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National Advocacy

Celebrate National Epilepsy Awareness Month

November is National Epilepsy Awareness Month (NEAM)! This NEAM, join the Epilepsy Foundation as we #RemoveTheFilter and highlight not only the challenges that people with epilepsy may face but the importance of creating awareness to support the more than 3.4 million people with epilepsy nationwide. Use the power of your journey to make a difference by asking your lawmakers to spread awareness about epilepsy and seizures!

Congress Forges Ahead on Social Infrastructure Bill and Stalls on Appropriations

On November 15th, President Biden signed the bipartisan infrastructure bill (H.R. 3684) into law, so Congress is shifting its focus to the reconciliation
package, also known as the social infrastructure bill or the *Build Back Better Act*. Amidst a lot of negotiations, many provisions of the package have been scaled back. The Foundation is still supportive of the following provisions currently included in the bill: extension of Advanced Premium Tax Credits for Marketplace plans through 2025; funding for Medicaid home- and community-based services (HCBS); capping consumers’ out-of-pocket costs in Medicare Part D’s prescription drug benefit; addressing the Medicaid coverage gap, and 4 weeks of paid family and medical leave. However, the Foundation along with 86 other organizations have asked for a provision that weakens the Orphan Drug Tax Credit to be removed from the bill. The House may be voting on the package as soon as Thursday (today). Then, the Senate is expected to make changes to the bill.

Regarding the FY 2022 budget, the current continuing resolution (CR) - keeping government agencies operating - expires on December 3rd. Congress has not progressed on negotiations, so it has been speculated that Congress will pass another short-term CR leading up to late December to provide more time for negotiations. The Foundation has sent a letter urging funding priorities that are important to the epilepsy community—including the CDC Epilepsy Program and VA Epilepsy Centers of Excellence—to be included in the final bill.

**CVS Health Withdraws Cert Petition in Response to Disability Community Advocacy**

The Epilepsy Foundation, working in tandem with close disability organization partners, asked CVS Health to remove the CVS v. Doe case from review by the U.S. Supreme Court. This case could have had disastrous consequences for disparate impact protections which protect against the most frequent type of discrimination against people with disabilities - facially neutral policies that operate to disadvantage people with disabilities. **On November 10th, CVS announced it was withdrawing its cert petition and pledged to work with the disability community to identify solutions** that protect equitable access to health care and the rights of people with disabilities. This remarkable victory is due to disability community organizing and advocacy.

**Epilepsy Foundation Endorses Medical Marijuana Research Act**

In late October, Representatives Earl Blumenauer (D-OR) and Andy Harris (R-MD) along with a bipartisan group of lawmakers, introduced **H.R. 5657, the Medical Marijuana Research Act**. The Foundation has endorsed this piece of legislation which would facilitate federal research into the potential therapeutic benefits and risks of medical cannabis by amending the Controlled Substances Act.
About 30-40% of individuals living with epilepsy live with uncontrolled or intractable epilepsy, despite available treatments. Some people living with uncontrolled seizures have reported beneficial effects and reduced seizure activity when using medical cannabis or cannabidiol (CBD) and therefore, in consultation with their health care provider, turn to it when other treatments have failed. Despite some evidence that cannabis and CBD help reduce seizure activity in some individuals, it is currently difficult and expensive to conduct further, more robust research into this connection. There are significant obstacles for scientists and researchers to organize clinical trials and other research involving cannabis. There are also additional costs and infrastructure requirements due to the Schedule I designation that further limit innovation and investment. Legislation such as H.R. 5657 would help remove these barriers. Learn more about the Foundation’s position on medical cannabis and CBD here.

Administration Nominates Robert Califf as FDA Commissioner

On Friday, November 12th, President Biden nominated Dr. Robert Califf, a cardiologist, to lead the Food and Drug Administration (FDA). Califf previously held the role as FDA Commissioner from 2016-2017 under the Obama Administration. An FDA Commissioner nominee must be confirmed by the U.S. Senate.

Open Enrollment for Medicare and Marketplace Plans

People seeking to enroll, renew, update, or change their Medicare or 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 annual open enrollment period for Medicare prescription drug coverage (part D) and Medicare Advantage (part C) began on October 15, 2021, and will run through December 7, 2021, for coverage beginning January 1, 2022. Visit Medicare.gov or call 1-800-MEDICARE (1-800-633-4227) to learn more (TTY users can call 1-877-486-2048). Read our 2022 Medicare Part D Open Enrollment FAQ Brochure.

The open enrollment period for the Health Insurance Marketplace began on November 1, 2021, and will run through January 15, 2022. For coverage beginning January 1, 2022, you must enroll 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.

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