Recommendation
Pass legislation like the Strengthening the Tenth Amendment Through Entrusting States (STATES) Act (H.R. 2093/S.1028) to ensure that people who legally use cannabis for the treatment of epilepsy or seizures in accordance with state law do not risk federal prosecution and the Expanding Cannabis Research and Information Act (H.R. 4322/S.2400) to facilitate federal research into the potential therapeutic benefits and harms of cannabis by removing onerous restrictions.

BACKGROUND
There is no “one size fits all” treatment for epilepsy, and around 30 – 40 percent of individuals living with epilepsy live with uncontrolled or intractable seizures, despite available treatments. Some people living with epilepsy and seizures and their providers have reported beneficial effects and reduced seizure activity when using medical cannabis or cannabidiol (CBD) and therefore turn to it when other treatments have failed. As with any other treatment regimen, it is critical that physicians have the ability to consult and closely monitor individuals using cannabis and/or CBD, and physicians must have the ability to legally do so.

Currently, the use of cannabis is legal in 33 states and the District of Columbia. However, without safeguards in place, individuals who legally use medical cannabis and/or CBD under state law are at a continual risk of federal prosecution. Federal protections for lawful state-level medical cannabis activities would help ensure safe and reliable access to medical cannabis through state-regulated programs.

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 involving cannabis due to its Schedule I designation, and only the National Institute for Drug Abuse (NIDA) can cultivate cannabis for medical research. There are also additional costs and infrastructure requirements due to the Schedule I designation that further limit innovation and investment into medical benefit research.

ABOUT EPILEPSY
Epilepsy is a disease or disorder of the brain which causes reoccurring seizures. Epilepsy is made up of many different types of seizures or syndromes, affects people throughout the lifespan, and can have many different causes and associated conditions.

3.4 million Americans live with active epilepsy. While some are able to gain seizure control, 30-40% of people with epilepsy live with uncontrolled seizures despite available treatments. Delayed recognition of seizures and inadequate treatment increase a person’s risk of subsequent seizures, brain damage, disability, and death. Epilepsy imposes an annual economic burden of $19.4 billion on the country.

33 states & DC have passed comprehensive medical cannabis laws
30 - 40% of individuals diagnosed with epilepsy have uncontrolled seizures
1 FDA approved therapy derived from cannabis for the treatment of seizures associated with two rare forms of epilepsy

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On June 30, 2008, when he was just two years and nine months old, Freeman Dando had his first seizure. Over the next 10 years, Freeman would experience thousands of seizures and countless trips to the hospital, unable to find a treatment to stop his seizures.

Freeman and his health care team tried to control his seizures with anti-seizure medications. He tried - and failed - on six different medications. Some medications failed to control his seizures despite being on the maximum dose, while other medications actually induced seizure activity. Despite being unable to completely control his seizures, Freeman and his health care team found a medication regimen that kept him from having seizures during the day. Freeman’s typical seizures happened while he slept and usually lasted about 45 seconds. Then, in spring 2018, Freeman began experiencing breakthrough seizures during the day while at school.

Soon, Freeman was experiencing hundreds of seizures day and night. He was unable to go to school and participate in his favorite sports. Having run out of other pharmaceutical options, Freeman’s parents worked with his health care team to access medical cannabis through the Texas Compassionate Use Program. After adding cannabidiol (CBD) to his existing medication regimen, Freeman’s life changed drastically and for the better. He went from having over 100 seizures daily to zero in just a matter of days. This has significantly improved his quality of life and ability to fully participate in school and activities. Freeman, now 14 years old, is part of his school’s National Junior Honor Society and is on the cross country and track team.

Freeman and his family are extremely relieved that through physician-directed care, they have found a treatment regimen that so far, has kept him almost seizure free. However, they would still like to more fully understand the benefits and risks associated with CBD and therefore urge Congress to help break down current research barriers. Simultaneously, it is vital that Freeman - and others like him - can continue to access safe and legal CBD. The consequences of stopping an effective treatment are too severe and Freeman deserves to continue on his successful and bright path.