

Reprinted from

Epilepsy & Behavior

Stronger together — the Epilepsy Therapy Project and
Epilepsy Foundation decide to merge. Our personal
stories and reflections

Warren Lammert

This article has been published online prior to it being assigned to a volume and issue of the journal. It is available to order and would be printed with a DOI (<http://dx.doi.org/10.1016/j.yebeh.2012.10.029>) as its reference. The DOI can and should be used in place of the absent volume, issue, and page numbers to cite this article.

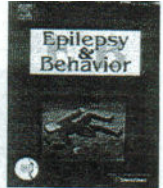
Testimonies submitted for the Institute of Medicine report
*Epilepsy across the spectrum: Promoting health and
understanding*

Joan K. Austin, Dale C. Hesdorffer, Catharyn T. Liverman, Andrea M. Schultz
and the Testimony Group

This article has been published online prior to it being assigned to a volume and issue of the journal. It is available to order and would be printed with a DOI (<http://dx.doi.org/10.1016/j.yebeh.2012.10.003>) as its reference. The DOI can and should be used in place of the absent volume, issue, and page numbers to cite this article.



ELSEVIER



Special Communication

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

Joan K. Austin ^{a,*}, Dale C. Hesdorffer ^b, Catharyn T. Liverman ^c, Andrea M. Schultz ^c
and the Testimony Group

^a School of Nursing, Indiana University, USA

^b Gertrude H. Sergievsky Center, Columbia University, USA

^c Institute of Medicine, USA

ARTICLE INFO

Article history:

Received 5 October 2012

Accepted 6 October 2012

Available online xxxx

Keywords:

Epilepsy

Personal perceptions

Family

SUDEP

Health care

Research

Institute of Medicine

Quality of life

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.

© 2012 Elsevier Inc. All rights reserved.

1. Introduction

The 2012 Institute of Medicine (IOM) report,¹ *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

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.

* Corresponding author at: 3040 N Ramble Road West, Bloomington, IN 47408, USA.
E-mail address: joausti@iupui.edu (J.K. Austin).

¹ The full-text version of the report is available by chapter as PDFs at 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.

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 discomfoting 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.

LIONEL CARMANT, M.D., Université de Montréal, Canada
CAROLYN COCOTAS, R.T., M.P.A., CHC, CHPC, F.E.G.S. Health and Human Services System, New York
SANDRA CUSHNER-WEINSTEIN, P.T., LICSW, LCSW-C, Children's National Medical Center, Washington, DC
RAMON DIAZ-ARRASTIA, M.D., Ph.D., Uniformed Services University of the Health Sciences, Rockville, Maryland
DAVID GRANT, Ph.D., University of California, Los Angeles
CHRISTIANNE N. HECK, M.D., M.M.M., University of Southern California, Los Angeles
DALE C. HESDORFFER, Ph.D., M.P.H., Columbia University, New York
GREGORY L. HOLMES, M.D., Dartmouth Medical School, Hanover, New Hampshire
PAUL E. JARRIS, M.D., M.B.A., Association of State and Territorial Health Officials, Arlington, Virginia
DILIP V. JESTE, M.D., University of California, San Diego
PATRICIA OSBORNE SHAFER, R.N., M.N., Beth Israel Deaconess Medical Center, Boston, Massachusetts
JOSEPH I. SIRVEN, M.D., Mayo Clinic, Scottsdale, Arizona

Acknowledgments

We wish to acknowledge the Testimony Group. They have raised awareness of the issues confronting people with epilepsy and their families and made these issues alive to all who read their stories. We thank them for their willingness to share their stories with a broader audience. The Testimony Group members are the following: Elizabeth Musick, Jim Ashlock, Michael Bornemann, Sabrina D. Cooke, Mark Brooks, Mary Macleish, John Gambo, Lisa Soeby, Joan Ashlock, Jeffrey Catania, Janna Moore, Tom Weizoerick, Jim Abrahams, Carmita Vaughan, Tracy Dixon-Salazar, Lori Towles, Steve Wolchin, Mylissa Daniels, Mark J. Stevenson, Linda Coughlin Brooks, Tiernae Buttars, Brandy Parker, Cheryl-Ann Tubby, Sandra L. Helmers, Richard Leslie, Laurie Kelly, Alayne and Jon VanWagoner, Ilene Miller, Paula Apodaca, Susan Farber, Rob Moss, Melinda Heine, Joan Skluzacek, Gary Mathern, Claude G. Wasterlain, Carrie Baum, Kevin Malone, and Frances Jensen. We are grateful to Steve Schachter who suggested that these testimonies be published and made it possible.

References

- [1] IOM. *Epilepsy across the spectrum: promoting health and understanding*. Washington, DC: The National Academies Press; 2012.
- [2] England MJ, Liverman CT, Schultz AM, Strawbridge LM. *Epilepsy across the spectrum: Promoting health and understanding. A summary of the Institute of Medicine Report*. *Epilepsy Behav* 2012;25:266-76.
- [3] Ficker DM, So EL, Shen WK, et al. Population-based study of the incidence of sudden unexpected death in epilepsy. *Neurology* 1998;51(5):1270-4.
- [4] Nashef L, So EL, Ryvlin P, Tomson T. Unifying the definitions of sudden unexpected death in epilepsy. *Epilepsia* 2012;53(2):227-33.
- [5] Nouri S. Sudden unexpected death in epilepsy. [cited 2012 September 21]; Available from: <http://emedicine.medscape.com/article/1187111-overview>; 2011.
- [6] Skluzacek JV, Watts KP, Parsy O, Wical B, Camfield P. Dravet syndrome and parent associations: the IDEA League experience with comorbid conditions, mortality, management, adaptation, and grief. *Epilepsia* 2011;52:95-101.
- [7] Meisler MH, Kearney JA. Sodium channel mutations in epilepsy and other neurological disorders. *JCL* 2005;115(8):2010-7.
- [8] Kwan P, Arzimanoglou A, Berg AT, et al. Definition of drug resistant epilepsy: consensus proposal by the ad hoc Task Force of the ILAE Commission on Therapeutic Strategies. *Epilepsia* 2010;51(6):1069-77.
- [9] Hauser WA, Kurland LT. The epidemiology of epilepsy in Rochester, Minnesota, 1935 through 1967. *Epilepsia* 1975;16(1):1-66.
- [10] Hauser WA, Annegers JF, Kurland LT. Incidence of epilepsy and unprovoked seizures in Rochester, Minnesota: 1935-1984. *Epilepsia* 1993;34(3):453-68.
- [11] Kobau R, Zahran H, Thurman DJ, et al. Epilepsy surveillance among adults—19 states, Behavioral Risk Factor Surveillance System, 2005. *MMWR Surveill Summ* 2008;57(6):1-20.
- [12] Tomson T, Beghi E, Sundqvist A, Johannessen SI. Medical risks in epilepsy: a review with focus on physical injuries, mortality, traffic accidents and their prevention. *Epilepsy Res* 2004;60(1):1-16.

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

MARY JANE ENGLAND, M.D. (*Chair*), Boston University, Massachusetts
JOAN KESSNER AUSTIN, Ph.D., R.N., FAAN, Indiana University School of Nursing, Indianapolis
VICKI BECK, M.S., Beck Communications, Carlsbad, California
CHARLES E. BEGLEY, Ph.D., University of Texas Health Science Center, Houston
MALACHY L. BISHOP, Ph.D., CRC, University of Kentucky, Lexington

This reprint is provided by Epilepsy Foundation.

ELSEVIER

email: reprints@elsevier.com