

IN THE UNITED STATES COURT OF APPEALS
FOR THE DISTRICT OF COLUMBIA CIRCUIT

STATE FARM MUTUAL AUTOMOBILE INSURANCE
CO., KENT MASON, PATRICIA WARREN AND
LEORLIN BODY,

Petitioners,

v.

DEPARTMENT OF TRANSPORTATION, DREW LEWIS,
as Secretary,
NATIONAL HIGHWAY TRAFFIC SAFETY
ADMINISTRATION, and RAYMOND PECK, JR.,
as Administrator,

Respondents.

No. 81-2220

BRIEF OF AMICUS CURIAE EPILEPSY FOUNDATION OF
AMERICA IN SUPPORT OF PETITION TO REVIEW AN
ORDER OF THE DEPARTMENT OF TRANSPORTATION

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Statutes

Act to Establish the Commission for the Control of Epilepsy and Its Consequences, 89 Stat. 348 (1975), P.L. 94-63

Other Authorities

Commission for the Control of Epilepsy and Its Consequences, U.S. Department of Health, Education, and Welfare, Plan for Nationwide Action On Epilepsy, Volumes I-IV (DHEW Publication Nos.: (NIH) 78-276, 78-279, 78-311), Bethesda, Md (1978)

Epilepsy Foundation of America, Basic Statistics on the Epilepsies, F.A. Davis Co., Philadelphia, Pa. (1975)

_____, The Cost of the Epilepsies To Individuals, Families and To The Nation, Washington, D.C. (1974)

_____, To What Extent and In What Ways Can Epilepsy and Its Consequences Be Prevented?, Washington, D.C. (1974)

INTEREST OF AMICUS CURIAE

The Epilepsy Foundation of America is a non-profit corporation founded in 1968 to advance the interests of the two million Americans with epilepsy, through public information and education, research, vocational and employment programs, professional education, and advocacy. The Epilepsy Foundation of America has a long-standing interest and commitment to foster means of preventing epilepsy, to secure the legal and civil rights of persons with epilepsy, and to encourage the development of legal principles based on current medical and psychosocial concepts, rather than on stereotypical prejudices or outmoded ideas about people with seizures.

Since its founding, the Epilepsy Foundation of America has compiled, maintained, published, and periodically updated a comprehensive survey of state laws and administrative policies relating to persons with epilepsy. Through this survey and other legal advocacy efforts, the Epilepsy Foundation of America has sought and attained the reform of state and federal laws, including the repeal of arbitrary laws which prohibited persons with epilepsy from marriage or subjected them to involuntary sterilization.

The legal and social science staff also provides information and assistance to attorneys, legislators, and various organizations working in areas involving epilepsy, through consultation, research, testimony, and serving in the role of amicus curiae. Advocacy activities are designed to facilitate legal reforms, to allow fuller realization of the individual's civil and legal rights, and to achieve a maximum integration of persons with epilepsy into the mainstream of life.

Epilepsy is a disorder that often evokes stereotyped images and fears despite vast improvements in medical knowledge and treatment of the condition. Since its inception, the Epilepsy Foundation of America has stood against the stigma and estrangement associated with epilepsy. The Foundation has encouraged society to view the person with epilepsy in a realistic fashion--as an individual who has many capabilities and whose dysfunction is often quite limited in scope and time rather than completely disabling.

At the same time the Epilepsy Foundation has always recognized that epilepsy and its consequences can have a severe adverse impact on individuals and their families with a resultant high cost to these individuals and society. It is the Foundation's mission to prevent epilepsy and its consequences, and to help persons with epilepsy, their families, and other concerned individuals, overcome the problems associated with the disorder.

The purpose of this amicus curiae brief is to present to the Court information on the causes and consequences of epilepsy with particular emphasis on the high individual and societal costs associated with the disorder and the consequent importance of efforts to prevent additional cases of epilepsy.

The Epilepsy Foundation of America, through its staff and volunteers, is familiar with the issues being presented in this proceeding, and hopes that the filing of this amicus curiae brief will be helpful to the Court in understanding the importance of measures designed to prevent epilepsy and its consequences.

ARGUMENT

Among the problems of persons with handicaps, those of people with epilepsy have been especially neglected. In recognition of this fact Congress established the Commission for the Control of Epilepsy and Its Consequences ("the Commission") on July 29, 1975, to review information about epilepsy and the needs of persons with epilepsy, and to recommend a national program to meet these needs. The Commission was specifically authorized to investigate and make recommendations concerning the prevention of epilepsy. The Commission's report, which was submitted to Congress and the President in 1977¹, stated that its plan "has been developed to enable people of the United States and its Territories to achieve effective prevention and control of epilepsy, and to reduce the negative impact of the consequences of epilepsy for both individuals and their families and for the nation as a whole." One of the specific goals established by the Commission was "[t]o reduce substantially the number of people who suffer from epilepsy by discovering and applying effective methods for the prevention of various forms of epilepsy."²

I. DESCRIPTION OF THE EPILEPSIES³

The term "epilepsy" refers to repeated seizures of any type. Epilepsy is not a disease but is rather a collection of symptoms which are outward signs of a temporary malfunction in the brain. The temporary electrical malfunction in the form of a sudden excessive discharge of electrical impulses between nerve cells in a person's brain will cause

various distinct actions and behaviors that are called epileptic seizures. Because of the wide variety of seizure activity they have more correctly been termed the "epilepsies."

The type of seizure that occurs depends upon the nature and location of the electrical disturbance in the brain. Seizures may be brief and mild, so that they are not even noticeable to another person, or they may produce convulsions and a lapse of consciousness. The range of severity of seizures among individuals is anywhere between these extremes. Seizures may likewise occur frequently or rarely, they may occur daily or they may occur years apart. In some cases seizures cease following effective treatment and do not recur. In some cases the symptoms of seizures may not be controllable by any means.

Epilepsy may be the result of a variety of conditions affecting the brain. These include scarring from head injuries; brain damage through lack of oxygen or ingestion of a toxic agent; tumors; the aftermath of infections involving the brain; certain metabolic disorders; tuberous sclerosis; or a genetic susceptibility in the form of a lowered seizure threshold. In about half of all persons with epilepsy no underlying cause for the seizures can be found. This is known as "idiopathic" epilepsy. Where the cause of seizures is known, it is referred to as "symptomatic" epilepsy.

Seizures are controlled primarily through proper diagnosis and the use of anti-convulsant medication. Sixteen anti-epileptic (or anti-convulsant) drugs are currently licensed in the United States. These drugs have produced a high degree of reliable seizure control in most persons who have epilepsy. It is estimated that one half of all people

with epilepsy gain complete seizure control enabling them to live normal or near-normal lives. Another 30 percent experience considerable reduction in the number of their seizures, and about 20 percent find that existing medications do not work for them.

II. MAGNIUDE OF THE PROBLEM

Due to the very nature of epilepsy it is extremely difficult to accurately determine the number of people in the United States who have the disorder. Except during a seizure, there are no outward signs to indicate that a person has epilepsy. In addition, because the stigma associated with epilepsy is often more of a handicap than the disorder itself, many people conceal the fact that they have epilepsy. Cognizant of these facts the Commission reviewed numerous studies and concluded that approximately 2 million Americans suffer from epilepsy.⁴ Head injuries account for an estimated 20,000 new cases each year.

Head injury due to automobile accidents remains the leading cause of epilepsy among adults. The Commission estimated that each year motor vehicle accidents account for 46,000 deaths and more than 1.8 million disabling injuries. Approximately 540,000 of these are head injuries, a significant proportion of which will result in epilepsy.

A lot of progress has been made in preventing epilepsy, where the cause of the epilepsy is known. This knowledge is often not applied. The Commission cited highway safety as possibly the outstanding example of this ironic situation. It found that enforced safety measures could save 10,000 to 20,000 lives each year and prevent an equal number of new cases of epilepsy. The result could be an annual financial saving of more than 500 million dollars

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for epilepsy alone.

111. COSTS OF EPILEPSY TO INDIVIDUALS AND SOCIETY ILLUSTRATE THE IMPORTANCE OF IMPLEMENTING AVAILABLE MEANS OF PREVENTING EPILEPSY

The savings estimated by the Commission which could be achieved through enforced highway safety measures do not present a complete picture of the costs of epilepsy. The estimated total costs of epilepsy to the nation exceeded 3 billion dollars in 1975.⁶ The wide ranging consequences of epilepsy illustrate the enormous costs that individuals and society must bear for the treatment and support of persons with epilepsy. Some of these costs are readily apparent, including medical costs--physician care, medication, hospitalization, the treatment needs of the severely disabled for continuous or residential care--which often persist throughout one's lifetime, the costs of special education, research, vocational rehabilitation, costs associated with lost future productivity due to increased mortality rates, and increased insurance rates. While some persons with epilepsy and their families are able to shoulder this burden themselves, society absorbs much of the costs in order to sustain and support individuals who have not been able to attain economic independence due to the seriousness of their condition or to societal attitudes.

The inability to afford these expenses is often a result of the less apparent consequences of epilepsy which significantly add to personal and societal costs of epilepsy. These are largely a result of the unfortunate social consequences that accompany epilepsy due to the

stereotyped images and misunderstanding associated with the disorder. The Commission found that every person affected by epilepsy experiences social, psychological and behavioral problems in degrees ranging from coping with and adjusting to the daily fears and uncertainties associated with epilepsy, to more severe problems which create effective barriers to social adjustment, to obvious psychiatric disorders.

These factors contribute to an unemployment rate among persons with epilepsy which is twice the national average. This rate exists despite dramatic advances in treatment and rehabilitation which allow such a large percent of those with epilepsy to lead seizure free lives, and regardless of federal and state prohibitions against discrimination in hiring because of a handicapping condition. The Commission recognized the even greater percentage of people who "are underemployed, working in low-paying, menial positions with little opportunity for advancement or change simply because they can find nothing else. The result is an immense waste of human potential among those who have ⁷ minimum disability and those who are severely handicapped."

The dollar costs are only part of the picture, however. There are imponderable costs which make the costs of epilepsy far greater than these monetary ones. We cannot measure the suffering, embarrassment, isolation, and alienation experienced by many people with epilepsy, nor the frustrations of being unable to find effective treatment, of being turned down for a job, insurance or a driver's license, or of being rejected by

family and friends. As the Commission stated

[a]ny effort to picture the problem of epilepsy in terms of numbers conveys little of its true meaning, which must be understood in human terms. Each... seizure...represents an interruption in the life of an individual--a deviation of function setting that person apart and cutting him off from natural and social contacts. The threat is ever-present--and no one can predict the time or place when a seizure may occur. It is no wonder that so many appear emotionally disturbed. Possibly it is more surprising that a majority do lead normal lives, interrupted only by the occasional episode which they and their 8 associates have learned to take in stride.

IV. ANY SLIGHT INFRINGEMENT OF PERSONAL CHOICE DUE TO THE PASSIVE RESTRAINT PROGRAM IS OUTWEIGHED BY THE BENEFITS TO BE REAPED FROM EFFORTS AT PREVENTING EPILEPSY

The Commission highlighted the prevention of head injury, particularly that caused by motor vehicle accidents "because head injury is such a clearly preventable cause of epilepsy, prevention could achieve immediate social and economic benefits, and the remedies are immediately applicable."⁹ The Commission recognized, however, that the nationwide cry for individual rights is the most serious bar to strict federal control of highway regulations.¹⁰ Recognizing that this is similar to the arguments made against mandatory motorcycle helmet laws the Commission stated that this "[c]oncern for individual freedom fails to recognize that it is the insurance companies and ultimately the public who must pay the cost for this type of self expression...."¹¹

In comments submitted to the Senate in hearings on automatic crash protection devices the Epilepsy Foundation of America stated that in the area of highway safety the personal liberty argument must be questioned when society must provide medical and custodial care following injury. "...personal freedoms must be tempered by personal and governmental responsibilities, especially in dealing with issues that have such potential impact upon an individual and his or her family, our health care system, and the well-being of society as a whole."

CONCLUSION

Congress recognized, in its mandate to the Commission for the Control of Epilepsy and Its Consequences, and the Commission's studies found ample support for, the importance of preventing epilepsy and its consequences. This is supported by the potential savings each year for individuals and society of both tangible and intangible costs associated with epilepsy.

Prevention of head injury due to automobile accidents, which is recognized as one of the foremost causes of new cases of epilepsy each year, is a readily achievable goal. It is the position of the Epilepsy Foundation of America that progress toward this goal will be enhanced

through reinstatement of the Department of Transportation's Passive Restraint Standard.

Respectfully submitted,

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END NOTES

1. Commission for the Control of Epilepsy and Its Consequences, U.S. Department of Health, Education and Welfare, Plan For Nationwide Action On Epilepsy, Volumes I-IV (DHEW Publication Nos.: (NIH) 78-276, 78-279, 78-311), Bethesda, Md. (1978), hereinafter, "Commission's Report"
2. Supra, at Vol. I, p. 13
3. The medical information contained in this part has been compiled by The Epilepsy Foundation of America for a lay audience and is current through 1980. Additional sources of information and background material on epilepsy for a variety of audiences may be obtained by phoning or writing The Epilepsy Foundation of America, Suite 406, 4351 Garden City Drive, Landover, Md. 20785, (301) 459-3700
4. Commission's Report, supra note 2, at 19
5. Id. at 29
6. Id. at 15
7. Id. at 85
8. Id. at 26
9. Commission's Report, supra note 1, at Vol.II Part I, p. 122
10. Id. at 123
11. Id.
12. Statement submitted to the Senate Commerce, Science and Transportation Committee, Subcomm. on the Consumer, Hearings on Automatic Crash Protection Devices, Epilepsy Foundation of America, Sept. 22, 1977