



Highlights from the Hill

September 2017

In this Issue:

National Advocacy

- Latest Developments in the Affordable Care Act Debate
- Epilepsy Foundation Urges Congress to Extend Funding for the Children's Health Insurance Program (CHIP)
- Preserving the Medicare Part D Six Protected Classes Policy
- Congress Takes Steps Forward on Spending Bills
- House Judiciary Committee Moves Forward with Bill Threatening the Americans with Disabilities Act
- Epilepsy Foundation Staff and Advocates Testify at the Food and Drug Administration

State Advocacy

- Protecting Access to Epilepsy Care in Massachusetts Medicaid
- Teens Speak Up About Epilepsy in Kentucky
- TSU Teen Cristian Girolamo Speaks Up About Epilepsy in Illinois

We encourage you to invite others to join our [Speak Up, Speak Out!](#) advocacy network. Members receive the monthly *Highlights from the Hill* 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](#).

National Advocacy

Latest Developments in the Affordable Care Act Debate

Congress continues to consider an overhaul of the Affordable Care Act (ACA) under a deadline of September 30. On September 13, 2017, Senator Graham introduced a new ACA "repeal and replace" proposal as an amendment to the House-passed Health Care Freedom Act, which would threaten health insurance coverage for millions of Americans - including many with epilepsy.

This proposal, referred to widely as Graham-Cassidy, is similar to other proposals defeated this summer. It would drastically cut the entire Medicaid program and could allow some insurance plans to drop coverage for basic services, including emergency care, prescription medications, and chronic disease treatment. On Monday, September 25, the Senate Committee on Finance will hold a hearing on this proposal.

In July, more than 2,000 members of the epilepsy community mobilized to help defeat a health care bill that would have been devastating for people living with pre-existing conditions and significant health needs. The new Graham-Cassidy bill will have similar negative effects on people living with epilepsy. Help us urge the Senate to reject this bill by using our [alert](#) to write to your members of Congress.

In the ongoing debate on health care, the Epilepsy Foundation continues to reinforce with Congress the need to protect Medicaid, which covers more than a third of people living with epilepsy, and preserve patient protections in the ACA that help ensure quality health coverage is available and affordable to those with chronic conditions and significant health care needs. On September 15, we joined a coalition [letter](#) to the full Senate highlighting our concerns and opposition to the proposal.

Prior to introduction of Senator Graham's proposal, the Senate Health, Education, Labor, and Pensions (HELP) Committee had been holding hearings with the goal of developing a bipartisan bill to stabilize the current ACA Marketplace. On September 13, 2017, the I Am Essential Coalition, which is jointly led by the Epilepsy Foundation, sent a [letter](#) to the leaders of the Senate HELP Committee praising the committee's approach and encouraging them to preserve specific ACA protections in their effort including: Essential Health Benefits, the prohibition on lifetime or annual limits and unlimited out-of-pocket costs, and the ban on health care discrimination against people with pre-existing conditions. The letter also expressed support for the continuation of cost-sharing subsidies, which help lower-income Americans on ACA plans afford health insurance. The future of these cost-sharing subsidies is unclear, and without certainty, the stability of the ACA Marketplace is at risk.

On September 5, 2017, the Epilepsy Foundation joined a coalition letter with dozens of other advocacy groups specifically urging Congress to guarantee funding for cost-sharing subsidies. The letter also encouraged Congress to continue funding for the premium stabilization programs, which shield insurance markets from high-cost claims, and the ACA grassroots outreach programs, which help individuals and families enroll in health insurance. Read the letter [here](#).

Follow the ongoing debate and the Epilepsy Foundation's advocacy on access to affordable health care at advocacy.epilepsy.com/ACA.

Epilepsy Foundation Urges Congress to Extend Funding for the Children's Health Insurance Program (CHIP)

Congress is currently considering a funding extension for the Children's Health Insurance Program (CHIP), which provides health insurance to 8.9 million American children. CHIP is a

critical health care option for children in families that earn too much to qualify for Medicaid, but too little to purchase other private insurance. More than one million members of the epilepsy community depend on CHIP or Medicaid to access high-quality, affordable health care. It is critical that Congress moves quickly to reauthorize CHIP or states may be forced to reduce enrollment and cut benefits.

CHIP has bipartisan support, but it must be at the top of the Congressional agenda for a funding extension to pass by the deadline. On September 11, 2017, the Epilepsy Foundation sent a [letter](#) to Congressional leadership in support of long-term funding for CHIP. Make a difference by writing to your members of Congress in support of CHIP [here](#).

Read more about CHIP at www.epilepsy.com/article/2017/9/its-time-fund-health-insurance-kids-again.

Preserving the Medicare Part D Six Protected Classes Policy

In 2005, the Centers for Medicare and Medicaid Services (CMS) established the "Six Protected Classes" policy, which requires Medicare Part D plans to cover all or most drugs in six specified classes - including many epilepsy medications. The Six Protected Classes policy preserves access to anticonvulsants that are used to treat epilepsy, and it is an important safeguard for people with epilepsy who rely on Medicare. Since the program was established, CMS has considered proposals to eliminate one or more protected classes, but has not done so.

Recently, the Office of Management and Budget (OMB) announced that a rule on the Part D program can be expected in September. In response, on September 8, 2017, the Epilepsy Foundation and many of our affiliates and chapters joined 110 patient advocacy groups in a [letter](#) to Department of Health and Human Services Secretary Dr. Tom Price, highlighting the importance of the Six Protected Classes policy. Read the coalition press release about the letter [here](#).

Learn more about the Medicaid Six Protected Classes Policy at advocacy.epilepsy.com/ProtectedClasses.

Congress Takes Steps Forward on Spending Bills

Earlier this month, the Senate Committee on Appropriations approved a bill for Fiscal Year (FY) 2018 that would provide \$36.1 billion for National Institutes of Health (NIH), an increase of \$2 billion from FY2017, continuing the trend from the past few years. Notably, this increase includes \$140 million more for the BRAIN Initiative, an important project to the epilepsy community with the goal of revolutionizing our understanding of the human brain. The bill also would provide a slight increase for Centers for Disease Control and Prevention (CDC). The House Committee on Appropriations also approved a FY2018 bill in July, which includes a more modest spending increase for NIH and a decrease in funding for CDC.

The full Senate and House will need to pass appropriations bills to fund the government for FY2018. While Congress continues to debate the various spending bills, on September 8, they

passed and the president signed into law a temporary funding deal that extended current funding levels for government programs like the NIH and CDC through early December.

Read about the Epilepsy Foundation's efforts related to appropriations at advocacy.epilepsy.com/federal-funding-for-epilepsy.

House Judiciary Committee Moves Forward with Bill Threatening Americans with Disabilities Act

On September 7, 2017, the House Judiciary Committee passed the ADA Education and Reform Act (H.R. 620) out of committee on a 15-9 vote. This bill would reduce the protections granted under Title III of the Americans with Disabilities Act (ADA), which safeguards the rights of people with disabilities to access public accommodations. It would limit the ability of the disability community to seek legal recourse for violations of the ADA and would remove the incentive for business owners to be proactive about ADA compliance.

The Epilepsy Foundation is opposed to H.R. 620 and all efforts to modify the ADA in ways that will limit the civil rights of the disability community. Take action and write to your member of Congress in opposition to this bill [here](#).

Learn more about H.R. 620 and the ADA at advocacy.epilepsy.com/ADA.

Epilepsy Foundation Staff and Advocates Testify at the Food and Drug Administration



On August 17, 2017, Epilepsy Foundation staff and advocates testified at a Food and Drug Administration (FDA) patient engagement meeting about the critical role that medical devices can play in treating epilepsy and reducing the risk of Sudden Unexplained Death in Epilepsy (SUDEP). During the meeting, Dr. Sonya Dumanis, director of the Epilepsy Innovation Institute (EI²) presented the Epilepsy Foundation's current device initiatives. Dr. Dumanis was joined as a presenter by Kennedy Witcher, 16, a 2017 Teens Speak Up! participant from Alabama, who testified at the FDA as part of her Teens Speak Up! Year of Service; Sean Andrish, a member of the epilepsy community from Colorado who uses an RNS device; Starr Phipps, a member of our community from Virginia who uses a VNS device; and Wendy Parker, the mother of a child who passed away from Sudden Unexpected Death in Epilepsy (SUDEP) and a member of the epilepsy community in Virginia.

State Advocacy

Protecting Access to Care in Massachusetts Medicaid

The Massachusetts Department of Health and Human Services is currently considering a proposed change to the Massachusetts Medicaid (MassHealth) program that would narrow

provider and medication options and increase costs for enrollees. On August 21, 2017, the Epilepsy Foundation and our local affiliate, the Epilepsy Foundation of New England, sent a [letter](#) to the state Department of Health and Human Services Office of Medicaid, expressing concerns with the proposed new policy.

Several other states may soon be considering similar changes to their Medicaid programs. The Epilepsy Foundation will continue to help share the voice of the epilepsy community and advocate for protections and adequate coverage for beneficiaries in the program, which is critical to the more than a third of Americans living with epilepsy who rely on the program.

Teens Advocate for Epilepsy at University of Kentucky's Epilepsy Day



In August, Charles Wilson, 14, and Lyndsey Crunk, 16, advocated for epilepsy at University of Kentucky's Epilepsy Day. Charles was also featured on local news station WLEX, where he spoke about issues affecting the epilepsy community.

Charles and Lyndsey both participated in the 2017 Teens Speak Up! conference and spoke at UK Epilepsy Day as part of their epilepsy Year of Service.

TSU Teen Cristian Girolamo Speaks Up About Epilepsy in Illinois



After returning from this year's Teens Speak Up! conference, Chicago teen Cristian Girolamo, 17, got right to work on his Epilepsy Year of Service. In May, Cristian traveled with the Epilepsy Foundation of Chicago delegation to the state capitol in Springfield, where he met with Illinois legislators to advocate for epilepsy policy priorities. In August, Cristian coordinated a 5k fundraiser at his high school to raise money

for epilepsy. Thanks for all your hard work, Cristian!

Learn more about the Teens Speak Up! program and the Year of Service at advocacy.epilepsy.com/TSU-PPI.

Email us at TSU@efa.org

Follow us on Twitter at [EpilepsyFdn](https://twitter.com/EpilepsyFdn)

Like us on Facebook at [Epilepsy Foundation of America](https://www.facebook.com/EpilepsyFoundationofAmerica)