



May 10, 2018

The Honorable Richard N. Gottfried  
LOB 823  
Albany, NY 12248

Dear Chair Gottfried and Members of the Assembly Standing Committee on Health:

On behalf of the Epilepsy Foundation and our local affiliates, Epilepsy Foundation of Metropolitan New York, Epilepsy Foundation Long Island, Epilepsy Foundation Northeastern New York, and Epilepsy Foundation Rochester-Syracuse-Binghamton, we urge you to support Assembly Bill 10468, 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. On April 19, 2018 the Peripheral and Central Nervous System Drug Advisory Committee of the FDA unanimously (13-0) voted to recommend this new treatment for approval by the FDA, which it could receive as early as Summer 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 state drug schedule, state action is needed to ensure proper rescheduling of FDA-approved therapies derived from CBD. Unless New York 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 A 10468.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the at least 3.4 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, the Epilepsy Foundation of Metropolitan New York, Epilepsy Foundation Long Island, Epilepsy Foundation Northeastern New York, and Epilepsy Foundation Rochester-Syracuse-Binghamton 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. We urge your support of A 10468. Please do not hesitate to contact Abbey Roudebush, Government Relations Manager, at 301-918-3784 or [aroudebush@efa.org](mailto:aroudebush@efa.org) with any questions or concerns.

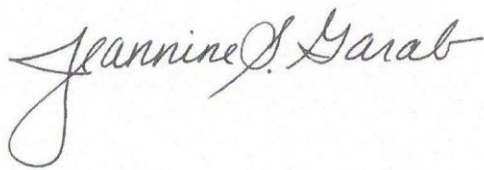
Sincerely,



Pam Conford  
Executive Director  
Epilepsy Foundation of Metropolitan New York



Tom Hopkins  
Executive Director  
Epilepsy Foundation Long Island



Jeannine Garab  
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Epilepsy Foundation Northeastern New York



Jeff Sinsebox  
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