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National Advocacy

**Congress Delays Appropriations, Grapples with *Build Back Better***

In early December, Congress passed, and President Biden signed, another continuing resolution to avoid a government shutdown and fund federal agencies through February 18th, 2022. Congress did not complete work on the FY 2022 spending bills by October 1 and is still negotiating the final package, which includes the budgets for many important agencies, including the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

With the budget punt ed until February, Congress is spending the remainder of December focusing on other pressing issues. The House of Representatives passed the *Build Back Better* package on November 19th and it now awaits consideration by the Senate. The Senate Health, Education, Labor and Pensions (HELP) and Finance Committees released new bill text of their
portions of the health care and social services package on December 11th, indicating progress. However it remains unclear if a vote will occur before an arbitrary December 25th deadline. The priorities the Epilepsy Foundation supports have remained unchanged in the legislation. However, the provision weakening the Orphan Drug Tax Credit provision - which the Foundation opposes – unfortunately remains in the bill (more details below).

24 Epilepsy Groups Urge Congress to Maintain Orphan Drug Tax Credit

The Epilepsy Foundation led an effort supported by 23 organizations representing people and families living with and affected by, the epilepsies urging Congress to maintain the Orphan Drug Tax Credit (ODTC). In late November, the undersigned organizations sent a letter asking Congress to remove a provision included in the Build Back Better legislation that would undermine the ODTC incentive by limiting its availability to only the first approved rare indication of a drug.

Advances in genetics have accelerated the discovery of many epilepsy-causing gene variants and complex chromosomal anomalies, leading to an increasing number of rare epilepsy diagnoses. While there has been progress and treatment approvals for a few of the rare, severe epilepsies, such as Dravet Syndrome and Lennox-Gastaut Syndrome, there is much more work to be done. The Epilepsy Foundation and the undersigned organizations urge Congress to maintain the ODTC as it stands today so that people with rare epilepsy and their families can maintain hope that new orphan uses of drugs will continue to be pursued.

Open Enrollment for Marketplace Plans – Deadlines Approaching

People seeking to enroll, renew, update, or change their Marketplace plan must do so during open enrollment unless a specific exception occurs like getting married, moving out of state, or losing health coverage. Each year, plans make changes to benefits and costs, and new plans are available. Therefore, your current plan may or may not be the best plan for you in 2022. It is very important to use the open enrollment period to compare your coverage choices and find the plan that best meets your health care needs at an affordable cost.

The open enrollment period for the Health Insurance Marketplace runs through January 15, 2022. For coverage beginning January 1, 2022, you must’ve enrolled by December 15, 2021. Coverage will begin February 1, 2022, if you sign up for a plan after December 15th and by the deadline. Learn more about your options at Healthcare.gov or call the toll-free Marketplace call center at 1-800-318-2596 (TTY: 1-855-889-4325) available 24 hours a day, 7
days a week (except holidays). Individuals may be eligible for premium tax credits that will help make coverage more affordable.

State Advocacy

2022 State Legislative Sessions

As 2021 comes to a close, the Foundation is gearing up for state legislative sessions beginning in January 2022. We are ready to engage and advocate on behalf of people living with the epilepsies, their families, and caregivers to ensure access to physician-directed and person-centered care and the rights of people with epilepsy. The Foundation will continue its nationwide initiative to pass Seizure Safe Schools bills in all 50 states and D.C. Building on the incredible momentum of 7 new states passing Seizure Safe Schools bills in 2021 for a total of 12 states, we will be working on Seizure Safe Schools bills in many states across the country in 2022.

Therefore, we want to make sure you are well informed about what is happening in your community so that you do not miss an opportunity to share your voice with federal or state policymakers. Please take a minute to make sure your contact information is up to date, including your home address, so that we can send you targeted alerts based on your state and congressional district. Or take a few minutes to recruit a few more advocates!

Update your information or recruit new advocates to sign up here!

Email us at publicpolicy@efa.org

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