



February 28, 2017

Iowa House of Representative Members  
1007 East Grand Avenue  
Des Moines, Iowa 50319

Dear Representative:

On behalf of the Epilepsy Foundation and the Epilepsy Foundation of North/Central Illinois, Iowa, and Nebraska, we urge your support of House Study Bill 164, which was introduced by Representative Clel Baudler. Principally, the bill would preserve the status quo in Iowa by repealing a sunset provision in an existing law that allowed individuals with intractable epilepsy to use cannabidiol (CBD). The existing law established a process for individuals to obtain a registration card that allows them to legally use CBD oil. While this bill falls short of ensuring Iowans with epilepsy are able to safely access CBD because it does not establish a comprehensive, state-regulated program for manufacturing and dispensing CBD, it is critically important to the epilepsy community that Iowa does not regress on this issue.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than three 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. This is why people living with uncontrolled seizures turn to treatment options like CBD and cannabis, when other options have failed.

CBD is legally available in the majority of states for treatment of epilepsy for individuals who have failed to gain seizure control after trying FDA-approved treatment options. In the states where medical use of CBD and/or cannabis is legal as a treatment for epilepsy, a number of people living with epilepsy report beneficial effects, including a decrease in seizure activity. Not everyone with epilepsy should or would consider cannabis, including CBD, as a treatment option, and further research is needed on the connection between cannabis and seizures. Nevertheless, cannabis, including CBD, when recommended by a treating physician, may be the best alternative for some individuals living with drug resistant epilepsy and uncontrolled seizures.

While we support HSB 164, we also strongly encourage you to explore expanding the bill to establish a state-regulated, comprehensive CBD or cannabis program in Iowa that includes licensing for manufacturing and dispensing. Currently, Iowa families seeking CBD as a treatment option for epilepsy have no legal way of purchasing CBD under the current system. While the majority of states allow for legal access to CBD and/or cannabis, these programs are state managed and not legally accessible to Iowans. Neighboring Illinois and Minnesota have passed medical cannabis legislation that allow for manufacturing and dispensing by state approved entities. These states, and many others throughout the country, have recognized that providing safe and comprehensive access to this treatment option requires the ability to cultivate, process and dispense CBD and/or cannabis under state regulation. The state can play a critical role in ensuring that access to these treatments is safe and reliable. We urge you to act so that families do not fall victim to unscrupulous individuals selling unsafe products marketed as CBD, or feel the need to consider breaking federal and state laws by traveling across state lines to obtain treatment.

Without a consistent and reliable supply of CBD or cannabis, a physician cannot work with a patient to create the optimal treatment regimen.

HSB 164 also includes a provision related to a potential therapy derived from CBD and approved by the Food and Drug Administration (FDA). 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 federal Drug Enforcement Administration (DEA) would schedule the therapy through administrative action and the medication would become available for patients. However, since CBD is currently a Schedule I substance under the Iowa state drug schedule, state action is needed to ensure proper rescheduling of FDA-approved treatments derived from CBD. Unless Iowa acts, patients will not have access to these new treatments, which would be available in neighboring states that have taken action. This is an issue of creating access to FDA-approved, prescription therapies. Access to new therapies is particularly important for the epilepsy community due to the significant unmet need and often debilitating side-effects to the currently available medications.

While we support the intent of the bill to address this issue, the current language would not provide for meaningful access to an FDA-approved product derived from CBD. This provision of the bill should be amended so that Iowa would adopt the federal schedule assigned to the therapy by the DEA.

Lastly, it is important to note that while an FDA approved therapy derived from CBD is a significant step for the epilepsy community, it will likely only be approved and indicated for specific types of epilepsies. There are many individuals living with epilepsy who cannot find seizure control even after working through all available prescription treatments with their physicians. For these individuals, access to CBD and cannabis more broadly is important. The Epilepsy Foundation is committed to supporting physician directed care, and to exploring and advocating for all potential treatment options for epilepsy, including CBD and medical cannabis. We support safe, legal access to medical cannabis if a patient and their health care team feel that the potential benefits of medical cannabis for uncontrolled epilepsy outweigh the risks. While not everyone with epilepsy should or would consider medical cannabis as a treatment option, some people living with uncontrolled seizures have reported beneficial effects and reduced seizure activity when using medical cannabis, especially strains rich in CBD. Furthermore, additional research is needed on the connection between cannabis and seizures and broader legal access will support increased research efforts.

The Epilepsy Foundation and the Epilepsy Foundation of North/Central Illinois, Iowa, and Nebraska, thank you for your careful consideration of our concerns and urges you to support HSB 164 with the suggested amendments. We look forward to working with the legislature to ensure safe, reliable, and legal access to CBD for Iowa residents living with epilepsy and uncontrolled seizures. Please reach out to Roxanne Cogil with the Epilepsy Foundation of North/Central Illinois, Iowa, Nebraska at [rcogil@epilepsyiowa.org](mailto:rcogil@epilepsyiowa.org) or (515) 238-7660 with any questions or concerns.

Sincerely,



Ben Slack  
Executive Director  
Epilepsy Foundation of North/Central Illinois,  
Iowa & Nebraska



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