



## Special Communication

## Testimonies submitted for the Institute of Medicine report *Epilepsy across the spectrum: Promoting health and understanding*

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## ABSTRACT

The 2012 Institute of Medicine (IOM) report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*, provides a vision for moving the field forward to improve the lives of people with epilepsy. The committee made 13 recommendations and identified a number of research priorities to promote accomplishing this vision. Its work was enriched by the contributions of many individuals who testified before the committee during its two public workshops and who submitted written testimony throughout the study process. Many of these testimonies included in this article were presented in-person at the committee's public workshops in Los Angeles, CA on March 21, 2011 and in Washington, DC on June 28–29, 2011. Among those providing testimony were people with epilepsy, their family members, health care professionals, and researchers specializing in epilepsy. The 36 testimonies that comprise this publication provided the committee with a more complete and current picture of epilepsy-related health care issues and the challenges that epilepsy imposes on the lives of people with epilepsy and their families.

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### 1. Introduction

The 2012 Institute of Medicine (IOM) report,<sup>1</sup> *Epilepsy Across the Spectrum: Promoting Health and Understanding* [1], provides a vision for moving the field forward to improve the lives of people with epilepsy. The committee made 13 recommendations and identified a number of research priorities to promote accomplishing this vision [2]. Its work was enriched by the contributions of many individuals who testified before the committee during its two public workshops and who submitted written testimony throughout the study process. Many of these testimonies included in this article were presented in-person at the committee's public workshops in Los Angeles, CA on March 21, 2011 and in Washington, DC on June 28–29, 2011. Among those providing testimony were people with epilepsy, their family members, health care professionals, and researchers specializing in epilepsy.

The 36 testimonies that follow provided the committee with a more complete picture of epilepsy-related health care issues and the challenges

that epilepsy imposes on the lives of people with epilepsy and their families. Although many testimonies focused on more than one topic, for ease of presentation we have grouped them into four broad areas and present them in the following order: personal perceptions of epilepsy, impact of epilepsy on the family, sudden unexpected death in epilepsy (SUDEP), and health care and community services. Each area is preceded by a brief introduction that identifies some of the themes and challenges described in the testimonies. Our hope is that these narratives provide a timely depiction of the current state of epilepsy in our society.

### 2. Introduction to personal perceptions of epilepsy

Seven adults testified about their personal experiences of living with epilepsy. Some provided insights into having epilepsy during childhood, and others described the onset of epilepsy in adulthood. Some described a life with seizures that were not controlled, while others described the challenges they had even though their seizures were well controlled. All provided glimpses into the difficulties that were unique to having epilepsy during adulthood. Although a few reported having a good support system, others reflected on struggles with interpersonal relationships and difficulties in finding needed resources and services. A major theme focused on the consequences of being unable to drive, including how transportation difficulties impact independence, limit employment opportunities, and reduce options in regard to living arrangements. One individual provided a

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<sup>1</sup> The full-text version of the report is available by chapter as PDFs at [www.iom.edu/epilepsy](http://www.iom.edu/epilepsy). The members of the report's authoring committee, the Committee on the Public Health Dimensions of the Epilepsies, are listed at the end of this article. The authors of this article are responsible for its content, which does not necessarily represent the views of the Institute of Medicine.

detailed narrative of financial struggles because of expensive epilepsy treatments and the inability to obtain financial help. Others reported experiencing side effects of seizure medications and the occurrence of comorbidities that were complicated by the difficulties in getting these other conditions diagnosed and treated. Finally, many referred to the emotional aspects of having epilepsy including social isolation, fears of having a seizure in public, worry about sudden unexpected death in epilepsy (SUDEP), and problems interacting with people who lack awareness about epilepsy.

## 2.1. Personal perceptions of epilepsy testimonies

### 2.1.1. Elizabeth Musick, person with epilepsy

**2.1.1.1. Biography.** My name is Elizabeth Musick. I turned 38 years old in October and have lived with epilepsy for 36 of those years. My current diagnosis is idiopathic epilepsy. In the span of these 36 years, I have had periods of almost exclusively absence seizures and other periods with overwhelmingly complex partial seizures. At present, I have exclusively grand mal seizures.

For the last 7 years, I have lived in Reston, VA, a suburb of Washington, DC. I am originally from Richmond, VA where I lived from birth to 22 years; I attended college at the University of Richmond and received a master's degree from American University. Since January 2011, I have been working at the Epilepsy Foundation in Landover, MD. I make \$45,000/year despite my education and personal story. Finally, at 38, I am single, without children and never married. I believe part of that is due to my epilepsy.

**2.1.1.2. Duration.** I was diagnosed with epilepsy at 21 months of age, so there are several things worth noting. First, epilepsy has been a constant in my life no matter how you look at things, when it is causing horrible seizures and when it is relatively controlled. There is not one without the other. Second, the question of how much it formed my personality will always linger. Third, like many chronic conditions, living with epilepsy requires not only hard medical treatment, but also soft treatments such as emotional coping skills, dealing with the unknown, and acceptance. Much of the treatment I have encountered for people with epilepsy is reactive, not proactive. Treatment reacts to a seizure by adjusting medication levels and reacts to intractable epilepsy by surgery; very little is done proactively. Aside from taking medications as prescribed and listening to the standard cautions to avoid sleep deprivation, alcohol or very stressful situations, other treatments are quite narrow (e.g., the ketogenic diet is primarily for children). Finally, with the projected length, I will have had epilepsy by the time I approach death, and with my seizures post 1992 (brain surgery) being exclusively grand mal type, there are no longitudinal data to project cases such as mine.

Two of these points are especially important in my mind. First, the proactive approach to treatment needs to be much more fully defined and actively applied. While most people only see the seizures themselves, there is far more to epilepsy. Being proactive in treatment means not only taking daily medication, but also participating in activities, talking to doctors or therapists as necessary, actively participating in school, and thriving at work. I have not done each of these well myself at times. Second, there is a dire need for a repository of information about patients with epilepsy, which we, the patients, are aware of, know how to access and are encouraged to use and update. The repository should contain demographics, date of first seizure if known, type of epilepsy, current medications, length of time as a person with epilepsy, longest period of being seizure free, any related procedures and their dates, and many similar details.

**Age 2–18:** School with epilepsy was less than standard. Elementary school can be described as 5–7 absence seizures each day. In middle

school, my seizures were especially problematic; I was taking multiple medications 4 times daily and also told to take a midmorning break at school for a snack to keep my blood sugar up. None of these, along with the obvious seizures, helped me fit in. When I had an absence seizure, felt overly tired, or overheated, I was allowed to go to the clinic, frequently without even requiring a note from the teacher because everyone knew my story so well. As one of the oldest students in my high school class of 525, it was emotionally hard to sit through 10th grade driver's education, knowing that I could not immediately get my freedom. When I eventually took the behind-the-wheel test after surgery, the Department of Motor Vehicles wanted to use a handicapped car for my exam. There is nothing wrong with my arms or legs. These kinds of 'mistakes' are what should not be taking place by people who supposedly are trained in fields that require direct contact with those of us who have epilepsy. When overlooked as sweeping generalizations, it further sets progress back.

I cannot overstate how many decisions appear to be made based on the cover-your-back mentality rather than what is in the best interest of the child. As a sophomore or junior in high school (I don't recall which), I tried out for and made the varsity tennis team, coached by one of the physical education teachers. However, I was not allowed on the team due to my epilepsy; the coach was worried about the chance that I might have a seizure during a game and harm myself. That is ignorant, insulting and inexcusable among many other things. That same coach, my physical education teacher (who should, therefore, know about epilepsy and be teaching about the subject), required that I take another student with me whenever I asked to go to the bathroom. To date, I have never harmed myself during a seizure. This is about dignity and respect among other things.

**Age 18–33:** This period, easily categorized as post surgery, is exclusively grand mal seizures. Depending on the year, the number varies. One thing which does not change, however, is the emotional effects on the individual. Although the seizure itself may last for approximately 1–3 min and recovery time varies, too infrequently, the personal ramifications for adults are discussed. Specifically, after having a grand mal seizure as an adult, you do not have the protection of a parent to shield you from being hurt or literally pick you up and make sure things are alright. Children are resilient and tend to bounce back more easily than adults; epilepsy is no different. Adults who have a grand mal seizure must face the crowds of stares during and immediately after the seizure, straddling the topic in a work context (who to tell, whether to tell at all, potential backlash), and long-term or short-term changes to lifestyle (driving privileges, living environment). The emotional roller coaster of believing that things are stable or even improving can be wiped out by a single and poorly orchestrated event.

College and epilepsy is an odd couple. The inconsistent and absent sleep pattern, saturation of alcohol, and necessity for medications to assure no seizures is a formula for something to go wrong. We cannot bury our heads in the sand when it comes to college students and the likeliness that they will miss or skip medications, or drink alcohol. It is one thing to know the ideal situation when sitting in a sterile doctor's office but quite another when away at college with the offer to attend a party.

**Age 33–37:** One of my last grand mal seizures occurred at a fitness club. To avoid too much embarrassment and effectively suffer in silence, I try to find the closest solitary place before the seizure begins. In this case, I was not successful. I had a grand mal at the elevator door/main entrance for the world to see as they came and went. When this happens, people hover unnecessarily, insist upon 911 (not always required) or are shocked that I am not speaking full sentences immediately. This happens like a broken record on replay every time I have a seizure; there is no systemic improvement in epilepsy education.

Two days before Christmas 2009, I underwent Vagus Nerve Stimulator (VNS) implantation. This was intended to be an adjunct treatment to existing medications, ideally leading to tapering off at

least one medication. To date, a year and a half later, I have not tapered.

The greatest benefit of this procedure for me, and possibly one reason I was approved, is because it serves a dual purpose since I am both epileptic as well as have major depressive disorder. After initial adjustments were made to the stimulation frequency and amplitude, I did notice a change in mood but believe as with other medications I have since established a tolerance level of sorts, where the effect begins to diminish. Although it cannot be credited solely to the VNS given the large number of medications in my system, I have not had any seizures since the surgery. I have had several close encounters where I needed to use the magnet to activate additional stimulation to the brain and use my other traditional distraction methods in hopes of preventing a seizure. The greatest concern to me, no matter how it is achieved, is to have 0 seizures.

Receiving approval for the surgery was an extensive process and required a bit of good fortune. Given that I have had epilepsy for so long I knew to press my former doctor about what were previously new treatment options and their success rates. He was not in favor; I switched doctors. It took several years and the right insurance to get the surgery. Very few people have heard of it for either epilepsy or depression, yet it is less risky than invasive surgery, which I also had.

*2.1.1.3. Clinical.* By medical standards, I have my seizures under control. However, that must be prefaced by saying that I require 7 standing medications to do so. Even at this stage, I continue to experience an average of 2 grand mal seizures annually. For each grand mal, a huge performance is put on and a new layer of restrictions is imposed, which then reintroduce accompanying psychological aspects. So, medically 'controlled' means something very different from what it means to me.

From diagnosis in July 1976 to the present, I have been on approximately 90% of all the medications available for epilepsy and have undergone both a left temporal lobectomy and VNS implant. In the late 1980s, I was part of the FDA/NIH study of gabapentin conducted at Wake Forest's Bowman Gray School of Medicine. Ultimately, it was not the correct medication for me yet again illustrates how I have received the newest medications and treatments. However, when they are unsuccessful, there are few alternatives. As someone who will have epilepsy for my lifespan, what medications or treatments are in the pipeline that I can resort to next?

In 1992, approximately 3 weeks before beginning my senior year of high school, I had brain surgery. Much of the preceding summer was spent undergoing tests where I interacted strictly with hospital staff. During one admission, I was in the Epilepsy Monitoring Unit for 23 days. There was never any interaction with other people who knew first-hand what it was like, either as the patient or family. This is a monumental issue for all parties involved and much more needs to be done to ease anxiety and bring brain surgery into the realm of possibilities for more patients.

One of the recurrent themes in my care for over 36 years has been top quality doctors and research hospitals. However, they do not come without a hefty price tag both in dollars and in time. Even with the thousands of hours I have accrued in doctors' offices, I am still no closer to being a 'non-epileptic' person today than I was 36 years ago. I still have to fight the same battles whether they are dormant or active. Unfortunately, it is a challenge to find a doctor who has a practice with epilepsy and mood disorders, especially when looking for specific insurance coverage, geography, or other restrictions.

*2.1.1.4. Psychosocial effects.* Potentially, some of the most significant side effects of my epilepsy have come not from the medications themselves but rather from changes in personality or behavior. The experiences of having many seizures at school each day, and the subsequently unacceptable reactions of students or teachers

becoming standard, eventually resulted in me developing a sense of self-reliance or independence to guard against hurt. I am also very introspective and intellectual (ISTJ — introversion, sensing, thinking, judgment), not all of which is due to the epilepsy. As my neurologist explained to me and my mother when I was only 8 or 9, epilepsy is the quintessential unknown. To manage it requires living with the fact that you do not know when a seizure will happen, where it will happen, how significant it will be, or why it happens at all. All the research in the world (and I have taken the approach of reading medical texts as well) is factual and suggestive but does not definitely answer why epilepsy occurs and to whom.

An overwhelming amount of my time in elementary and middle school was focused on providing rudimentary knowledge of the subject to people who should already understand (nurses, teachers, principals, coaches, etc.). This forced me to do things I shouldn't have been required to do and for the dynamics with other students to shift. Schools were more concerned about covering their backs than my emotional well-being. This is one of the most long-lasting effects across all measures. I still have very vivid memories of being taken to the principal's office in 4th grade after a seizure, placed on top of a trunk and surrounded with four chairs so I wouldn't roll off before my mother arrived. Clearly, this is not the way to handle a situation.

It is a constant challenge to exert a feeling of independence when you rely on someone else for transportation. Driving is a sign of passage. More importantly, however, where I reside also depends on whether or not I can drive. If I do not have a license, I must live in an area with extremely accessible public transportation, and that means frequent routines to the entire area at all hours in limited time. Losing a license can happen overnight, just like seizures do, but it turns your world upside down for the long run.

Intimate relationships may also be measured by the effect of epilepsy. It is difficult to determine how much is due to personality and to epilepsy, but it is fair to say they have been severely hindered. I have a fear of being alone for the long run. While I am very independent on the one hand, it does not absolve the need to have companionship and a core level of understanding. While rejection may have been learned somewhat earlier or faster than I or my parents wanted, it makes me more guarded in relationships now.

Collectively over 36 years, I have become more accustomed to other people's ignorance about epilepsy. However, that does not mean it is either easy or acceptable. Even Emergency Medical Technicians continue to overreact rather than see what is best for the specific situation.

*2.1.1.5. Financial.* There is not a single day that I feel financially secure, and much of this is due to the constant cost I pay toward medical expenses, whether they are for health insurance, prescriptions, or my primary doctor (a neuropsychologist who accepts no insurance). These cover the minimum requirements to assure I have no seizures; to live an otherwise healthy life requires additional medical expense. More telling, however, is the impact my prescriptions have had on my overall finances. In the last 5–6 years, I have been seeing the same doctor. Though my list of medications is rather long, there are two which have been consistent over this period: ZONEGRAN and CYMBALTA. However, while on a COBRA plan and taking approximately 6 medications for my epilepsy, they being two, I was paying \$525/month for the ZONEGRAN alone after co-insurance. The long-term effect of this unfair pricing was that I now have basic medical expenses on credit card with no acceptable way to forgive them (catastrophic expenses, undue hardship, medical expenses greater than income, etc.). The annual cost is very telling of the financial impact my epilepsy care has had on my well-being. Last year, I spent \$7315.78 on prescriptions, after co-pays, and I did not work.

I spent 2010 undergoing treatment for major depression, not uncommon for patients with epilepsy. In retrospect, it was present

as early as 2001 but my doctor at that time did not do any check-ups to assess my psychological well-being; appointments were less than 5 min every 6 months. When I did get diagnosed, it was very hard to accept. As I have learned more about the symbiotic relationship between epilepsy and depression, other details make more sense. At the same time, however, I have become increasingly frustrated: if there is such a strong link between the two diagnoses, then why are no useful, accessible resources available?

As an adult with chronic health conditions taking multiple standing medications, I researched available prescription assistance programs. Shockingly, nothing is available for the average adult. I must either be on Medicaid or have no possessions of value, since some have income limits. The latter requirement seems counterintuitive in the current climate. Anyone taking multiple antiepileptic medications, even with insurance, will appreciate the expense of a standing prescription. It seems illogical as one of the manufacturer's standing patients not to receive cost reductions.

Moreover, having to place routine medical costs on credit without the ability to pay it off has an adverse effect on credit history and emotional well-being. Every bit of 'spare' income I receive is allocated to reducing credit card balances, thereby preventing any money going toward savings, which further adds to anxiety and emotional unease. I have contacted each of the credit card companies and gone so far as to explain that my expenses fit the definition of catastrophic medical expenses and ask that they be partially waived or written off. In all cases, they have been denied. It is shocking to me that I am very close to true debt, and the overwhelming reason is epilepsy and all its ramifications.

**2.1.1.6. Treatment gaps.** Despite the knowledge that epilepsy has been around for thousands of years, we seem to know very little about how to treat it, much less how to cure it. While maintenance medications may be a satisfactory solution to preventing further seizures, they do not eliminate the epilepsy and all its corollary issues. There seems to be very good academic understanding about the need to seamlessly integrate the epilepsy care with comorbidity treatment; however, there is a great disconnect in the practical application. The longer it takes to adopt a truly integrated or coordinated care approach, the more patients will be lost.

Further research in areas such as DBS (deep brain stimulation) should be done so that it is not 'cutting edge' but rather normal treatment. There are far too few treatment options for myself and others with epilepsy that have exhausted the standard medications.

**2.1.1.7. Recommendations.** In addition, an extreme amount of attention is given to children with epilepsy since that is quite frequently when someone is diagnosed. However, very little energy has been paid to the adult population (21–55) who by definition are the chronically ill. They are in need of multiple services (job, food, housing, medical, transportation) yet have the greatest trouble accessing them as a working population. Moreover, the number of services available to this age group is far fewer than to children or seniors.

Medications are probably the clearest way patients associate cost with care. Unfortunately, no antiepileptic medication is cheap, and pharmaceutical makers are not racing to production with new ones. When forced to wait until the next paycheck, I know how to extend my pills by skipping a dose or cutting a dose in half. I am certain I am not alone. Unfortunately, I also know this is not 'as doctor prescribed' on the label.

As a much longer-term goal, there needs to be careful consideration about epilepsy in all levels of the academic curriculum from elementary schools to specialist education after college. There is currently no standard knowledge at any grade level about epilepsy, which perpetuates the misunderstanding and stigma. More importantly, I find it shocking that there is so little requirement of epilepsy knowledge in basic medical school. How can we possibly expect

someone to go into the field much less ask the right questions if they are never taught the right information to begin with?

**2.1.1.8. Conclusion.** I appreciate the opportunity to submit this testimony. If you would like to discuss any portion of it, I am more than willing.

What I have provided is a very thorough and, at times, intimate assessment of my life with epilepsy. I speak about it openly. I hope that is beneficial here. Far too many times, other people's ignorance about my epilepsy led to tears and questions. I know I am not the only person to whom this has happened. Thank you for the work you are doing.

### 2.1.2. *Jim Ashlock, person with epilepsy*

My epilepsy journey started in February 2002 at age 58. I experienced a couple of complex partial seizures for the first time, then a dozen or so complex partial seizures in a single day. Our family doctor was unavailable, so I saw one of his associates. He was baffled and prescribed Tylenol, Gatorade, and rest. That night, I experienced my first tonic-clonic seizure while sleeping. My wife called 911, and the paramedics took me to the local hospital. After a few days of exhaustive testing, they found nothing and sent me home. As required by law, the neurologist, on the hospital staff, reported the seizure to the Department of Motor Vehicles. My driver's license was suspended for 90 days. No seizures followed, so I was able to regain my driver's license after 90 days via a personal interview and brief driving test.

My next seizure was a tonic-clonic one in my sleep eight months later. That is when I was officially diagnosed with epilepsy by the same neurologist who had previously treated me. He initially prescribed a low dose of Dilantin. I, then, started having complex partial seizures about once or twice a month. The Dilantin dosage was gradually increased without any decrease in seizure activity. The higher dosage just made me less energetic and more sleepy.

My wife and I finally found an epilepsy support group in Orange County (30 miles away) and learned about the existence of epileptologists. I immediately made an appointment with an epileptologist in late 2006. He prescribed Keppra and Lyrica and deleted Dilantin. As a result, my seizure control and alertness improved significantly.

In 2007, I experienced two additional tonic-clonic seizures while undergoing chemotherapy for non-Hodgkin's lymphoma cancer. My epileptologist attributed these seizures to one of my chemotherapy drugs which inhibited sleep. I completed chemotherapy in the fall of 2007.

My epileptologist moved away, and I began seeing a new one in Orange County. I have completed two sleep-deprived electroencephalograms, and they have not shown any abnormalities. I am, therefore, probably not a candidate for surgery. In addition, Lyrica has been replaced by Zonegran.

My seizure activity began to steadily decline from complex partial seizures to simple partial seizures and no tonic-clonic seizures. I have been totally seizure free since June of 2011. I attribute this, in part, to a change in environment and the use of a CPAP machine after also being diagnosed with sleep apnea in July 2011.

My life feels almost normal now. I am still on the same dosages of medication (Keppra and Zonegran) to make sure seizures do not return. Of course, there are the side effects of these medications that my wife and I must deal with. The drug side effects are certainly preferable to seizures.

### 2.1.3. *Michael Bornemann, person with epilepsy*

I am a 63-year-old person with epilepsy who was diagnosed after my first observed tonic-clonic seizure at age 34. As such, I represent a group – let's call us those with a later-life diagnosis – which is quite different from those who have had epilepsy and knew it from childhood. I lived a young life without the apprehension I have now

for my health and safety and without being the target of my own ignorance, misconceptions, and biases about people with disabilities in general and epilepsy in particular. As a practical consequence of my disorder, I have had to give up driving and to stop working. Epilepsy has put demands on my wife and sons to do for me many of the chores I used to do for our household. In other words, my later-life diagnosis of epilepsy threatened initially to measure me as insufficient in many of the respects by which society and I defined myself as a husband, a father, and a citizen – those standards, in fact, of how we determine the value of a man.

In the 29 years since my diagnosis, therefore, I have had to reshape my lifestyle in order to maintain my usefulness and the esteem of those whose opinion of me matters the most, as well as my own self-respect. Though I am not employed, I serve on three local boards of directors and perform volunteer work for a number of community-based not-for-profit agencies for my local Roman Catholic parish and for the Archdiocese of Baltimore. I have traded many duties around the house with my wife and sons so that they now do anything that requires driving while I have taken over many more house-husband routines. To the extent that epilepsy has challenged us to be a better team, we have become a stronger family. It has taken a lot of work, and that work has taken change, and change has taken courage and commitment, and all of that from all of us has taken love.

It has been my experience that adults with epilepsy – particularly those who are newly diagnosed in later life – tend to struggle mightily with their interpersonal relationships and self-esteem. Whatever they believed about the burden of disabled people on society, whatever jokes they might have told about seizures and people with epilepsy, whatever distaste they might have felt working with, shopping with, dating, or otherwise interacting with disabled people, comes back as an attack on their own self-image and dignity. The expression “hoisted with one’s own petard” comes to mind. If they had not been enlightened and accepting of people with seizure disorders before their own diagnosis, they will have profound adjustments that the person who grew up with the diagnosis would not likely have – at least in the same respect and to the same degree.

My recommendation to this workshop is to recognize those with a diagnosis in later-life as a subset of everyone with epilepsy and to acknowledge that this group has a specialized need for (1) unique education and training strategies for the professional care community, as well as for (2) understanding of epilepsy in patients and the general public in order to create supportive communities.

On a closing and somewhat unrelated note, please let me encourage this committee and you as individuals to support House Resolution 298 introduced on June 3 that expresses the sense of the House of Representatives that there is need for specified federal agencies to coordinate and capitalize on existing programs for epilepsy awareness.

Thank you.

*Notes about the author:*

Michael Bornemann had worked for 12 years as a direct care provider and administrator of services in the developmental disabilities field before he was diagnosed with epilepsy at age 34. He continued to work in this field for 18 years and to drive a car until other medical diagnoses, including cardiovascular disease, severe osteoarthritis, and adult-onset diabetes, exacerbated his seizure disorder requiring him to surrender his driver’s license and to take long-term disability retirement at age 52. Mr. Bornemann has written articles on disability, death and dying, and family relationships that have appeared on the Opinion-Commentary page of the Baltimore Sun. He lives with his wife of 34 years, Angela, and their two boys, Isaac and Robert, in the Hamilton section of northeast Baltimore City, Maryland.

#### 2.1.4. Sabrina D. Cooke, person with epilepsy

Thank you for this opportunity to testify at this workshop. My name is Sabrina Cooke, and I have been living with epilepsy since

the age of 12, when I fell out of the top of a bunk bed and didn’t wake up until minutes later. My mom and sister witnessed my first tonic-clonic seizure on that day. After a stay in the hospital and several tests, I was officially diagnosed with epilepsy. We had a diagnosis but not a clue to what this meant.

Over the years, I have had tonic-clonic, absence, and complex partial seizures. Currently, I experience complex partial seizures approximately 4 times per week and a nocturnal tonic-clonic seizure monthly. I have tried all the medications, experienced most side effects (some worse than others) and spent two separate weeks in the hospital to see if I was a candidate for surgery. I refuse to try a new or experimental medication because I’m just tired of trying something that usually doesn’t work or works only for a brief time. Surgery? Well the decision is a family one that hasn’t been ruled out.

As I got older, living with epilepsy became more difficult. I thought I was well-adjusted. I accepted the seizures, the side effects of medications and somewhat the lack of control. I realized my situation wasn’t going to change and adapted my life accordingly. The difficulties coincided with wonderful events in my life – getting married and having a child. It was no longer “me,” it was now “us”. So let me concentrate on an area that I believe affects me (and I believe my family) most – transportation.

Not being able to drive because of my epilepsy has always been difficult. It seems like such a little thing, but it has been a major factor in making decisions on where we live, where I work, who will employ me, what activities my son can participate in, who goes to the grocery store, etc. At one time, it even affected what job my husband took. He wanted to be there for our transportation needs, but it also put barriers on him.

I qualify for a reduced fare card for the bus, but it limits where I go, the days I can go and the time I can leave and arrive to a destination. Several months ago, I was at risk of losing my employment. Looking for a job became exasperating. I was qualified for many jobs but didn’t pass the ‘needs a driver’s license’ requirement. A person with epilepsy needs to get his/her foot in the door. Then we need to figure out if we should disclose our disability at the interview and if we get hired, should we provide epilepsy education and dispel myths that surround epilepsy. Wow, we have our work cut out for us!

The final issue I would like to leave you thinking about is Sudden Unexplained Death in Epilepsy (SUDEP). Until recently, I was not very educated about SUDEP. In fact, this is not a conversation I have had with my primary care physician or neurologist. I feel it is important to echo the need for more awareness. Another presenter said, “If I had been made aware of SUDEP could I have saved Eric’s life? Possibly, possibly not. But without being told I wasn’t even given the chance. It all starts with awareness.” This statement really touched my heart, and this issue is important not only because I am a person with epilepsy; I am a parent, and should this ever happen to me, I would leave behind loved ones trying to figure out the cause.

Thank you.

#### 2.1.5. Mark Brooks, person with epilepsy

Hi, I’m Mark Brooks, and the first of my two tonic-clonic seizures occurred back in January of 2004, so only about 7 1/2 years ago. I have also sustained another 2 or 3 seizures of a different type, although my weak memory is failing me at this time, and I’m not able to recall the type they are. I, like others, have been able to control my seizures through medication. However, I do have to text a paid case manager twice a day to ensure that my medications are taken.

The two issues I would like to briefly discuss this morning are the manner in which many people with epilepsy view themselves and the genesis of my seizures. Through my relatively brief span of living with epilepsy, I have encountered a large number of individuals who feel very ostracized and excluded from the general public. This emotion can lead to some tragic outcomes. I did get to know one man, approximately my age, who actually took his own life as a result

of this apprehension. He mentioned a number of times, during our monthly epilepsy support groups, his consideration of suicide. He even stated that he had gone to Home Depot and looked into buying the proper type of rope to use to hang himself. He repeatedly had mentioned the fear his two teenage daughters had to be seen with him, lest a seizure should occur. Perhaps it is a bit premature to assume that the primary cause of his suicide was his discomfort with his condition, but it certainly leads one to that conclusion.

Another individual, who I had met, was a young lady who was also facing struggles with epilepsy. I do recall her saying that she “simply wanted someone to go out to eat with or even just to see a movie.” Needless to say, those sentiments are completely unnecessary. What can be done to correct this situation? I don't know. I would feel quite confident, though, in stating that if the public were better aware of the actual diagnosis of the disease and the fact that it is not, in many cases, worthy of more than just a slight adaptation to one's plans, the apprehension would eventually fade away.

The second issue dates back to October of 1982. I was involved in a horrible motor vehicle accident at the age of 19, while I was in college. The primary damage I sustained was traumatic brain injury, or what is now called TBI. Although I did not suffer any signs of epilepsy for a bit over 21 years, TBI did cause the first seizure I had. By the way, that seizure caused me to break both my shoulders, which led to 3 weeks in the hospital, 6 1/2 h of surgery, and 7 months of physical therapy. I had to miss full-time work for well over 7 months.

While you may very well sympathize with my situation, you might also wonder my reason for bringing this issue up. As is well known, we are currently engaged in a great deal of military activity in Afghanistan and Iraq. In light of the technological advancements in weapons, armor, and medicine, the number of soldiers returning with TBI has greatly increased. Each one of those individuals has already made a huge sacrifice for our country, and it is not fair to ask any more of them. Based on my very sketchy knowledge of the situation, a TBI survivor who develops epilepsy takes an enormous step back with each seizure they suffer. It seems extremely counter-productive to take two steps back with each step that a survivor is given.

I thank you very much for your time.

#### 2.1.6. *Mary Macleish, Epilepsy Foundation of Arizona and person with epilepsy*

My name is Mary Macleish. I have epilepsy. I was a volunteer and then the executive director of the Epilepsy Foundation of Arizona for 15 years. So not only do I have personal experience, but many, many years of professional experience with people with epilepsy. When classified by my clinical trajectory, just to tell you a little bit about myself, I am a person whose seizures responded well to medication, but, alas, did not get off the medication. So I've been on medication for over 50 years now. So I've had lots of experience with that.

My thought, before I started hanging around with people like you, I just had this vision of epilepsy. And, it was always the little stool that you use to milk the cow, with three legs. The first leg was seizures. And as I just told you, my seizures responded very well to medication. So that's not really been an issue for me. The second leg is treatment, which for me has always been medication. And for most people with epilepsy, if they're responding well to medication, then the issue is side effects. While I have not had significant side effects 95% of the time, we're not here today to talk about the other 5% in my talk.

Why am I here? It's the third leg, which you all would call psychosocial or health-related quality of life. Me, I just call it my life. And that's the part that for those of us with epilepsy is so much more. I really like to talk about the *epilepsies* because it's really almost intimidating for me to get up here and compare my epilepsy to what C.J. Soeby has experienced, as explained by C.J.'s mother (see Impact of Epilepsy on the Family). To say that we have the same

thing is really humbling for me. I almost want to slink away and say I don't really have that, not that I'm ashamed of that, but it's so much different. So I really, really like the term *the epilepsies*, which I've used for many years when I've given speeches.

And with that, I want to tell you a few things about myself, my personal experiences, and then working with people of the Epilepsy Foundation. By the time I was in high school, everybody knew I had epilepsy, and it was not really a big deal. So that was way back when. But then one day, I decided I wanted a job. There was a mall about three or four blocks away, so I went down. I got on my interview clothes, and I went into a store, and I filled out the application. Now, this was 1972, which I'll get back to in a few minutes, but the application looked more like a new patient intake form. It actually listed a huge long list of medical disorders, and one of them was epilepsy. I was telling everybody I had epilepsy, so I marked it. And, so I took my little application up, handed in it at the window, and the person there right in front of me picks up a red pen and makes circles where I checked I had epilepsy. They did not call me for an interview.

The next day, I went to another store. I saw they had a help wanted sign. I filled out the application, and they did not ask for specifics, but there was a health-related question. And right there, 18 years before the Congress did it, I enacted my own Americans with Disabilities Act. I had two qualifications. One, could I do the job? Two, if I did have a seizure, would somebody else get hurt? If I got hurt, well, couldn't do anything about that. Since then, I have never put epilepsy on the application.

Fast forward a few years, when I was in college getting my degree in education and working in the Registrar's office. One day, I noticed a new form – this was before everything was on computer – we actually had forms and you had to file them! So, the Education Department had a new form that we had to give to new applicants. Now, I had already been accepted into the department, so I didn't have to fill out the form. Well, in looking at the form, what I saw was there was only one question on there that wasn't on all the other forms the department had them fill out, and it was related to health. It was a small college. I knew the student who worked over in the Health Department. I went over and just happened to run into him and said, “What's this new form? You're making us do all this work. We have to file. It's one more thing. Everything is on there.” He said, “No. No. No. We had a student assistant who had a seizure in the classroom when they were doing their student teaching, and we don't want that to ever happen again.”

So, again, it was just I'm a fast learner. What I learned was where I could take a pill to control my seizures, then if I wanted my life, I had to hide it. And that's what a lot of us with epilepsy learned – it has to be the secret.

Fast forward another couple of years. I did have that teaching job. They didn't know I had epilepsy. But I had a co-worker. One day, he was saying that his father, who was an Ob-Gyn from out of state, was visiting him, and he had had a dinner party the night before. His father started talking about how all people with epilepsy, all women with epilepsy, should be sterilized.

And, anyway, these are the kinds of experiences that a lot of us have that lead us to hide the fact that we have epilepsy. I don't know if there's a word for Ob-Gyn phobia, but you can be sure I picked my doctors very carefully later on. And other people do the same. When I started working with people with epilepsy, there were people who would – I knew one who got a post office box in order to have information about epilepsy mailed to him, and it was in another name. People really hide the fact that they have epilepsy.

And, as all of you are talking about doing registries and having people report and do surveys on us, we don't want to be found.

I can't go into the whole history of it, but in 1927, the Supreme Court upheld a lower court's opinion that people with epilepsy could be sterilized. Even 60 years later, when I was looking at having

children myself, there were still doctors out there who were telling people that, and there may be today.

One of the biggest reasons for secrecy, I believe, is employment. I think most of us have a very fine line between personally what we tell our friends, but we know that in order to have a job, which is so important to us, we have to hide the fact that we have epilepsy.

When I do work with families with epilepsy, the one commonality is fear. Everyone with epilepsy, everybody in their family, they all know fear. The fear of when I wake up today, what's going to happen? How are people going to react to it? Is it going to impact my job? Is it going to impact my husband's job? Or if you are the parent, are you going to be losing work? Everybody knows fear. Like I said, for so many of us, the solution to people knowing about it is to keep it a secret. But a side effect of keeping your epilepsy a secret is shame.

And a lot of people are not so much afraid or ashamed of the fact that they have epilepsy, but I think that they are ashamed of the fact that they don't stand up and talk about it. I think that's really important for those of you who are doing surveillance and registries to understand how people with epilepsy think.

There is a lot of confusion and a lot of lack of self-identifying. The terminology used such as seizure, seizure disorder, and epilepsy has something to do with this. In Arizona, we did a lot of work with seniors. We never used the word "epilepsy." So, often, it was in connection with another condition. People who have Alzheimer's or have had a stroke are not going to see themselves as having epilepsy. They may have recurrent seizures, but they see it as part of another condition. I think that really goes along with the whole concept of "the epilepsies" – if you break those out, affected persons may self-identify better.

People with epilepsy never see their seizure, and so they have a hard time reporting what happens. Also, children with epilepsy are not necessarily told that they have epilepsy. I've run into lots of people who had no idea as children that they had epilepsy, and sometimes that was because the family was ashamed of it. And, oftentimes, it was that I think we had years and years and years of people and doctors saying don't tell the children. They'll be afraid of it. So, oftentimes, those of us who grew up with epilepsy weren't told anything about it.

Those of you who are doctors may be very surprised to find this out, but we don't tell you everything. Sometimes, we just decide what we want. We want that medication reduced or increased or something, and what we can tell you, but we don't want to tell you everything because it might embarrass us.

If I lived in a state like California that requires doctors to report persons whose seizures are not fully controlled, am I going to report a breakthrough seizure to my doctor, especially if I maybe can identify why? I have run into people who were basically the doctor – you need the doctor to write the prescription, but you kind of figure out your dose yourself because you know more than that doctor anyway.

The doctors don't necessarily ask the right questions, and people don't necessarily tell their doctors what they should. Often, someone called me at the Epilepsy Foundation with some issue or another, and I would say "Did you ever tell your doctor that?" And they might say "No, never thought to tell the doctor about this rash covering my arms and legs and it's 110 out and I'm wearing long sleeves."

What I really want, getting into opportunities now, is as you look at registries, as you look at surveys, you need to think like marketing people. You need to break down the groups of people with epilepsy. WIIFM is a marketing term for 'what's in it for me.' Why should I as someone going about my life (I may be hiding it at work, maybe not) – why should I sign up for a registry? So you really need to think – why would they tell you?

The one thing I do want to point out is altruism. I do think that people segment their life. These people – my family, my friends – know. I have to keep it a secret at work. There are also a lot of volunteers with the Epilepsy Foundation who really want to make a difference. They want it to be better for other people.

I want to mention intractable seizures. We've talked about that, but I don't think we've necessarily broken down intractable seizures because there are a lot of people, depending on their seizure type, who still hide the fact that they have seizures and can successfully hide it and work and maybe not even get them treated. So, I think even when we talk intractable seizures, these people are probably the most likely to want to be part of your research, but for many of the ones with intractable seizures, if it's a seizure type that they can hide, they will.

One thing I want to point out here is for volunteering, when employment secrecy often is associated with employment. So, I really see some opportunities here as we've got this huge segment of baby boomers about to retire, and I think that for me, it is going to be an interesting point whether that is going to affect their willingness to participate in surveys and registries when they don't have to worry about the paycheck anymore.

I think it's really important when you look and break down the demographics to look at what the law was when the people that you're looking at serving came into consciousness. Like I said, in 1927, they were passing laws so people with epilepsy couldn't get married and for sterilization. I mentioned that I went and filled out that application in 1972. The Rehabilitation Act of 1973 changed all the applications because that affected what questions could be asked of people in businesses receiving federal funds, which is most people. So that changed.

I really see the Americans with Disabilities Act of 1990 as a line in the sand, though it's not a chiseled line to me. It's just a little dotted line. As a result, how people with disabilities were viewed began to change. And it's been changed. They had to go back and amend it because it still had some problems. And people with epilepsy weren't covered among other groups. But I see, in my view of working with people with epilepsy – it's almost where they were in 1990. Were they diagnosed before or after, and how they view themselves is very much aligned with the Americans with Disabilities Act, which reflected the change in the whole country.

Some of the opportunities are working with other organizations, other subpopulations. I want to point out in Arizona we've done a lot of work with Native Americans and Latinos, and we really found that working with the community health representatives was key to not only services, but also data collection. All of the tribes have community health representatives through the Indian Health Services, and I think that would be a wonderful opportunity to pursue.

Here are my recommendations. You have to ensure confidentiality. If you say it, you need to mean it. I mean I really think as much as you can do to have registries and surveys where people's identities aren't going to be compromised. It's really frightening to me to think of having a whole list of people with epilepsy listed someplace. If you've ever been to the Holocaust Museum, before you get to the part about how they started going after Jewish people, the first part talks about how they went after people with epilepsy. So a whole list of people with epilepsy in some database someplace is really frightening to me.

The terminology we've talked about – again, think like a marketing director. Segment your population. If you're going after seniors, it's going to be a whole different thing than if you're going after teenagers. So, I think that is really important.

I just mentioned the community health representatives. I think in going after ethnic racial minorities that that is a wonderful way to do it.

And add seizure disorder and epilepsy questions to other surveillance mechanisms for other comorbidities. I think if you're going after seniors, they're not going to be identifying themselves as having epilepsy; but if you're doing something for the senior population or Alzheimer's or people who have had strokes, they're going to be very willing to fill out maybe some of those, especially everybody I know who has an Alzheimer's parent or grandparent wants to do research because they're terrified, and fear is a great motivator.

Thank you.

### 2.1.7. *John Gambo, person with epilepsy*

Good morning and thank you for the opportunity. I've had epilepsy since I was 10 years old, and over the years, I've been studying the ability to get around for transportation. I live in a part of the country where it's very hard to get light rail or metro or bus service. Fortunately, I've had a great support system, but over the years, it's been difficult to drive around since I can't drive.

I've also been studying on different things that I've been through over the years with seizures and everything, just trying to, it's just been hard to do. Over the years, I've been fortunate to have a great support system also with health care, I've been able to get insurance, but I know for some people, it's difficult to do. And if I didn't have extra people in health care in the industry, or in insurance, I wouldn't be able to get health care as well. So I've been able to look and find different ways to get insurance for myself and I've been able to get around. That's all I have to say.

## 3. Introduction to impact of epilepsy on the family

The testimonies from the following eight family members provide compelling insights into how the nature of epilepsy can disrupt family life. Most testimonies provided a parent's view of life with epilepsy, with some mentioning challenges with friendships and indicating that their children had no friends. Others described the challenges associated with having a sibling, a parent, or a husband living with epilepsy. Although a few describe experiences with health care that were successful and satisfying, most provide a contrasting view that portrayed delays in getting an accurate diagnosis, struggles with treatments that were ineffective, and difficulties in getting services for comorbidities. Many describe a financial burden, arising not only from the cost of treating the epilepsy, but also from services for comorbidities and the need to forgo employment to stay home to care for the person with epilepsy. Other common themes that were expressed included feelings of helplessness and worry, stress in dealing with seizures and comorbidities, and difficulties in finding community services. Embedded in their journeys were also references to families helping other families to alleviate the burden of living with epilepsy.

### 3.1. Impact on the family testimonies

#### 3.1.1. *Lisa Soeby, Hope for Hypothalamic Hamartomas and parent of a child with epilepsy*

First of all, I would like to thank the IOM for this opportunity to tell our story.

For us, the most difficult part of our journey has not been about access to care but being heard and getting to the right specialists for the appropriate treatments.

My husband and I were both active duty military, and we have health care as retired military. We have been able to see doctors – but getting to professionals who would listen, knew anything about my son's disorder, and could treat appropriately has been a huge challenge.

My son CJ was born with a rare tumor – called a hypothalamic hamartoma. My husband and I sensed from birth that something was not right. My son was making strange noises and jerky, random movements 24 h a day. We saw 3 doctors over the period of 3 months who all said he simply had colic and to quit bothering them. Finally, we saw a doctor who agreed to do a magnetic resonance image (MRI) scan. That is when the tumor, roughly the size of a walnut, was discovered. It ended up that my son had been having roughly 100–300 gelastic seizures a day, around the clock, for the first 3 months of his life.

After a biopsy was done and the hamartoma pronounced, we were told that nothing could be done for the seizures that, in fact, medications would not work because the seizures were known to be

unresponsive to antiepilepsy drugs. CJ would develop more debilitating seizures, and they would become even more frequent. He would experience cognitive decline; behavior issues such as rages, anxiety and depression; as well as endocrine disturbances. The recommendation was made to find a good group home for him by the time he turned 5. There was nothing that could be done for our son.

Needless to say, we were not willing to accept that prognosis. We searched medical libraries, sought second opinions, and turned to the Internet for possible answers. We discovered a doctor in Australia who had been working on cadavers for 6 months to find a way to reach these tumors successfully. After consulting surgeons in the US who said surgery was impossible, we went to Australia. CJ was patient number 25 to have the new procedure. Surgery was successful, a portion of the tumor was removed, and CJ became seizure free. When we returned to the US, we were able to convince the doctors at Barrow Neurological Institute (BNI) in Phoenix, AZ to invite the Australian doctor to the US to teach them the surgical approach. BNI has since become the leading center in the US for multidisciplinary care and treatment of hypothalamic hamartomas.

Unfortunately, my son's seizures returned 4 years after his surgery in Australia, and so, he underwent yet another surgery (at age 8), this time at BNI. My son was again seizure free for almost 5 years; however, once again, the seizures have recently returned (age 13), and we are facing possible Gamma Knife Surgery (GKS) in an attempt to remove the last of the tumor.

Surgery is only one of the many issues we are continually facing. My son has extensive short-term memory loss, learning difficulties, low self-esteem, and is at great risk for behavior issues. Once again we are being told he will not live independently and may need to be in a group home. We struggle with the education system to implement an individualized education program (IEP) that meets our son's needs. Neuropsychologists aren't sure where to begin to try to help. The focus is on the fact this is a rare disorder, and no one knows what will work. Instead of focusing on what we don't know, we need to focus on what can be done. Needless to say, he wasn't put in a group home at age 5 because we fought to get him the treatments and services that would prevent that. Yet we still have to fight, 13 years later, to ensure he has the best chance at being a productive member of society and enjoying the highest quality of life possible.

Every day, we worry about who will take care of our son if something were to happen to my husband and me. How will CJ's medical needs be met? How can we possibly provide for him financially in the future? What are his chances of meaningful employment and leading any type of independent life?

As a family, we have struggled in many ways – financially, with me having to stop working outside of the home and emotionally, as the primary caregiver with my husband being away from home half the month with his job as a pilot. Our quality of life is turned upside down with each new challenge as the disorder progresses.

The stigma of epilepsy still looms large. Until it is recognized and individuals are treated with respect, our job as parents and advocates is not done.

#### 3.1.2. *Joan Ashlock, spouse of a person with epilepsy*

We began our family's epilepsy journey in February 2002, when my 58-year-old husband began having what we called 'spells' for a couple of days, then a large cluster of them in one day. He would stare, be unable to respond, then smack his lips, and heave a big sigh in the span of about 20–30 s. We went to our family doctor's office. He was not available, so we saw one of his partners. My husband actually had a 'spell' right in front of the doctor. He performed an electrocardiogram (EKG) and monitored him for stroke. He advised him to go home, take two Tylenol, drink some Gatorade, and rest because he was probably dehydrated.

That night, I was awakened at midnight by my husband having a tonic-clonic seizure. I called the paramedics, and they strapped my

non-communicative but very combative husband to a gurney, and took him to the emergency room at the local hospital where he was soon talking, but didn't know what had happened. They admitted him for four days, performing electrocardiograms (EKGs), EEGs, MRIs, computerized tomography (CT) scans, and blood work, and found nothing abnormal. His driver's license was revoked due to loss of consciousness, and I became the chauffeur. After three months of being seizure-free, he was able to complete an interview and a test drive to regain his license.

Life went on until eight months later, when I again awoke to my husband having a midnight tonic-clonic seizure. Another trip to the emergency room, and the staff neurologist now gave the diagnosis of epilepsy since my husband had had two seizures. The neurologist started him on 200 mg of Dilantin and sent us home. Months went by, and we reported to the neurologist that he was still having the 'spells' in clusters about once a month, which we had now learned were complex partial seizures. The dosages of Dilantin kept increasing over the next two years, up to 500 mg, which made my husband very sleepy and lethargic, but had no effect on the number of his complex partial seizures, which were affecting his short-term memory.

In the meantime, we struggled to find support – there was none in our area. In 2005, we finally found a support group 30 miles away. We were given information, support, and the encouragement to find an epileptologist – a word we'd never heard before. Again, there was none in our area, so we traveled the 30 miles to begin with an epileptologist, who changed his medications to Keppra and Lyrica with an emergency bottle of Ativan. We saw a dramatic decrease in my husband's complex partial seizures, along with a marked quality of life improvement.

In March of 2007, my husband was diagnosed with stage 3, non-Hodgkin's lymphoma. The epileptologist and the oncologist worked together to manage the epilepsy medications and the chemo medications. My husband did have two tonic-clonic seizures while on chemotherapy. Prednisone, one of his drug cocktail medications, caused lack of sleep, which we now know is a seizure trigger. After chemotherapy treatments were completed and my husband was in remission, seizure control was regained in 2008, with Keppra and a change to Zonegran instead of Lyrica, due to weight gain.

In the last year and a half, my husband has had only a few simple partial seizures, where he feels dizzy for a few seconds without the confusion or short-term memory effects of the complex partial or tonic-clonic seizures. The epileptologist has performed two sleep-deprived EEGs, which both showed nothing abnormal. My husband is one of the mystery patients.

We have learned that keeping sleep regular, medication regular, and stress abated, gives my husband the best chance for seizure freedom. He naps for an hour a day – or he gets very irritable and impatient. I walk a fine line between filling in for his short-term memory loss versus being controlling, but we are certainly in a better place than we were 9 years ago. We now work with Epilepsy Support Network of Orange County to repay the knowledge and support that we have received by helping others connect to the proper medical care and resources sooner than we had to experience.

### 3.1.3. *Jeffrey Catania, Children's Institute, Inc. and parent of a child with epilepsy*

On January 16, 2010, our son, Dylan Catania, was born in Santa Monica. It was a full-term pregnancy and all seemed normal until the following day when we observed some nearly imperceptible ticks in his eyes. Within four days, we were at a children's hospital in Los Angeles, and what had begun as an enormously joyous time has become a journey that continues to test our strength and resolve as a family.

My name is Jeffrey Catania, and I am Dylan's very proud, grateful and loving father. Within hours of being at the children's hospital, we met the doctor who would become Dylan's neurologist. An MRI

and video-EEG revealed that Dylan's frequent seizure activity was the result of a very rare condition called hemimegalencephaly, a severe malformation of the cortex on one side of the brain (his right) that is most effectively treated by a hemispherectomy. Now, that is quite a sentence to comprehend all at once, and there is nothing that adequately describes the fear and terror that overcame his mother and me at the moment that the doctor, with great compassion, spoke those words. It is a terrifying helplessness that one feels as a parent knowing that your child's brain is misfiring so badly that if left to continue untreated, it will result in a vastly reduced life expectancy and severely reduced intellectual function. The decision to do the hemispherectomy was not a difficult one. The fear and apprehension of what that decision meant for our son, however, was profound.

During the next two weeks in the neonatal intensive care unit, we worked with a dedicated and highly competent team of nurses and doctors to bring Dylan's epileptic seizures under control. That is also when we met Dylan's neurosurgeon, who instilled in us the hope that our precious infant son may have a chance at living a full life free of epileptic seizures and be left with the ability to learn and grow intellectually.

For the next two months, we cared for Dylan at home, working to bring him up to weight so the life-saving surgery could be performed. We held him 24/7 and recorded and timed each of his more than 1000 seizures. The heavy medications and breakthrough seizures rendered him a shadow of the baby we had once envisioned, but we, as we learned, are a very determined family. The strength we developed is best exemplified by our then 9-year-old daughter, Isabella, who would hold her baby brother and implore him to send his seizures to her.

Our neurologist was but a cell phone call away, and he kept our son alive with his experience and skill as a world-class neurologist until we could put him into the neurosurgeon's skilled and experienced hands for this most radical of brain surgeries: a hemispherectomy.

On April the 9th of 2010, Dylan had one large seizure at the very moment the anesthesiologist took him from our arms. It would be his last. His small body, not even three months old, racked by epileptic seizures, flooded by four strong antiseizure medications was now in the hands of the most skilled pediatric neurosurgeon on the planet. Nine hours later, he handed us back a baby – a simple ordinary baby, free of epileptic seizures. In the last eleven months, Dylan has become that "ordinary" baby. He is a gift, however, of an extraordinary team of medical professionals who have given and continue to give selflessly and skillfully of themselves to care for Dylan.

Today, he sits up by himself, tracks every movement in the room, and is beginning to stand and take steps. He recognizes many people, has an engaging sense of humor and there is even independent confirmation that he says "dada." He has occupational therapy, physical therapy, and infant stimulation five days a week. Our medical insurance has covered nearly all of a bill that may now have exceeded a million dollars.

Our prayers and thanks always come back to the medical community that works just 10 min from our home here in Los Angeles. It is there that we received, by the grace of God, the best care on earth for our young son, an ordinary little boy.

### 3.1.4. *Janna Moore and Tom Weizoerick, parents of a child with epilepsy*

We would like our daughter back. The daughter we have not seen since she was 4 years old. That is when she started epilepsy medication, which quadrupled her seizures due to a wrong diagnosis followed by the wrong medications. How could this happen? We did everything right?

We miss the daughter that was funny, outgoing, bright, fearless, confident, and the leader of mischief for the neighborhood girls. She attended a private school for gifted learners. After her first three epilepsy medications that she should have never been on, she lost most

of her skills, stopped talking and walking, and went from gifted to special education. What other pediatric medical condition robs a child of his/her health, education, and friendships like epilepsy? The downward emotional, neurological, financial, and social spiral begins.

At her first neurological appointment, the pediatric neurologist's notes read "a bright, outgoing, talkative 4-year-old with fire in her eyes." That was the last day she had fire in her eyes because she started epilepsy medication that increased her seizures and harmed her brain. We gave our child medication that increased her seizures because the doctor didn't care enough to watch our video of seizures or read the EEG report which stated "generalized seizures – 3 per second spike and wave."

We saw four pediatric neurologists in that first year. The fourth doctor told us to stop worrying about stopping the seizures because he could not figure out her EEG. He told us to concentrate on her quality of life. She was four, not talking, no longer walking, and could not even smile. We were losing everything. What quality of life did she have, and where was the bottom of this spiral? We did not want to find out, but we did. We now live at the bottom of the spiral looking up.

Soon, after the doctors gave up on our four-year-old, the school district told us they did not know what to do with her. By the time our daughter was 6 years old, we had to hire a special education attorney (\$5,000) and fight a claim by the school district that our daughter was mentally retarded and could not learn due to her constant seizure activity. We then spent \$15,000 on a reading program to prove our daughter could learn. We spent a total of \$40,000 in one year on speech therapy, occupational therapy, cognitive testing, medical diets, etc. It is so painful to do the math for the cost of epilepsy – \$60,000 in one year – to keep her from losing ground while she continues to seize every day. There went our life's savings.

Seizures and epilepsy medications continue to torture our daughter right before our eyes. It is too much for parents to brave. We feel so helpless battling the unknown. We have seen the world's best doctors, and they all say the same thing; the wrong diagnosis and medications have altered our daughter's brain beyond repair or even predictable outcomes. There is no going back to fix these mistakes, only forward into the epilepsy abyss and unknown. How do you plan for an unknown future?

Let's talk about what epilepsy has done to our daughter from her perspective. She is now 16 and has endured 12 years of testing, medications, thousands of seizures, and on top of that, constant teasing at school for being different and having seizures. She will not be getting her driver's license. Epilepsy has robbed our daughter of her childhood, adolescence and is now eyeing her future. She did not get to play after school like the other kids in the neighborhood. She had therapy and tutoring every day. No ballet, soccer, girl scouts or dance lessons. We were going to get to all of that when the seizures stopped. They never stopped. We have not gotten to any of it. Our daughter will tell you the hardest part of epilepsy is the teasing and not having friends. She hates having to be monitored at all times (we don't call it babysitting) but understands someone has to recognize when the absence seizures begin and give her the emergency medication to stop them in order to prevent a tonic/clonic seizure. They will not stop on their own. This happens 2-3 times per week. She wants so badly to be independent like the rest of the teens she sees at high school and around town, but she can never be alone—never.

Academically, we gave up trying to catch up or even getting close to average. We never imagined average would be so far from our reach. She is approximately 3-7 years behind her peers academically and socially. We battle epilepsy every day for common skills that most people take for granted.

As parents, we feel we are doing our part to raise awareness about this horrific condition. As Madison's mom, I quit my job to work for a non-profit that helps families like ours who battle this condition. I

make half of what I was making. My husband works all the overtime he can to compensate for the lost wages, bonuses, and benefits.

Our family and friends have done everything possible to help, but it has become too much for most of them to bear – watching our beautiful daughter's life brutally consumed by the insidious regression of life and hope.

We truly feel like we are serving a life sentence in epilepsy prison. Epilepsy dictates every move and decision we make having to factor in worst case scenarios. We live in constant fear about the next seizure; how long will it last, will the emergency medication work this time, will someone call paramedics, will it damage her brain or kill her?

Please help us. We have no other hope.

October 2012 Addendum: On 7/7/11 Madison saw her 9th epilepsy specialist, a world-class, pediatric epileptologist, who took a very aggressive and comprehensive approach to her treatment. We are elated to report that Madison has had a record 11-month seizure-free period under her care. Hope has returned to our family and it feels great.

### 3.1.5. *Jim Abrahams, Charlie Foundation to Help Cure Pediatric Epilepsy and parent with a child with epilepsy*

Thank you for this opportunity to speak today.

I would first like to briefly address the profound and frequently emotionally crippling effects that epilepsy can have on the siblings of children with epilepsy. In 1994, my eldest son, Joseph, was 7 when his one-year-old brother, Charlie, started having epilepsy. Today, at age 26, Joseph shares the feelings I know are common to other siblings.

"As a young boy, having a brother with epilepsy was something I was incapable of processing in a healthy way. My family and I took a trip to Florida once, and in the midst of my enjoyment and bliss, Charlie, who had been seizure free for a couple months, had a relapse. He rolled his eyes back like a picture on a slot machine and started shaking with a high pitched squeal released from a body so innocent and sweet that it seemed impossible to produce such a faith crushing noise. That sound sent my parents into shock, my sister into tears, and me into a hurricane of resentment, fear, anger, and hatred. Why did he have to have these things at the most inopportune times? Why did everybody drop everything and go attend to him? Why did he ruin happy situations? Why did the room go dead and stale leaving everybody unable to make eye contact with each other? Why did I hate someone I love for having a disease he could not control? I went further and further inside trying to distance myself from others in order to protect myself from further hurt and guilt. I loved him, but I hated the fact that he stole the spotlight. I was afraid he would die, but I disliked that every family conversation focused on his disease. And I didn't want to disturb the already fragile nest, which was my family, by inserting my own issues regarding the situation. I was wracked with confusion, despair, but most of all guilt."

Today I know that epilepsy's emotional trauma to my son Joseph, its physical damage to my son Charlie, and the impact on many others whose lives have been disrupted by the agony of epilepsy, were, and continue to be avoidable and unnecessary.

In 1995, after thousands of seizures, endless drug cocktails, a destructive brain surgery, and irreparable damage to his brain, Charlie's epilepsy was cured by the ketogenic diet – but sadly much later than he deserved. To this day, Charlie has never had another seizure, never taken another antiepileptic drug, and eats regular foods.

The ketogenic diet was developed at the Mayo Clinic in 1921. In every decade since, it has been medically documented to improve over two-thirds of the thousands of children who have had access to it. In 2008, a randomized controlled study was published that corroborated its efficacy; and in that same year, international medical consensus guidelines were published in *Epilepsia* that concluded, among other things, "the ketogenic diet should be strongly considered after the failure of 2 or 3 medications regardless of age or gender." Yet

today, despite the scientific repudiation of virtually all the excuses for ignoring it, the ketogenic diet largely continues to fulfill the neurology community's self-fulfilling prophecy as "a treatment of last resort." The collateral damage over the decades is incalculable. What made Charlie's story unusual was not that the ketogenic diet cured his epilepsy, but that he got to the diet at all.

So, I request that you keep in mind that for a large percentage of the epilepsy population, health policy is the issue, and that policy needs to focus on existing cure and prevention rather than on damage control. Much of epilepsy's destruction is avoidable and unnecessary; and the safest, least expensive, most effective treatment for most children with difficult-to-control epilepsy needs to be spotlighted, encouraged and moved to the head of the list of treatment options.

### 3.1.6. Carmita Vaughan, daughter of a mother with epilepsy

It is my pleasure and honor to provide public testimony today. My reason for standing before you is because I have personally witnessed the challenges and devastation that epilepsy can cause for those impacted.

My introduction to epilepsy came in the form of a shocking phone call when I was 12 years old. My mother, who had suffered a stroke at the age of 29, had begun to have seizures. In the coming weeks, she was diagnosed with epilepsy, and our lives were never the same. In light of my mother's stroke and resulting ill health, I had already grown accustomed to being the only child of a disabled parent and all that it entailed, yet I was ill-equipped to deal with the uncertainty and disruption that epilepsy would cause. My parents had divorced years earlier, which left my mom and me alone to deal with this new chapter in our lives.

As an adolescent, I struggled with being my mother's primary caretaker when she was in the greatest need while also dealing with the emotional trauma of being thrust into that role. I vacillated between fear and anger, grief and bitterness, self-sacrifice and resentment. These emotions are often conveyed by parents of children with epilepsy, but I'm here to tell you that those feelings are no less intense for the children of those who suffer. Imagine being the one immediately responsible for a patient's care – and now imagine shouldering that burden as a 12- or 13-year-old.

Our struggle was amplified by a dire financial situation and lack of specialist treatment because of it. My mother's only source of income was disability payments and occasional private tutoring assignments. With an annual take-home amount of less than 10 K per year, no transportation and inconsistent living conditions, including one bout of homelessness, it was often difficult to advocate for adequate treatment or even understand that we should. While we were never referred to an epilepsy center (nor did we even know they existed), doctors were finally able to identify a "cocktail" which kept my mother's seizures at bay after a series of heart-breaking attempts at failed medications. Unfortunately, that cocktail took another toll on my mother – severe depression, constant weight fluctuations, and erratic behavior. However, we regarded these side effects as a welcome reprieve and a small price to pay for seizure freedom. We were told that my mother would continue to live well as long as she maintained her regimen, and she did live relatively well, until her untimely death just after her 53rd birthday. After enjoying years of seizure freedom and with NO warning, my mother suffered two severe tonic-clonic seizures and never recovered. After weeks of battling for her life in an intensive care unit, she ultimately passed away, which was just after her 53rd birthday and 11 years after her epilepsy diagnosis. I was just shy of 24 years old.

I share this story with you not to elicit sympathy but to put a real face to the potentially devastating effects of epilepsy. My sense of urgency has nothing to do with the organization I represent, but EVERYTHING to do with the mother that I was forced to bury and whom I honor every day. I am a living witness that pumping

medication after medication into patients is not and cannot be the solution. The only answer is a cure. We, in this community, must double down and commit the resources necessary to unlock the keys to a cure to give hope to the families who wrestle with epilepsy every day.

Our commitment must be "No seizures .... No side effects .... No exceptions!" Anything less and we're doing a disservice to the millions of patients and families whose faith is in us as stewards of this movement.

### 3.1.7. Tracy Dixon-Salazar, University of California, San Diego, Howard Hughes Medical Institute and mother of a child with epilepsy

I'm Tracy Dixon-Salazar, an epilepsy researcher. But today I will speak to you as a mother.

Our daughter Savannah was healthy and typically developing until age 2. Our introduction to epilepsy came when we were abruptly awakened to the sound of Savannah shaking and gagging. We didn't know she was seizing. We thought she was choking. Doctors called her seizures attacks and spells but never seizures, and we were repeatedly assured she would "outgrow them." Savannah is now 17 and seizes daily. She is intellectually disabled from the seizures and will never be independent. Here is a snapshot of 15 years of epilepsy from a surveillance standpoint.

#### Medical:

- Seizures to date – 27,949. Savannah has yet to outgrow them.
- Years before diagnosis – 3
- Neurologists we saw before diagnosis – 7
- Epilepsy treatments tried to date – 26
- Treatments that have stopped her seizures – 0
- Cause of her epilepsy – unknown

#### Financial:

- Monthly cost of Savannah's current 5-drug regimen – \$1640 (excluding Diastat)
- Times she needed emergency rectal medication (Diastat) to stop her seizures last month – 7
- Cost of one Diastat – \$183 ( $\$183 \times 7 = \$1281$  in one month)
- Epilepsy-related hospitalizations (including 3 surgeries) – 11
- Cost of Savannah's last hospital stay – \$53,475

#### Life:

- Days of school she's missed so far this year – 43 (out of 121 days)
- Years she's had an individualized education program (IEP) – 12
- Years we've had to fiercely advocate for an appropriate education under that IEP – 12
- Time in a day that Savannah can be left unattended – 0. This includes showering and toileting.

#### Family:

- Times I was late to work last week because of seizures – 2. This is common.
- Times my husband and I have been on the brink of divorce because of epilepsy – 3
- Times I've been clinically depressed since her diagnosis and needed treatment – 5

#### And then there are the factors we can't quantify:

- Times we've had to cancel an outing because of seizures – ???
- Years Savannah will live before the seizures kill her – ???

As a family living these statistics, what do we need? In the early years, we needed:

- To be told she had epilepsy. Tiptoeing around the diagnosis robbed us of precious time.

- We needed the facts – like the fact that seizures in ~33% of people with epilepsy don't respond to treatment. We lost a great deal of trust in doctors because of their choice to censor.
- We needed to know that seizures could manifest in ways other than as tonic-clonic type. We unknowingly stood by as Savannah had subtle seizures for hours in the early years.
- We needed support! Grief counseling would have shown me I wasn't losing my sanity in those early years – I was grieving. Introductions to other families would have helped us feel like we weren't alone. And a general public awareness of epilepsy would have been useful. The last thing you need to see when your child is seizing in the middle of the soccer field are parents shielding their child as if your child is contagious or offensive.

*What do we need today?*

- We need to know the cause of her epilepsy. Why do we treat the seizures and not the cause??? I've never understood this treatment dogma.
- We need to bring down her medical costs. We're drowning.
- We need doctors and teachers that won't give up.
- And we need help. And I'm not just Savannah's mother but I've also had to become her doctor, pharmacist, EMT, lawyer, teacher and advocate. No one person or family can do all of this.

Please. Please. Help.  
Thank you.

*3.1.8. Lori Towles, parent of a child with epilepsy*

My name is Lori Towles and I am a seizure mom.

My son Max was diagnosed with complex partial seizures 6 years ago at the age of 10. Between age 10 and 16, Max had on average 2 seizures a week. He just turned 17 last month.

Eight months ago, he had brain surgery to remove a lesion (called a type 1-cortical dysplasia).

Thank you to the neurosurgeon and the wonderful medical team.

Since the surgery, he has not had a seizure. He continues to take Keppra and Lamictal.

I have some numbers to share with you...

\$3000	The amount I've paid to an advocate to secure services for Max at his current high school because of the ignorance of the school district regarding epilepsy and students with medical disabilities
19	Number of anti-seizure pills Max has taken per day
10	Medical and service providers that make up Max's support team
9	Antiseizure meds he's tried
6:30	Pill time – morning and night – it's set as an alarm on everyone's cell phone in the house
5	Number of caring and gifted teachers that come to the house to teach Math, English, and Science over the last three years
4	Number of neurologists he sees regularly
3	Number of times Max has received the Anointing of the Sick
2	Number of additional diagnoses: ADD at age 7, and anxiety at age 10 due to the seizures
1	Year of homeschooling while we tried to find a working combination of meds to control the seizures
0	Number of times he has said, "why me?"
Countless	Number of friends he has now
	Hours lost waiting in line at the pharmacy, driving to doctor's appointments, and documenting his seizure activity
	Days missed from school due to seizures
	Insulting and rude remarks made by classmates (ignorant and informed) because of his twitching, mumbling, seizing, and falling asleep in class
	Meetings, e-mails and phone calls to his teachers and school support personnel to explain what to expect with his medical condition
	Days missed from my work to take him to doctor appointments, have meetings at the school, and just be there for him
	Minutes where my daughter and I watch Max slip away into another place while his brain seizes
	Prayers from family and friends, co-workers and neighbors

I implore you to use your influence, expertise and any other resources at your disposal to fund programs for education, research, and family support. Thank you for your efforts and consideration.

**4. Introduction to perceptions on sudden unexpected death in epilepsy**

Among people with epilepsy, the risk of dying suddenly and unexpectedly is 20 times greater than in the general population [3]. SUDEP is a cause of death that occurs suddenly and unexpectedly in an otherwise healthy person with epilepsy where autopsy provides no other explanation [4]. Common to the four testimonies shared in this section is the fact that the treating physician never mentioned SUDEP as a possible outcome before the death occurred. Since the deaths of their loved ones, these families have met many similar families who had not been informed about the possibility of SUDEP either. These families were all deeply affected by not having been told, because they lacked the opportunity to understand which SUDEP risk factors might be moderated. Each individual harbors the feeling that if he/she had known about the risk for SUDEP the death might have been prevented. One father discusses the similarities between SUDEP and sudden infant death (SIDS), highlighting the effective publicity campaigns about SIDS prevention that are currently absent for SUDEP. Together these testimonies are an entreaty to health professionals who work with people who have epilepsy and their families to discuss SUDEP.

*4.1. Perceptions on sudden unexpected death in epilepsy testimonies*

*4.1.1. Steve Wulchin, parent of a child with epilepsy*

At 5 am, on March 28, 2006, my wife and I were awakened to the sound of a loud crash. We ran toward the sound into our 15-year-old son's room to find him on the floor, wedged between his bed and the nightstand, his lips blue and his teeth clenched. He was having a seizure. We called the ambulance and went to the ER. After a couple of hours, he was ready to go home, with many more questions than answers.

This was new to us, and we had no idea what we were in for. In the visits to the doctor that followed, we were told it might be a one-time event. His second seizure occurred 3 weeks later, then another one 3 days after that. Clearly this was not a one-time event.

We plunged into this, taking him to different doctors, questioning, challenging, and doing our own research. We took him to the Mayo Clinic for a battery of tests. We learned that there are 4 underlying causes of seizures:

- 1) Drug and alcohol abuse
- 2) Tumors
- 3) Trauma
- 4) I don't know

Eric fell into the fourth category.

We were told that Eric could lead a long and normal life with epilepsy, that there were only 2 conditions to be concerned about:

1. Having a seizure that would lead to a dangerous situation (such as while driving, swimming, or rock climbing)
2. Status epilepticus

We learned about the harsh realities of epilepsy – there's no test to show that you have it and no test to show that you're cured. You take medications and hope the seizures go away. We learned to live with the very discomforting reality that being cured meant an absence of seizures and that at any moment another seizure could come along and reset the clock. Needless to say, none of this was in any way, shape, or form satisfying. Instead of having a test come back negative, our only hope was for our son to go months without having a seizure and just hope that we're not getting lulled into a false sense of security.

The possibility of SUDEP was never brought up.

Over time, the doctors found the right combination of medications that seemed to work with Eric. After about a year and a half, the seizures appeared to be under control, for the most part they were infrequent and mild. For Eric, they always happened when he was sleeping, and they always woke us up. It was a return to the days of having an infant in the house. You go to sleep knowing that there's another dimension, a quick-wake mode in play that will protect you and your loved ones, where you can jump to action at the first sign of trouble. No different than if a burglar breaks the front door down.

On July 9, 2009, I awoke next to my wife, it was her birthday. I went to make coffee, stopping at Eric's room to check on him as I did every morning. His door was half-closed, as he got older he wanted more privacy. I opened the door and walked into the room. Eric was lying half on his bed, half on the floor. The dog was next to him. It reminded me of the video clips from America's Funniest Videos. As I walked in, the dog looked up at me and smiled (yes, he smiled. This is one of his traits). I walked over to Eric to get him back into bed and noticed something was wrong. I screamed my wife's name, nothing else, just her name. But that's all it took, she called 911 and I started CPR.

Eric had died in the middle of the night, on his mother's and brother's birthday. Our 6'5", big strapping seemingly healthy son, who hadn't had a seizure in 6 months, who said good night to us at midnight, had died in his sleep just a few hours later.

In the ensuing days and weeks, I tried to cope with the loss of my son, to be there for his brother and mother, to make some sense of it all. I worked with the coroner to find the cause of death. Toxicology reports came back with nothing out of the ordinary, medications were in the therapeutic range. I read an article about epilepsy when it hit me: Eric died from SUDEP. This information had been available since I had become involved in epilepsy, but it had never registered with me. I had done a lot of research and seen it in a number of places, but no doctor had ever brought it up. So, even though I consider myself to be well-educated and active in these issues, without hearing it from a credible source, a trusted source of authority like a doctor, it had no impact.

During this time, I kept in touch with the coroner to get regular updates on his progress. Early on (way before the funeral), we were asked if they could take a tissue sample from Eric. In this case, a tissue sample is a euphemism for removing my son's brain. We agreed – anything we could do to try to understand, to hopefully one day make enough progress that other families won't have to go through this. And then, 6 months later, I found out that the genetic tests required samples to be frozen, but Eric's were in formalin. Clearly a consistent and standard practice is lacking.

We worked through possible causes of death, and as the potential causes got eliminated one by one, I told the coroner that unless he could prove otherwise, I wanted Eric's death to be classified as SUDEP. *As a father, I had to tell the coroner what my son's cause of death was.* His response made it very clear that he was not familiar with SUDEP, didn't know what the term meant. When I explained what it was, he said "Oh, we've had 3 or 4 similar cases in Boulder County in the past year". The clear implication is that SUDEP is vastly underreported.

I expressed my frustration about the lack of visibility of SUDEP to my primary physician. He is an emergency room (ER) doctor and was also involved in Eric's treatment and prides himself on staying abreast of all of the latest developments in medicine. He replied that he didn't know about SUDEP until I had brought it to his attention.

In an attempt to standardize the definition of SUDEP, the US Food and Drug Administration (FDA) and Burroughs-Wellcome developed criteria for SUDEP. These criteria are now used in most SUDEP studies. However, this standardization was developed in 1993 [5].

So, here it is 18 years later. Why are so many people, including doctors, still unaware of SUDEP?

I found it interesting and frustrating to compare SUDEP with sudden death in infancy syndrome (SIDS) – they have similar characteristics, strike seemingly healthy people, leave no evidence after the fact, and there is nothing that can be done to prevent them. Yet SIDS is widely known among the general population, while 90% of doctors, including many neurologists, have never heard of SUDEP. And as shown below, SUDEP deaths are at least comparable, if not significantly higher.

SIDS is widely understood by the population as a result of the Back-To-Sleep campaign launched in 1994. The essence of the campaign is simple: it's safer for infants to sleep on their backs. According to NIH, since the campaign started, the percentage of infants placed on their backs to sleep has increased dramatically, and the overall SIDS rates have declined by more than 50%. According to the Centers for Disease Control and Prevention (CDC), approximately 2250 infants die annually from SIDS in the US.

So if we can warn all parents about SIDS – a condition that we don't understand, don't know who is at risk, don't know what causes it – why can't we do this with SUDEP? By comparison, it is estimated that 3 million people in the US have been diagnosed with epilepsy. Of this number, an estimated 25,000–50,000 will die annually of seizures and related causes. It is estimated that SUDEP accounts for 8–17% of these deaths, resulting in 2000 to 8500 annual deaths from SUDEP [5]. Given the lack of awareness surrounding SUDEP, these estimates are undoubtedly low.

If I had been made aware of SUDEP, could I have saved Eric's life? Possibly, possibly not. But without being told I wasn't even given the chance. It all starts with awareness.

My family is committed to generating awareness for SUDEP. Last month, in commemoration of Eric's 21st birthday, an awareness campaign was announced through SUDEP Aware. The current policy of "Don't Ask, Don't Tell" that the medical community appears to be employing is unacceptable. People have a right to know that epilepsy is potentially much more dangerous than they have been led to believe. They need to understand that there are risks with epilepsy, risks that they cannot control, but risks that they might be able to influence, even if it's over time.

Epilepsy in general and SUDEP in particular need a multi-pronged approach – there is no simple solution. Massive amounts of government spending won't provide a solution. Big pharmaceutical programs won't provide the solution. The solution, in my opinion, is likely to come from a combination of government-sponsored programs, big pharmaceutical companies, entrepreneurs in search of seed capital, and passionate individuals dedicated to a cause. It's possibly going to be the tinkerer working in his garage to find a solution because his daughter or son has epilepsy, and now he knows how dangerous it is, and he's going to figure it out – that's who's going to find a cure. Or it's the parent who has lost a child to SUDEP that is going to make a difference by setting up a registry or an awareness campaign that will make a difference. But all of this points to the need for more awareness.

SUDEP affects many, many more people and families than we know. It's time to get our best and brightest focused on this so we can solve the problem. But until they know not only what the problem is, but more importantly that there is a problem, they don't stand a chance. And people with epilepsy will continue to die needlessly.

*What we need:*

- Open and honest discussion about SUDEP from credible sources – neurologists and epileptologists
- Education about SUDEP to all members of the medical community, neurologists, general practitioners, cardiologists, and coroners
- Ways to recognize potential SUDEP cases by coroners and standardized coding for deaths from SUDEP
- Electrocardiograms (EKGs) as a standard course of action for all epilepsy patients. They are becoming required for all athletes in a number of places – the European Society of Cardiology and the

International Olympic Committee recommend EKG screening for all competitive athletes (New York Times, March 2, 2010). This for sudden cardiac death, which kills 90 people in the US annually — 90 people a year, *compared to up to 8500 deaths from SUDEP*. Recent research has uncovered the first gene that links epilepsy, cardiac arrhythmias, and sudden death and is recommending a screening EKG for all people with epilepsy. Drugs known as beta blockers can be given to prevent these arrhythmias and sudden death. The EKG should be added to the standard medical workup of new-onset seizures, to ensure that a silent abnormality in the cardiac rhythm is not tragically overlooked.\*

- The need for more basic scientific and clinical research into the causes and prevention of SUDEP
- Genetic testing to explore links with conditions such as long QT syndrome
- A national registry of epilepsy patients and SUDEP victims
- Standard practices for handling of tissue samples in the event of death

It is a long list, but we don't need to be overwhelmed by its size or magnitude. We can start with the simple concept of making people aware. Epilepsy patients and their families have the need to know and deserve nothing less.

\*This is of particular interest to me personally. I was hospitalized briefly in 2008 with atrial fibrillation, so I can't help but think of the possibility of a genetic link.

#### 4.1.2. Mylissa Daniels, Danny Did Foundation and parent of a child with epilepsy

My son Dallas, at the age of 5, passed away on January the 12th of this year from Sudden Unexplained Death in Epilepsy, known as SUDEP. The medical community has a responsibility to properly inform patients and parents of SUDEP risk factors. There is recent research that shows existing risk factors and preventive resources. Physicians are not discussing SUDEP or possible resources with patients.

I and many other parents had never even heard of SUDEP until we lost our child. I am speaking on behalf of thousands of parents in the US. There are 50,000 seizure-related deaths each year, and we aren't discussing this. I read in one recent medical report that physicians don't want to scare parents, so they don't discuss SUDEP.

Well, you never scared me and my husband, but we are now seriously grieving parents that feel we could have prevented our son's death by being properly informed of SUDEP and allowing us to decide on resources that are available to give our son a better chance to survive. We were never informed of our son's risk factors for SUDEP.

There are several strong supportive resources that 'are' available and need to be known by patients and parents, in order for all parents to decide on their preventive approach.

Do physicians not explain the risk factors of a child that has cancer? Do they not explain the risk factors to a parent of a child with diabetes? The risk factors may not be always controlled, but is it only fair to tell parents the risks that are involved? It is a medical professional's responsibility.

I am now supporting The Danny Did Foundation that was created just over a year ago from the parents of Danny, who passed away from SUDEP too. The Danny Did Foundation is now the first foundation to support the Food and Drug Administration (FDA) research of the Emfit monitors that can potentially prevent SUDEP. One of the Foundation's missions is to educate the community along with collaborating with the medical professionals in educating families of epilepsy awareness. The medical community has a responsibility to inform parents not only of SUDEP risk factors but to create informative handouts on SUDEP, as well as give financial support to prevent deaths from epilepsy.

I personally contacted the Epilepsy Foundation and received numerous free parent resources to educate families in all aspects of

epilepsy. I now am putting together parent packets to get in the hands of parents whose child has epilepsy. The medical community needs to join this journey with The Danny Did Foundation in Preventing SUDEP and properly inform families of all aspects of epilepsy.

#### 4.1.3. Mark J. Stevenson, parent of a child with epilepsy

Good morning. Thank you for the opportunity to submit public testimony to the committee. I am submitting testimony on behalf of my son, Tyler Joseph Stevenson, who passed away on January 23, 2011 from a seizure in his sleep at the young age of 20. A sophomore at the University of Colorado in Boulder, he most likely passed away in his sleep on Friday night/Saturday morning and lay in his bed face down for almost 48 h in his college dorm room, alone. The stench of his decomposing body in the hallway alerted residents that something was wrong, and they called campus police who found him.

We spoke to Tyler Friday night via text messages and wished him good night and told him that we loved him. We tried contacting him Saturday on his cell phone, but there was no answer. It was not unusual for him to be out and about ice skating, studying or enjoying the beautiful outdoors in Boulder. Besides his epilepsy, he was very healthy. On Sunday, January 23rd, I took a late night flight from Denver to Washington, DC to attend and speak at the 2011 Military Health System Conference at the Gaylord Hotel and Conference Center. At 1:30 am, my wife called me crying hysterically and barely able to talk. She said "Tyler" in between breaths, and I immediately knew what was next. She fell to the floor, and the police officers who were at the house gave me the details. I was told to call the Boulder County Coroner's office. I asked the police officers to stay with my wife until I called her parents to come and stay with her until I got home. I called the coroner's office and spoke to the investigator who gave me the details. Tyler's room was clean and half of his seizure medications were still in the bottle. That was a good sign to me that he didn't take his own life, and that he was taking his medications as directed. He was sleeping in his street clothes and face down in bed. I was asked about his medical history and gave her the pediatric neurologist's name in Denver who treated Tyler for the past 7 1/2 years. I was told the autopsy would be performed at 8:00 am that morning. I then made reservations to fly back to Denver on the first flight out. For the next four hours, I couldn't sleep. No parent thinks about having to make funeral arrangements including a funeral home and cemetery for their children. I searched websites for funeral homes and cemeteries.

I took the longest flight of my life back to Denver. My wife and her sister met me at the airport. I was told to call the coroner's office when I landed, which I did. The investigator said that they confirmed the body was that of Tyler's. His brain showed signs of the surgical procedure in September 2008 to remove parts of his left temporal lobe to "stop his seizures." The investigator said that he most likely died of a seizure, but they would have to send out toxicology tests which would take four to six weeks to get results, thus no death certificate until that time. I asked if I could come to Boulder to see the body. I was told 'no' by the investigator. She said that his body was badly decomposed, and that it wasn't a good idea. She asked if we had funeral arrangements and/or arrangements to pick up the body, which I did not.

I drove home and called a funeral home in our town. We met with the funeral director for two hours making arrangements. We picked out a casket in Tyler's favorite color of green, flower arrangements, service arrangements, etc. I served in the military for 25 years before retiring in 2008. Tyler was a Navy brat who was born in Oakland, CA and moved with us to Pearl Harbor, HI, Washington, DC, Monterey, CA, Washington, DC, Colorado Springs, CO, Oak Harbor, WA, and finally Denver, CO. We were relieved to find out that Tyler could be buried at Fort Logan National Cemetery in Denver due to his young age and my veteran status. The funeral director was going to call the coroner and arrange to pick up the body. I told him that the

investigator said the body was badly decomposed and that she didn't want us seeing him. The funeral home director said that "he was good," that he worked on John Denver after he died and that he could make Tyler presentable. On the next day, the funeral director picked up the body, and I went over to the funeral home. I asked to see the body, and the director said 'no.' He said that there were varying stages of decomposition and that Tyler's body was in the last stage. He said that his body was black and green and that it was swollen three times its size. He further said that you could not recognize him as Caucasian, that the only part of his body recognizable was his right hand, which was under his body when he died.

My wife and I were allowed to see and touch his right hand the next day. He was buried in a body bag because his clothes wouldn't fit him. The stench of decomposing body was evident with the open casket. We had a closed casket visitation.

We buried him on January 31, 2011. We watched his casket get lowered to the ground. We will never see him again.

It was Sudden Unexpected/Unexplained Death in Epilepsy or SUDEP as it is known, and as my wife and I have come to know all too well in the days and months following his death. The more research we do and the interactions with families who have lost loved ones to SUDEP all share that we/they were NEVER advised that their loved one could die from epilepsy or a seizure. I knew in my previous research that people with epilepsy do not normally live as long as others, but did not think that Tyler would die so young.

Tyler had a febrile seizure at 19 months old. As brand new parents, we put him in a heated waterbed and wrapped him in a blanket. He had a 105-degree temperature. My wife found him on the bed and brought him downstairs seizing. We called 911 and that would be Tyler's first ambulance ride and first emergency room visit of dozens in the years to come. We were told by the ER doctor that febrile seizures are not uncommon and that many who have these types of seizures never have another seizure again. 10 1/2 years later while I was working in the Pentagon, my wife called me. In broken speech, I heard Tyler turned blue, passed out on the floor, and ambulance. I met Tyler at the hospital ER. They did a CT and said that he most likely suffered a seizure. I got him into a pediatric neurology unit at another medical center later that week. They did an EEG, which was normal. We were told that at his age, 12, he would most likely grow out of them. We were also advised to keep an eye on him and if there were any more seizures to come back. During this first visit, the neurologist also mentioned surgery. We were taken back. Two seizures and we're talking surgery? Two weeks later while driving to Cape Hatteras for vacation, Tyler had a tonic-clonic seizure in the back seat of the car. Tonic-clonic and partial complex, words we also would begin to know too well. I pulled over and that was the first seizure we observed. Scared to death, I called the pediatric neurologist's office from the side of the road. We were instructed to take Tyler to the ER. Tyler was prescribed Tegretol. Tyler had multiple seizures every day after the episode in the car. Ambulance rides, ERs, EEGs, MRIs, CT scans, and medication changes were the norm. Tyler's appendix ruptured later that year, which required surgery. While recovering in the hospital, he had more frequent seizures.

Two years later, we were getting ready to move to Colorado. We saw a neurosurgeon who looked at Tyler's MRI. She pointed out a "ganglioglioma" in his left temporal lobe, most likely the origin of his seizures. We also saw another neurologist at a different medical center for a second opinion and took Tyler's MRI films. The second neurologist said that "there is no ganglioglioma in these films" and that "Tyler was fine, he'll probably grow out of them." We left confused.

When we arrived in Colorado, we made an appointment with a pediatric neurologist/epileptologist in Denver who came with terrific credentials (Harvard, Mayo Clinic, etc.). We took the MRI films and copies of Tyler's medical records. After looking at the MRI films, the doctor said that he could see the ganglioglioma or "lesion" clear

as day. He said that he was going to call another hospital and report the neurologist who said that nothing was wrong with Tyler. For the next two years, Tyler did not have any seizures. We followed up with the neurologist every six months. During one visit, the neurologist showed signs of disbelief that Tyler ever had epilepsy. On a subsequent visit, the neurologist was more energized and said that he recently attended an epilepsy conference in Boston. He said that a presenter talked about temporal lobe epilepsy and dormant stages. He said that Tyler was probably in a dormant stage.

In 2005, we transferred to Oak Harbor, Washington. Tyler started having seizures again. We had him seen by a neurologist in Washington. Medication changes, more seizures, MRIs, CT scans, etc. The hospital was almost three hours away and Tyler's seizures continued more frequently. I asked for and was granted a humanitarian reassignment back to Colorado after eight months in Oak Harbor to take care of Tyler's epilepsy. We returned to the neurologist's care in Denver. The discussion of surgery began and continued. Medications included Keppra, Depakote, and carbamazepine. Tyler went to Detroit for a positron emission tomography (PET) scan. The side effects from the medications were disheartening to Tyler — memory and cognitive issues. In late July 2008, the neurologist referred Tyler to the neurosurgeon. Surgery work-up was performed (MRI, WADA, neuropsychological exam, etc.). We were told that after the surgery "Tyler would never have seizures again." One week before the surgery, the doctor prescribed Lamictal to ensure that Tyler would not have a seizure leading up to the surgery. Tyler developed Stevens–Johnson syndrome from the Lamictal, which was stopped immediately.

On September 26th, Tyler had most of his left hippocampus removed. The recovery went well. We were hopeful. On December 31, 2008, Tyler had a seizure while standing up in our kitchen. We called 911 and another ambulance ride to the emergency room. Depressing. Tyler's medication was changed to Topamax.

Tyler graduated from high school in May 2008. He applied to the University of Colorado and Colorado State University. He received his acceptance from Colorado State University and while we were touring the University of Colorado, Boulder, we visited the admissions office where we found out Tyler was accepted to the University. Tyler was so happy. We, too, were happy; especially since the University of Colorado, Boulder was only 53 miles from our house compared to Colorado State, which was 93 miles away. We had thought that if anything happened to Tyler, we could drive to Boulder a lot faster. Due to the pending surgery, we agreed to have Tyler delay starting college for one year.

Tyler was very proud, and we were very proud of him. My wife said that he was destined for great things; maybe he would become a doctor and find a cure for epilepsy.

Tyler started college in the fall of 2009. He had a roommate. We were reluctant to see him go and constantly worried about him. We visited him just about every weekend. One night, I received a call from his roommate stating that Tyler had a seizure. The roommate called 911, and Tyler was in the local ER. We drove up to Boulder and when he stabilized, I took Tyler back to his dorm room. I instructed the roommate in what to do the next time Tyler had a seizure — seizure positioning, make sure his airway was not obstructed, postictal stage, etc. Tyler had three more seizures during his first year in school. The roommate would call us and let us know. Tyler's grades were suffering from the medication side effects. He was having problems concentrating, remembering things for tests, etc. The neurologist switched him to zonisimide. Tyler made it through his first year. During the start of his second year, he became president of the Gamer's Club at the University of Colorado, Boulder. Tyler enjoyed video games and wanted to write video games in the future. He hosted and interviewed with Microsoft for a summer internship program after his sophomore year, which would have been now. One day, while at work, I received a call from my wife stating that Tyler passed out on the ice rink at school. The rink manager

said that he just fell down. No seizure noted. I drove up to the ER, and the doctor said that everything was normal. The doctor mentioned that we should get his heart looked at just in case and made a referral. Tyler saw a cardiologist and was issued a heart monitor to wear. The results of the tests were normal.

Tyler came home for Christmas break in the middle of December 2010. Again, he was struggling in school. In our conversations with Tyler, we said that if he wanted to take a break from school for a while he could and that there was no pressure for him to finish at University of Colorado, Boulder. Tyler thought about it and wanted to return. He did have one request; he did not want a roommate. The roommate and he did not get along, and I don't believe the roommate was comfortable with Tyler's seizures. We reluctantly agreed. During Christmas break, Tyler had one of the worst seizures we have ever seen. We had already scheduled a follow-up with his neurologist, and Tyler was seen on December 29th. While in the waiting area, my wife was reading a Neurology magazine, and it had an article about John Travolta's son, Eric Wulchin's death and SUDEP. My wife gasped. We were immediately scared and debated whether to tell Tyler, or bring it up to the doctor. Without bringing up SUDEP, the neurologist (for the first time ever) discussed seizure risks with Tyler, including not to sleep on his stomach, and not to swim alone. I knew why he brought it up.

We were afraid to tell Tyler because we did not want to scare him. Then, 24 days later, SUDEP takes his beautiful life away from us.

We are a devastated family. Tears every day. We are still in shock, and we get energized one minute and then down in the dumps the next. Valentine's Day, Mother's Day, his birthday on May 21st, University of Colorado graduation on the news, all bring bad days especially just five months after his death. As a family, we skied every weekend. I would drive up to Boulder to get Tyler and take him back to school on the way home. After Tyler's death, we lost all interest in skiing, and when we did go up to the mountains, we would ski a few runs and go home. We have a younger son (17 years) who took this very hard. His schoolwork and grades plummeted after January, so we worked with his teachers to get him through 11th grade. It just feels like a big piece of us was taken away. His room is untouched. I go in there and just sit. It smells like Tyler.

I was looking for other opinions/options after his last neurology appointment in December. The guilt, the anger and the constant thoughts of what we should have done differently to save his life go through our heads every day. I wish it was me in that cemetery and that Tyler could have another 40–50 years to experience life, get married, have kids, and enjoy the things to come. Tyler was starting to get more positive about school and life just before he died. Tyler was patient, loving, and gentle, very smart and had lots of potential. Now, we visit the cemetery every weekend and take flowers.

As we look back, Tyler was seen by neurologists at many hospitals in many cities. We were NEVER told that Tyler could die from a seizure. In the literature, there is much debate on whether providers should bring up the risk of SUDEP with patients and families since the risk of SUDEP is low. The supporters say 'yes' and compare it to SIDS. The supporters also say that it should be presented in a non-alarming manner, that the risk is low and there are steps to decrease the risk. The skeptics say 'no' and say that you should not put people with epilepsy and/or their family through the fear/worry when the risk is so low. We wish that we would have been told about SUDEP sooner. In reviewing the literature, Tyler was in the high-risk category for SUDEP: seizures at night in his sleep, tonic-clonic seizures, medication not controlling the seizures, young male, started seizures at a young age, and medication changes.

We STRONGLY believe that people with epilepsy in the high risk category should be counseled about the risk of SUDEP. We would have done things differently. Tyler might still be alive today and I would not be giving this testimony to you. We established a

scholarship in Tyler's name at the University of Colorado, Boulder for students with epilepsy. We want to keep Tyler's memory alive and show that he did not die in vain.

As we do more research into SUDEP, we are very disheartened about the lack of education, awareness and support for SUDEP in this country. The newly elected coroner in Boulder County did not have any clue about SUDEP. We tried directing her toward a SUDEP review. We left messages for the coroner, but they were not returned. My wife and I, along with many families and friends, participated in the Epilepsy Foundation of Colorado (EFC) Epilepsy 5 K Run/Walk on June 12th in Denver. After Tyler's death, I noticed there was NO information on EFC's website regarding SUDEP. It took several e-mails and constant nagging, but they finally put a link to SUDEP information on their website. The Director of EFC told me there would be a booth at the Epilepsy Run/Walk dedicated specifically to SUDEP. There was not. There is a lot of talk in this country and no action. More people are diagnosed in this country each year with epilepsy than with muscular dystrophy, multiple sclerosis, and breast cancer. And people are dying from epilepsy, and the medical community is doing nothing to warn patients of this potential risk. This is a travesty especially in a country that boasts the best health care system in the world. Canada, the United Kingdom, Australia, and other European countries are far ahead of the United States in SUDEP research and awareness. One quote from a SUDEP advocate in Australia "I took a book on SUDEP to the epilepsy meeting in the U.S. in 2005. However, the U.S., while a world leader in so many things, has been slow to get moving on this issue. The book did not get picked up as we hoped, despite the fact that it was free! CURE was quick to put it on their website and epilepsy.com used bits of it." She further states "Unfortunately, even as SUDEP discussion has picked up over there (U.S.), I have seen a reluctance to draw on the early success work of others especially the United Kingdom. It is like everything has to be rediscovered U.S. style and then it will get going .... There are some wonderful people engaged in this now in the U.S. and they have found the slow pace of work as frustrating as some of us outside the U.S."

There is hope ... the recent kick-off of the U.S. and Canadian SUDEP Awareness Campaign is a very strong start and indication of good things to come. Steve Wulchin, who lost his son to SUDEP and is a strong advocate, is doing great things in this country and is presenting at this meeting. We STRONGLY believe that parents/patients with epilepsy in the high-risk category should be counseled on the risks and the precautions. We believe that many of these deaths are avoidable given patient/family education, education of coroners and the medical community, greater research, and public awareness. We hope to become active in SUDEP awareness and eventually help other families who have children with epilepsy because we don't want to see anyone else go through this unbearable pain. As the world leader, which boasts the best health care system in the world, we should do more research and education in the area of SUDEP, so no one has to die from epilepsy. Thank you for listening and sharing your valuable time.

#### 4.1.4. Linda Coughlin Brooks, *The Grief Journey, LLC and parent of a child with epilepsy*

I am every parent's worst nightmare, my child died. I am the reality that no parent wants to face. I'd love to be writing "A Mother's Story" that finishes with a happy ending. This one, like so many, ended in tragedy. We, in the medical profession, could fill volumes with tragic stories. This one is different, because it is mine. It is a tragedy of *omission*. It is the tragedy of *silence*. It is the tragedy of *passivity*. The course of the events has forever changed my life. I am a member of a club where dues would gladly be exchanged for the price of an Ivy League education. So many of my colleagues who preceded me in membership have been looked upon with pity. I now live with recognition of those stares, whispers and avoidances. I have a PhD

in grief and never stepped inside an institution, nor spent a dime to get it. In our realm of medical analytical thinking, grief is an abstract concept. I, like many, am an enigma the untouched don't understand.

It was six days before Christmas and eight days before my wedding. The house was decorated for the holidays and filled with wedding gifts, Christmas presents, and excited anticipation. My children were eager to be part of a blended family, and the end of the era of my role as a single parent. Carei, "the romantic," was particularly excited about her upcoming first experience as a maid of honor at the age of 17. She loved her floor-length green velvet gown with matching shoes. She frequently donned her elegant outfit in the weeks preceding the wedding, practicing that future walk down the church aisle.

There were so many last minute things to do as the days clipped by. It was the last day of school before the holiday break. My son was staying the night at church for a lock in, and Carei had a date with a new young man. As I had done for years, I parented by phone, gathering information regarding their whereabouts. When I talked to Carei from the operating room I worked in at 6:30 p.m., she complained of feeling very tired, but she never missed an opportunity to go out on a date. She had worked at the opening of a Dave and Buster's the night before until 2 a.m., got up to go to school at 6 a.m., then worked out at the health club after school. It was reasonable that she was tired. I encouraged her to get up and take a shower. I told her she would feel better and she could make it an early evening. I signed out the narcotic keys at 7:25, glanced at the phone, and shook it off knowing the kids would page me if they needed me. I have been known to be an overprotective mom at times. I stopped by Foley's in Cherry Creek for a last-minute gift certificate for my oldest daughter, and then headed home. I arrived at 8:20. The house was dark as I made the rounds on the first floor, turning all the Christmas lights on. I noticed the basement was dark except for the flickering light of the TV; why is it kids can never manage to turn everything off? "Oh no!" Carei forgot to get up, she's going to be late I thought, as I rubbed her back, calling her name. Her arm was hanging off the couch, and I could see by the light of the TV it was mottled from lack of circulation.

My resuscitative efforts, and those of the paramedics, were a gallant attempt to save her life until she was pronounced dead at the hospital at 9:15.

How does this happen? Children are not supposed to die. I was supposed to go first. The events that followed are a blur except for the word DEAD. It was the beginning of a journey I never dreamed I'd take.

Carei was a beautiful full-term strawberry blonde — active and challenging, developmentally on target. At 14, she was diagnosed with epilepsy. She went through the gamut of inpatient and outpatient testing, resulting in a diagnosis of idiopathic epilepsy. Our job was to move forward through the battery of pharmacological regimens (8 in 3 years) in search of one that brought good seizure control for her predominantly complex partial seizures.

All of us have recollections of our first exposure to epilepsy: the stigma, the fear of the tonic-clonic episodes, the restrictions, but not death. People don't die from epilepsy. Carei did, her death certificate reads "cause of death SUDEP" (sudden unexplained death in epilepsy). The Arapahoe County coroner was nice enough to put together some information on SUDEP for me after performing Carei's autopsy. A physician encouraged me to write this paper after losing a friend and fellow MD to this syndrome in 1999; she was appalled that there was so little information in her own medical community and by the code of silence that existed surrounding it.

SUDEP is defined as "sudden unexpected witnessed or unwitnessed nontraumatic and nondrowning death in a patient with epilepsy with or without evidence of a seizure and excluding documented status epilepticus in which postmortem examination does not reveal a toxicological or anatomic cause for death".

This can't be, no one told me she could die, no one ever mentioned this. We were cautioned about the importance of regular medication schedules, about avoiding alcohol, not getting too tired, and maintaining proper nutrition as well as no tub baths alone, but the critical nature of this advice was never stressed. Here, began my search for truth.

In my job, I interface with countless physicians, and the majority have never heard of the term, SUDEP. Our neighbor, a neurosurgeon, was on the scene the night of Carei's death; he had never heard the term, SUDEP. After working for Medtronic Neurological, I was stunned and amazed at how many physicians I met had never heard the term, SUDEP. When I asked Carei's neurologist why she never mentioned it, she told me, "We don't like to alarm patients when they are already in a somewhat protected state." She is not alone; there seems to be a trend toward this code of silence regarding SUDEP. Withholding this information helps no one. Clearly there isn't a bounty of medical information surrounding SUDEP. There is merely a paragraph in the medical text. Research in this field has been limited. SUDEP is an end point, not something with hallmarks of treatment. The small amount of available literature consistently identifies risk factors. It is realistic to expect patients to take responsibility for themselves in their own care. Sharing information with them regarding the potential for SUDEP may be upsetting for many, but this knowledge may foster better compliance and follow-up. This may also prevent families from feelings of betrayal by the doctor should a sudden death occur.

There is a significant and under-appreciated risk of mortality in epilepsy. The disease gets little attention relative to other chronic conditions. It is clear that research thus far is inconclusive and that the mysteries of epilepsy still complicate efforts to successfully treat many patients.

Proper postmortem identification in epilepsy deaths will bring useful clues for research. The coroner from Arapahoe County and I have spoken to coroners to promote identification and understanding of the postmortem pathological hallmarks. Families need and deserve to know why their loved one died. A mother contacted me regarding her son's death certificate, which read "unknown cause of death." After Mike reviewed the postmortem findings it was clear her son's death was SUDEP. The parents asked the Larimer County coroner to reclassify his death, stating causation; this gave them some closure. The outcome of this information encouraged the coroner to retrospectively examine and reclassify 23 epilepsy-related deaths to "SUDEP" in Arapahoe County. Denver County has also participated in a retrospective review and reclassification. I commend Mike on his commitment to this effort. Contributing as a researcher with the forensic pathologists and his fellow medical examiner helped me feel as though Carei's death was not in vain. Our work was ultimately published in *The Journal of Forensic Pathology*.

It is time for serious public and patient education about SUDEP. It wouldn't be prudent to withhold cardiac education or diabetic education from patients or minimize the potential for respiratory distress in asthma patients.

In this era of managed care, with all its financial implications, physicians are finding less and less to feel good about. Those who remain dedicated to survival and their Hippocratic Oath have a chance to help and "do no harm." You can spread the word to your friends, family, and your patients, no matter what your specialty is. Omissions can be DEADLY.

## 5. Introduction to health care and community services

Parents of children with epilepsy, adults with epilepsy, representatives of voluntary epilepsy organizations and health professionals caring for people with epilepsy spoke about health care and community services for epilepsy from their different perspectives. Gaps in care were discussed at the state level for a rural state, by parents

who described the search for optimal epilepsy care, and by others who highlighted the need to educate neurologists to refer patients to epileptologists. Providing education about epilepsy to health professionals, teachers, school aides, school nurses, and the general public was also a common theme in several testimonies. Parents described their frustrations when trying to obtain the best care for their children and the degree to which they had to advocate for needed resources and services. Other barriers to accessing optimal care were also described, including lack of adequate insurance and/or prescription coverage, difficulties obtaining transportation to a medical visit, and problems obtaining needed referrals. The need for more research data was a constant theme.

### 5.1. Health care and community services testimonies

#### 5.1.1. Tiernae Buttars, parent of a child with epilepsy

My son William is 5 1/2 years old and underwent a right brain hemispherectomy at 1 year of age due to uncontrollable seizures from birth. William was born in Bellevue, Washington, and so, he was treated for epilepsy through a nearby children's hospital. The staff was very knowledgeable but lacked cohesive communication with one another many times. My pediatrician had been the chief resident of pediatrics there and was very familiar with the neurology team of doctors, and she would call to see what she could do to make things run smoother for us.

Our main neurologist was in a private practice in Bellevue. He was affiliated with the children's hospital and wanted to have an MRI done after William was a month old and was still seizing on phenobarbital. MRI tests at the hospital were booked out for six months, since that was the only MRI equipped for a baby in the area. He was able to get William in sooner within a month after he explained the urgency. At two months, William had the MRI, and it showed polymicrogyria and pachygyria (cortical dysplasia) on the right side of his brain. This now gave us the cause of his seizures. He had seizures every 12 s from birth recorded from the first EEG to now; about 80 a day of different types that I tracked. William was given his second seizure medicine.

When William was 4 months old, my husband and I explained to our neurologist these different types of seizures that were repetitive in nature and would be a series of short stomach contractions lasting a few minutes. We also brought a video recording from home to show him since by now we were describing up to 4 different types of seizures. He said it sounded like West syndrome or infantile spasms and that it need to be confirmed by an EEG at the children's hospital. We were instructed to take in the home videos and show the doctors so they could see. None of the other EEGs we had done previously had picked up on those spasms specifically. William was admitted the next morning and connected to the EEG with video recording. He didn't have the spasms during the recording, but he was prepped to return Monday to the hospital for longer monitoring.

On Monday, William was monitored for 24 h, and I showed the nurses, doctors, and residents our home recordings of William's infantile spasms. He had several seizures recorded during that time and a few spasms. The EEG recordings were vague and not consistent. Fortunately, the home video and monitoring video confirmed the diagnosis. We started ACTH treatment and continued for three months. There were several side effects from William being on ACTH, I had to get his blood pressure checked weekly. My pediatrician called to tell me I had to go to the hospital to get his blood pressure checked since they were the only ones who had a machine small enough. I was given priority status to get right in and out of the hospital since William's immune system was vulnerable. It was very frustrating taking my baby to a hospital with all the sick kids weekly.

ACTH worked for William in getting rid of the spasms but not his seizures. He was evaluated overnight and was still having at least 40 seizures and was on his third medicine. We had a brief consultation

with the neurosurgeon when William was diagnosed with infantile spasms who explained to us that as a last resort, a hemispherectomy was an option for William.

So, when William was 8 months old and during an appointment with our neurologist, he kindly explained it was time for a second opinion and to go to a well-known epilepsy center in California, and whatever they tell you to do, do it. I called and set up an appointment to have William tested and checked there. The equipment that they were using for his EEGs, video, and etc. was what our hospital had just received. I asked the nurse when and how long they had been using their equipment, and she said at least two years. All the tests confirmed what the other hospital had said as well, that a hemispherectomy was William's best option.

So, at that point, we knew a hemispherectomy was the best choice for William. I also e-mailed an epilepsy center in the Midwest who said one year of age was when the surgeon liked to do hemispherectomies, and our hospital at home said one year of age was the time as well. But the team at the California center felt that the sooner we do it, the better. They gave me his 4th seizure medicine until surgery (William was on all four at the same time). I appreciated the cohesive communication I got from each team member there. It was so refreshing to not have to call and manage William's care among the health team — previously it was an extra burden to expend effort to get everyone on the same page with my child's care.

At 11 months old, William's infantile spasms came back, but he was already going to have surgery, and so his Keppra dosage was increased. Just before William's 1st birthday (it likely would have been done at 10 months but we had scheduling conflicts), he had the hemispherectomy surgery.

William has been completely seizure free since then. It wasn't the perfect miracle my husband and I prayed for, but it has been the right miracle for my son to have a better quality of life. William still takes Keppra twice a day as a precautionary measure for seizure control. He has minimal side effects, and we visit with a neurologist once a year. We now live in Salt Lake City.

We were fortunate to have the means to travel and take our son to where he can get the best care. I know not everyone has that option. It would be nice to see the pediatric epilepsy team built up stronger at our neighboring hospital as it would for many others out there as well.

William has amazed me with all he can achieve. He is mainstreamed in the regular kindergarten class. He can read, write, count and speak well. He loves to run, jump, hop, swim and gallop. He has always been a very social child and very happy. His mind has been cleared of the seizures, and he has been able to take advantage of every moment so far. He gives me and many others a lot of hope if all children could be seizure free.

In the beginning of William's journey in life, people would say seizures aren't a big deal — people live with them every day. It was tough to not get angry because it is just like cancer or other diseases that attack people's bodies. William's brain was being attacked, and for many, they couldn't see that or know what the early mortality rates in epilepsy patients are. I hope we can improve public education on seizures, because the right education teaches more tolerance and sensitivity. I wish more people understood, and I believe they can with the right education and care. Please support epilepsy research. Thank you in advance for taking the time to read my words.

#### 5.1.2. Brandy Parker, founder of My Epilepsy Story and person with epilepsy

How would you feel if the antiepileptic drug you or your wife took during pregnancy ended up harming your son or daughter? I am Brandy Parker, and I am one of the 3 million Americans living with epilepsy. I am someone's neighbor, co-worker, friend, mother, sister, wife, daughter and I am one of the lucky 70% of people with epilepsy who responds to treatment. Yet, epilepsy has dramatically impacted

my life. Research now shows that the antiepileptic drug I took while pregnant with my first child can cause developmental delay. This is characterized by low verbal IQ in children when exposed in utero. My eight-year-old son, Samuel, has been diagnosed with a language disorder and spends countless hours in occupational, physical, and language therapy. Imagine Samuel was your son, how would you feel if the antiepileptic drug you or your wife took during pregnancy ended up harming your child? I grapple with these emotions daily while watching my son fight to overcome his challenges.

I have had epilepsy for 20 years, and I have been fortunate to have only had generalized tonic-clonic seizures on two occasions. I have been successful in that my seizures responded to epilepsy treatment, but I was not prepared for how my epilepsy would impact my son's life the way it has. We need to know and address the full effects of antiepileptic drugs prescribed to patients with epilepsy. These drugs impact the mother, as well as her unborn children. This must be included when we talk about the true impact of epilepsy. In my case, the effects have been passed to my son.

There needs to be greater funding for accelerated research for curing epilepsy. I have been lucky, but at any moment, I could be one of the 33% of epilepsy sufferers for whom medication or surgery is not effective. We have a moral and ethical responsibility for finding a cure for epilepsy. This will allow people to live seizure-free lives without the side effects from medication harming them or their children. Epilepsy is not beyond a cure; what is desperately needed is well-funded biomedical research to discover its cure. If this would have happened years ago, I would not be struggling with feelings of guilt, while watching Samuel fighting to overcome his numerous challenges at such a young age. In short, this is My Epilepsy Story.

#### 5.1.3. Cheryl-Ann Tubby, American Epilepsy Society and Sandra L. Helmers, Emory University School of Medicine

Thank you for the opportunity to testify. I am Cheryl-Ann Tubby, Assistant Executive Director of the American Epilepsy Society (AES). AES seeks to advance and improve the treatment of epilepsy through the promotion of epilepsy research and education for health care professionals who are dedicated to the prevention, treatment and cure of the disorder. The Society's Annual Meeting is the preeminent scientific meeting in epilepsy, and each year attracts physicians, scientists and health care professionals from around the globe.

One of the questions on the statement of task for IOM was on access to health care. Unfortunately, in epilepsy, there has been little research in health services delivery. AES has a committee looking at practice issues and health care reform. I'm here representing that group of volunteers and particularly Dr. Sandra Helmers of Emory University, who couldn't be here today.

This committee decided to conduct a survey focusing on the perceptions of care providers as well as the patients, their caregivers and advocates about access barriers.

The survey was conducted earlier this spring through the Epilepsy Foundation and the American Epilepsy Society. The survey was designed to informally ask questions about barriers to access and treatment from the perspective of providers of epilepsy health care as well as people with epilepsy, their caregivers, and advocates. The survey was posted on the respective web sites with multiple reminders for people to respond.

Over 635 patients and caregivers responded to the Epilepsy Foundation survey. Results show that the three most common challenges for patients in getting to their epilepsy appointments are the following:

- transportation need,
- not being able to afford to go to their doctor, and
- getting a referral from their primary care or neurology provider.

Once at the epilepsy appointment, challenges for being able to follow directions for their treatment can present difficulties. The top three difficulties were the following:

- side effects of the medications,
- not having health care insurance, and
- insufficient health insurance which did not cover needed treatment.

Sixty-four professionals replied to the AES survey. Initial results show that there are some similarities from the care provider responses about perceptions of their patients' ability to access the needed care. Transportation and health insurance coverage are again big problems. People with active epilepsy cannot drive, and public transportation is not always available. Health insurance, either none or underinsurance, appears to play a large part in not only access to an epileptologist but also in being able to get the needed care once access to the provider is gained. Finally, the "understanding of their disease" and their "attitudes or beliefs about epilepsy and treatments" seem to play a large role in accessing and following care plans. This raises issues with health literacy and our ability, as care providers, to educate patients about their condition and treatment options in a culturally sensitive, understandable way.

There are other issues, but what is evident from the survey is a need to better understand access to care for people with epilepsy.

#### 5.1.4. Richard Leslie, Wyoming Epilepsy Association

Wyoming is a frontier state, where just over 509,000 people live in 97,100 square miles. Like other rural/frontier populations, Wyoming's citizens continually face problems in accessing quality health care and health education. Health care accessibility is particularly problematic in Wyoming, where distance, geography, inclement weather, and isolated communities all present challenges for the state's residents in gaining education and access to health care. Traveling long distances to access health care services is routine for many of Wyoming's residents; they often seek needed care in neighboring states because it is unavailable within the state.

In relation to epilepsy, the difficulties are great due to the shortage of family practice physicians and neurologists, but our greatest asset in Wyoming is one epileptologist and the Wyoming Epilepsy Center (a member of the National Association of Epilepsy Centers).

*Problem:* Our major concern is providing professional education to community health care centers, family practice physicians, pediatric practices, public health officials, and nursing constituents in Wyoming. These opportunities are scarce since most educational opportunities are offered at out-of-state conferences. Conferences that are held in our state address other important health care issues besides epilepsy.

*Recommendation:* The Wyoming Epilepsy Association (WEA) recommends that a program be developed for medical professionals with the following objectives addressed:

1. Public campaign on medical professionals and epilepsy
2. Program should be promoted to medical boards, physician groups, health organizations, etc.
3. A training program that can be accessed online plus an education program available to organizations that focuses on epilepsy
4. Credits for this program
5. Options for promotion of epilepsy in their medical field
6. Other options as well

The program could have various types of criteria developed for each stage of general medical service and would be great for a rural state. It will reach small groups in any type of medical profession and have a productive outcome toward patient education, public education, and awareness.

WEA participated as a contracted partner with the University of Wyoming in the Federal funded grant 2007–2010 Access to Care for Children and Youth with Epilepsy. This grant assisted WEA in

discovering that more than just children and youth with epilepsy were leaving our state for medical services. The best accomplishment with this grant was the training of school nurses and seizure actions plans.

Based on what we learned, WEA established funding of \$24,000.00 a year through the Wyoming Department of Health for epilepsy services. Our recommendation for training medical professionals about epilepsy is a major issue that still must be addressed.

WEA believes that education starts with the participation of medical professionals, who can then in turn provide education to patients, members of the community and educators.

#### 5.1.5. *Laurie Kelly, parent of a child with epilepsy*

There are so many things I would like to say and would so love to hear the comments by everyone. The epilepsies cover such a broad range. My daughter (now 16) started having seizures when she was 9 (Feb. 20, 2005). Her first seizure was big, and we thought she was dying ... maybe she was having a brain hemorrhage ... we couldn't figure it out. It was terrifying. So there are definitely a lot of emotions when you go through something so traumatic, and it is most helpful to have a doctor sensitive to the fact that you have recently gone through the worst experience of your life. We were very blessed to meet a good neurologist from the start. He was rare — a small-town doctor (Fishersville, VA) with big-town connections. He directed me to two reputable web sites to help answer my questions: EFA.org and Epilepsy.com. He encouraged us to get a second opinion and was extremely accessible to us. He had personal experience with epilepsy in his family, a real plus.

In my volunteering with the Epilepsy Foundation of Virginia, I have encountered many people whose neurologist did not refer them to an epileptologist or a neurologist with a special interest in epilepsy. I think this would be important in educating neurologists ... tell them to refer their patients with epilepsy to a neurologist with more expertise in epilepsy ... put their egos aside if that is a problem! I wish there were more small-town neurologists specializing in epilepsy. Since our neurologist died, we have had to jump into a bigger pond of patients and are more lost in the shuffle.

When my daughter was first diagnosed, we were on a several-month-long waiting list to get into the epilepsy monitoring unit. Fortunately, our original neurologist had enough calls from us about episodes and was able to get us there on an emergency basis. This is very important in the beginning to protect the brain! I was shocked there was a waiting list for something so severe.

The national Epilepsy Foundation and my local Epilepsy Foundation of Virginia (EFVA) have been invaluable to me. When my daughter first started having seizures after 9 years of being perfectly "normal," I called the EFVA to come in to her classroom to explain it to her classmates. She was kind of anxious about what would happen if she had a seizure at school, etc. Suzanne Bischoff came to our school and did a great job educating my daughter's class and also educating the teachers at a meeting after school. This was very important because it was a private school without a school nurse, and it made the teachers and me more comfortable with having my daughter there. It was hard to let her out of my sight, yet at the same time I didn't want others to say that she had to repeat her grade because they were afraid to deal with a seizure.

This past year, my daughter was in a public high school for the first time. We talked to the school nurse about her carrying her own Klonopin. I sent an e-mail to the guidance counselor asking her to let my daughter's teachers know she had epilepsy and personally talked to the gym teacher. But since Shannon hasn't had a seizure since 2005, I didn't talk to each teacher. I found out during the course of the year that her teachers didn't know about it unless they clicked on her name under a certain place. So, I think it would be very beneficial to educate not only school nurses, but also have an in-service with the teachers each year as well. I'm an elementary teacher

myself, and I know I would appreciate it. Sometimes, you get more support from the teachers than your school nurses. EFVA also does a poster contest called: *Wear a Helmet, Prevent Epilepsy* each year for 4th graders. Winners get to go to the governor's mansion in Richmond, etc.

Another thing the Epilepsy Foundation did for me was to get us involved with policy. Since my daughter wasn't allowed to ride horses at summer camp (even though her neurologist said she was safe to ride!), thanks to the Epilepsy Foundation, Shannon and I were able to go to our Congressmen (at Kids Speak Up) and tell our story. It was important because our representative was Bob Goodlatte, a ranking member of the judiciary committee and a key person in helping with the passage of the Americans with Disabilities Act (ADA) Amendments Act of 2008. That was one of the most important accomplishments in my life — knowing I could make a difference to improve the laws to make living with epilepsy easier and fairer. This would never have happened without the Epilepsy Foundation!

Also, through the EFVA, I have personally met many neurologists and epileptologists at our yearly epilepsy strolls and have even gone with one to the Virginia General Assembly. So, I have made some personal connections with neurologists and their families, and that is important to me. I think it is important for neurologists dealing with epilepsy to be involved with their local Epilepsy Foundations and to meet the families in a casual setting.

Now that the ADA Amendments Act of 2008 has passed, I would like to see improvements in the Department of Motor Vehicles — another nearly impossible feat to take on. My Shannon got her permit in December 2010. All went well until February when she had an aura (which she has about once a year or once every 1 1/2 years). This happens because she is growing and gaining weight and needs to increase her medication to keep up with her body weight. So, she was told she couldn't drive for 6 months. It wasn't even a full-blown seizure — just a strong aura.

This makes it tempting for adults with epilepsy not to tell their doctors if they are experiencing difficulty because they need to be able to drive. Now, I would definitely not want Shannon to be driving if I thought she was putting others in danger. I would not want to be killed by someone having a seizure! Nor would I want my daughter to be killed while driving and having a seizure! But since the epilepsies are all so different, I would like to see neurologists becoming more educated in this area. Some do not have any concept of what it is like to really live like this. My daughter's little episode was, I think, more upsetting to me than to her because I realized she will need to live where she has access to public transportation at all times just in case. (And she is a country girl!) I think of people with diabetes ... their blood sugar can drop without warning, yet they can drive. My daughter has an aura before a seizure and could actually have time to pull off to the side of the road. Plus, she hasn't had a seizure since 2005. I will be sure to look for another neurologist for her when she actually needs to drive to a job — one who is more reasonable in understanding the real-life aspects of living with epilepsy. And I love my daughter's neurologist!

It is very easy to slap restrictions on others until you are in their shoes. I'm sorry for this long story, but I wanted you to hear it from one person living with epilepsy. God bless you all as you have these meetings aimed at helping those of us living with epilepsy.

Thank you for taking the time to listen.

*Update:* I spoke with my daughter's neurologist at her next appointment about the driving problem. And I cried when I did, wondering how hard life will be for her. He patiently listened and then told me that a long time ago, if you were diagnosed with epilepsy you could never drive again. He told me, he sat on many boards to help get the time down to what it is today — 6 months for most states. He also told me this rule applies to anyone who has lost consciousness. He even had some colleagues who had to stop driving for 6 months for reasons other than epilepsy. That made me feel a lot better and

helped me to put my frustration into perspective. I shouldn't have been so frustrated. I am blessed to have one of the best neurologists for my daughter. We know he cares about us even though he sees thousands of patients. We are blessed to have him.

#### 5.1.6. *Alayne and Jon VanWagoner, parents of a child with epilepsy*

Our daughter, adopted from China at age three, has intractable seizure activity caused by a prenatal stroke which caused extensive left hemisphere damage (called encephalomalacia) and some right temporal lobe damage also. She experiences complex partial seizures that we have controlled with Lamictal. She is on 10 mg/kg/day right now. We had her on Depakote to try to control the startle-type seizures and staring episodes that appear seizure-like but do not show up on EEG. She was considered a candidate for hemispherectomy if we could have seen the seizure activity more clearly. The Depakote had too many side effects for her to continue. You may be interested to know that in China she was not diagnosed with seizure activity – they thought she was clumsy because of her hemiplegia. (They thought it was only cerebral palsy.) We originally took her to a neurologist but have since switched to an epileptologist and have had better results.

I wish we had more information about our daughter's seizures. She is almost six now and is in a functional skills class and mainstream kindergarten. The startle activity is extremely uncomfortable for her, and she will cling to me and cry when it occurs. It happens in response to sounds at least 10–20 times each day. It seems to be more severe since we are off the Depakote, and that is why we are considering the Keppra. It is disconcerting that we cannot see the episodes on the EEG. She is very good about taking her medicine and knows that she needs it because her seizure activity is always close to the surface. We worry that the staring spells are interfering with her ability to learn, but since we cannot see them on the EEG, we don't know for sure how to treat them. It is very worrisome to make decisions without more information.

She is an adorable child who is making wonderful progress despite her many challenges and is full of determination. We hope that increased research in the field of epilepsy might provide more information about seizure activity and treatment for people like our little daughter.

Update – September 2012: Our daughter had a functional hemispherectomy because the seizures were unstoppable. She has not had any obvious seizures since her hospital discharge. She has made remarkable progress with speech, reading, behavior, and everything since the surgery. The seizures were more disruptive, more devastating than we ever could have imagined. Life without the seizures is so different. At first, we jumped to her aid every time a seizure trigger occurred. Finally, we realized they were gone. What is really incredible is the amount of time it took to realize that she was having constant, severe seizures. I guess it wasn't clear in the beginning on the EEGs, but the difference is so profound. It is our hope and desire that those who suffer from seizures can find assistance, that research can find new ways to identify and treat this problem, and that public awareness will be raised to more fully understand the extreme disruption seizures are for those who experience them.

#### 5.1.7. *Ilene Miller, Hope for Hypothalamic Hamartomas and parent of a child with epilepsy*

My name is Ilene Miller. When our son Mark was 3, my husband and I noticed episodes where he would get very quiet and appear to be swallowing. The episodes lasted 1–3 min, and during this time, he had a blank stare and was unable to speak. Sometimes, the episode was preceded by uncontrollable laughter or giggling (which we later learned are called gelastic seizures).

My husband is an orthopedic surgeon, and I am an attorney and health advocate. We had a gnawing feeling things were not right. However, our friends and family thought we were just being new,

anxious parents. Meanwhile, our veteran pediatrician diagnosed Mark with reflux. Still, the feeling persisted.

Affirmation of our concerns came first from Mark's preschool teachers who described him as “*getting lost in his own space*,” but a diagnosis would not come until nearly two years later. Just before Mark's 5th birthday, our “giggling, staring, swallowing” son who was a proficient ice skater fell and could not regain his balance. “Dr. Dad” suddenly realized Mark was *postictal*. A neurologist confirmed epilepsy. Complex partial and grand mal seizures began soon after. Mark began working his way up and down different medications even though gelastic seizures are refractory to medications. EEGs and video-EEGs were ordered, which were invasive, time-consuming, emotionally exhausting and inconclusive.

At first glance, Mark's MRI was normal. However, when we described the symptoms – staring, giggling, and swallowing – to the radiologist, he reviewed the MRI again and returned with a diagnosis of hypothalamic hamartoma. The giggles were gelastic seizures; the staring was absence seizures; and the swallowing was automatisms.

You would think that finally armed with a correct diagnosis, things would get easier. We were educated advocates with resources and sent Mark's MRI and reports to the top international pediatric neurosurgeons and centers worldwide. The diversity of recommendations returned was overwhelming. “Camp one” confirmed hypothalamic hamartoma and recommended Mark for gamma knife surgery – then still considered experimental; now standard of care. “Camp Two” advised us to watch and wait until he declined or the tumor grew or changed (ps hypothalamic hamartoma tumors don't typically grow). And “Camp Three” questioned the diagnosis altogether and recommended more testing – video-EEG, ictal single-photon emission computed tomography (SPECT) coregistered to MRI (SISCOM), PET scan, MRI (STIR sequence), 3 T MRI ....

Ultimately, we relied on the advice of the epilepsy centers that had seen the most hypothalamic hamartoma cases – still only in the 100s – and Mark had gamma knife surgery in July 2007. 4 1/2 years later, he is having fewer seizures – but he is not cured. We worry constantly about whether he will decline; we fear what impact the daily Depakote he takes will have on his body; we struggle with educating him given his learning disabilities and discerning what stems from the tumor, the seizures, the gamma knife surgery, and the medications; and we grapple with how to keep Mark's self-esteem high as his awareness of his differences increases with age.

We co-founded Hope for Hypothalamic Hamartomas in 2010 to educate the public and health professionals about hypothalamic hamartomas and prevent other families from living in the dark, receiving misdiagnoses, and undergoing invasive tests or treatments as we did. Three key goals include:

- Educating the front line – pediatricians, neurologists, endocrinologists, radiologists – about the subtle signs of hypothalamic hamartoma
  - Gelastic seizures are a tip-off for a diagnosis of hypothalamic hamartoma
  - Describing Mark's symptoms directly to the radiologist unequivocally led to the right diagnosis; short of that conversation we might still be in the dark. Sadly, the diagnosis of hypothalamic hamartoma in many families is discovered by chance after years of living with the mystery symptoms – more families than not are first misdiagnosed with and treated for gastrointestinal, psychiatric, and behavioral disorders
  - Yet, if you search the majority of epilepsy and other seizure sites on the web, you will be hard-pressed to find gelastic seizures described among the other more commonly described seizure types like absence, grand mal, etc.
  - Hope for hypothalamic hamartoma is advocating for recognition of gelastic/dacrystic seizures and working with ILAE, Epilepsy Foundation, and others to promote public and professional awareness of this key diagnostic clue.

- Educating neurologists/neurosurgeons about how to work up/treat hypothalamic hamartoma
  - When a hypothalamic hamartoma is suspected, clinical evaluation and the right MRI are the most conclusive tests
  - Video-EEG, EEG, SPECT scan, and PET scan are costly, time-consuming, invasive, and do not advance diagnosis or treatment of hypothalamic hamartoma
  - Our Medical Advisory Board Chairman has published a hypothalamic hamartoma diagnosis and treatment algorithm that we are working to disseminate internationally.
  - Also, our Medical Advisory Board Member is working with ILAE to define hypothalamic hamartoma and ultimately disseminate that definition worldwide.
- Like other epilepsies, hypothalamic hamartoma impacts neurology, endocrinology, psychiatry and requires multi-disciplinary, coordinated care at an Epilepsy Center of excellence
  - Hypothalamic hamartoma patients have brain tumors and epilepsy. They can have endocrine issues, rages, learning disabilities, and psychiatric challenges.
  - Hope for hypothalamic hamartoma is joining with other epilepsy organizations to spread the word that the medical diagnosis and treatment of epilepsy is often just the beginning. Patients with epilepsy need access to Epilepsy Centers that can provide coordinated multi-symptom management, treatment and care.

*5.1.8. Paula Apodaca, person with epilepsy and author: “E. is for Epilepsy by Paula Apodaca” blog (<http://www.epilepsypaula.blogspot.com>)*

My thanks to the IOM committee for the opportunity to address you today. The points raised in my address reflect my experiences with epilepsy over the majority of my lifetime. I may be one of the few people you will have the opportunity to hear from with over a half century of life with epilepsy. I hope my observations will inform each of you.

3) Health policy, health care, and human services...

There is a terrible gap in the quality of care owing to a lack of comprehension about epilepsy. The phrase “a commonly occurring neurological disorder” frequently leads laypersons and professionals to assume that epilepsy is not serious or dangerous to the patient. A more refined amendment to approaches in medical school education would benefit patients of all ages and might make general practitioners and neurologists more comfortable treating their patients with epilepsy.

Within the past ten years, I have been told by neurologists that “It could be worse, at least epilepsy can’t kill you” and “Well, we’ll see if you really have epilepsy: I will take you off all of your medications, and then if you seize, we will know for certain”. During the same time, general practitioners have suggested that a tonic-clonic seizure has not occurred unless it is “accompanied by urination” and “It is very easy to fake epilepsy. Some of you people do it for the attention.”

Clearly, these are physicians who are behind on their reading and who might benefit from a specific educational approach. Initially, I would suggest a survey into the attitudes of physicians toward their patients with epilepsy.

Because physicians can, by their personal attitudes, enhance or diminish stigma to epilepsy in the community and within the family, they are also central to quality-of-life issues. Additionally, physicians with poor knowledge of epilepsy often have the tendency to view this disorder according to the germ theory model. They become easily frustrated when they cannot fulfill their own expectations to find a cure for epilepsy; this can breed hostility between patient and doctor.

It is also important that health insurers be more broadly introduced to the neurological sub-specialty, epileptology. The diagnostic codes and data used to make referral decisions for patients could be smoothed if this category were supplied to them as a legitimate category in neurology.

So, it seems that I am speaking about the need for a more intensified educational approach, not only for the public at large, but also for the professional population as a whole.

Treating epilepsy can be as frustrating for doctors as it is for patients. Still, passing along bad information or resorting to cruelty is not an answer. A cardiologist would not suggest taking a new heart patient off his medications to see if he would have a heart attack to confirm a diagnosis.

Perhaps one of the more ridiculous “cures” ever provided happened when I was a child. In about 1960, my mother went to see a neurologist. She talked about me with the doctor, describing my condition in detail. She mentioned to him that I had long red hair and that she brushed my hair every morning. She told him that I frequently seized during this process and more than once, it had triggered status epilepticus. He thought about what she told him for a moment then concluded that it was my hair that was the problem. My hair, he told her, was too heavy for my head and should be cut short to relieve my seizures. She cut my hair off that very afternoon, and it wasn’t until I was 25 years old that I dared to grow it out again. Thirty years later, my hair reaches down to the middle of my back.

I have learned a lot in the past 55 years of studying and living with this disorder. I can hardly wait to see how much more we can change things, together.

Thanks for the opportunity to provide testimony and my observations. As the committee will hear from many others, there is considerable need for patients with epilepsy to speak. Your discussions on what constitutes the major problems will ultimately inform what you will tackle first.

*5.1.9. Susan Farber, parent of a child with epilepsy*

Thank you for allowing me to give my testimony.

Eleven years ago, I was wrenched from sleep by the sounds and sight of my 13-year-old daughter, Kate, seizing. Her body was flailing, the bed was rocking, and her eyes stared sightless as both of our lives slipped into an alternate universe. Of course, we sought medical help immediately. What follows is my story of how the medical help we received failed at the most basic level until we found doctors who were adequately trained. What also follows is my heartfelt request to you about how I believe this kind of tragedy can be avoided with very little effort.

Here is the story. I am a clinical psychologist trained at the University of Chicago and Columbia University. I have practiced both on Park Avenue in Manhattan and, now, in my home state of Idaho. By any standard, I am an elite health care consumer. If what follows happened to me, imagine what probably happens every day to less privileged patients.

For years prior to Kate’s seizure, I had taken her to an otherwise excellent pediatric practice. She had a variety of odd, nonspecific complaints. The roster included inexplicable losses of bladder control, strange hot flashes, sensations of “electric jolts” or “twinges” going through her body, and odd auditory experiences even though she clearly was emotionally well-balanced and cognitively gifted. She put on weight. I once found her unconscious on the floor of her bedroom but was told “not to worry”, though no explanation was sought. Not once was epilepsy considered as a possible diagnosis.

We now know that all of these experiences were seizure related, and that she probably had been having events since early grade school, if not before.

Following the seizure when she was 13, we went to a neurologist (there was no epilepsy specialist in the state at the time) where she was misdiagnosed with benign rolandic epilepsy. Seizures worsened over time, and multiple medications were tried unsuccessfully. Her life and mine went downhill. My beautiful, blond child now went to school with pads in her underwear in case she lost bladder control. I always sat on the aisle at school events in fear she would pitch forward unconscious. She once fell against a door at our house and

lay convulsing on the floor with blood pooling under her face. She was sent for expensive and humiliating procedures that supposedly would help the bladder issues.

I knew psychological damage was being done despite my best efforts to help all of us cope with what we were told was going to be a chronic illness. I became hypertensive though I had always had low normal blood pressure all my life. My world narrowed and, as the seizures worsened, I put my best face forward but had images floating frequently in and out of my consciousness of her dying.

Kate, in turn, began dealing with thoughts of an altered future. Her friends were giggling about boys and movies and, on the surface, so was she. However, in her truest thoughts, she was wondering if she could ever bear children, or hold her babies without the fear of dropping them, or have a job. Her world inexorably constricted. Humor, in many ways, saved us. What do you do when light darkens around you? Either fold or make twisted observations about the universe. We chose the latter.

No imaging was done until finally I went to the doctor's office and insisted. We then learned that Kate had suffered a stroke to her right frontal lobe either in utero or soon after. Despite learning of a probable focal point for the seizures and the multiple medication failures, still no referral was made to an epilepsy center or teaching hospital. Surgery was never discussed as a possibility. I now know that this was a violation of good medical practice.

In desperation, and without a valid referral, I finally wrote to an academic medical center in California and sent a CD of her MRI. To the end of my life, I will never forget the call on my answering machine saying "Dr. Farber, I think we may be able to help your daughter..." I went into the room behind my office and sobbed and could not move for a long time at the thought there might be hope.

The end of the story is a happy one. Kate had nine hours of neurosurgery, and she has been seizure free for six years. All of the many odd symptoms she had been experiencing are gone. She graduated college a year late but was on the Dean's list, and she is working at a technology company where her humor and people skills make her an ideal interface between the real "techies" and the public.

My blood pressure returned to normal. My health improved with hers. I found tension draining from me about issues I had not realized existed. You can only imagine how it altered my practice and how I now felt for families dealing with the unmanageable and unbearable. I began recognizing more and more patients who should be referred for neurologic workups.

You probably also can imagine my rage at how medicine had failed us until we went to California. I really understood why people bring malpractice suits. In time, my anger was tempered by my realization that I was not serving my patients any better in this area than my daughter and I had been served. People who deal with the public on the front lines – physicians in every branch of medicine and mental health workers in every branch of mental health – need to recognize the symptoms of epilepsy and they need to know where to refer and what good treatment looks like. The public trusts us to have this knowledge and we do not.

Out of this realization came the BAND Conference (Behavioral Aspects of Neurological Diseases Conference). It is multidisciplinary and covers recognition and referral of epilepsy as a core component. It is jointly sponsored by the Idaho Psychological Association, the Epilepsy Foundation of Idaho, a local hospital and the Idaho Comprehensive Epilepsy Center. Yes, we now have an epilepsy center where people can be evaluated and treated. The remaining problem is that huge numbers of professionals remain too ignorant to know when to refer.

All three of our conferences have been considered world-class. We have trained probably half of the practicing psychologists in the state. However, we have difficulty pulling in more than a handful of psychiatrists, even fewer family practice doctors, and no pediatricians or internists. They just don't think they need the information.

From all of this comes my considered and heartfelt request. There are many people who can be helped now, just with what already is known about epilepsy. Some, like our family, can benefit from surgery. However, first, epilepsy has to be correctly recognized and referred.

Please, because you have power that I do not, and on behalf of my patients as well as my family, please require physicians already in practice to take coursework every few years that informs them of signs to observe that would suggest a seizure disorder. Teach them where to refer so the patient can be competently evaluated. Tell them that anyone, but especially a child, should be referred to an epilepsy center if their seizures have failed to improve on two or more medications or combinations of medications. Don't let physicians renew their licenses unless they have this basic information. We are able to convey the information on these issues at our conference in as little as three hours.

Given the prevalence of epilepsy, it is shameful that it exists in the shadows not only for the public but also for the medical and mental health professions. There is no excuse for this amount of suffering and damaged lives.

Truly, I thank you for allowing me to have this voice. If you can move medicine toward daylight on this disease, I promise I will do everything in my power to move my own field.

#### *5.1.10. Rob Moss, co-founder of seizuretracker.com and parent of a child with epilepsy*

What is quality care? And how do I find the best person or team to provide it? My wife, Lisa, and I have thought long and hard about these questions. We are the parents of a bright, cheerful 7-year-old boy, Evan, who is full of energy.

Evan has tuberous sclerosis complex and epilepsy, and he has had seizures since birth. He has been on combinations of 11 different antiepileptic medications and had brain surgery to remove three different tubers. He has hemiparesis in his left leg and muscle weakness across his left side.

At age two, Evan was placed into early intervention services in our county, and he was evaluated for special education which included being placed on an Individual Education Program (IEP) when he was three.

The IEP process provides a systematic way for the IEP team, consisting of educators, therapists, and parents, to set educational goals and provide individualized services in the least restrictive environment. An IEP is legally binding for the school system, and parents are equal partners in the process. The IEP process empowers parents to be effective advocates for their children.

At five years of age and less than 6 months after brain surgery, Evan was reevaluated for continuation in the IEP system and transitioned into his home school district. My wife Lisa and I work extensively with an amazing team of teachers, therapists, and health care providers – including his neurologists and private therapists – to understand Evan's needs and make sure they are provided for him in a way that enables him to reach his highest potential.

Through the IEP process, we realized early on that many of the teaching staff were unfamiliar with epilepsy and apprehensive about caring for individuals with seizures. Included in his IEP was the request for seizure training for all staff members who would have Evan in their care, and that this training would occur prior to him entering kindergarten. We were under the impression this would involve a small meeting with Lisa and I describing his seizures and how we handled them at home to his teacher and, possibly, the school nurse. We walked to the library with the school principal, who was carrying a case of water, and we weren't quite sure what we had gotten ourselves into!

We learned that "staff caring for Evan" included his teachers, the school health aid, physical education teachers, art teachers, office staff, librarians, and the list goes on. We meet with 25 to 30 staff members yearly to describe Evan's typical seizures, and how they

may affect his ability to perform in the school setting. The staff members are also trained by the county nurse and are required to review a seizure training video created by the national Epilepsy Foundation. There is openness from the staff to discuss epilepsy with us and noted confidence in being able to care for individuals with seizures. We expect that by the time Evan exits elementary school, over 100 teachers and staff will have received extensive seizure training, and many teachers will have had annual refreshers. But this is just Evan's school, and training like this needs to be expanded to all schools nationwide.

After nearly two years of post-surgery seizure freedom, Evan's seizures began to return. His mood and focus would change a few days prior to his seizures. Lisa and I immediately called an IEP meeting to discuss this with his educational team and reviewed his seizure diary. The timing of each seizure was indeed having an effect on his educational performance. His teachers refer to his online seizure diary routinely and adjust Evan's school curriculum accordingly. This close communication and interaction would not be possible outside the IEP process.

Evan will soon be up for a three-year re-evaluation for continuation of his IEP. As a team, we have worked hard, and it has paid off. Evan's current academic level lies in the 90th percentile, and this may exclude Evan from continuing in special education. We have noticed him having memory and comprehension issues and are fearful of the impact this will have as he progresses through higher grades. Because his seizures continue, his medications are adjusted frequently, and we are unsure how this may impact him. Evan compensates well, and the subtleness of his deficits can be easily overlooked until they have had a major impact.

The evaluation process for special education should take 90 calendar days, but, in reality, it commonly takes up to one full school year. Children like Evan can have significant regression because of this reactive rather than proactive evaluation process. With the fluctuating nature of uncontrolled seizures, a school year of not receiving the proper educational services can be devastating. Not having special education accountability and parent engagement can leave families and teachers feeling helpless. We need the engagement of the medical community in this process to educate on the nuances of care surrounding epilepsy.

True impact on quality of life for individuals and families living with epilepsy will come not only with seizure control but also with a strong interaction between public education and the medical community. I would ask that when considering "quality of care" this group and the epilepsy community as a whole take into account the role of parents, school systems, health care providers, and long-term care facilities.

#### 5.1.11. *Melinda Heine, person with epilepsy*

Good morning everyone. My name is Melinda Heine. I have refractory epilepsy, and I'm here to give you a glance at the patient's perspective. Thank you for listening.

Article 25 of the Universal Declaration of Human Rights states: "Everyone has the right to a standard of living adequate for the health and well being of himself and of his family, including food, clothing, housing and medical care and necessary social services and the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control."

Vermont's House 100 and Senate 88 bills, which are 'Vermont's Universal Health Care Bills,' are the best blueprint and representation of what we can strive for nationally. Everyone receives health care regardless of their ability to pay while being able to choose their care and receive care out of state. This would stop any limitations due to the private insurers, guaranteeing highest quality care and preventative medicine regardless of income or status. Vermont's way insures that "Health care is a Human Right!"

What would universal health care reform mean for a patient like me? Well, after nearly a decade of craniotomies, research, progress, therapy, and treatment with the same wonderful neurological team I wouldn't show up for an appointment to be told, without warning, I was no longer allowed at that facility due to my private insurer changing. When I go to find new care for myself, while being disabled, I will not have to wait for a referral appointment with an undereducated primary care physician (who is unfamiliar with my condition) resulting in recommendations that can endanger my health and ultimately my life – while I wait even longer to see the specialist.

Once I can see a specialist, my main concerns are staff education and prescription coverage. One thing I've found to be the most beneficial is the Patient Assistance Program. For those of you not familiar, this is a program where drug-makers such as Johnson & Johnson cover 100% of the cost of your prescription. It is an excellent program but not the easiest or most timely to get on. Many people with epilepsy are not high functioning, and little tasks seem difficult, so the health care professional staff should have readily available information regarding this program assisting the patient in cutting down the red tape.

Fortunately, I found great specialists. However, quarterly staff education on new advancements and triggers for people with epilepsy should become mandatory. When you are dealing with a person who has a seizure disorder, sometimes even a slamming door can startle them into a seizure. The staff's demeanor and care is just as important as the specialist caring for the individual.

Everyone knows why people wear pink ribbons, why do we not have something similar for epilepsy? The public education system can create understanding and raise awareness among our youth. Everyone may know someone with a seizure disorder during their life, whether or not they are aware. Seizure protocol and mental health specialists should be mandatory in the public school systems and available at all times, as a means of coping and reducing stigma. With awareness starting at an earlier age, stigma is less likely to exist.

The workforce today is absolutely ill-equipped to work with people with epilepsy. This is my number one challenge. First, I have to be able to find work and stay focused all the way through the interview. If insurance is an option, I then wait for that. Seizures are very dangerous to me – causing me to miss work, injury and not be functional for some time after. The challenge comes into play about when and whom do I tell? How do I tell them? Do I have to go through seizure protocol with them? 'Yes I do!' Will they let me go right away? Are these people going to treat me differently?

Well, I don't have the solutions for these. I've worked with good and bad or just uninformed people and that's why we're all here. Good luck to everyone here!!

This has been a pleasure, challenge and a triumph for me personally – and I thank you for letting me be a part of this.

#### 5.1.12. *Joan Skluzacek, founder of Dravet.org and parent of a child with epilepsy*

I'm Joan Skluzacek, attending this meeting on behalf of Dravet.org (formerly known as the IDEA League), a sponsoring organization of this study and participant in the Vision 20–20 working group on patient and family advocacy. We are privileged to represent families who have a member with Dravet syndrome or other devastating form of epilepsy. I also represent my own family, which includes an 18-year-old with Dravet syndrome.

In order to accurately capture the burden of the epilepsies, data are needed on their costs, which for families of children with Dravet syndrome are staggering. Costs gleaned from over 800 of these families are documented in an article in *Epilepsia* [6].

First, consider the costs of obtaining an accurate epilepsy diagnosis, appropriate specialty care and treatment. Our survey found that 50% of families did not receive a diagnosis for >3 years after the initial seizure. In addition, diagnosis was delayed >5 years for 23% and

> 10 years for 8% of families surveyed. Sixty-eight (68%) of these families consulted 3 or more neurologists before receiving the diagnosis of Dravet syndrome (DS), 29% consulted 5 or more neurologists, and 46% reported that the diagnosis of DS was first suggested by a person who was not a physician. During this time, hospitalizations occur often, and early intervention strategies that support development and improve outcomes are delayed, leading to additional costs that are preventable with a faster diagnosis. Treatment of Dravet syndrome is unique and may be misunderstood by many in the medical community. Some therapies used to treat other epilepsies are contraindicated and often lead to worsening of symptoms, resulting in additional hospitalizations and further delaying early intervention strategies that may improve outcomes.

These delays lead to delays in the identification and treatment of comorbidities, thus substantial additional costs are accrued. In the survey I just mentioned, parents were asked about the types of medical specialists needed to provide care for their child. Thirty different medical specialties were identified. At least 25% of families have consulted 20 different types of specialists or more. This illustrates the large cost for specialty care, but there are further costs for untreated or incorrectly treated comorbidities and failure to coordinate care.

Most parents navigate this process with very little information. There are costs for that, too, especially for the failure to provide resources and information to patients, families and care providers.

Developing strategies to remedy these challenges requires assessment of payment for services, medication and equipment; as well as understanding the cost of time dedicated to these activities, lost work time and cost of travel to locate and obtain support and costs related to changes in quality of life that may include in-home care, obtaining appropriate educational services for the person with epilepsy, modification of family budgets, careers and work choices, modification of homes and vehicles, changes in friendships and leisure activities, and costs for the health of primary care providers.

There is a dearth of published research that may inform the prevention and treatment of familial or genetic epilepsies. In her January presentation to this committee, Frances Jensen referred to mutations of more than 100 genes linked to epilepsy. In the case of Dravet syndrome, 70% of affected individuals carry mutations in the SCN1A gene, and more than 640 different mutations of this gene alone have been identified [7]. But it is still early. Current technology allows sequencing of only the coding regions, or about 6% of the gene. To better understand the epidemiology, population studies on genetic and familial epilepsies are needed in order to achieve an accurate, comprehensive description of the disease spectrum and the incidence and prevalence of mild to severe forms. Detailed longitudinal studies of extended families with epilepsy have the potential to improve our understanding of the etiologies of the epilepsies and lead to strategies for prevention and intervention.

#### 5.1.13. Gary Mathern, *International League Against Epilepsy (ILAE) and David Geffen School of Medicine at University of California, Los Angeles*

Thank you to the IOM committee for the opportunity to speak to you briefly today. The points raised below for the committee's consideration reflect global observations in my role as the Chair of the ILAE Strategic Taskforce, and a more focused perspective on medical advisory boards for rarer conditions related to pediatric epilepsy and pediatric epilepsy surgery. Hence, I wear several hats in attempting to address the worldwide and specific current state-of-affairs and future needs for patients with epilepsy. Within these roles, we ask the IOM committee to consider the following:

Many diseases and syndromes cause epilepsy. Our public health, insurance, and government systems and surveillance methods worldwide should not treat epilepsy as a single entity.

Our public health culture has adopted biases that treat all epilepsy patients the same. As the IOM committee and others are learning,

epilepsy is associated with many known and unknown syndromes and diseases. Industry and government policies are developed for all individuals with epilepsy without taking into consideration the different etiologies and ages of onset. Forward progress will be made when our culture within public health is to repeatedly acknowledge that epilepsy involves multiple diseases. The list of sponsors for the IOM report is an example of the multiple constituents that have come together. The IOM committee can help in this process in their final report by repeatedly acknowledging that epilepsy is not a single disease.

Public surveillance studies to date have not been large enough or sufficiently detailed to understand the epidemiology of common and rare epilepsy syndromes and diseases.

In concert with point 1, information on the incidence and natural history of ALL known epilepsy syndromes and diseases, common and rare, is essential to formulate public policy decisions for patients with epilepsy. While useful, not all patients fit into the currently applied classification of genetic, structural, and unknown (50%). As an example, it is currently impossible from existing epidemiology studies to get accurate data on the incidence of diseases linked with epilepsy commonly treated at specialty centers. What is the incidence and prognosis from population studies of patients with hemimegalencephaly, cortical dysplasia, mesial temporal lobe epilepsy from hippocampal sclerosis, Sturge–Weber syndrome, Rasmussen encephalitis, hypothalamic hamartomas, Aicardi syndrome, and other etiologies seen at comprehensive epilepsy centers?

Surveillance instruments and study methods should be performed so data can be shared and applied internationally for public health policy.

Understanding the global burden of epilepsy requires an ability to understand the epidemiology of the epilepsies across geographic and cultural boundaries. Patients with epilepsy may or may not be similar in different regions of the world. The IOM could help provide leadership by calling for international standards on the methods and reporting of surveillance data for patients with epilepsy. For example, there are initiatives in the European Union and possibly through the Pan American Health Organization that have some common goals and purposes. Forming international alliances to share surveillance data would help serve patients around the world. Population health research and data collection for the epilepsies should include more information on assessment of needs, comorbidities, and access to care.

The IOM committee will repeatedly hear stories about the comorbidities linked with epilepsy. While we know these problems exist, as professionals we have little idea of the scope of the problems. Future surveillance studies should incorporate methods to assess access to care, comorbidities, and available services. What populations with epilepsy currently are not controlled by available methods? All we currently have are estimates. We need factual data. This would include the incidence and severity of patients with refractory seizures, disparities in access to care, comorbidities from drugs in seizure-free patients, and impact on finances and on quality of life to patients and providers. Accurate surveillance data on the epilepsies are needed to plan and justify education and training for providers.

With current and future restrictions on resources for graduate medical education, we as professionals need data in order to plan for training positions. This is true not only in North America but also the world. Understanding the professional needs would help health ministers adjust and plan policy.

Newer surveillance methods should consider cost-effective methods to collect and distribute data on patients with epilepsy. Marketing departments and pollsters have mastered the art of identifying needs and attitudes of the public as anyone knows through home telemarketers and focused advertisements on

cable TV. Is there a role for these methods proven in mass marketing or in the use of emerging internet social media to collect information on epilepsy patients with rarer conditions and provide useful data on emerging treatments and trials?

Thank you for the opportunity to provide testimony and thoughts to the IOM committee. As the committee will hear from the testimony of many others, there are considerable needs for patients with epilepsy. Just as important for the committee are discussions on what constitutes the major problems in order to decide what to tackle first.

*5.1.14. Claude G. Wasterlain, David Geffen School of Medicine at University of California, Los Angeles and Department of Veterans Affairs Greater Los Angeles Health Care System*

I want to express some of my own individual opinions, born of a life spent taking care of patients with epilepsy and doing research on epilepsy. Epilepsy ruins many lives, and it is essential that we identify and address the enormous treatment gaps which still exist today. I want to call your attention to two of these treatment gaps, which I experience every day in practice.

Epilepsy in the elderly is a rapidly growing problem and now accounts for the largest group of patients with epilepsy. Its relationship with cerebrovascular disease has to be studied and may be key to understanding this most rapidly growing segment of the epilepsy population. Post-traumatic epilepsy is also poorly understood, and this is true not only of epilepsy in the military but also of epilepsy which follows civilian head injuries, associated with traffic accidents or with the practice of sports.

My second, and most important point, concerns the mechanisms that we use to fund research. Medical progress is not linear – it proceeds by unpredictable quantum leaps. It is essential that we identify key problems and prioritize them. It is equally important to allow ideas to flow from the investigators in the field rather than from central directives. The best plans that we can make today can only derive from today's limited knowledge of epilepsy and cannot anticipate the truly novel ideas that tomorrow will bring. Investigator-initiated research is far more efficient than centrally directed research because it allows for the unexpected to develop, producing quantum leaps, which is how medical science truly progresses. So the treatment gaps that we identify should be defined broadly, and the strategy used to address them should be left to investigators in the field. The system should be designed to fund tomorrow's investigator-initiated ideas addressing areas of high priority, it should not be limited to the best ideas that even our greatest experts can generate today.

*5.1.15. Carrie Baum, parent of a child with epilepsy*

Thank you for this opportunity. As parents, we urge the panel to address the lack of specialists and training of doctors.

Shortly after our son's first birthday, we asked for a special appointment because Sebastian wasn't very mobile yet. Our pediatrician dropped a bomb on us: Sebastian has "a severe, global, developmental delay and will probably need special assistance all his life."

WHAT?! We were blindsided. Our bright future disappeared instantly – I couldn't envision anything beyond driving home.

Our child was seen for every well-baby check-up by three pediatricians over 8 visits, and none of them noticed developmental delays? Each doctor asked about car seats, home safety, and second-hand smoke, but none noticed seizures or developmental delays until we asked! How is that?

Are pediatricians missing critical training in epilepsy? Given the numbers of children with epilepsy, how does one with seizures and delays go unnoticed by doctors who see 50 children per day? Is it the volume of patients or a lack of training?

The months between that pediatrician visit and the day we brought Sebastian to the ER were a nightmare of stress, anxiety, sleeplessness

and depression. We did test after test and everything came back normal and negative. Each "inconclusive" result was torture; it meant we needed new questions. At 14 months of age, his development was evaluated to be in the 5–6 month age range.

Again, how did three pediatricians miss delays that significant? Where were the recommendations for early intervention?

We called an old family friend, a pediatrician in New York, and spoke at length about Sebastian. Though she never physically saw Sebastian, she suggested he might be having seizures. This was the first time anyone mentioned "seizures" to us.

We called our pediatrician, who referred us to a neurologist about one hour from our home. The earliest appointment was months away. The neurologist agreed Sebastian "might be having seizures." We would have to wait a few more months to get an MRI, and a few weeks to get an EEG and another week to get the results: "a tendency towards seizures" and recommendation: "start phenobarbital." That made no sense. A "tendency towards?" Shouldn't we explore more before medicating a 16-month-old?

The following week, on an ordinary day, with just a little information, I was able to catch 20 subtle eye movements in 18 min. I called the neurologist; she wasn't available on Fridays. We went to the ER. The ER nurse quickly confirmed I was right: "those were seizures. Sebastian was in status." By the time we went home, a week later, Sebastian was diagnosed with a generalized seizure disorder, his seizures had failed to improve from two medications, and he was not a candidate for surgery.

Since that first ER visit on November 2, 2007, Sebastian has never gone a day without multiple anti-seizure medications. He has never had one seizure-free day. And that is just the beginning of our story.

Our experiences are too common and must inform critical changes in the care of children with epilepsy. I urge the panel to address the lack of specialists and the training of doctors in epilepsy. That is our plea as parents.

*5.1.16. Kevin Malone, Epilepsy Therapy Project and parent of a child with epilepsy*

Thank you for the work you are doing in analyzing needs in epilepsy. Thank you also for allowing me to discuss the current state of epilepsy in our society today and what we envision as the future impact of epilepsy on our society.

By way of introduction, I am a board member of the Epilepsy Therapy Project (ETP) and the father of a son who has had epilepsy for 18 years.

The two goals of the Epilepsy Therapy Project are the following:

1. To accelerate the advancement of effective therapies and, thus, to improve the lives of those living with epilepsy and their families. We do so by bringing the discipline and sense of urgency found in the for-profit world to our non-profit funding of research along the drug and device pipelines.
2. In addition, ETP's website is the most widely used and most informative website for people living with epilepsy and their families. Epilepsy.com has nearly 400,000 unique visitors monthly.

You will hear all of the devastating facts about epilepsy from other speakers: largest neurological disorder, impacts 1% of our population, one-third of whom have no relief from seizures, two-thirds of whom suffer devastating, life-impairing side effects of epilepsy, and I could go on.

There are no good diseases, and all of us who are in this fight to improve the lives of those living with epilepsy acknowledge that you are in the difficult position of addressing all diseases with limited funding resources.

What I would like to do is to provide a perspective on funding, or lack thereof, of research to date, and give you some insight into one aspect of epilepsy that will only get worse in the near term because of the conflicts our soldiers are facing today.

18 years ago when my wife and I were informed that our then 17-year-old son had a grand mal seizure, our first question was “What is a grand mal seizure?” In short order we learned more about epilepsy than we ever envisioned. This disease has been around as long as we have been on earth. It is mentioned in the New Testament as a demonic possession. Yet, the advancements of treatment have been miserable. In terms of funding and improvements of the lives of those living with epilepsy, we have failed.

Now, I will admit that this is difficult, as any brain disease is difficult. But, frankly, after my wife and I dug into the current state of epilepsy research and advancements in treatments 18 years ago, we were both amazed and appalled at how little had been accomplished.

So my plea to you today is do not hide behind the mask of saying that this is hard or there is no good research. We need to increase funding for epilepsy research today so that in some tomorrow those parents who find themselves in the position my wife and I found ourselves will not be as devastated as we were. More importantly, those people who have epilepsy will have better drugs, devices and other therapies, perhaps not yet imagined.

Our son developed epilepsy because of a trauma to his head. He was playing in a high school basketball game and went up for what should have been an uncontested layup. He was, however, fouled aggressively and in a fluke the first part of his body to hit the floor was his head. This shook his brain and caused an injury to his brain.

Today, he takes daily medication to prevent seizures and lives with the debilitating side effects of those drugs. Side effects are significant for all epilepsy patients and include diminished brain capacity, depression, significant weight changes, and a variety of physical impairments, just to name a few.

My son went to college not far from here at Georgetown. The route from his dorm to the cafeteria at one point included a walk down a 2-story steel and cement stairway. He once had a seizure after making it down the stairway and taking two steps on to a lawn. What if he had had that seizure ten seconds prior? What if he had had that seizure at the top of that stairway? This is the fear that every one of the 3 million people in this country living with epilepsy lives with on a daily basis. Epilepsy affects more people than autism, cerebral palsy, multiple sclerosis and Parkinson's disease combined.

On Memorial Day this year, you perhaps heard Colin Powell note that 400,000 of our veterans returning from Iraq and Afghanistan have traumatic brain injuries — not to mention those on other fronts who suffer traumatic brain injury. These are injuries similar to the one my son experienced 18 years ago. While we thankfully are experiencing fewer deaths in our armed forces today, we are seeing dramatic increases in brain trauma. Some of these soldiers will develop epilepsy. This is a certainty, not a maybe. We must adequately fund epilepsy research today so that we can provide effective therapies to those soldiers tomorrow. Our young men and women in the military have put their lives on the line for our freedom and the freedom of those people in the countries where they serve. We need to be a country and a people who do not let those who have experienced head trauma end up with a hellish life. It will be hard; there are no promising, easy answers. But do you want to have those soldiers live their lives believing that their country did not think enough of their sacrifice to improve the drugs and devices available for them? Epilepsy takes freedom from those who suffer from it. We cannot allow our citizens who have fought for freedom to lose their own freedom.

Thank you.

*5.1.17. Frances Jensen, Perelman Medical School University of Pennsylvania and the American Epilepsy Society*

Thank you for the opportunity to address the committee on behalf of the American Epilepsy Society, and professionals involved in the care of patients with epilepsy.

*5.1.17.1. Regarding the impact of epilepsy on patients, families, the health care system, and society, and the challenges and opportunities this poses to epilepsy surveillance.* Unlike certain other neuropsychiatric diseases, there is no current estimate of the impact of epilepsy on these factors. While we have limited understanding of the incidence and prevalence of patients with spontaneous seizures, we in the health care community believe that this does not have the granularity necessary to assess the impact. Prior studies show that epilepsy is one of the most common neurologic conditions in the US, affecting at least 1 in 100 adults, and up to 5–7% of children, with an even greater incidence in the developing world. One in ten individuals will experience at least one seizure in their lifetime. While epilepsy is defined as recurrent seizures, its burden is much greater, and epilepsy can be associated with or cause brain damage, neurological, cognitive and psychiatric impairment, or death. Existing studies have not differentiated treatment resistant from treatable epilepsy symptoms and have not to date treated comorbidities in any consistent way. Indeed, unlike other disorders that have definable stages, we have not defined epilepsy for epidemiologic purposes in a reproducible manner. We may better understand the problem if we had “stages” of disease severity and extent. The concept of more uniform measures of epilepsy severity, including the comorbid conditions, is discussed in a report by Kwan et al. [8] regarding the definition of treatment-resistant epilepsy.

Advances in clinical and basic research in the past 2 decades are redefining the disorder. This is both a challenge and an opportunity for epilepsy surveillance. Epilepsy is a spectrum disorder, with multiple etiologies, manifesting multiple levels of severity from mild impairment of consciousness to devastating seizures inducing brain damage and mental retardation. Approximately 50% of patients with epilepsy have cognitive and/or psychiatric problems. Recent data reveal that epilepsy is embedded in other neuropsychiatric conditions: at least 40% of children with autism suffer from epilepsy, and epilepsy occurs more frequently in patients with other neuropsychiatric conditions such as depression and Alzheimer's dementia. Basic neuroscience is revealing important interactions between neuronal dysfunction in epilepsy, autism, depression, and dementia, and more research is needed to understand how seizures may alter brain function to either induce cognitive impairment or exacerbate an existing cognitive disorder. These data point to important new associations to be captured by surveillance as well as directions for therapies aimed at disease modification and cure.

Death rates are 3 times higher in the epilepsy population, and sudden unexplained death in epilepsy occurs in a select subpopulation of people with epilepsy. According to a study of the global burden of disease by the World Health Organization, for life years lost due to disability or premature death, epilepsy was equivalent to lung cancer in men and breast cancer in women. Moreover, as the rates of epilepsy are not well documented in children or the elderly, we have very little data on how family caregivers' quality of life and productivity are impaired by providing care for their dependent with epilepsy.

*5.1.17.2. Concerning the improvement of epilepsy surveillance.* The Rochester study released by Hauser [9,10] remains the current reference for the prevalence, incidence and etiology of epilepsy in the United States. This study has two serious limitations. It is grossly outdated, and the studies of epilepsy etiology and classification were mainly performed *without* modern diagnostic tools such as MRI, CT scan, and the EEG. In 2005, the CDC began collecting prevalence data in 18 states with the Behavior Risk Factor Surveillance System (BRFSS) questionnaire, and this was published in the MMWR in August 2008 [11]. This survey is administered by phone to collect self-reported data on epilepsy prevalence among adults (18+). The study design alone does not reach those who are the most severely impacted by epilepsy: children, those over the ages of 18 who cannot answer the phone, and those cared for in homes or institutions, hence past surveillance systems were particularly limited in capturing individuals in the pediatric, elderly, low socioeconomic, and intellectually disabled populations.

We believe the following existing or new systems may be useful and could be utilized for some focused epidemiological studies relating to specific epidemiological topics:

- CDC mail and phone-based survey systems (e.g., BRFSS, with caveats that this omits those unable to self-report by phone or mail)
- Closed private health care systems (e.g., Kaiser Permanente: omits socioeconomic groups without coverage)
- VA system: useful for assessing change in epidemiology in military
- National Children's study (expand to add additional questions in epilepsy)
- National Neurological Diseases Surveillance System Act of 2010 (still to be approved by the Senate)
- Analysis of national public coverage programs (e.g., Medicaid and Medicare)

*5.1.17.3. Assessment of risk factors and prevention.* Patients with epilepsy represent a highly heterogeneous population. It is imperative that this heterogeneity be tracked in all assessments of risk. It is clear from clinical and basic research that the disease process is multifactorial and dependent on age, genetics, intercurrent medical and associated neurologic conditions. Only such information will be truly useful in informing physicians and patients of a specific individual's risk for epilepsy or epilepsy progression, as well as ultimately informing research and development of prevention. This assessment should also address the problem of stigma and its impact on self-reporting, as well as the impact of neuroimaging data and genetic data. Finally, a thorough analysis of the relationship between comorbidities and risk of epilepsy, its progression, and response to treatment needs to be considered. Likewise, we ask the committee to assess risk in the context of the degree of health care utilization, as a function of demographic characteristics, such as race, socioeconomic, and age.

## 6. Conclusion

As a whole, these testimonies provide a greater understanding of the day-to-day challenges experienced by people with epilepsy, by their families, and by health care providers who are seeking to improve epilepsy care. Testimonies from family members about death of their loved ones due to SUDEP emphasize the importance of routinely providing education on SUDEP, especially in light of it being the leading cause of epilepsy-related death [12]. The most commonly discussed topic in the testimonies was health care. Many people with epilepsy and their families described frustrations related to getting needed health care and their difficulties finding resources and services. The health professionals and researchers who provided testimony offered strategies for moving epilepsy research and health care forward in order to improve resources and services for people with epilepsy; the need for advances in research and health care was echoed by people with epilepsy and their families. Some families also provided specific recommendations and suggestions for improving services and care. Together, these testimonies make a compelling case that much work remains if we are to improve the lives of people with epilepsy.

## Committee on the Public Health Dimensions of the Epilepsies

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