



## *Public Policy Agenda 2016*

**1 in 26 Americans** will have epilepsy over the course of their lifetime. Nearly three million children and adults in the United States have epilepsy. Epilepsy is defined as an enduring predisposition to seizures after having at least one seizure and can develop at any stage of life. Children and the elderly are particularly affected.

Epilepsy can result from a variety of causes including head trauma, brain tumor, stroke, infection, neurodegenerative disorders -- including Alzheimer's disease, genetic predisposition, and poisoning. Often no cause is identified. The effects of epilepsy vary widely from individual to individual and often create medical, economic, and social hardship. Epilepsy and seizures can affect anyone from any age, ethnic background, or gender -- everyone is at risk of developing seizures or epilepsy

At least 100,000 people in Michigan suffer from a seizure disorder. About 30 percent, or 30,000, are children.

Treatment options available today hold the promise of a life free of seizures and side-effects for about 60 percent of people with epilepsy. Yet, many people with epilepsy suffer unnecessary seizures. Many more live with debilitating consequences of the seizures and/or treatments such as poor awareness, memory problems, mood disorders, and a host of other side-effects.

The Epilepsy Foundation is committed to closing the gap between what modern medicine can do for the person with epilepsy and the inferior level of care that too often is provided. Ineffective treatment and delayed or lack of access to specialized care contribute to the development of intractable epilepsy. The costs of intractable epilepsy are enormous in terms of dependency, lost productivity, and higher healthcare expenditures.

Some evidence suggests that the sooner seizure disorders are diagnosed and effective treatment started, the better the chances of positive long-term outcome. Early recognition and treatment may decrease the risk of disruptions in education, employment, self-esteem, and personal life. The primary treatment of epilepsy is medication. Access to the newer anti-epilepsy drugs is particularly crucial for those who have intractable epilepsy. Children and older adults are at far greater risk for brain damage and increased mortality when seizures persist.

The Epilepsy Foundation of Michigan is committed to work on behalf of people with epilepsy, their family members, and caregivers. Our goal is to ensure the coverage and access to essential services, the protection of the rights of individuals with disabilities, and the promotion of research into treatments, better understanding of causes, consequences, and outcomes, and ultimately, cures for all the epilepsies.

The Epilepsy Foundation of Michigan, founded in 1948, is the only statewide nonprofit organization that focuses entirely on epilepsy. The Foundation is a separately incorporated affiliate with the national Epilepsy Foundation.



**The following are the Epilepsy Foundation of Michigan’s public policy priorities for the state of Michigan:**

### **Access to Specialty Care**

There is a gap between what we can do for people with epilepsy and what is actually done. Some of this is related to lack of health insurance or resources to pay for care. Others may be prevented from seeing an appropriate specialist because of benefit limitations with their insurance. And still others are not receiving the level of care that they require, but are unaware that there are treatments that might help them.

For people with epilepsy and their families, access to quality, affordable, health care is critical to living with this serious chronic disorder. People incur significant direct costs in the form of doctor office visits; hospitalizations; medications and other therapies; evaluations and consultations with experts; diagnostics and monitoring; and often physical, speech, and other therapies.

The diagnosis and treatment of epilepsy can be complex and may require a specialist. For some epilepsies, the primary care physician may be able to prescribe the correct treatment to resolve the seizures. Should that fail, people usually are referred to a neurologist for diagnosis and treatment. Those whose seizures resist treatment should be seen by a comprehensive epilepsy center where the neurologists specialize in diagnosis and treatment, and where a comprehensive array of diagnostic techniques and treatment options are available.

### **The Epilepsy Foundation of Michigan shall:**

- Supports universal health care system that ensures availability, portability, and access to appropriate and affordable health care for all children and adults with epilepsy, including easy access to specialty care and all available treatments.
- Ensure that people with epilepsy are protected by all state and federal laws designed to ensure nondiscriminatory access to insurance and health benefits.
- Ensure the needs of people with epilepsy are met in implementing insurance reforms under the Affordable Care Act.

### **Access to Pharmaceuticals**

Any prescription drug plan should provide access to anti-epileptic products at an affordable price. Formulary plans should include all anti-epileptic products, whether generic or brand name.

The Epilepsy Foundation of Michigan **does not support** prior authorization programs because of the potential for delays for patients in getting needed prescriptions. We believe that the physician, in the context of the patient –physician relationship, should make decisions on medications. Patients will be put at risk if their physician must prescribe a substitute medication that may not be the best treatment for the patient. .



**The Foundation urges:**

- **That prescription drug plans provide access to all anti-epileptic products at an affordable price. Formulary plans should include all anti-epileptic products, whether generic or brand name.**
- **That anti-epileptic products should not be interchanged by a pharmacy without consent of the practitioner and the patient.**
- **Epilepsy medications remain fully exempted from the pre-authorization process because of the difficulties inherent in the treatment of epilepsy.**

### **Access to Marijuana and Extracts like CBD Oil to Treat Epilepsy**

Approximately one-third of people with epilepsy are not able to achieve seizure control despite the best medical, dietary, and surgical therapies. The need for better treatments for children and adults with epilepsy is enormous. Those who live with uncontrolled seizures live in continual risk of serious injuries and loss of life.

CBD oil is a non-psychoactive component of the cannabis plant. Delta-9-tetrahydrocannabinol (THC) is the psychoactive component. Non-euphoric, CBD oil is derived from a cannabis plant that is high in CBD and low in THC, therefore resulting in no “high” to the user. There is research, including animal studies and pharmaceutical-led investigational studies, to support that CBD may have significant therapeutic benefits. While doctors agree that further research is needed, many researchers also agree that marijuana products should be offered to patients who have failed or are adversely affected by existing therapies. They would also agree that the Drug Enforcement Agency should change the classification of marijuana and its constituents from a Schedule 1 drug so that more clinical trials can be conducted. You can view the position of the national Epilepsy Foundation [here](#)

The Epilepsy Foundation of Michigan believes that nothing should stand in the way of patients gaining access to potentially life-saving treatment. If a patient and their healthcare professionals feel that the potential benefits of medical marijuana for uncontrolled epilepsy outweigh the risks, then families need to have that legal option now -- not in five years or ten years. For people living with severe uncontrolled epilepsy, time is not on their side. This is a very important, difficult, and personal decision that should be made by a patient and family working with their healthcare team.

While medical marijuana is legal in the state of Michigan, there is still a gap in the availability of edible and non-smokeable forms. This is especially important for children with Dravet Syndrome and other severe epilepsy syndromes who have found some relief through the use of CBD oil. This has been well publicized by Paige Figi, whose daughter Charlotte had tried many therapies until she was helped by the so called Charlotte’s Web strain of marijuana which has been bred to be high in CBD oil.

**The Epilepsy Foundation of Michigan supports access to medical marijuana and its extracts to treat epilepsy.**

### **Mental Health Parity**

Southfield: 25200 Telegraph Road, Suite 110 • Southfield, MI 48033  
Grand Rapids: 161 Ottawa Avenue NW, Suite 211 • Grand Rapids, MI 49503  
(800)377-6226 • fax (248) 351-2101



Persons living with epilepsy often find themselves dealing with mental illness, and they may be more likely than other people to experience emotional changes. In some people, the mood disorder, such as depression, may be associated with the seizure itself. However, in other cases it may be related to where the seizure is coming from in the brain. Studies show that up to 60 percent of people living with epilepsy are also living with a mood disorder.

Michigan is only one of 11 states without some manner of parity law. Over 6 million people in Michigan have private health insurance; state parity would protect 40 to 50 percent of the privately insured.

Studies support that the cost of mental health parity is very low. The negligible direct cost of parity is more than offset by increased employee productivity; decreased absenteeism; less use of emergency rooms and medical resources; and other benefits to employers and society.

**The Epilepsy Foundation of Michigan supports efforts to correct the disparity between physical and mental illness in private health insurance.**

### **Transportation**

Individuals who have active seizure disorders cannot drive, but safe, reliable public transportation is not available in most areas. This affects the person's with epilepsy ability to work, to shop, to get medical treatment, and to be more fully integrated into the community. Transportation has been identified as one of the top five concerns of people with epilepsy identified in our 2001, 1998, and 1995 needs assessments.

**The Epilepsy Foundation of Michigan supports:**

- **The establishment and maintenance of well-coordinated, accessible, and affordable regional public transit and paratransit systems.**
- **Support efforts to change Michigan state laws and regulations to more closely conform to the Epilepsy Foundation, the American Epilepsy Society, and the American Academy of Neurology consensus model law.**

### **Employment**

People with epilepsy face multiple barriers to entering the workplace and many are unemployed or underemployed. Surveys show that unemployment rates among people with epilepsy are higher than for the general population. Additionally, many people with epilepsy are living in households with incomes of \$10,000 or below because of lack of adequate employment.

Some of the common reasons are: lack of training, skills, or on-the-job experience; lack of transportation; negative attitude of employers towards epilepsy; and negative attitude of co-workers.

The Americans with Disabilities Act (ADA) was enacted to prohibit disability-based discrimination. Title I of the Act prohibits employment discrimination against qualified individuals with disabilities and



applies to private employers with 15 or more employees. A "qualified individual" with a disability is one who is able to perform the essential functions of the job, with or without reasonable accommodation.

**The Epilepsy Foundation of Michigan supports:**

- **Programs that provide additional financial supports and services to enable those seeking employment to either work at home or obtain transportation to and from worksites.**
- **Active enforcement and promotion of laws that prohibit discrimination and require accommodation in the workplace.**

**Safety**

About 25 percent of all cases of epilepsy are attributed to some kind of injury to the head. Motor vehicle accidents are the leading cause of head injuries--about 50-60 percent in most studies. Epilepsy occurs in two to five percent of those who have had a head injury. Nationally, about 5,000 new cases of epilepsy are attributed to head injury each year.

**The Epilepsy Foundation of Michigan supports:**

- **Maintenance and enforcement seatbelt laws, and the re-instatement of motor cycle helmet laws which not only save lives but also save health care dollars by preventing traumatic brain injuries and the epilepsy often associated with such injuries**

**Education**

While most children with epilepsy can participate with the other students in the classroom, some may require additional services or specialized instruction. Federal law and state law, grants children with epilepsy the right to receive those supplemental services, and if necessary, special education. Frequently, schools may fail to provide children with epilepsy adequate special education services or accommodations to address learning or cognitive impairments caused by their seizures or the side effects of antiepileptic medication.

**The Epilepsy Foundation of Michigan supports:**

- **The rights of children with epilepsy and seizures to full inclusion in all educational activities and programs whether or not they need such auxiliary services such as access to medication and treatment in order to safely participate in such educational activities.**
- **Support parents in their right to be members of their children's IEP team.**
- **Supports measures to increase the number of school nurses in Michigan**



### **Availability of Non-motorized Transportation Facilities**

If people wish to walk or bike in order to get to work, medical appointments, shopping centers, or other community destinations, they may not be able to do so safely. This is due, in large part, to gaps in the availability of sidewalks, crosswalks, bicycle lanes, or wide shoulders along the routes from people's homes to their intended destinations. In other cases, poorly maintained facilities, inadequate lighting, or lack of enforcement of parking violations may act as barriers to non-motorized transportation.

Improving the safety and availability of non-motorized transportation facilities is an important step in reducing injuries that can lead to epilepsy and other disabilities. It also enables people with epilepsy or other disabilities to use walking and bicycling as transportation. Such improvements will also yield innumerable public health and environmental benefits.

#### **The Epilepsy Foundation of Michigan supports:**

- **Building public support for non-motorized transportation through educational campaigns emphasizing the health and environmental benefits of walking and bicycling.**
- **Urban planning and development practices that reduce the need for motorized transportation.**

#### **Increase the Number of School Nurses in Michigan**

Michigan ranks as having the lowest number of school nurses per pupils in the nation. It is estimated that nearly 1 in 5 children and youth have some type of chronic health condition; nearly half of whom could be considered disabled. School nurses are part of the solution and provide an important safety need for our vulnerable children and adolescents. Schools are struggling to meet the needs of students with chronic conditions, including epilepsy, leaving many families struggling to keep their children healthy, in school, and ready to learn.

**The Epilepsy Foundation of Michigan supports efforts that would lead to an increase in the number of school nurses in Michigan.**