Full Funding for Home and Community-Based Services (HCBS)

This week, a broad coalition of disability, aging, civil rights, and consumer organizations sent letters to Congressional leadership urging them to include and prioritize the full $400 billion to support access to Medicaid Home and Community-Based Services (HCBS) in the next legislative package. Historically, funding for these critical services has been inadequate – leading to over 800,000 people with disabilities on waiting lists for these services and supports and many more entering institutions against their wishes. The letters stress that a full investment is necessary to finally address the magnitude of need in the disability and aging communities and expand the direct care workforce.

Epilepsy Foundation Celebrates 31st Anniversary of the Americans with Disabilities Act (ADA)

The Foundation is excited to join other organizations and individuals across the nation to celebrate the 31st 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.

The Foundation, long being headquartered in Prince George’s County, Maryland, is honored to be recognized by the Prince George’s County Commission for Individuals with Disabilities on July 26th for our service to the community to ensure that all people with disabilities, including epilepsy, live their fullest and most independent lives possible.

**Foundation Supports Creation of Neuroscience Center of Excellence at the FDA**

Many in the neurological community, including the American Brain Coalition and the Epilepsy Foundation, are advocating for the creation of a Neuroscience Center of Excellence at the Food and Drug Administration (FDA). A Neuroscience Center of Excellence would allow the FDA to consolidate its neuroscience expertise to create the guidance and processes necessary to ease the review and approval of safe and effective brain and central nervous system (CNS) treatments.

In late June, Representatives Diana DeGette (CO-01) and Fred Upton (MI-06) released a Cures 2.0 discussion draft which builds upon enactment of 21st Century Cures in 2015 and aims to continue accelerating innovation and cures of diseases including epilepsy. This discussion draft would authorize creation of two new Centers of Excellence, including one that addresses diseases that are a leading cause of mortality or disability, affect at least 50 million Americans per year, contribute to increasing health care costs, and for which medical products take longer to be approved—all of which apply to brain and central nervous system conditions. The [American Brain Coalition and over 100 organizations, including the Epilepsy Foundation, sent a letter supporting this provision as it would be a pathway to create a Neuroscience Center of Excellence.](https://epilepsyfoundation.org/)

Representatives DeGette and Upton are currently accepting feedback on the discussion draft and, after reviewing that, will introduce a legislative text. Stay tuned for advocacy opportunities around the creation of a Neuroscience Center of Excellence.

**Take Action to Support the Safe Step Act**
Congress has reintroduced step therapy reform legislation that the Epilepsy Foundation and many other patient organizations have supported – the Safe Step Act (H.R. 2163/S. 464). 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. For people with the epilepsies, this can increase the risk of developing breakthrough seizures and related complications, including death. The Safe Step Act would streamline step therapy protocols, establish a clear exemption process, and require exceptions to step therapy requirements so that people with serious and chronic conditions, like the epilepsies, can access the most effective medications in a timely manner.

**Urge your members of Congress TODAY to co-sponsor this critical legislation!** If your member of Congress is already a sponsor of the bill, you will have the opportunity to thank them for their support. We strongly encourage you to personalize the message and inform your elected officials if you or your loved one has been affected by step therapy protocols and why this bill is so important.

**Special Enrollment Period for Marketplace Plans**

Time is running out! 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. Additionally, consumers may now 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.
State Advocacy

Seizure Safe Schools Legislation Passed in 12 States and Counting

On June 30th, Minnesota Governor Tim Walz signed the 2021 education budget bill into law, which included Seizure Smart Schools legislation. With its passage, 12 states total have now enacted Seizure Safe Schools legislation including: Kentucky, Indiana, Texas, Illinois, New Jersey, Virginia, Washington, Oklahoma, Nebraska, Alabama, Colorado, and Minnesota. We congratulate all the incredible advocates and families on the ground, many Foundation staff, and supportive state elected officials, who have helped make this bill a reality.

While most state legislative sessions have adjourned, a few bills remain active, including in Michigan and Rhode Island. Most recently, Ohio’s state legislature also introduced a Seizure Safe Schools bill, HB 370. The Foundation, grassroots advocates, staff, and state elected officials will continue to ramp up efforts in the fall to prepare to pass bills across the country in the 2022 state legislative session.

Visit our Action Alert Center to see if you can take action to support a bill in your state!

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