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**National Advocacy**

Patient and Consumer Organizations Urge Administration and Congress to Prioritize Policies to Improve Health Care Access

Last week, 34 patient and consumer organizations, including the Epilepsy Foundation, sent the Administration and congressional leadership letters outlining policy priorities that should be enacted to improve coverage and care for the millions of individuals with pre-existing conditions, like the epilepsies. The letter calls for improving affordability of health insurance premiums, addressing high out-of-pocket costs, expanding Medicaid eligibility and coverage, and restricting access to inadequate health care coverage. These changes, if enacted, would greatly improve the health and wellbeing of not only those living with acute, serious, and chronic conditions but the health and wellbeing of all Americans.
Safe Step Act Reintroduced in 117th Congress

In April, the House and Senate reintroduced step therapy reform legislation, the Safe Step Act (H.R. 2163/S. 464), in the 117th Congress. The Foundation, along with dozens of other patient and consumer organizations, has endorsed this legislation.

Step therapy, or fail first, is a process that requires individuals who have been prescribed a medication by their healthcare provider to try and fail one or more medication(s) preferred by the insurer before receiving the originally prescribed drug. There is no “one size fits all” treatment option for epilepsy, and the response to epilepsy medications can be different for each person. Individuals living with the epilepsies who are forced to fail on one or more medications other than those prescribed by their physician due to step therapy requirements are at a higher risk for developing breakthrough seizures and related complications, including death.

The Safe Step Act amends the Employee Retirement Income Security Act (ERISA) to streamline step therapy protocols, establish a clear exemption process, and require exceptions to step therapy requirements so that people with serious and chronic conditions, like the epilepsies, can access the most effective medications in a timely manner.

Disability Community Helps Shape HCBS Access Act

Home- and Community-Based Services (HCBS) provide supports necessary for people with disabilities, including the epilepsies, to remain in their homes and communities and out of institutions or congregate settings. However, under Medicaid currently, HCBS are optional—creating long wait lists for services and forcing people into settings that isolate them from society and their family and friends.

The Epilepsy Foundation, as part of the broader disability community, has helped shape the HCBS Access Act (HAA) and recently signed on to the disability community’s comments to the bill’s discussion draft. This bill would make HCBS mandatory in Medicaid, end the waiting list, enhance HCBS services, and provide proper support to the direct support workforce.

Increased Navigator Funding and Special Enrollment Period for Marketplace Plans

In January, President Biden issued an Executive Order calling for a Special Enrollment Period (SEP) for individuals and families to enroll in Marketplace health insurance plans due to the COVID-19 pandemic. On April 21st, the Department of Health and Human Services (HHS) announced that in order to
continue its efforts to increase access to Marketplace enrollment assistance for consumers, the Centers for Medicare and Medicaid Services (CMS) will make $80 million available in grants to Navigators in Federal Marketplaces for the 2022 plan year.

Navigators play a key role in helping educate consumers about their health plan options. This increased funding will be used for outreach and education efforts and is the largest allocation CMS has ever made available for Navigator grants – representing an eight-fold increase in funding from the previous year. The Foundation applauds these efforts given that the patient and consumer communities have been strongly advocating for increased funding over the past several years in the face of continued cuts in recent years.

Now through **August 15, 2021**, individuals and families can enroll in a new Marketplace plan or change plans. This SEP will be available to consumers in the 36 states served by Marketplaces that use the [HealthCare.gov](https://HealthCare.gov) platform. Consumers who are uninsured will be able to look for coverage that would start prospectively the first of the month after plan selection and learn whether they qualify for financial assistance to help pay for health insurance. Currently, 9 out of 10 consumers enrolled in coverage through Healthcare.gov receive financial help and 75% of consumers can purchase a plan for $50 or less per month after financial assistance. Additionally, consumers will not need to provide any documentation of a qualifying event (e.g., loss of a job or birth of a child), which is typically required for SEP eligibility. Starting April 1, consumers may be able to get more savings and lower costs on Marketplace health insurance coverage due to provisions included in the **American Rescue Plan Act**, which was signed into law in mid-March.

Visit [HealthCare.gov](https://HealthCare.gov) or [CuidadoDeSalud.gov](https://CuidadoDeSalud.gov) to learn more and enroll or see if you qualify for Medicaid or CHIP. Consumers can also call the Marketplace Call Center at 1-800-318-2596 which provides assistance in over 150 languages. TTY callers should use 1-855-889-4325.

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**State Advocacy**

**Passage of Seizure Safe Schools Legislation Expands to 8 States**

On April 27th, Governor Kevin Stitt signed SB 128 into law, making Oklahoma the 8th state in the nation to pass Seizure Safe Schools legislation. Oklahoma was preceded by Washington state, which became the 7th to pass the legislation when Governor Jay Inslee signed HB 1085 in mid-April. Seizure Safe Schools legislation has now been passed in Kentucky, Indiana, Texas,
Illinois, New Jersey, Virginia, Washington, and Oklahoma. We thank incredible advocates on the ground in these states who’ve helped make this happen!

During the 2021 state legislative session, several states have continued to see promising movement and have made powerful strides in raising awareness and breaking down stigma, including a Colorado state legislator who passionately shared her own epilepsy diagnosis for the first time publicly on the House floor. This critical bill has been introduced thus far in Alabama, Arizona, Colorado, Iowa, Maryland, Michigan, Minnesota, Missouri, Nebraska, Rhode Island, and South Carolina. Visit our Action Alert Center to see if you can take action to support a bill in your state!

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