



March 1, 2017

The Honorable Brad M. Daw, Chair
The Honorable Michael S. Kennedy, Vice Chair
House Health and Human Services Committee
350 North State, Suite 350
PO Box 145030
Salt Lake City, Utah 84114

Dear Chair Ray, Co-Chair Kennedy and Members of the House Health and Human Services Committee:

On behalf of the Epilepsy of Utah and the Epilepsy Foundation, we urge you to support Senate Bill 219, which would allow therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration (FDA) to become available to patients. 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 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 I substance under the Utah state drug schedule, state action is needed to ensure proper rescheduling of FDA-approved therapies derived from CBD. Unless Utah acts, patients will not have access to these new therapies, which would be available in neighboring states that have taken action. This is an issue of creating access to FDA-approved, prescription drugs and we strongly urge your support of SB 219.

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 Epilepsy Foundation of Utah and the Epilepsy Foundation are 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. The Epilepsy Foundation of Utah and the Epilepsy Foundation urge your support of SB 219. Please do not hesitate to contact Angela Ostrom, Chief Legal Officer & Vice President Public Policy, at 301-918-3766 or aostrom@efa.org with any questions or concerns.

Sincerely,



Margo Thurman
Executive Director
Epilepsy Foundation of Utah



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