The Capitol Circuit
September 2021

In this Issue:

National Advocacy

- Congress Takes Up Budget and Major Legislative Package
- 87 Organizations Urge Congress to Maintain Orphan Drug Tax Credit
- Epilepsy Foundation Endorses the LIFT the BAR Act

State Advocacy

- Foundation Celebrates Progress Made on its Seizure Safe Schools Nationwide Initiative on Two Year Anniversary

National Advocacy

Congress Takes Up Budget and Major Legislative Package

Capitol Hill is a flurry of legislative activity this week. Members of Congress are actively working to avert a government shutdown as the September 30th midnight deadline quickly approaches. Since both chambers have not completed work on all Fiscal Year 2022 spending bills, Congress will need to pass a continuing resolution (CR) to provide temporary funding for federal agencies to avoid a lapse. Last week, the House of Representatives passed a bill that included a short-term funding fix and a debt limit suspension until December; however, the Senate blocked the measure due to the inclusion of the debt limit issue. In a race to beat the clock, Congress is expected to pass a standalone continuing resolution to fund the government through December 3rd. Congress would then need to address the debt limit issue separately.
In addition to passing a stop-gap spending measure, the House may vote on the Senate’s bipartisan infrastructure bill today, Thursday. A vote on the reconciliation package, known as the Build Back Better Act, has been put on hold. The Build Back Better Act currently includes many priorities the Epilepsy Foundation strongly supports, including funding for Medicaid home- and community-based services (HCBS), a Medicare Part D out-of-pocket cap, the creation of a paid family and medical leave program, and improving affordability of Marketplace plans by making increases to premium subsidies permanent. However, as negotiations on this package continue, some members of Congress are pushing for it to be scaled back and some of the health care provisions—and particularly the funding for Medicaid HCBS—are in jeopardy. Take action today to ensure that Congress includes $400 billion for Medicaid HCBS!

87 Organizations Urge Congress to Maintain Orphan Drug Tax Credit

The Epilepsy Foundation, along with 86 other organizations representing individuals living with rare diseases (defined as a condition affecting 200,000 Americans or fewer) sent letters to the House and Senate urging members of Congress to remove a provision in the Build Back Better Act that would undermine the Orphan Drug Tax Credit (ODTC) incentive by limiting its availability to only the first approved orphan use of a new drug. The letters call on Congress to maintain the ODTC as it stands today.

Congress passed the Orphan Drug Act (ODA) in 1983 to provide incentives for drug manufacturers, including the Orphan Drug Tax Credit, to develop treatments for rare diseases, including the rare epilepsies. Prior to the passage of the ODA, less than 30 medications specifically approved for rare diseases were available. Today, there are over 650 drugs approved for over 1,000 rare conditions. However, more than 90% of rare diseases still lack an FDA-approved treatment. The tax credit has already been reduced from 50% to 25% over the years and continued incentives for innovation in the rare disease space are important for individuals with rare forms of epilepsy and for the more than one-third of people living with uncontrolled seizures despite available FDA-approved medications.

Epilepsy Foundation Endorses the LIFT the BAR Act

On September 10th, Representatives Pramila Jayapal (WA-07) and Tony Cárdenas (CA-29) introduced the Lifting Immigrant Families Through Benefits Access Restoration (LIFT the BAR) Act. Over 500 local, state, and national organizations, including the Epilepsy Foundation, proudly endorsed this critical piece of legislation that would restore access to federal public benefits and services for people who are lawfully present in the U.S., including people with Lawful Permanent Resident (LPR) status, DACA recipients,
individuals granted Special Immigrant Juvenile Status (SIJS), and other immigrants with legal status. The LIFT the BAR Act would eliminate a five-year waiting period for access to Medicaid, the Children’s Health Insurance Program (CHIP), the Supplemental Nutrition Assistance Program (SNAP), Temporary Assistance for Needy Families (TANF), and the Supplemental Security Income (SSI) program. By removing these barriers, the legislation begins to address deep-seated inequities and allows immigrant families access to fundamental health care coverage and other life-saving services.

State Advocacy

Foundation Celebrates Progress Made on its Seizure Safe Schools Nationwide Initiative on Two Year Anniversary

September marks two years since the Foundation launched its Seizure Safe Schools nationwide initiative. In just two years, the total number of states that have enacted versions of Seizure Safe Schools has tripled, bringing the total to 12 states—Kentucky, Indiana, Texas, Illinois, New Jersey, Virginia, Washington, Oklahoma, Colorado, Alabama, Nebraska, and Minnesota.

Through our initiative, the Foundation has trained more than 170,000 school nurses and school personnel across the country. We will continue to push the legislation until it has been passed in all 50 states and Washington, D.C. Passionate grassroots advocates and partners, including the local Epilepsy Foundation network, the Seizure Action Plan Coalition, and the National Epilepsy Advocates for Seizure Safe Schools Facebook group, have been instrumental in these achievements. As the nationwide initiative enters its third year, the Foundation calls on state-level elected officials and volunteers, including parents, community organizations, healthcare providers, and others to join its efforts. If you are interested in learning more about each state’s legislative efforts, contact publicpolicy@efa.org.

Email us at publicpolicy@efa.org

Follow us on Twitter at @EpilepsyFdn

Follow us on Instagram @epilepsyfdn

Like us on Facebook at Epilepsy Foundation of America

Learn more at epilepsy.com/advocacy