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National Advocacy

U.S. Supreme Court 7-2 Ruling Preserves the Affordable Care Act Law

Today, the U.S. Supreme Court ruled 7-2 in California v. Texas (previously Texas v. United States) that the plaintiffs had no legal standing, thereby dismissing the case, and preserving the entire Affordable Care Act law. This is the third time that the law has been challenged and upheld by the Supreme Court. Plaintiffs in this case attempted to argue that because Congress repealed the penalty associated with the law’s individual mandate, that the individual mandate itself and rest of the law were invalid. Seven justices, however, found that the plaintiffs were not able to show “standing” — or that their injuries were related to enforcing the part of the law they were challenging — and therefore did not proceed to the other legal questions in the case. The decision preserves health insurance for more than 20 million
Americans and preserves the law's patient protections, such as those for individuals with pre-existing conditions like the epilepsies.

The Foundation had joined national patient advocacy organizations on an amicus curiae ("friend-of-the-court") brief that was submitted to the Supreme Court in advance of oral arguments last year, highlighting the devastating impact individuals living with acute and chronic conditions would face should the court rule to invalidate the entire Affordable Care Act. The Foundation joins with the organizations from the amicus on a statement celebrating the decision, as well as a statement released by 34 national patient and consumer organizations.

Take Action to Support the Safe Step Act

Congress has reintroduced step therapy reform legislation that the Epilepsy Foundation and other patient organizations have supported, the Safe Step Act (H.R. 2163/S. 464). 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. For people with the epilepsies, this can increase the risk of 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.

Urge your members of Congress TODAY to co-sponsor this critical legislation! If your member of Congress is already a sponsor of the bill you will have the opportunity to thank them for their support. We strongly encourage you to personalize the message and inform your elected officials if you or your loved one has been impacted by step therapy protocols and why this bill is so important.

Disability Community Pushes for Healthcare Priorities with Congress

In early June, 29 disability organizations from the Consortium for Citizens with Disabilities (CCD) coalition, including the Foundation, urged Congress to include the $400 billion investment in the Medicaid home-and community-based services (HCBS) infrastructure outlined in the American Jobs Plan in the next recovery package. Additionally, the coalition stresses the need for Congress to make other critical investments to make health care more accessible and affordable for people with disabilities, such as supporting and
expanding Medicaid coverage, improving Medicare coverage benefits, making insurance premiums and cost-sharing more affordable, ensuring prescription drug pricing reforms address consumer cost and prohibit discrimination, and supporting multidisciplinary care for people experiencing post-COVID symptoms.

Fiscal Year 2022 Congressional Budget Update

Every year by September 30, Congress must pass a budget to fully fund federal agencies and programs or pass a continuing resolution to provide more time to complete work on the budget. Members of the House Appropriations Committee are preparing to get to work on the 12 annual spending bills in the coming weeks. The Senate Appropriations Committee is not expected to take action on these bills until fall or potentially late summer.

A few of the 12 spending bills fund agencies and programs that are vitally important to the epilepsy community. One of these is the Labor, Health and Human Services, Education and Related Agencies (LHHS) bill which includes funding for the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH). The CDC’s National Center for Chronic Disease Prevention and Health Promotion’s Epilepsy Program is the only public health program specifically related to epilepsy that offers a national scope and community programs. It helps promote awareness, collect data, and support programs that improve the quality of life and care for people with the epilepsies. The Foundation and its grassroots advocates have been advocating for $13 million for the CDC’s Epilepsy Program in FY 2022.

As of now, the House Appropriations LHHS Subcommittee is expected to mark up its bill on July 12, with the full Committee marking up on July 15. As the Appropriations Committees begin to hold markups, we will be reaching out to advocates who reside in these districts and states with opportunities to take action!

Senate Confirms Chiquita Brooks-LaSure as CMS Administrator

In late May, the Senate narrowly confirmed Chiquita Brooks-LaSure as the new Administrator for the Centers for Medicare & Medicaid Services. As CMS Administrator, Brooks-LaSure will have oversight over the Medicare and Medicaid programs and the Affordable Care Act (ACA) exchanges. She makes history as the first Black woman to lead CMS. Many Administration posts have been made official, but the Biden administration has not yet named an FDA Commissioner nominee.

Special Enrollment Period for Marketplace Plans
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 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. Additionally, consumers may now 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](http://HealthCare.gov) or [CuidadoDeSalud.gov](http://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**

**11 States Total Have Seizure Safe Schools Legislation**

On May 5th, the Colorado Senate unanimously passed Joey’s Law (HB 21-1133) and it was signed by Governor Jared Polis on Friday, May 28th. On Monday, May 17, Alabama’s Seizure Safe Schools bill, HB 76, passed through the legislature and was signed into law by Governor Kay Ivey on Wednesday, May 26th. Nebraska’s Seizure Safe Schools bill, LB 639, passed on Wednesday, May 19th and was approved by Governor Pete Ricketts on May 24th.

With the passage of these 3 bills, 11 states total have enacted Seizure Safe Schools legislation including: Kentucky, Indiana, Texas, Illinois, New Jersey, Virginia, Washington, Oklahoma, Nebraska, Alabama, and Colorado. Congratulations to the incredible advocates and families on the ground, many Foundation staff, and supportive state elected officials, who have helped make this bill a reality in over 20% of states now.

Six additional states introduced a Seizure Safe Schools bill in 2021 and made promising strides. Most state legislative sessions have drawn to a close, but a few bills remain active. For those that did not make it across the finish line this year, the Foundation is grateful to all local Epilepsy Foundation
offices, staff, volunteers, and grassroots advocates who worked diligently and will continue to push this bill in the next legislative cycle.

Visit our Action Alert Center to see if you can take action to support a bill in your state!

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