



**EPILEPSY  
FOUNDATION®**  
CONNECTICUT

*Not another moment lost to seizures™*

386 Main Street • Middletown, CT 06457

Written Testimony of  
Charles Nash, Vice President, Board of Directors  
Epilepsy Foundation of Connecticut, Inc.

## **Senate Bill No. 809, An Act Concerning Appropriating Funds for Epilepsy**

February 13, 2007  
General Assembly's Human Services Committee

Good morning Senator Harris, Representative Villano and members of the Human Services Committee. My name is Charlie Nash and I am testifying on behalf of the Epilepsy Foundation of Connecticut. I am here to testify in strong support of Senate Bill 809, "An Act Concerning Appropriating Funds for Epilepsy."

The funding request in Senate Bill 809 would provide the Epilepsy Foundation of Connecticut the opportunity to maintain and expand its information, education and support programs for people with epilepsy, their families and the people who care for them in Connecticut.

I come to you not only as a board member of the Epilepsy Foundation of Connecticut but also as the father of two children who have suffered with epilepsy since childhood. Epilepsy is a neurological condition that afflicts approximately 2.7 million Americans. In There are an estimated 60,000 people in Connecticut with epilepsy; however that number is probably greatly underestimated since many people try to conceal it and because it often occurs with other disabling conditions. Epilepsy is a chronic condition that affects the individual's quality of life in areas of education, employment and social relationships. It can and usually does affect the entire family, both emotionally and financially. In addition, there are substantial indirect costs to the state. These costs result from the impact epilepsy can have on employment, which requires a combination of strategies, including public education, individual counseling and targeted employment programs.

The diagnosis of epilepsy can encompass approximately 40 syndromes that all share the common symptom of a disruption of electrical brain activity with resultant loss of consciousness and uncoordinated body movements. Because of the physical manifestations of these disorders, people afflicted with epilepsy have been ostracized and the subject of public scorn and ridicule. If the individual is a child, there is an increased risk compared to other children of compromised social and intellectual development. Identifying learning difficulties and addressing emotional and social problems soon after

a diagnosis is critical to future development. The Epilepsy Foundation of Connecticut works with school systems across the state to provide teachers, nurses and students with the tools and resources to identify and manage these issues.

Epilepsy is not just a disease of childhood but instead can afflict individuals of all ages and socioeconomic status. An adult who is diagnosed with epilepsy for the first time can experience significant lifestyle limitations, such as driving, loss of income and strained family relationships. All of these effects involve major lifestyle adjustments that require support and intervention, which the Epilepsy Foundation currently provides. Another growing population of those affected is in the 65 and older age group. At this time, there are 570,000 Americans over the age of 65 who have been diagnosed with epilepsy. This growing number of people with epilepsy, both young and old, are costing Americans approximately \$15.5 billion dollars in healthcare costs, losses in employment, wages and productivity.

Unless you know someone with epilepsy, you cannot begin to realize the implications that the diagnosis brings. Conversely, if you know someone with epilepsy, the implications are too great to be ignored. Although it is one of the most common neurological disorders in the United States, affecting more people than those with cerebral palsy, multiple sclerosis and parkinson's disease combined, it is truly the most neglected. The Epilepsy Foundation of Connecticut is the only agency in the state that specifically provides support to people with epilepsy. Currently the organization responds to hundreds of requests for information, educates thousands of individuals in a variety of settings, and provides various support services throughout the state, including a summer camp for children and teens with epilepsy. We work hard to develop a diversified funding base that includes revenue from individuals, corporations, federations, and foundations, and are only looking for a fraction of the total cost to provide services throughout the state.

In summary, I appreciate this opportunity to testify on this critical legislation for individuals with epilepsy. All of you have the power to offer help and hope to the thousands of people in Connecticut who have epilepsy, and I strongly urge you to honor our request. At this time, I'd be glad to answer any questions.