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National Advocacy

Congress at Standstill with Budget Deadline on the Horizon

Congress is back in session but at a standstill on a few key issues. A deal on the next COVID-19 relief package has not yet been reached. While the House of Representatives passed a COVID-19 package in May, the Senate voted on a scaled down COVID-19 package last week, but it did not pass. Congress will not be able to approve a finalized Fiscal Year 2021 spending bill before the September 30th deadline. An informal agreement has been reached that should allow Congress to pass a continuing resolution in order to avoid a government shutdown, but its duration has not yet been settled. The Epilepsy
Foundation will continue to engage grassroots advocates to urge members of Congress to work across the aisle to pass a final spending bill as soon as possible that includes our community’s priorities including $11.5 million for the CDC’s Epilepsy Program.

It’s Almost Time to Get Out the Vote – Are You Registered?

Local, state, and federal elected officials are constantly making policy decisions that can affect the epilepsy community. One of the best ways to make sure your voice is heard is by exercising your right to vote. The 2020 general election is November 3, 2020 – less than 50 days away. Voters will be electing officials up and down the ballot. At this time, it is important to register to vote or check your voting registration status. Each state makes its own voting and election rules, including how to confirm your registration. Check with your state’s election office to get the most detailed and up-to-date information for where you live. In many states, the deadline to register to vote is typically within 15-30 days of the election so make sure to check your state’s voter registration deadline. Learn about accessible voting and voting rights here. Due to COVID-19, you may also want to check your state’s election office for details about how to vote safely. Note: The Epilepsy Foundation is a 501(c)(3) charitable organization and as such, cannot and does not endorse or oppose candidates for political office.

Foundation Advocates for People with Disabilities in COVID-19 Vaccine Distribution

In early September, the Foundation joined a comment letter led by the Consortium for Citizens with Disabilities (CCD) responding to the National Academy of Sciences, Engineering and Medicine Committee on Equitable Allocation of Vaccine for the Novel Coronavirus’ draft framework distribution of a COVID-19 vaccine to the public. CCD’s comment letter emphasizes the need for all people who live or work in institutional or congregate settings to receive priority allocation of the vaccine due to their increased exposure and high risk. The National Academies’ draft framework only included older adults in these settings in phase 1 of allocation and did not include people with disabilities or the staff who work in such settings. The letter also addresses the need for transparency and public trust in the allocation process, as well as accessibility of information on distribution. Additionally, the Foundation also joined CCD’s letter to the Office of Civil Rights of the Department of Health and Human Services. The letter highlights the importance of civil rights protections in the distribution of the COVID-19 vaccine as well as the need to ensure accessibility of vaccine distribution.

Over 30 Patient & Consumer Advocacy Groups Unveil Telehealth Principles
During the COVID-19 pandemic, restrictions were lifted allowing many more Americans including people with the epilepsies to rely on telehealth visits to receive primary and specialized health care services. The Foundation has heard from the epilepsy community about the many benefits of telehealth and has supported telehealth continuing to be an option even after the public health emergency ends. As policymakers start to consider more permanent telehealth policies, the Foundation has joined the disability and patient communities in developing telehealth principles that will be used to gauge future legislative and regulatory proposals. Most recently, in late August, the Foundation as part of the Partnership to Protect Coverage coalition released these telehealth principles which outline the need for accessible, equitable, and affordable access to telehealth services.

State Advocacy

Epilepsy Foundation and Epilepsy California Endorse Proposition 14

Epilepsy California, comprised of all the Epilepsy Foundations in California, and the Epilepsy Foundation recently endorsed Proposition 14 – also known as the California Stem Cell Research, Treatments and Cures Initiative of 2020 – which will authorize $5.5 billion in state general obligation bonds to continue funding stem cell research and the development and delivery of treatments in California. If approved by California voters on November 3rd, it would specifically channel $1.5 billion towards central nervous system diseases like epilepsy.

Proposition 14 will continue to build on California’s initial investment in stem cell research through Proposition 71, passed in 2004. Since then, the California Institute for Regenerative Medicine (CIRM), a statewide stem cell research and therapy funding institute, has advanced research and therapy development for more than 75 diseases and conditions and over 90 clinical trials with more than 4,000 patients enrolled or expected to be enrolled throughout the state. If Proposition 14 fails to pass, vital research and therapies will come to a halt, delaying lifesaving and life-changing treatments for years or decades.

To learn more about this initiative and how you can join hundreds of patient advocacy organizations, patients, Nobel Prize winners, respected medical professionals and scientists to VOTE YES on Proposition 14 on November 3rd, please visit Yeson14.com.
Georgia Proposal Threatens Access to Healthcare Coverage for Thousands

At the beginning of September, the state of Georgia submitted a waiver through Section 1332 of the Affordable Care Act (ACA), proposing to eliminate HealthCare.gov as a pathway for Georgians to enroll in health care coverage. Healthcare.gov provides a one-stop shop where consumers can compare all plans and apply for coverage. Approximately 500,000 Georgians use HealthCare.gov every year to enroll in private health plans and Medicaid. The state’s proposal would not create a state-based marketplace to replace it. Instead, consumers would be forced to navigate plans through various private web brokers or insurance companies, and potentially end up with less comprehensive coverage. Georgians would also lose the ability to enroll in Medicaid through HealthCare.gov. The Epilepsy Foundation and the Epilepsy Foundation of Georgia submitted comments to Secretary Azar and Secretary Mnuchin strongly opposing the proposal’s dismantling of Healthcare.gov, which will impede access to comprehensive health care coverage for tens of thousands of Georgians.

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