March 16, 2017

Kentucky Senate
Senate Judiciary Committee
The Honorable Whitney Westerfield
702 Capitol Avenue, Annex Room 228
Frankfort KY 40601

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The Honorable Wil Schroder
702 Capitol Avenue, Annex Room 228
Frankfort KY 40601

Dear Chair Westerfield, Vice-Chair Schroder and Members of the Senate Judiciary Committee:

On behalf of the epilepsy community, we, the undersigned organizations, urge you to support House Bill 333, which would ensure timely access to medications derived from cannabidiol (CBD) once approved by the Food and Drug Administration (FDA) and scheduled by the Drug Enforcement Agency (DEA).

Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Our organizations represent the 3 million Americans living with epilepsy and seizure disorders. We have seen firsthand the devastation that uncontrolled seizures can bring, including developmental delays, medical complications, and even death. Access to new therapies is particularly important for the one third of people living with epilepsy who experience intractable or uncontrolled seizures and are living with rare epilepsies, and the many more who experience significant adverse effects from their current medication.

The FDA is currently reviewing at least one CBD-derived therapy that shows promise for the treatment of Dravet and Lennox Gastaut syndromes (LGS), tuberous sclerosis complex (TSC) and potentially other rare epilepsies. This potential treatment option has both Orphan Drug Designation and Fast Track Designation from the Food and Drug Administration (FDA) and could be approved as soon as early 2018. After FDA approval, the Drug Enforcement Administration (DEA) would schedule the therapy through administrative action and the medication would become available for individuals living with epilepsy. Because CBD is a Schedule I substance under the Kentucky state drug schedule, state action is needed to ensure Kentucky residents will have access to FDA-approved therapies derived from CBD. This is an issue of creating access to FDA-approved prescription medications and we strongly urge your support HB 333.

We urge you to support of HB 333 to ensure timely access to future FDA approved therapies derived from CBD. Please do not hesitate to contact Angela Ostrom, Chief Legal Officer & Vice President Public Policy, at 301-918-3766 with any questions or concerns.

Sincerely,

Epilepsy Foundation
Epilepsy Foundation of Kentuckiana
LGS Foundation
Tuberous Sclerosis Alliance