EPILEPSY FOUNDATION

February 27, 2017

The Honorable David A. Baram
Chair
Joint Committee on General Law
Legislative Office Building, Room 3500
Hartford, CT 06106

The Honorable Richard A. Smith
Ranking Member
Joint Committee on General Law
Legislative Office Building, Room 3500
Hartford, CT 06106

Dear Chairman Baram, Ranking Member Smith and Members of the Joint Committee on General Law:

On behalf of the Epilepsy Foundation and our Connecticut affiliate, the Epilepsy Foundation of Connecticut, we urge your support of efforts to take steps to ensure that therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration (FDA) are available to individuals living with epilepsy in a timely manner without undue burden. 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 Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than 3 million Americans with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. There is no "one size fits all" treatment for epilepsy, and about a third of people living with epilepsy suffer from uncontrolled or intractable seizures, with many more living with significant side-effects, despite available treatments. Uncontrolled seizures can lead to disability, injury, and even death.

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 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 patients. However, since CBD is a Schedule II substance under the Connecticut state drug schedule, state action is needed to ensure proper rescheduling of FDA-approved treatments derived from CBD. Unless Connecticut acts, patients will have very limited access to these new treatments, which would be readily available in neighboring states that have taken action. This is an issue of creating access to FDA-approved therapies.

The Epilepsy Foundation is committed to supporting physician-directed care and to exploring and advocating for all potential treatment options for epilepsy. Bureaucratic processes should not

stand in the way of patients gaining access to proven and potentially lifesaving treatment once they have been reviewed and approved by FDA. Please do not hesitate to contact Angela Ostrom, Chief Legal Officer & Vice President Public Policy, at 301-918-3766 or aostrom@efa.org or Linda Wallace with the Epilepsy Foundation of Connecticut at 860-446-1924 or lwallace.efct@sbsglobal.net with any questions or concerns.

Sincerely,

Linda Wallace
Executive Director
Epilepsy Foundation of Connecticut

Philip M. Gattone, M.Ed.
President & CEO
Epilepsy Foundation