



The Capitol Circuit

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National Advocacy

Epilepsy Foundation Issues Updated Positions and Call-to-Action Around Access to Prescription Medications

Earlier this month, the Epilepsy Foundation [released updated principles and positions on access to prescription medications](#) in response to state-level, Congressional, and Administrative efforts to address high drug prices, rising out-of-pocket costs and insurance hurdles. Given that there is currently a plethora of policy proposals to address mounting drug prices and other access barriers being considered at the state and federal levels, the Foundation formed a working group to examine these proposals and update its positions on policies relevant to the epilepsy community. The working group evaluated a vast array of proposals aimed at improving prescription medication access and costs against the following principles: safety and efficacy; affordability; accessibility and continuity; and physician-directed and person-centered care. Using those principles as a guide, the Foundation updated its positions, taking a comprehensive approach that supports

insurance reforms, lowering costs for consumers and calls for addressing anticompetitive behavior and transparency throughout the drug supply chain, but opposes proposals that attempt to lower prices by restricting access.

Read the press release [here](#).

Learn more about access to prescription medications at advocacy.epilepsy.com/medication-access.

Foundation Submits Comment to FDA on Cannabis and Cannabis-Derived Products

Only July 12, 2019, the Foundation [submitted comments to the U.S. Food and Drug Administration \(FDA\)](#) in response to their request for data and information on regulation of cannabis or cannabis-derived products, following a public hearing held in May, where the [Foundation also testified](#). The Foundation urges the agency to allow these products – particularly those with therapeutic levels of CBD – to remain available and accessible for those in the epilepsy community who rely on CBD, while creating a regulatory framework that ensures that there is consistency in available products, manufacturing, safety, testing, and labeling standards, and increases the availability of important information such as potential side effects and drug interactions so that consumers and practitioners may be better informed.

In late 2018, the Agriculture Improvement Act (Farm Bill) federally legalized hemp including hemp-derived CBD with 0.3% or less THC by dry weight. At the same time, that legislation specifically preserved the FDA's responsibility over such products. Since the passage of the Farm Bill, the FDA has been taking an Agency-wide, integrated, and collaborative approach to addressing the regulation of products made from CBD that fall under their jurisdiction. The Foundation is encouraged by the FDA's public process regarding regulations on cannabis and cannabis-derived compounds, including cannabidiol (CBD). Decisions and regulations will take time.

Read more about medical cannabis and CBD at advocacy.epilepsy.com/medical-cannabis.

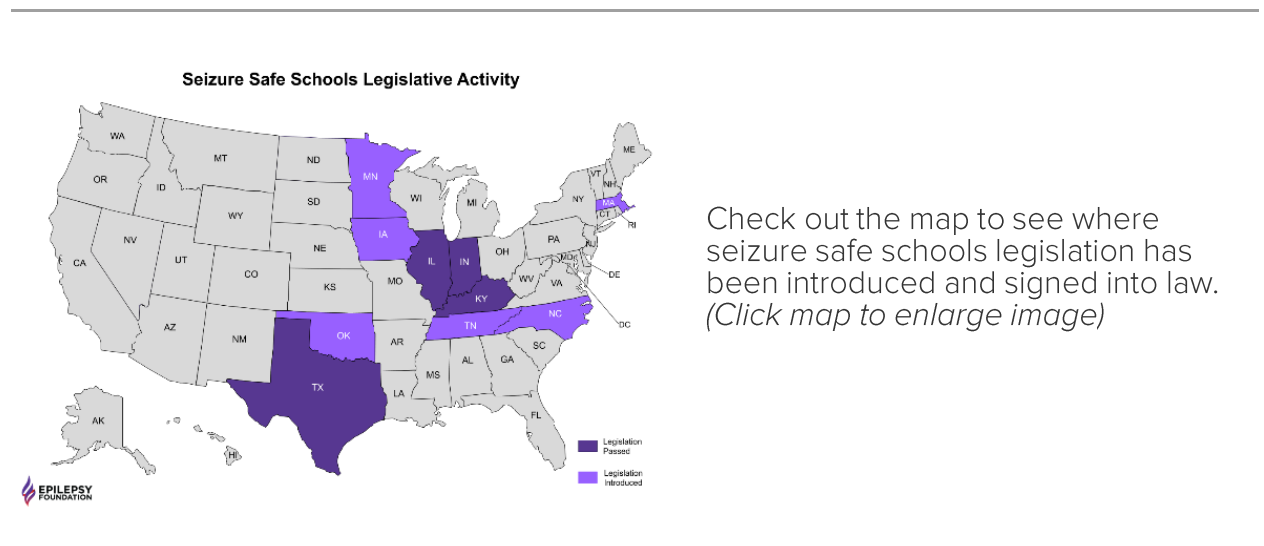
16 National Patient Groups Call on Court to Protect Individuals with Pre-Existing Conditions and Uphold Health Care Law

On July 9, 2019, the Fifth Circuit Court of Appeals began hearing oral arguments in the *Texas v. United States* case. [Sixteen national patient groups, including the Epilepsy Foundation, issued a joint statement](#) urging the court to prioritize patient protections and uphold the Affordable Care Act (ACA). The case was appealed to the Fifth Circuit after a lower court ruled that the entire health care law should be struck down because of the change in federal tax law that repealed the penalty associated with the individual mandate. It is unclear how long it will take the Fifth Circuit to rule and the case could then be appealed and taken up by the U.S. Supreme Court. The lower court ruling and appeal to the Fifth Circuit does not affect current health insurance coverage, coverage you have signed up for to receive in 2019, or those who have benefited from Medicaid expansion.

Read the amicus brief [here](#).

Foundation Celebrates 29th Anniversary of the Americans with Disabilities Act

The Foundation is delighted to join other organizations and individuals across the nation to celebrate the 29th anniversary of the Americans with Disabilities Act (ADA), which was signed into law by President George H.W. Bush on July 26, 1990. The ADA prohibits discrimination and guarantees the civil rights of people with disabilities. In 2008, President George W. Bush signed the ADA Amendments Act that clarified and broadened the definition of “disability” to encompass episodic conditions like epilepsy. The Foundation is proud to have served in such a critical advocacy role in helping to pass the ADA and the ADA Amendments Act alongside the collaborative efforts of the disability community, local offices, business leaders, and Congress – including former Congressman Tony Coelho, a person living with epilepsy, a member of the Foundation’s Board of Directors and lead sponsor of the ADA.



STATE ADVOCACY

Seizure Smart Schools Legislation Signed into Law in Illinois

On July 12, 2019, Governor J.B. Pritzker signed House Bill 1475 into law, making Illinois the fourth state in the nation to enact Seizure Smart Schools legislation. Spearheaded by Epilepsy Foundation of Greater Chicago, the bill will ensure that schools have the tools needed to improve the care of the 18,600 students living with epilepsy in Illinois. Under the law, all school employees and delegated care aids must receive training in the basics of seizure recognition, first aid and appropriate emergency protocols; a seizure action plan shall serve as the basis of the student's federal Section 504 plan; and a student living with epilepsy will be permitted to possess all necessary supplies, equipment, and medications.

Learn more about the Seizure Safe Schools initiative at advocacy.epilepsy.com/seizuresafeschools.

Stay up to date with the legislation in your state by visiting advocacy.epilepsy.com/states.



We encourage you to invite others to join our **Speak Up, Speak Out!** advocacy network. Members receive the monthly *Capitol Circuit* newsletter and alerts about opportunities to advocate for the epilepsy community throughout the year. Growing our advocacy network is critical to achieving our public policy goals as we move through busy state and federal legislative sessions. Make a difference today by sharing our Speak Up, Speak Out! Network on **Facebook** and **Twitter**.

Email us at **TSU@efa.org**

Follow us on Twitter at **[@EpilepsyFdn](https://twitter.com/EpilepsyFdn)**

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