

## **Epilepsy Foundation of America**

### **Written Testimony – Senate Judiciary Committee**

#### **Subcommittee on Constitution, Civil Rights, and Human Rights**

**Tuesday, April 29, 2014**

Thank you, Chairman Durbin and Ranking Member Cruz for allowing the Epilepsy Foundation to submit testimony on behalf of the more than 2.8 million Americans living with epilepsy and their families. We write specifically to support initiatives to train and educate law enforcement, to help them safely address issues regarding those with physical or mental disabilities. We partner with the Centers for Disease Control (CDC) to train law enforcement personnel, as well as first responders, teachers, and others, about epilepsy and seizures as well as how to best help someone experiencing a seizure. The CDC has been an invaluable resource in this challenging task, and with their help we have been able to train and educate hundreds of thousands of people throughout the United States.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the more than 2.8 million Americans with epilepsy. The Foundation fosters the well-being of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. We would like to share with the committee information about epilepsy so that you might better understand why our organization

supports training law enforcement personnel on how to address issues regarding those with disabilities.

Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions; it is also called a *seizure disorder*. A person is considered to have epilepsy if they have two or more seizures.<sup>1</sup> Epilepsy is a family of more than 40 syndromes<sup>2</sup> including Dravet syndrome, hypothalamic hamartomas (HH), and Lennox-Gastaut syndrome (LGS). Epilepsy affects more than 2.8 million Americans<sup>3</sup> and 65 million people worldwide.<sup>4</sup> This condition will develop in approximately one out of 26 people at some point in their lives,<sup>5</sup> making it the fourth most common neurological disorder in the United States after Alzheimer's disease, stroke, and migraines.<sup>6</sup> This year 200,000 people in the U.S. will be diagnosed with epilepsy<sup>7</sup>, with the very young and the very old being the most affected. Currently, 326,000 children under the age of fifteen have epilepsy, and more than 90,000 of them have severe seizures that cannot be adequately treated.<sup>8</sup> Meanwhile, as the baby boomer generation approaches retirement age the number of cases in the elderly population is beginning to soar, with more than 570,000 adults age 65 and above living with epilepsy in the United States.<sup>9</sup>

Many people with epilepsy live with significant co-morbidities. Research has shown that 25.4 percent of people with autism have epilepsy, as well as 13 percent of those with cerebral

---

<sup>1</sup> Kobau R, Price P. Knowledge of epilepsy and familiarity with this disorder in the U.S. population: Results from the 2002 HealthStyles survey. *Epilepsia*. 2003;44(11):1449–1454.

<sup>2</sup> National Institute of Neurological Disorders and Stroke. Web site, <http://www.ninds.nih.gov/>

<sup>3</sup> Projection based on Begley CE, et al. The cost of epilepsy in the United States: An estimate from population-based clinical and survey data. *Epilepsia*. 2000;41(3):342–351 and U.S. Census Bureau 2010 population estimate of 308,000,000.

<sup>4</sup> Annual Report 2003: Global Campaign Against Epilepsy, p. 2. Published by World Health Organization, International Bureau for Epilepsy and International League Against Epilepsy.

<sup>5</sup> M.J. England et al. / *Epilepsy & Behavior* 25 (2012) 266–276. Web site, <http://iom.edu/~media/Files/Report%20Files/2012/Epilepsy/epilepsyEBarticleFinal.pdf>

<sup>6</sup> Hauser A. Epidemiology of seizures and epilepsy in the elderly. In: Rowan A, Ramsay R, eds. *Seizures and epilepsy in the elderly*. Boston: Butterworth-Heinemann, 1997:7–18.

<sup>7</sup> See note 6 above

<sup>8</sup> See note 6 above

<sup>9</sup> See note 6 above

palsy, 13.6 percent of those with Down syndrome, and 25.5 percent of those with intellectual disabilities live with epilepsy. The percentage increases when you look at those who have both cerebral palsy and an intellectual disability, with 40 percent living with epilepsy.<sup>10</sup>

Those living with epilepsy also face serious barriers to proper care and first aid. A lack of knowledge about proper seizure first aid exposes affected individuals to injury from unnecessary restraint and from objects needlessly forced into their mouths.<sup>11</sup>

While most law enforcement personnel do an outstanding job recognizing and handling individuals experiencing seizures, in limited cases they may respond with inappropriate force to those experiencing a seizure, especially a complex partial seizure. Complex partial seizures are the most common type of seizure and are non-convulsive seizures with altered awareness and automatic behavior. This type of seizure is also sometimes called a psychomotor or temporal lobe seizure, and can be difficult to recognize. The unusual behavior associated with complex partial seizures is often misinterpreted as stemming from intoxication or mental illness. It is this type of seizure that is also associated with symptoms that may be erroneously perceived as aggression. A lack of public understanding has resulted in people with complex partial seizures being unfairly arrested and sometimes seriously injured in the process.

During hearings on the Americans with Disabilities Act (ADA) held by the House Judiciary Committee, the Epilepsy Foundation brought the problem of inappropriate arrests of those with epilepsy to the attention of the Committee in 1990. In their final report the Committee stated:

---

<sup>10</sup> McDermott S, Moran R. Prevalence of epilepsy in adults with mental retardation and related disabilities in primary care. *American Journal of Mental Retardation*. 2005;10(1):48-56

<sup>11</sup> Repeated surveys by the Epilepsy Foundation, the previously cited CDC report, and numerous other surveys have documented the low level of public knowledge about seizures and epilepsy, including persistent misconceptions about seizure first aid.

*In order to comply with the non-discrimination mandate, it is often necessary to provide training to public employees about disability. For example, persons who have epilepsy, and a variety of other disabilities, are frequently inappropriately arrested and jailed because police officers have not received proper training in the recognition of and aid for seizures. Often, after being arrested, they are deprived of medications while in jail, resulting in further seizures. Such discriminatory treatment based on disability can be avoided by proper training.*

The Epilepsy Foundation has been working to train law enforcement personnel on how to recognize a seizure and the proper steps to take to ensure everyone's safety. Our training strives to educate law enforcement personnel on signs that the person in question is, in fact, experiencing a seizure and not being aggressive or purposefully unresponsive. When an officer is called to a scene where a person may be experiencing a seizure, we encourage them to consult witnesses regarding the individual who was the subject of the call. It is important to identify if they have a history of epilepsy or seizures, if the unusual behavior was preceded by normal behavior, or if a cry or blank stare began the event. If any of these are true then it would be more likely the person in question is experiencing a seizure and should be treated as such. Furthermore, if the officer notices that the individual is unresponsive throughout the event, has a blank stare when asked a question, or if his or her body stiffens and begins to jerk as muscles contract and relax involuntarily, these could all be signs that they are in the midst of a seizure. After the event, if the officer notices epilepsy medication or medical identification that says "Epilepsy" or "Seizure Disorder" in the person's possession we encourage them to strongly consider the likelihood that the individual was experiencing a seizure.

If an officer suspects that someone is experiencing a seizure we encourage them to follow a few simple guidelines in order to help keep everyone involved safe. The most important step is to not restrain someone experiencing a seizure, unless it is essential for his or her personal safety or the safety of others. Restraint of persons during or soon after a seizure may exacerbate or precipitate combativeness – the opposite of the intended result. Furthermore, restraining someone face-down and/or with his or her arms restricted behind the back is especially dangerous. Additionally, we encourage officers to refrain from putting anything into an individual's mouth, as it can cause damage to the teeth and/or jaw. Furthermore, we also encourage officers to make sure someone is fully conscious before giving anything to drink or administering medications.

After a seizure, law enforcement personnel should help to slowly reorient an individual by asking simple questions and being a calming influence. The threat of arrest should not be mentioned until the seizure is over and the individual is fully conscious so that questioning can be conducted accordingly. Officers should also ensure that individuals receive the proper medication in order to help avoid further seizures.

There is more that law enforcement could do, and that is why we offer comprehensive online trainings as well as shorter videos that teach the basics. All of this can be found on our First Responder Training page at <http://www.epilepsy.com/get-help/services-and-support/training-programs/first-responder-training>. When we first developed our curriculum we distributed the information to 20,000 police departments nationwide, and have continued to train law enforcement personnel every year. Last year alone we trained 1,289 law enforcement personnel on seizure recognition and how to handle the situation.

Despite our trainings and distribution of materials, there are still far too many instances of individuals facing arrest, being subjected to excessive force, and even dying. In Michigan, “John” was out walking as part of rehabilitation following brain surgery to help his seizures. During this walk “John” experienced a seizure that left him in a state of semi-consciousness. A person noticed “John” acting erratically and called the police who showed up and took his involuntary movements and failure to respond as resistance. They didn’t recognize the obvious signs of a seizure and ignored the medical alert bracelet he was wearing. Instead, “John” was tasered, hit with a police baton, threatened at gunpoint, and handcuffed behind his back. As discussed earlier, restraining a person experiencing a seizure, especially with their arms behind their back, is extremely dangerous and can lead to an escalation of the situation. After his arrest, “John” was prosecuted for assaulting police officers and disorderly conduct, disregarding considerable evidence, including the state’s own mental health evaluation confirming that his actions were solely the product of a seizure. Due to a gap in Michigan law, “John” was forced to plead not guilty by reason of insanity and then spend the next three weeks in a psychiatric facility. This hardship could have been avoided if the officers were trained to properly recognize the symptoms of a seizure and how best to handle the situation so as to avoid any harm to themselves or “John”.

“Dan,” from Colorado, experienced a seizure and his fiancé called for help. When the police and EMTs arrived, “Dan” was in a post-ictal state of confusion, which caused him to walk away from the officers and EMTs. They then used force to restrain him, even though “Dan” had not made any violent gestures. “Dan” was repeatedly struck, then handcuffed, and put in custody. The incident aggravated “Dan’s” epilepsy and shoulder problem.

There was another case in California where “Mike” experienced a seizure and, due to confusion after the fact, wandered from his home and attempted to enter his neighbor’s

house. When police officers arrived, “Mike” was not responsive to their commands because of his impaired consciousness. To try to subdue “Mike,” officers struck him in the throat and attempted to wrestle him to the ground. When that failed, officers shot him with a taser several times and beat him. “Mike” then fell to the ground, face down, and was handcuffed behind the back with officers applying pressure to his back with their bodies. Shortly afterwards “Mike” stopped breathing and died. Due to a lack of training, the deputies assumed that “Mike” was intentionally combative and possibly high on illicit drugs.

In New Jersey, “Sam” experienced a seizure at a garment factory where he worked. The officers who arrived on the scene determined “Sam” was being combative, even though he was in a post-seizure state of confusion. The officers restrained him by placing pressure on his back and neck, despite his co-workers insisting that such force was unnecessary. “Sam” stopped breathing at one point during the incident, but started again before reaching the hospital, where he died. The cause of death was determined to be homicide by mechanical asphyxiation.

These are only some of the many cases where a lack of education and awareness has led to improper arrests, serious injury, and even death. These tragedies, as well as the immense hardship to the families, could have been avoided with proper seizure recognition and education training.

The Epilepsy Foundation strongly encourages Congress to work to train more law enforcement personnel on how to appropriately identify someone experiencing a seizure, and how best to respond in this situation. It is important for the safety of the epilepsy community as well as the safety of police officers. Our program with the CDC has helped to impact thousands of lives, as we continue to train first responders and other professionals who can

be so important to someone living with epilepsy. The training we have been able to provide due to the CDC's support is an example of how, with proper education and training, we can avoid unnecessary arrests, injuries, and deaths that have caused so much anguish in our community. We thank the Committee for considering our input on this important issue.