



The Capitol Circuit

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National Advocacy

Epilepsy Foundation Continues Fighting for People with the Epilepsies in Forthcoming COVID-19 Relief Packages

On March 27, the Coronavirus Aid, Relief, and Economic Security (CARES) Act (H.R. 748), the third package to provide relief and support in response to the COVID-19 pandemic, was signed into law. Congress is already working on an interim package to provide additional funding for some of the provisions included in the CARES Act, as well as preparing for a fourth package which will be more comprehensive.

Leading up to the third package being passed in March, the Foundation engaged in many policy areas including leading [a letter signed by over 200 patient and disability community organizations urging Congress and the Administration to take action to ensure that people have adequate supplies of their medications](#) through the pandemic. This helped secure the provision included in the CARES Act requiring Medicare plans to provide up to a 90-day supply of medications. However, Congress did not extend this requirement to Medicaid or any other insurers, nor waive refill limits or other requirements for controlled substances under any payer (since many anti-seizure medications are controlled substances). The Foundation has now focused its efforts to make these changes at the state level. Additionally, to ensure access to needed treatments and in response to escalating efforts to slow the spread of COVID-19 by social distancing, the Foundation signed on to an [open letter urging governors and legislative leaders to take necessary actions to ensure continued safe access to medical cannabis and cannabidiol \(CBD\)](#) in a way that is consistent with public health.

The Foundation supported several additional priorities that were ultimately included in the initial congressional packages including increased funding for state Medicaid programs, expanded paid leave and funding to ensure that the rights of students with disabilities are protected during distance learning. The Foundation also advocated that Social Security Income (SSI) beneficiaries can easily access stimulus checks, which was achieved outside of legislation.

Leading up to the next congressional packages, in early April, [the Foundation signed on to letter led by the Consortium for Citizens with Disabilities \(CCD\) urging Congress to focus on the needs of people with disabilities in the next COVID-19 legislative package and pass many specific related provisions](#). Additionally, [on April 13, the Foundation joined over 30 national patient and consumer groups requesting that Congress include provisions related to health coverage](#), such as re-opening the enrollment period for Healthcare.gov; securing additional funding for state Medicaid programs; ensuring coverage of testing, treatment, vaccines, recovery services, and telemedicine services; and putting an end to all surprise medical billing in light of the pandemic.

The Foundation will continue to advocate and keep you apprised of further opportunities for action during these unprecedented times.

[Stay up to date by reading the Foundation's FAQ on COVID-19 \(Coronavirus\) and Epilepsy](#), which will be updated as information becomes available.

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.

Foundation Joins Patient and Disability Communities in Advocating for Nondiscrimination in Rationing of Care During COVID-19

On March 28, the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services, (HHS) [released a bulletin stating that rationing care solely on the basis of disability during the COVID-19 pandemic](#) violates the Americans with Disabilities Act (ADA), the Rehabilitation Act and Section 1557 of the Affordable Care Act (ACA). On April 8, the OCR and the State of Alabama reached an agreement to resolve a complaint alleging that the state's guidelines on rationing ventilators discriminated on the basis of disability. While the resolution reached on the Alabama guidelines is a positive step forward, many states have similar guidelines that need to be updated to comply with federal law. The Foundation [signed on to guidelines for states and health care providers that outline how to avoid disability-based discrimination in treatment rationing](#).

FY 2021 Appropriations Update

Congress announced this week that they do not plan to return to Washington, D.C. until May 4 - extending their spring recess by several weeks. When they return, it is anticipated that they will focus on COVID-19-related bills. Currently, the House and Senate appropriations committees indicate that they will be proceeding with markups, but COVID-19 legislation may take priority and delay that schedule. It is the appropriations bills that include important annual funding like for the epilepsy program at the Centers for Disease Control & Prevention (CDC).

We Want to Hear from You: Share Your Story with the Foundation

Congress and state legislatures are constantly considering and putting in place policies that can affect the epilepsy community. The best way to make sure that your needs are considered in these decisions is by sharing your story and explaining how these policies would affect you. You know first-hand the challenges that come from living with epilepsy. Your experiences help inform your story. Without speaking up and telling your story, elected officials may never know what epilepsy is, what living with epilepsy is like or even know that an issue is important to you. If you are willing to share your story with the Epilepsy Foundation, we can share it with elected officials to advance important policies for you and the epilepsy community.

Share your story with us by filling out the form at advocacy.epilepsy.com/advocacymatters.

State Advocacy

Block Grant Threatens Access to Care for Thousands of Oklahomans

On January 30, Oklahoma Governor Kevin Stitt, alongside the Centers for Medicare and Medicaid Services (CMS) Administrator Seema Verma, announced that the state would be the first to participate in the Administration's new "Healthy Adult Opportunity" program – a Medicaid block grant policy. In March, Oklahoma submitted a State Plan Amendment (SPA) to expand Medicaid coverage to individuals making less than 138 percent of the federal poverty level (\$2,498 for a family of three) beginning July 1, 2020. However, the proposal 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 new administrative and financial barriers to the program, such as work requirements and premiums. The Foundation opposes the proposal and [submitted a joint letter with the Epilepsy Foundation Oklahoma to the state Medicaid Director](#) during the public comment period expressing our concerns.

State Legislative Activity

Due to COVID-19, many state legislatures have been adjourning early to protect the health and safety of the public and legislators. We will continue to monitor how this unique situation will affect state-level legislation.



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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