The Capitol Circuit
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Phil Gattone, President & CEO of the Epilepsy Foundation, (pictured second to the left) speaking at a congressional briefing on Capitol Hill. Organizations on the panel include the National Council for Behavioral Health, Avalere Health, The AIDS Institute, and the American Society of Consultant Pharmacists.

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**National Advocacy**

**Epilepsy Foundation CEO Speaks on Capitol Hill about Medicare Part D’s Six Protected Classes**

On March 13, 2019, Phil Gattone, President & CEO of the Epilepsy Foundation, spoke at two briefings on Capitol Hill about the need to preserve Medicare Part D’s Six Protected Classes policy for individuals living with epilepsy.

In late 2018, the Centers for Medicare and Medicaid Services (CMS) proposed a new rule that threatens to weaken the Six Protected Classes policy. The policy was designed to ensure that Medicare Part D beneficiaries living with serious conditions — like epilepsy, HIV/AIDS, mental illness, cancer and organ transplants — have reliable and affordable access to life-changing and life-saving medications. The proposed rule would allow plans to exclude protected class drugs, such as anticonvulsants, from their formularies in certain instances, as well as allow for greater use of step therapy and prior authorization including for people who are currently stable on their medication.

In the past, Congress has played a critical role in reminding the Administration about the policy’s purpose and getting it to pull back dangerous proposals that would have harmed beneficiary access. The briefings were a great opportunity to educate and activate the current Congress. **Tell your members of Congress to stand up alongside you and tell the Administration to stop these changes!**

Learn more about Medicare’s six protected classes at [advocacy.epilepsy.com/ProtectedClasses](http://advocacy.epilepsy.com/ProtectedClasses).

**Air Carrier Access Amendments Act — Supported by the Foundation – Introduced**

On March 6, 2019, Senators Baldwin (WI), Blumenthal (CT), Duckworth (IL), Hassan (NH), Markey (MA), and Merkley (OR) re-introduced the **Air Carrier Access Amendments Act (S. 669)**, to protect the rights of airplane passengers with disabilities. Companion legislation, H.R. 1549, was introduced in the House by Representatives Langevin (RI -02), Titus (NV-01), Cohen (TN-09), Schakowsky (IL-09), Serrano (NY-15), Meng (NY-06), Moore (WI-04), and Lamb (PA-17).

For more than 30 years, the Air Carrier Access Act (ACAA) has prohibited discrimination based on disability in air travel. Despite this progress, too many travelers with disabilities encounter significant barriers—such as damaged assistive devices and wheelchairs, delayed assistance, ineffective communications, and lack of seating accommodations.

The **Air Carrier Access Amendments Act** will strengthen enforcement of the existing legislation by requiring referral of passenger-filed complaints to the Department of Justice
and establishment of a private right of action, ensure new airplanes are designed to accommodate the needs of people with disabilities by requiring airplanes to meet defined accessibility standards, require removal of access barriers on existing airplanes, and improve overall safety of air travel for passengers with disabilities. The legislation is endorsed by the Foundation and over 20 patient, veterans, and disability organizations.

**Foundation Endorses the Medicare Extra Rx HELP Act**

On March 7, 2019, Senators Casey (PA) Blumenthal (CT), Gillibrand (NY), Baldwin (WI), and Brown (OH) introduced S. 691, the Medicare Extra Rx HELP (Higher Eligibility Limits in Part D) Act. The legislation would allow millions more seniors and people with disabilities to benefit from the Extra Help program. The Foundation, along with 16 national patient and disability organizations, has endorsed this important legislation.

The Part D Low-Income Subsidy, commonly known as the Extra Help program, was created almost 15 years ago when the Medicare prescription drug benefit (Part D) was first enacted. The program was established to help low-income seniors and people with disabilities shoulder the cost of premiums and cost-sharing (deductibles, copayments and coinsurance) for needed medicines. In 2018, more than 12 million people with Medicare were enrolled in the program.

Today, complex, bureaucratic application processes limit participation in Extra Help. The program’s outdated eligibility thresholds have failed to keep pace with protections advanced through the Affordable Care Act (ACA) leaving behind seniors and people with disabilities who are often forced to choose among prescription drugs and other basic needs. Importantly, the ACA expanded Medicaid and provided cost-sharing assistance in the Marketplaces with no asset test to determine eligibility. The bill would eliminate the asset test and streamline program administration and provide full Extra Help benefits to those living on the edge of poverty.

**Foundation Joins 22 Organizations in Response to Senator Alexander’s Lowering Health Care Costs RFI**

On March 1, 2019, 23 national patient and consumer organizations, including the Foundation, submitted feedback and recommendations to Senator Alexander in response to his Request for Information on lowering health care costs.

Using the guiding principles that health care must be adequate, affordable, and accessible, the letter highlights the importance of increasing access to reduce individual and systemic costs through recommendations such as Medicaid expansion, improving access to Medicaid, expanding Advanced Premium Tax Credit eligibility on the exchange, simplifying the process for states to establish reinsurance programs, and increasing consumer transparency.
The Epilepsy Foundation of Minnesota hosted its annual Day at the Capitol on February 27, 2019.

President Releases Federal Budget Proposal

This month, the White House released the Budget of the United States Government, Fiscal Year 2020 request. The President’s proposed budget has cut $237 million to the Centers for Disease Control’s Chronic Disease Prevention and Health Promotion program overall and specifically calls for the funding towards epilepsy to be eliminated. However, this has been proposed in recent years and the President’s proposed budget is a non-binding blueprint. Congress has not yet gone forward with this proposal and now, the Congressional Appropriations Committees will begin their work.

The Foundation will be closely monitoring the appropriations process and will continue to advocate for federal funding for programs important to the epilepsy community such as the CDC’s epilepsy program.

Find out more on federal funding for epilepsy research and programs at advocacy.epilepsy.com/federal-funding-for-epilepsy.

Scott Gottlieb, FDA Commissioner, Resigns – Acting Commissioner Announced

On March 5, 2019, Scott Gottlieb, Food and Drug Administration (FDA) Commissioner, announced that he will be stepping down from his role next month. During his tenure at the FDA, the agency approved a record number of generic drugs and began tackling the opioid epidemic and cracking down on e-cigarettes and youth vaping. The current Director of the National Cancer Institute, Dr. Norman “Ned” Sharpless, was named acting commissioner on March 12.
The Epilepsy Foundation of Kentuckiana’s Epilepsy Advocacy Day at the Kentucky State Capitol took place on February 26, 2019.

STATE ADVOCACY

Iowa Governor Signs End Epilepsy® Proclamation

The Epilepsy Foundation of Iowa hosted its Iowa Epilepsy Advocacy Day on March 12, 2019 at the Iowa State Capitol in Des Moines. Participants were able to take part in an advocacy training, meet with their legislators, and experience a virtual reality technology opportunity that simulated “stepping into the shoes” of a person with epilepsy. The day culminated with Governor Kim Reynolds signing the End Epilepsy® Proclamation in her office, declaring March 12, 2019 as End Epilepsy® Day in Iowa.
On March 12, 2019 Iowa Epilepsy Advocacy Day participants gathered in Governor Kim Reynolds’ office to witness the signing of the End Epilepsy® proclamation. End Epilepsy® proclamation pictured on the left.

New York Budget Threatens Individuals with Chronic Diseases and People with Disabilities

On February 22, 2019, 45 organizations representing millions of cancer patients, people with disabilities and serious chronic conditions, and families throughout New York, including the Epilepsy Foundation, the Epilepsy Foundation of Long Island, the Epilepsy Foundation of Metropolitan New York, and the Epilepsy Foundation of Northeastern New York, sent a letter to the New York State Legislature majority and minority leadership. The letter expressed opposition over the inclusion of an Executive Budget provision that explicitly authorizes reliance on a third-party researcher, with no limitations on their research methods such as using quality-adjusted-life-years (QALYs) to decide on the value of treatments.

Methods such as QALYs are well-known to discriminate against individuals with chronic conditions, seniors, and people with disabilities. QALYs are a one-size-fits-all measurement of health outcomes based on the overall population. This analysis ignores the important differences in individual patient needs and preferences, and in effect values individuals in "perfect health" more highly than those with a chronic condition or disability. Instead of promoting the deeply personal, individual health care decisions between a patient and their provider, this assessment favors an impersonal algorithm that does not address the needs of patients or special populations. These thresholds of cost-effectiveness fail to consider important differences among patients.

Last week the New York Senate budget bill was released, reflecting that our voices were heard. The budget will continue to authorize the use of cost effectiveness studies, but it does not allow for the use of research methods such as QALYs to decide the value of treatments. However, the New York Assembly included a provision in their budget proposal that would allow for the use of a QALY.

New Yorkers: Take Action - Urge New York legislators to prohibit the use of discriminatory methods and oppose the Assembly’s budget language!

Stay up to date with the legislation in your state by visiting advocacy.epilepsy.com/states.
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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