



November 21, 2018

The Honorable Lincoln Fillmore, Chair
Health and Human Services Interim Committee
210 Senate Building
350 N. State Street
Salt Lake City, UT 84114

Dear Chair Fillmore:

On behalf of the Epilepsy Foundation and our local chapter, Epilepsy Foundation of Utah, we write to support the implementation of a medical cannabis program in the state, which would ensure individuals living with epilepsy and uncontrolled seizures can gain safe, legal access to medical cannabis as a treatment option. While we support many provisions in the proposed legislative framework in the *Utah Medical Cannabis Act* – most of which were approved as part of Proposition 2 – we are concerned that, if passed, some requirements will hinder access to this program and further delay physician-directed care. As such, we urge full implementation of Proposition 2 as approved by Utahns. In the alternative, we request amendment of the legislative compromise to ensure that individuals in the state have access to this treatment option.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the at least 3.4 million Americans living with epilepsy and seizures. Our local chapter, Epilepsy Foundation of Utah, advocates and provides services for the over 29,000 individuals living with epilepsy and seizures in the state. Collectively, 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 early death. This is why people living with uncontrolled seizures turn to medical cannabis when other options have failed.

The Epilepsy Foundation and Epilepsy Foundation of Utah are committed to supporting physician-directed care, and to exploring and advocating for all potential treatment options for epilepsy, including cannabidiol (CBD) and medical cannabis. People with uncontrolled seizures live with the continual risk of serious injuries and loss of life. If an individual and their health care professional(s) feel that the potential benefits of medical cannabis outweigh the risks, then families need to have that legal option. Nothing should stand in the way of individuals gaining access to this potentially life-changing and lifesaving treatment. Currently, the medical use of cannabis is legal per state law in a majority of the states. In these states, a number of people living with epilepsy report beneficial effects, including a decrease in seizure activity, when using a cannabis strain rich in cannabidiol. The state can play a critical role in ensuring that access to medical cannabis is safe and reliable.

Earlier this month, voters in Utah approved Proposition 2 – formally known as the *Utah Medical Cannabis Act* – which is supported by both the Epilepsy Foundation and Epilepsy Foundation of Utah. This ballot initiative would provide access to medical cannabis for individuals living with a qualifying condition including epilepsy. Further, this initiative provides safety measures and clear guidelines, similar to state laws in other states that have allowed for the use of medical cannabis.



The Epilepsy Foundation and Epilepsy Foundation of Utah urge the legislature to allow Proposition 2 to go into effect but should the legislative compromise to the *Utah Medical Cannabis Act* move forward, we implore you to carefully consider the negative impact some provisions will have on access for individuals who need it most. While we understand the sensitive nature of children using cannabis, the provision requiring minor patients to receive a second opinion before they are permitted to access medical cannabis would act as a significant hurdle for those seeking care. The Epilepsy Foundation and Epilepsy Foundation of Utah believe that an individual and their physician are in the best position to choose which treatment option may work best for them. Requiring a non-treating physician to give a second opinion on the treatment option chosen by a minor, their parent or guardian, and their treating physician, would devalue the expert and personalized care offered to that child. Further, this places a burden on the child and their family who must schedule an additional visit in order to access medical cannabis. We recognize that there is another way to receive a second opinion outlined in the bill but requiring a physician to use their office time to jump through bureaucratic hoops will take away time they could be spending with other patients in their office. We urge you to remove this requirement and treat the physician-patient relationship equally for both minors and adults.

The Epilepsy Foundation and Epilepsy Foundation of Utah support physician-directed care and oppose provisions that place arbitrary limits on the care physicians provide. The establishment of a prescribing cap for physicians would undermine physician-directed care and may result in substantial wait times for individuals living with epilepsy. In Louisiana, physicians were limited to the number of patients for whom they could recommend cannabis.¹ As a result, some physicians amassed large waiting lists – up to 700 patients – for individuals for whom the doctor believed would benefit from medical cannabis. An individual’s treatment plan, and access to those treatments, should not depend on outside factors including the number or type of other patients a physician sees.

The Epilepsy Foundation and Epilepsy Foundation of Utah urge the legislature to allow implementation of Proposition 2 which would ensure that Utah residents living with epilepsy and uncontrolled seizures can gain safe, legal access to medical cannabis as a treatment option. If the legislature moves forward with the proposed changes to the *Utah Medical Cannabis Act*, we urge scaling back certain measures which would act as a barrier to access in the state for those who need it most. Please do not hesitate to contact Laura Weidner, Esq., Vice President of Government Relations and Advocacy, at 301-918-3766 or lweidner@efa.org with any questions or concerns.

Sincerely,

A handwritten signature in black ink that reads "Margo Thurman".

Margo Thurman
Executive Director
Epilepsy Foundation of Utah

A handwritten signature in black ink that reads "Philip M. Gattone".

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

¹ Clark, M. (2018, September 17). Louisiana lifts limit on patients who can access medical marijuana. Retrieved from https://www.nola.com/health/index.ssf/2018/09/patient_cap_medical_marijuana.html