AFTER THAT DAY

Stories of Epilepsy

presented by Sofie's Journey

PHOTOGRAPHY BY KAREN HABERBERG WRITTEN & EDITED BY AMYLIZ PERA

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DESIGNED BY MONTY PERA

ABBREVIATIONS

AAC augmentative alternative communication
ADHD attention deficit hyperactivity disorder
AED antiepilepsy drug
(AED) antiepileptic drug
ASD autism spectrum disorder
AVM arteriovenous malformation
CAT/CT computer tomography
CBD cannabidiol
CDKL5 cyclin-dependent kinase-like 5
CHD2 chromodomain-helicase-DNA-binding protein 2
CHOC Children's Hospital of Orange County
CHLA Children's Hospital of Los Angeles
CP cerebral palsy
CPL Canine Partners for Life
CPR cardiopulmonary resuscitation
CPS child protective services
DNA deoxyribonucleic acid
EADDL Epilepsy Awareness Day at *Disneyland*® Resort
EEG electroencephalogram
EKG electrocardiogram
EMAS epileptic myoclonic-atonic seizures
EMS emergency medical service
EMT emergency medical technician
ER emergency room
FDA Food and Drug Administration
G-TUBE gastrostomy tube
ICU intensive care unit
IEP individualized education program
IGE idiopathic generalized epilepsy

ILAE International League Against Epilepsy
ISAP intracarotoid sodium amobarbital procedure
J-TUBE jejunostomy tube
LGS Lennox-Gastaut syndrome
LLUCH Loma Linda University Children's Hospital Pediatric Intensive Care Unit
MAE myoclonic-astatic epilepsy
MEG magnetoencephalography
MPS III mucopolysaccharidosis type three
MRI magnetic resonance imaging
MTS mesial temporal sclerosis
NIH National Institute of Health
OT occupational therapy
PCDH protocadherin
PET positron emission tomography
POLG polymerase gamma, catalytic subunit mitochondrial DNA
PT physical therapy
SCN1A sodium voltage-gated channel alpha subunit 1
SMEI severe myoclonic epilepsy of infancy
SPECT single-photon emission computed tomography
STEM science, technology, engineering, and math
SUDEP sudden unexpected death in epilepsy
TACA The Autism Community in Action
TC tonic-clonic
THC tetrahydrocannabinol
UCI University of California, Irvine Medical Center
UCLA University of California, Los Angeles Mattel Children's Hospital
UCSF University of California, San Francisco Medical Center
VA veteran affairs
VNS vagus nerve stimulator

FOREWORD

BY BRAD & CANDY LEVY,
CO-FOUNDERS, SOFIE'S JOURNEY

I'm not sure where to even start. Fourteen years ago, epilepsy invaded our lives. We had no knowledge of or connection to anyone who had epilepsy. We asked everyone we knew, and soon we were on a new path—well, more like a bumpy winding, downhill slope. It took almost five years to finally get an answer to solving our epilepsy puzzle.

The long version of this story is similar to stories of so many families we meet each year as advocates and producers of Epilepsy Awareness Day at *Disneyland*® Resort and the *Epilespy Awareness and Education Expo*. I don't need to lay out all of the details, but I am happy to say the journey to cure our daughter, Sofie, ended on a Friday, ten years ago, at University of California, Los Angeles Mattel Children's Hospital. Sofie was fortunate to be a candidate for epilepsy surgery. She has just surpassed the ten-year seizure-free mark, but this is hardly the end of our journey. Not by a long shot.

In a family, every member is effected by epilepsy. It may be a single child having the seizures, but know that while one parent is frightened at every jerk, the other is crying more hours than not, and the siblings don't understand why everyone can't simply play, swim, or go to school together. Epilepsy is not fun. It's hard on relationships and hard on those living with the constant fear of having their next seizure.

When our family decided it was time to give back, to really show our doctors some appreciation for helping Sofie, we organized our first ever event at *Disneyland*® Resort. That day in the park brought us the opportunity to launch the *Epilespy Awareness and Education Expo* the following year. November 2019 will be our seventh annual event, and every year, we meet more and more families in search of a better path.

You might be wondering how this book connects to all of this: Each year, we have families that seek us out at the event, relaying stories of their struggles and victories and often how they found a great resource or future epileptologist at our expo. The stories often include troubles and sorrow, but it seems like everyone finds some light, something positive to grab onto like a bolt of hope. We see people networking and finding answers from the nation's top epilepsy specialists. They attend for a solution, a cure, and for hope.

We feel a need to share some of these stories; They are stories of kids who wake each day to fight the fight, of adults who have been fighting their whole lives, and of others who received the gift of epilepsy later in life. Some are healthier than others, yet everyone within these pages understands the struggle of living with epilepsy. Epilepsy is often invisible. Unless you see a seizure, you may never know what it looks like. It comes in all shapes and colors and from all over the world. Unfortunately, being invisible is the root of a problem that diminishes awareness, education, and funding for research for a cure for epilepsy. We want—no, we need this book to break that barrier, to open eyes, to spread awareness, and to educate others about our battle against epilepsy and our search for a cure.

PREFACE

by AMYLIZ PERA

Sometimes creative projects emerge out of the need to explore a story, and sometimes the topic finds you. With this book, the latter is true. Epilepsy has unexpectedly permeated the last year of my life and primarily because of a relationship with the book's photographer, Karen Haberberg.

Not unlike many adult relationships, ours solidified through our children's preschool playdates. We had a shared experience with navigating special needs within the school setting, and we quickly discovered other interests in common. Part of my job history includes consultation with directors and photographers, and I happily sat down with Karen one day to discuss her work.

Meetings like the one I had with Karen often culminate in a suggested to—do list, and some of those items are intentionally lofty. Sometimes people take my suggestions into account, but often they continue to send me the exact same work—without a hint of heeded advice or affected change. Over the years, I'm sure I've told hundreds of photographers to create or publish a cohesive book. Karen Haberberg is one of the rare few who completed that task, and she did it in record time. Karen's book, *An Ordinary Day: Kids With Rare Genetic Conditions* profiles children whose conditions are extremely varied. An understanding this book offers a deeper exploration of the origin of *After That Day: Stories of Epilepsy*. Our process with the first book helped define the process with this book.

Karen lost a little brother to Tay-Sachs disease, and one of her closest friends has a son with Angelman syndrome, so *An Ordinary Day* was easily a passionate endeavor for her. As she compiled her interviews and photographs, I could see her balance her own emotional investment with the strength to listen, to imagine and empathize, and to temper with objectivity. Karen exudes a natural steadiness. She doesn't bustle, but she keeps going like a painted highway line. Her demeanor is of effortless sincerity, and her sweet voice does not betray her unflagging determination. Sometimes I'll see her wipe an eye or swallow a tear, but often, she's handing someone else a cup of tea or a box of tissues.

With Karen's first book, we talked about selecting photos that were honest, and luckily most of the families shared the mission to create a window to an average day in their lives. Some parents only wanted to show lovely head shots of their children, and Karen graciously omitted people who had a change of heart, gently allowing threats and ultimatums to roll off her as a byproduct of the experience. Many parents showed an amazing amount of courage, admitting to raw human instincts, sometimes with frankness born from exhaustion. There were parents ready to commit suicide along with their children; these parents nursed a kernel of hope from which an organization with redefining therapy emerged. We saw the same type of realization for authors in *After That Day;* they also felt a desire to activate.

Despite the wide range of afflictions Karen's first book covered, there were commonalities these families had in their place in the world and their daily struggle to define that. It quickly became apparent to me that rare genetic conditions meant these kids didn't have a large support group of others who shared their experience, and they were often treated by specialists in their affliction. This meant that Karen was in a unique position to draw connections to different diseases in a way that others hadn't. There are certainly rare disease conferences, but these personal profiles brought some basic social—emotional connections to the foreground. Additionally, many of these diseases are hard to diagnose. Karen received letters from people who read her book and discovered they were not alone or that there was a name for what they suffered from. We talked a lot about the purpose of her first book, and we realized it was about connecting people—including the world of healthy people to the inadvertently estranged world of affliction.

Shortly after her book release, Karen attended a west coast—based conference for genetic disorders. Enter Brad and Candy Levy, co-founders of Sofie's Journey. They met Karen and were inspired by her book. Even though she covered conditions that were rare, she cited a compelling statistic: one in ten people are

connected to someone with a rare disease. Brad and Candy easily saw a parallel with epilepsy; an enormous number of people are touched by epilepsy, yet it's not part of our society's vernacular. They had a vision for a book to profile the range of experiences and treatments for people dealing with epilepsy. Their intention was to primarily distribute the book to medical facilities to increase epilepsy education and awareness with a secondary goal to make the book available to the world at large. They knew time and cost would dissuade them from sending Karen into homes to procure photos and stories, but luckily, they already had a forum in place.

Sofie's Journey established Epilepsy Awareness Day at *Disneyland*® Resort (EADDL) and the *Epilespy Awareness and Education Expo* held as part of that event. Karen was able to set up an area at the event to profile potential candidates for the book. We were still discussing the content at that point. Karen's previous book depended on imagery and quotes to tell the story. *After That Day*, however, emerged from stories people were sharing and writing on the event website; there are many people with epilepsy who have full cognitive ability and are, in fact, quite literate. Karen made subsequent trips, as needed, and attended EADDL the following year where additional interviews were recorded, and stories were solicited.

Karen knew I would either unofficially help her with the book or officially accept some creative responsibility. With her first book, I approached my husband, Monty, a Creative Director and Designer entrenched in the world of advertising, to help name the book, handle layout, and preserve the conceptual objectives Karen had through his design treatment. Brad and Candy understood the benefit of proximity for us, and Monty and I agreed to collaborate together again.

I had little connection to epilepsy. In my youth, I had worked at a care home where epilepsy was among the many things the residents battled. I enjoyed my time working there, but memories of those residents are tinged with drama. On the flipside, I once had a friend whose epilepsy was made known to me by way of a confession of sorts, and I remember wondering what the big deal was. He seemed like any other guy I knew, and I struggled to understand the implications. So it was with virtually no connection to epilepsy that I embarked on this project. The book will be completed exactly two years after I committed to the project, and I've grown enormously in my relationship to this condition.

In some cases, I worked from a narrative version of the story, and in other cases, I pulled together responses from questions I had posed, which touched on the areas of interest that supported our mission. I gave myself a sabbatical from other work for the final six months before publishing, so I could sit with each story while editing. I wanted to maintain the voice and writing style of each author but needed the stories to be clearly understood and in adherence to our confines of length and objective. I labored over that; some authors had written pages with detailed account of drugs they had tried and doctors they had seen. I knew the weight of each of those trials, and the opportunity for these authors to vent and be heard was not lost on me. Similarly, I felt a sadness when I saw so many experiences reduced to words—a few sentences to express the impact of a child's death. Many nights I'd wipe off my laptop keys, which were wet with tears. I'd wonder how these authors were able to be strong and if I could be so hopeful in their shoes; I continually came to the conclusion that there was little choice. Ultimately, it's not the words that hold the power in this book. The power lies in the ability of the reader to imagine these circumstances and try to understand what is between the words in the lives that are lived.

Near the end of the writing process, my daughter described an episode she had at school. I gulped in disbelief as the details of her description matched some of those I had read about in my seizure research. I immediately called Brad who echoed my concern and offered his help and advice. My pediatrician brushed it off. I felt the smallest example of what it was like to hear the fear in my daughter's voice and be scared for her and to be heard by someone who was willing to help. This book has changed my relationship to epilepsy, and I hope it will do the same for countless others.

FOR THE FIGHTERS, THE FAMILIES, THE DOCTORS, AND THOSE WHO KEEP FIGHTING EVEN AFTER A BATTLE HAS BEEN LOST.

After that day

Epilepsy wasn't there, and then it was. *After that day, our baby didn't smile. After that day, I lived in fear of falling. After that day, I wondered when it would happen again, reclaiming more of me.*

Epilepsy is a neurological disorder characterized by seizures or abnormal electrical activity. The word *epilepsy*'s origin can offer us translations to synonyms like *seize* and *attack* or *take hold of*. The sudden and unwanted nature of this condition is aptly inherent in its name. It conjures up helpless and defensive feelings. It is not something that seems to grow slowly to be stunted, held back, or assuaged with preventative care. It manifests in events, and the victims await to tally what remains in the aftermath of the assault. Epilepsy is a monster in the closet; you know it will come out, but you don't know when. To complicate matters, everything in the closet is your very own.

These profiles of people with epilepsy represent the voices of the vast number of people worldwide who live with the uncertainty of this condition. Many of the stories are authored by caregivers who have been thrust into a relationship with this affliction. These pieces are not assiduous accounts; they're just a taste of life with this condition, but with a little imagination, one can find empathy with the mortality we all wrestle with.

There is a variance and complexity to epilepsy, which this book embodies. One person's salvation offers another person failure—in the form of medication, therapy, or specialists. Seizures can grip you in a swirling drama, sneak in unnoticed, or come relentlessly in clusters. Sometimes epilepsy can be resolved. Other times it will drag on while it gathers momentum, or sadly, claim a life. Fear, love, and hope ripple through these stories, finding a place to settle. Helplessness can seek relief as pooled emotion spills out into action. Sofie's Journey and foundations like Danny Did or Chelsea Hutchison, all have their genesis in personal experience.

This book is a cry for attention. Epilepsy is not an uncommon phenomenon. Maybe you don't have epilepsy or maybe you do. Maybe you will. Regardless, these stories are here to offer empowerment and perseverance—to encourage us to claim responsibility, to highlight the quest for alternatives, and to inspire us to keep up with life as it marches on.

SOFIE

A Wada test (officially known as an intracarotoid sodium amobarbital procedure or ISAP) allows each side of the brain to be evaluated independently for language and memory function by anesthetizing one side at a time through an arterial catheter.

Although most people, myself included, often see epilepsy as a hindrance in someone's life, it is what has led me to be the advocate that I am today. My story starts when I was five years old. I have no recollection of the first seizure—exactly when it happened or what it felt like. However, I have heard the story so many times, that I can repeat it with ease. From what I have been told, I was sleeping in my parents' bed, when I woke up saying, "I, I, I..." as if I was trying to form a word. In a panicked state, my parents did what all scared parents would do: they called 911. Once the ambulance came to the house to help me, the seizure had already passed. My parents explained what happened, and the emergency medical technicians (EMTs) said they most likely witnessed a seizure.

At this time, my parents were unaware of the fact that not all seizures appear as convulsions, leading them to be curious as to how this could possibly be a seizure. Over the next several years, my body would do a variety of things during a seizure. For example, as my seizures progressed, I would blink profusely. As I got older, I would see a white line appear, which was an aura leading up to the seizure. Then, my arm would start to twitch up and down, and my cheek would push itself up. Then the seizure would pass.

As you could imagine, living a childhood with seizures forced me to be dependent on others for many years. We tried several doctors and medications over the first four years. When I turned nine years old, everything changed for us. We met Dr. Gary Mathern at University of California, Los Angeles Mattel Children's Hospital (UCLA). Who knew that he would later perform brain surgery on me? After a full work up—including electroencephalograms (EEGs), magnetic resonance imaging (MRI), and a Wada test, Dr. Mathern was ready to go, and so was I! Dr. Mathern had told my parents I would have to stay in the hospital to recover for up to two weeks; I ended up being able to leave the hospital after two days. When the doctor came in to see me the morning after the surgery, he smiled and said, "In order to go home, you need to do three things: eat, walk, and go to the bathroom by yourself." I did, and the next morning, I was out! After I left the hospital, I went back home, and after about three weeks, I was back to doing my normal activities including swimming, horseback riding, and ice-skating.

In 2013, I turned thirteen years old, and my family started Epilepsy Awareness Day at *Disneyland*® Resort (EADDL), which is still held every November. We hope our event continues to grow throughout the years to come, as we carry on spreading awareness. I am currently nineteen years old, and I'm a student at Saddleback College. I'm studying journalism and also training to be an EEG technologist to work with my dad, which brings my story full circle. I have also created an Instagram page, based solely on epilepsy, which has reached over three hundred followers so far.

I would like to say that growing up with a history of brain surgery made me feel different from other people at times, but as I got older, that feeling faded. What's more important to me is that I'm seizure-free.

An epileptic aura is the result of neuronal discharge and can manifest in an altered sensory perception through sight, sound, or smell. Auras can precede a seizure or come and go throughout the event. The nature of the aura can be helpful in determining brain activity.

by MICHELLE DEL ROSARIO

If there's one thing I've learned along our journey, it's that sometimes we are taken on a path we had no idea we'd be on, full of twists and turns, unfamiliar territory, scary at times, and ultimately, a learning experience that can steer the direction we take. Discovering seizures for William was one such path. William was diagnosed with autism at age three, and the neurologist we saw at the time brushed off my inquiry about epilepsy and seizures, telling me I didn't need to be concerned about them unless William had a visible convulsive seizure. It was a question I asked, a box checked off with a breath of relief, and we moved on to treating autism.

By age twelve, we had explored several treatments and therapies, hoping to make gains in the areas William was most affected—speech. Even with these interventions, William remained nonspeaking. It was around this time, while attending a parent education meeting with The Autism Community in Action (TACA), that I listened to a physician speak about autism and speech. During this talk, the physician mentioned that an estimated thirty to forty percent of individuals with autism have seizures, and sometimes there is a subclinical seizure activity that can be affecting speech. We were already suspecting that William had apraxia, a speech disorder, in addition to his autism. We decided to consult with a new neurologist who ordered an EEG. When the results came in, we were taken aback that William was experiencing seizure activity throughout the day and night in his left temporal lobe (speech area of the brain). We began to put the pieces together, and the vocalizations or verbal stims he made as words escaped him, the far off stares, and some of the night wakings, all made sense.

Together with our neurologist and physician, we developed a treatment plan, and William began to respond favorably. At first, we noticed the improvement in his sleep. Eventually we saw improvements in receptive language and more responsiveness to speech therapy. Much to our delight, he spoke his first words at age twelve! We have been making steady gains ever since. While we continue to work on verbal speech, it's important to note that William still has apraxia, which makes the motor act of speaking difficult. It doesn't mean he has nothing to say, though! Through the use of augmentative alternative communication (AAC) and effective treatments, we've learned that William has plenty to share. He also has a full and active lifestyle, which includes swimming and playing baseball, and he is always eager to learn.

What I hope families will learn from our story is to keep looking for answers, both the obvious and subtle, and to stay current with new and effective treatments. They are ever evolving and can make a big impact on an individual's life.

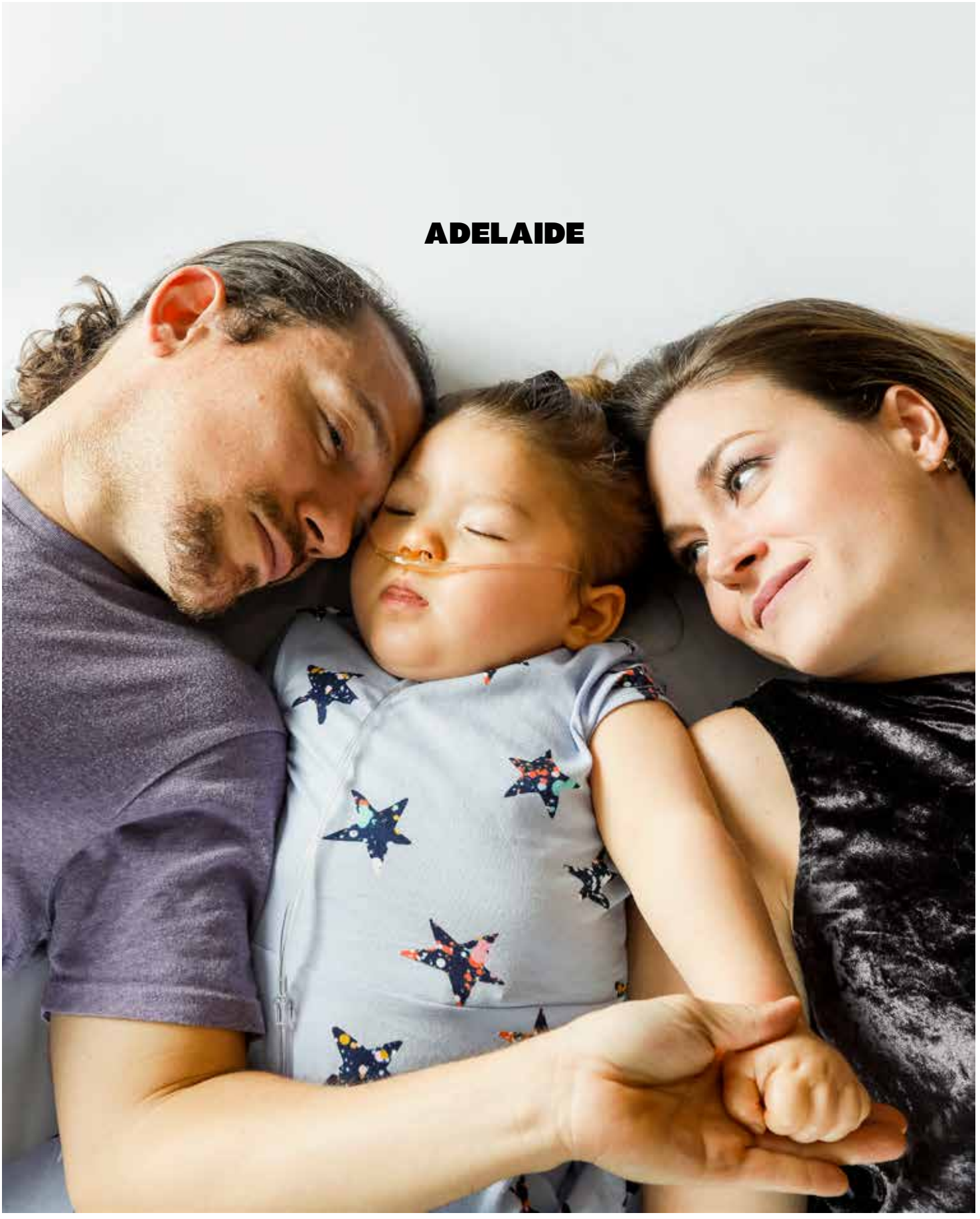
WILLIAM

To best diagnose epilepsy, doctors do a diagnostic test called an electroencephalogram, or EEG. The test is noninvasive and detects electrical activity in the brain via small metal discs (electrodes), which are placed on the head.

It has taken a long time to come to a place of acceptance—and longer to realize that acceptance isn't the same as giving up.

KELLY CERVANTES

ADELAIDE



by KELLY CERVANTES

I should have known when she shot into this world in just over an hour of labor that Miss Adelaide Grace would be a force. Even in her hospital baby photo, she had a look on her face that meant, "I mean business". Early on, we knew that something wasn't quite right, but not wanting to admit anything was wrong, we lived blissfully in denial.

We narrowly avoided a hospital stay in her first few weeks when she struggled to put on weight, but by her two-month checkup, when Adelaide wasn't holding her head up or trying to roll over, her pediatrician advised we meet with a neurologist. After waiting two months to get into a neurologist, Adelaide still wasn't meeting physical milestones and was promptly diagnosed with hypotonia or low muscle tone. We tried not to panic. Ok, she wouldn't be an athlete, but that's fine, neither were we. The battery of tests began when we tried to locate the source of her hypotonia.

Three months later, at seven months old, the next test on our list was an EEG. All other tests had come back normal, so we assumed this one would, too. Four days before the EEG, she had her first seizure. Shortly after, our Adelaideybug was diagnosed with generalized epilepsy. I remember thinking that the seizures were a distraction; that if we could just get them under control, we could get back to the hypotonia, which was clearly the real issue. We had no idea just how damaging the seizures would be.

Over the next two months, we didn't see another seizure. In fact, Adelaide was thriving. She was holding onto objects, singing, laughing, banging toys on her highchair, and sitting with just a little assistance. Our family was preparing to move from New Jersey to Chicago for my husband's job, and I was in Chicago looking for our family's new home, when I got the call. After noticing weird head drops, my husband took Adelaide to the hospital, where a doctor diagnosed her with infantile spasms. By the time I could make it back to the hospital in New Jersey, Adelaide was a shadow of the baby I had left just three days before.

To this day, we do not know what causes Adelaide's seizures or the rest of her symptoms. We have put her through nearly every clinically available test and even gotten her accepted for tests only available on a research basis. Still no answers. Which also means no leads on what the best treatment might be, no clue what her future might hold, and nowhere to direct our anger and frustration.

After the initial regression, Adelaide eventually got her smile back and regained most of her lost motor control, but she never made it back fully. Since then, she has experienced three more regressions due to infantile spasms. Never fully recovering from each, she is now developmentally equivalent to a newborn. It's been over a year since we've seen her smile or seen any real developmental progress. She is now on oxygen twenty-four hours a day and is still having near daily seizures. But she's a fighter. With what she's been through in her short life, she wouldn't be with us today, if she didn't mean to be. To others, they may see a child that rarely opens her eyes, who may be sleeping or slumped over or sucking her thumb. But I know how much work it is for her to suck her thumb, and yet she manages the coordination and the strength to suck, because she wants to. Heaven forbid you try and help her get her thumb to her mouth; she will jerk away and insist on doing it herself. My independent dependent child. You can almost hear her say, "No! I do it myself!" like the stubborn three-year old I know she is.

Every day, I mourn some piece of the life Adelaide should have had before epilepsy stole her development and cognition. It has taken a long time to come to a place of acceptance—and longer to realize that acceptance isn't the same as giving up. It just means we don't have to be as sad all the time. That we can give ourselves permission to enjoy Adelaide for who she is, because, truth be told, there is no better snuggler around. Adelaide has given us the gift of compassion, patience, empathy, and determination beyond anything I could have imagined in my life. And yet, I would trade it all in to have my baby be a typical little girl—a feisty, independent, tantrum-throwing, three-year old... who could smile. What I wouldn't give just to see her smile.

FACT: EPILEPSY IS A COMMON CONDITION AND AFFECTS AT LEAST 65 MILLION PEOPLE AROUND THE WORLD.

SAM

I was born in 1975, and I'm from Bristol in South West England. Throughout my life, I've been affected by a variety of physical situations such as ending up in hospital when I was age three after falling down a flight of stairs; my sleep being affected a lot by moans, feeling hot and feverish, confused and jerking; losing my balance quite a bit; and daydreaming. During my childhood, this was seen as anxiety problems. It wasn't until 2008, when I ended up in hospital after a fall at work that a link was discovered. The fall had included a six-hour recovery time, unresponsiveness followed by unprovoked range of emotion, affected balance and hearing, and erratic body temperature. I seemed to be in and out of consciousness. After seeing my doctor, I was finally referred to a neurologist who told me I had idiopathic generalised epilepsy (IGE).

The diagnosis later changed to simple generalised partial seizures. To manage this, I take various antiepilepsy drugs (AEDs). In 2016, a blood test indicated allergies to some ingredients in AEDs and also the possibility of genetic faults. As a result, I was invited to apply to the NHS 1000 Genomes Project, and to date, I'm still awaiting the result of that. In addition to management through drugs, I've cut out almost all alcohol (although I do like an ale now and then), and I do a lot of walking and hiking. I travel via public transport such as buses, trains, and sometimes taxis, when there is no connection. I try not to let stress get to me.

Along with epilepsy, I was born with spina bifida occulta (known as closed spina bifida), which causes hydrocephalus. In October 2017, I was late diagnosed as an adult with autism. My balance is affected, and I also have tinnitus. Various neurologists have ignored this, along with my needs and some communication issues I have, so I've had to leave ignorant doctors and seek second opinions. I've had

cases where video EEGs have come back normal, but later discovered the reports weren't read, so they failed to see I was having seizures every night while being recorded. I've had three MRI scans, and I also had a neurologist and epileptologist completely ignore my MRI which shows scarring (lesions) on my brain between my right temporal lobe and frontal lobe.

My healthcare in the UK has become disjointed, and I feel there is no continuity of care. My healthcare professionals aren't talking with each other, so I am looking to other experts in epilepsy who understand co-morbid conditions such as autism and spina bifida occulta. Friends and family members, who have ignored my conditions and symptoms, have also impacted me, and I've experienced bullying and emotional impact at work from other employees who don't understand epilepsy and seizures. I've started to fight back by using employment and disability laws, and I've helped to inspire others with epilepsy to use the laws and protect their rights.

I want people to remember that epilepsy is common. There are a variety of foundations and charities to turn to, and we can help bring epilepsy and its various rare syndromes and co-morbidities out of the shadows by talking to others and forming a community of people to support one another online or at events in person. Attend EADDL and the *Epilepsy Awareness and Education Expo* to network and have fun with families affected by epilepsy, and learn to ask questions at this unique event—and above all else, don't worry, be happy!

Sam has been working in television, radio, stage, and film for the past couple of decades and has a diverse body of work as an actor, presenter, public speaker, and producer. He has deep range of experience in advocacy and activism. He has spoken on a variety of topics, which includes, in broad strokes, technology, coffee, entertainment, and healthcare.


ALIANA

Cannabidiol (CBD) is an active ingredient in cannabis, derived from the hemp plant and is a popular natural remedy used for many ailments. (It can be taken as CBD oil, which only contains CBD as the active ingredient.)

by MARIA SELVA

Aliana was ten months old the day we rushed her to the emergency room. It wasn't until we arrived and spoke to the nurse that she let us know Ali had experienced a seizure. After tests and evaluations with no signs of a cause, the doctors explained that it's common for babies to experience one febrile seizure. But in the weeks to follow, Ali continued to have seizures with no explanation. Weeks turned into months, and months turned into years. The seizures were consistent.

By the time Ali was two, it was obvious she had delays in her speech, cognitive, and physical abilities. In addition, she was very sensitive to rough textures and extremely picky about certain fabrics on her body. She was intolerant to loud noises and would cover her ears around blenders, loud music, and screaming kids. Every day, she would flap her hands when in deep thought or out of excitement. She started speech and physical therapy (PT). After a year, she had accomplished her goals in PT and moved on from that program. Simultaneously, her seizures started declining naturally. She averaged about one minor absence seizure a month, and we (along with her doctors) had never given her any regular anti-seizure medication, in hopes she'd grow out of them. Seemingly she did.

A few months before her sixth birthday, while on vacation, Aliana had a partial seizure, followed by two general seizures that same day. She was released from the emergency room and prescribed Keppra but the side effects were almost immediate. Within minutes of her first dose, she experienced mood swings and aggressiveness, which was completely out of the norm for her. My sweet, kind, loving, little girl was out of control, and her erratic behavior terrified me. She was a different person. After a few days, I called the doctor to express my concerns. The doctor suggested keeping her on the medication, but my motherly instincts won out, and I took her off within a week but vowed to find the best treatment for her.

Over the next year, we moved to southern California, and Ali experienced a bunch of absence seizures. It was summer of 2017 when we came across cannabidiol (CBD) oil in our research. We read about its many health benefits without any psychoactive side effects, and we knew this was it. We bought our first bottle at a health food store and started Ali on an extremely low dose. We didn't realize at the time that the dosage was too low. That fall, during the first week of her new school, Ali had a grand mal seizure and experienced two more after she was rushed to the hospital. The doctor gave her a high dose of Keppra, and she stayed over the weekend to be monitored. Despite the concerns we expressed, she was prescribed Keppra again, and we were told to keep her on it. The moodiness and aggressiveness returned, and we felt trapped. Doctors were not listening to us or providing other options. Such harsh medication for minimal seizures didn't add up to us, and we opted to try a higher dose of CBD oil. We put her on seven drops twice a day. Ali had an absence seizure at school, and the school nurse pressured us to take her to the hospital and put her back on Keppra. We knew the CBD oil was effective, but we just needed more time, and there was no need to take her to the hospital over a one minute absence seizure. Just a few days later, child protective services (CPS) showed up at our door.

They conducted an investigation under allegations of severe medical neglect, stating they had serious concerns about the safety of our children. A week later, on October 28th, 2017, the police showed up at our door, along with the social worker that conducted the investigation, with a warrant to take Aliana into custody. All this, because of our choice to use CBD oil instead of Keppra. I went live on Facebook to record what was happening. I was in disbelief, and there was nothing any of us could do to keep her from leaving. Our biggest prayer was that she could return home soon and not suffer any seizures due to the trauma of being medically kidnapped from us. It was four days and nights before the judge allowed Aliana to come home, but it came with conditions, including putting her back on Keppra. We reluctantly agreed, but like any loving parent, we'd do anything to get our child back.

Our case was ongoing and was dismissed in court in December, but the damage had been done. Our family had been violated in a way I never knew possible. Aliana had experienced a cluster of seizures, migraines, and withdrawals, as we tried to wean her off the medication. A different neurologist worked with us to get Ali's stability back, using CBD oils. It took months, but eventually she was able to go back solely to CBD oil. Today, she is still on CBD oil and goes months without a seizure.

Not a day goes by that we don't think about what happened to us, but it makes us grateful for our health and for being together. We've used this experience to help educate other parents and create awareness about CBD oil and the contradictory federal and state laws surrounding it. Although it's legal in California, children can still be separated from their parents for using it.

Ali became a little hero on Facebook for many who witnessed our nightmare. Articles have been written about our ordeal in Orange County, I was asked to share our story at the *Epilespy Awareness and Education Expo*, and our family will be featured in a documentary coming out later this year. No parent deserves to go through what we went through for seeking the right treatment for our child. I encourage all parents to learn your patient rights when going to a hospital, learn your legal rights as parents, listen to your child, and listen to your intuition.

It was 1998. That's when it all began. Up to that point, I had been a normal teenager, albeit a little clumsy. The amount of dishware I broke in the couple of years then is astounding, particularly in the mornings. At school, I gazed off into space. I went from being a top-notch student to a kid struggling with basic information. My body ached. I woke up sore and had no idea why. At age fourteen, I had my first tonic-clonic (TC) seizure. Nothing is more embarrassing than being pulled out of a shower (naked) by your parents. A neurologist eventually diagnosed me as a "person with epilepsy". Things changed. Suddenly, I faced an onslaught of MRIs, EEGs, electrocardiograms (EKGs), special appointments, medications, side effects, and of course, the seizures. I was told by the doctors that there were a lot of things I would never be able to do. I wouldn't live on my own, travel, work, be in a relationship, attend normal schools, be athletic, or live a regular life. School was horrid. The students (previously my friends) thought I was faking it for attention, and the teachers that actually believed I had a condition didn't know how to deal with it or didn't want to. It's hard enough being a teenager without a major medical condition included.

Jump forward eighteen years. My life has been a very different experience. I have lived on my own and have been married. I have two post secondary degrees, numerous certificates, travelled extensively, worked on archaeological sites, and have a law enforcement career. I have competed in countless races. Many are international marathons and half marathons, and I have registered for several more. I write a blog about my experiences with epilepsy and running and have had positive feedback from people with numerous other medical conditions.

I take four different prescription medications. The medicine that best controlled my epilepsy was damaging my liver, so I had to go off of it. Some of the side effects have been drowsiness, irritability, vertigo, and focus. I have experienced depression, particularly when I was young and first diagnosed. Unrelated emotional circumstances become inflated with the side effects of medication and the impact of epilepsy and seizures. Athleticism as management has resulted in a high level of fitness, overall health, drive to focus, and knowledge that challenges can be overcome.

I still have seizures. That is the reality of being epileptic. Sometimes, despite the seizures, I can still race. Sometimes it stops me. There have been challenges in my profession. I have had seizures in front of the Eiffel Tower, on a staircase in Rome, on an archaeological site in Greece, and at a guesthouse in Germany. The only thing the doctors were right about: I have not had a regular life. I have had an amazing life. Every single day, I am epileptic. I am also an athlete. I am also on Officer. I am also a blogger. I don't know where my epilepsy experience will go or how my story will end. Until it does, I will embrace and love every moment of the life I have made.

Teen epilepsy presents unique issues that benefit from a holistic model of treatment; biological, psychological, and social support helps transition teens into adulthood.

AMANDA

DA
NE

by KRISTA CAPO

In the early years of Dane's seizure episodes, he never seemed to have a chance to fully emerge from his fog after having a seizure. The episodes would reoccur with clocklike frequency for up to a week or more and last up to four hours at a time. We would take him to the emergency room (ER) with status epilepticus, or he'd cluster with a series of shorter, generalized TC seizures. Sometimes we would go a couple of weeks between episodes, and sometimes it'd be a month. His behavior, language, and responsiveness seemed to improve with distance and time from his last episode. Then, before he had the chance to show what he might be capable of, he would begin another episode, and his behavior would slide back. It was hard to tell what was causing the regression, the seizure episodes or the drugs he took to fight them. These drugs did not appear to alter the severity or length of the seizures in any way. The seizures just seemed to come when his body and mind could not fight them off and then ceased when his body stopped them.

Between the seizure activity, Dane would become more active and responsive. During these periods, he'd enjoy activities that included swimming and diving underwater in pools and the ocean. He seemed to love hearing the same books reads to him over and over. He loved to climb, or at least he was inclined to. He would climb high up fences and trees, seemingly unaware of the danger of falling. He also had a high tolerance of pain when he became injured. Dane would wander off at times, as if he had a predetermined place to go. He seemed to have no fear of leaving the safety of his parents behind. His vocabulary was not extensive and became less so around seizure episodes. He'd throw angry fits about things that bothered him. Sometimes he'd pitch a fit about driving down a different street on the way home.

He lived with refractory epilepsy and autism, but his seizures mostly disappeared from age twelve to eighteen, with only four seizures that entire time. We found normalcy and made huge gains in everything. Then BOOM! It was like the world opened up to hell and swallowed us whole. He got sick, and he seized for two solid weeks around the clock. Out of complete panic and fear, we put him on Klonopin, as recommended by his neurologist. We decided it didn't work, and after two years, we began the dreadful process of weaning him off. The first attempt was a nightmare. The second attempt took a whole year, and he suffered horribly. His seizures were awful with every taper, but we blazed forward because we noticed big changes in him.

Recently, Dane was found to have a protocadherin (Pcdh) gene mutation as the likely etiology of his epilepsy. He's twenty-three now, and as of late, he is seizing every Saturday morning around 6:30 a.m. The last two years have been complete hell, to be honest. He was hospitalized earlier this year due to withdrawal. He was having hallucinations and shitting himself.

Somewhere in all of this, we started an art business. When he turned eighteen, Dane decided he wanted a job and set out to get one. He applied at over one hundred places to no avail. After seeing him sink, we agreed to an art show with all of his art around my house. The night was incredible, and he came alive. For the first time in his life, he was able to shine and have success that was only his. In that moment, Dane Capo Art was born. I am not sure how we do it. He paints when he can, and I market and handle everything else. For years, Dane was told that he couldn't, and then magic came out of him. Clearly, he can.

Status epilepticus is a dangerous emergency condition in which seizures are long lasting or close together without consciousness recovered in between them.


SEIZURES

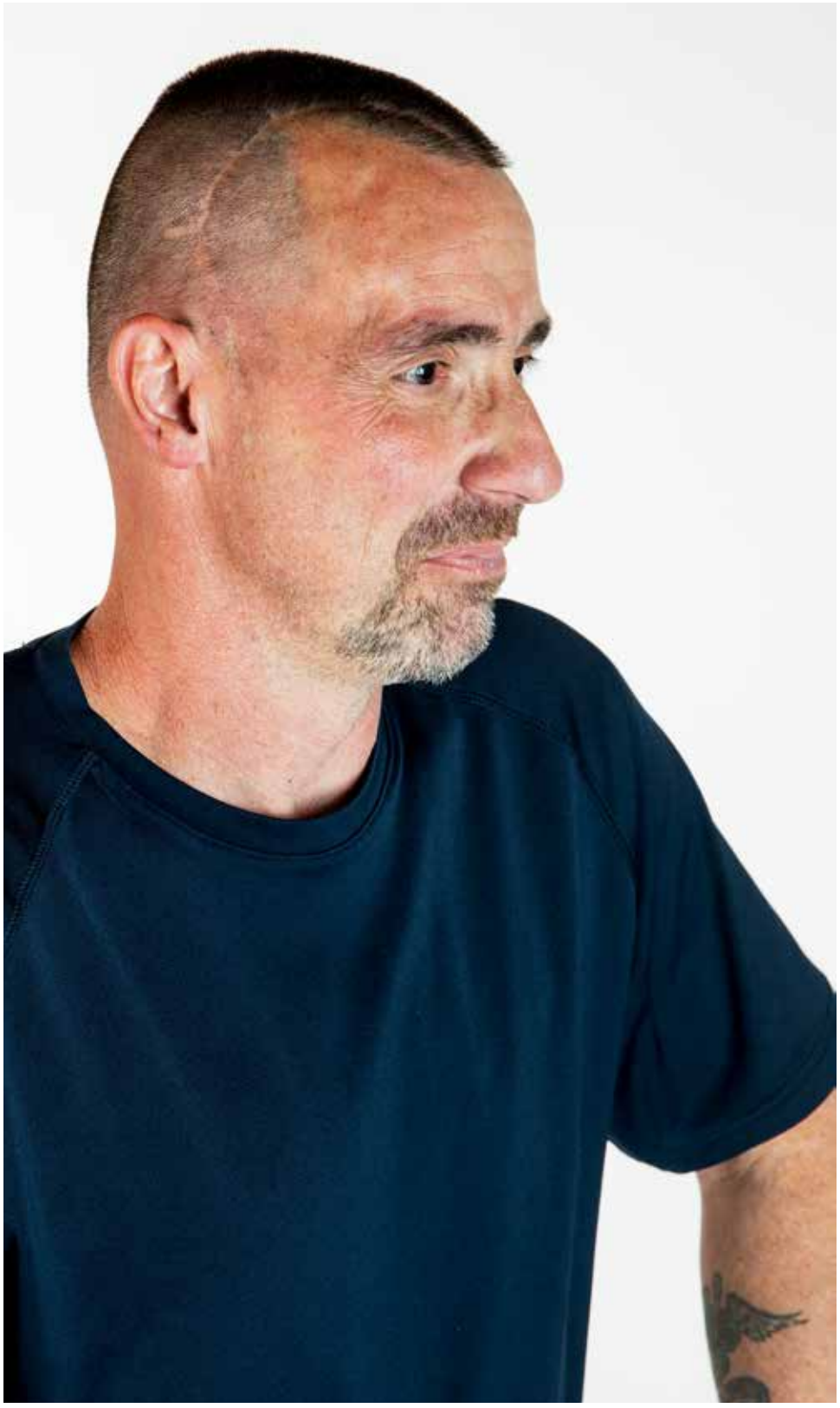
JOHN

by KATIE BOWEN

John Bowen was raised in a law enforcement family. To afford college after high school, he joined the United States Navy and served in the Persian Gulf War. After his service, John went to college and graduated from the Police Academy as a certified police officer. He was hired by the same sheriff's office his dad worked in as a deputy. He was enjoying his time in law enforcement when that came to an abrupt halt.

John was working in the central command room for the jail one evening, when suddenly his hands started to tingle. His hands and arms slowly started to curl up to the point where he couldn't move them. He used his elbows to call for help. His sergeant saw that John's arms were curled up, and his face was droopy, so he called the squad to take him to the hospital. By the time he arrived at the hospital, he was normal, and they couldn't determine what had happened. They suggested he see a cardiologist, and the next six weeks were filled with appointments, one test after another. Finally, a neurologist ordered an EEG, which showed seizure-like activity, so a computed tomography (CT) scan was ordered.

The day of the CT scan is one we will never forget. The children were dropped off with a relative. The moment we returned home with them, the phone rang. They needed John back in the office as soon as possible. We were informed that John had a mass on his right temporal



In an epic foreshadowing, John and Katie's check enginelight pointed out a problem with their spark plugs while embarking on a six-hour drive to the hospital for neurology tests. Their harrowing experience over the following days left Katie spent; "I feel guilty when I am so tired and just want to cry when I look at what he goes through on a daily basis."

lobe and needed an angioplasty the next day to determine if it was an aneurysm or a tumor. Only three weeks to the day after finding out John had a tumor, he was having a five-and-a-half-hour brain surgery. The surgeon felt confident he had removed the entire tumor and hoped it would stop the seizures.

He recovered, but the seizures continued. The neurologist kept changing and increasing the meds. John's father-in-law sold his house and moved in with us to help take care of the kids, because John was not able to do anything other than sleep. Some of the tumor remained, so two and a half years later, he had another surgery to remove the rest of the tumor and as much of the damaged temporal lobe as possible without impacting his memory. Four centimeters were removed, but the seizures continued.

The neurologist suggested a second opinion. After countless appointments, monitored seizures, and various theories, she decided John was creating these episodes in his head so she couldn't help him anymore. We reached out to another neurologist at the Cleveland Clinic. John's case was accepted, and we headed there in hopes of getting answers. John was put on Dilantin, and that day was his last seizure for three years.

Fast forward. We were living in Georgia, and John appeared to pass out in his daughter's room. In the ER, we learned it was a grand mal seizure. This was new territory. After a review, the new neurologist suggested a vagus nerve stimulator (VNS). He went from eight seizures a day to one a week, and then eventually to one a month. He said John might never be seizure-free, and we started to accept the reality.

After four years in Georgia, we moved to Arizona. We heard the all too familiar words, "I can't help you", until the director of the Epilepsy Program at Barrow's Neurological Center accepted John's case, and we were excited. A new medication, in addition to the two he already took, along with VNS, offered ten months without a seizure. That didn't last. After five years, this doctor determined that John is a "honeymooner". His body will respond to new treatments, but eventually the newness will wear off, and his seizures will return. During the past year, John has developed toxicity and has been weaned off critically high levels of Dilantin. In addition, I had to fight the Veteran Affairs (VA) to get a second opinion from an out-of-state doctor, which is something most non-veterans don't have to fight for.

Recently, we were finally able to do additional neurology tests, and his positron emission tomography (PET) scan indicated a non-functional right temporal lobe. In addition, they discovered a partially collapsed lung and a need for a pacemaker. He had a seizure, and his heart and brain stopped functioning for twenty seconds during testing in the hospital. The neurologist said the drop in heart rate was rare in an epilepsy patient, and we determined to address the heart first and work in a pacemaker surgery. I was also told he is high risk for sudden unexpected death in epilepsy (SUDEP), and I'm not going to lie, between that and the flatlining, it was hard to sleep. John asked if he needed to put a heart around his tattoo now.

In the hospital, John woke up, and blood was everywhere. It was coming out of the wound from the pacemaker procedure, and he had to lay flat. He had another seizure and ripped off the electrodes, feeling itchy and angry. It might've been the high dose of drugs. He is back on Onfi and Zonisamide again, as he can't take the sodium channel blockers. On top of this, we're getting a dog. We'll use a book that Little Angels Service Dogs wrote to train her as an assistance dog. Through it all, I'm still grateful—to Brad and Candy's event EADDL, which has seen us through and also connected us with The Danny Did Foundation for a monitor, and I'm grateful that we're the lucky ones. John is still alive. We will not give up hope and will continue to fight for a cure.

[On March 11th, 2019, John underwent a successful temporal lobectomy at University of California, Irvine Medical Center (UCI). Just two days post surgery, he was dancing in the hall and eating chocolate cake. Not to be mistaken, he'll still have some recovery ahead of him, but his surgeon and epileptologist are very happy with the general outcome.]

Vagus nerve stimulation (VNS) sends regular energy pulses to the brain. The device is implanted in the chest and the pulses are sent through a wire that connects to the vagus nerve in the neck.

JOCELYN

by IRIS MOLLISON

My daughter was diagnosed with epilepsy right before she turned two years old. At first, doctors didn't think she was having a seizure by the way she was responding, but that wasn't the case. We brought her home, and later that evening, it happened again, and the seizures continued.

Today, Jocelyn (nicknamed Bella) has intractable (uncontrolled), clonic, myoclonic seizures. She has been grouped with Lennox-Gastaut syndrome because of the type of seizures she has, but they don't know if that's the cause. Sh e has no other condition. She is healthy and strong. Her seizures have caused her to have mental and speech delays and have given her an extreme lack of safety awareness.

Up until two and a half years ago, she was on high doses of felbamate, Onfi, and Depakote. She had been hospitalized for pneumonia, and her [previous] doctor had made changes that caused extreme harm to Jocelyn's well-being and quality of life. Her dad and I made the decision to change doctors, and a VNS was reintroduced. Soon after that implant, we were able to lower her medication, and she quickly started getting better and back to herself. We have seen remarkable improvements in the areas of awareness and alertness since then.

One of the things that has impacted her life is the lack of safety awareness, which does not allow her to be left unattended at anytime. Another impact is the deficit in her cognition, which requires assistance in all areas of her life. Because of her lack of speech, she can get frustrated or have behaviors that are outside of the typical child's. I have learned a lot of patience and understanding, since these are things that she can't control.

Jocelyn was very young when this first started. It's all she has ever known; taking medicine, going to the doctor, and getting help with everything is normal for her. She loves being with us, and it's rare that I leave her behind. She is happy and easy-going. I feel she behaves better than her siblings sometimes. She doesn't cry and has a very high tolerance for pain. God has given her incredible gifts to help her deal with everyday life. I feel the hardest times have been at the hospital for long periods of time. It's hard for us as a family, but the VNS implant has made it easier with fewer hospital stays. Jocelyn goes to middle school and has an individualized education program (IEP) with a personal helper all day. They work on making progress toward her goals. She likes school along with music, painting, cartoons, Cinderella, and playing dress-up.

My advice is not to believe everything the doctors say. They are just like us and can make mistakes, too. Take their input, do your research, and stay informed. I continue to learn new ways to help my daughter. Stay hopeful. I don't think anything in life is easy. My perspective has changed, and what I've learned, through God's grace, is that Jocelyn is a blessing.

An individualized education program (IEP) is an evaluation-based, special education plan used in public schools. An IEP includes services and devices needed to create the necessary learning environment for a child with disabilities and enables a communication process for the student's support team.

BROCK

by MANDY GRAHAM

Brock was three when it happened. I was home on maternity leave with our youngest, who was just two weeks old. Brock leaned over the bed to play with him and had his first seizure. At the time, we thought he had a random fall and hit his head, which caused the seizure. In hindsight, we know it was an absence seizure that preceded the fall, turning it into a grand mal.

Brock was so little when all of this happened, so this is all he knows. For the rest of us, emotionally, this has been a huge roller coaster. His younger brother is amazing with him, but he has anxiety from the seizure activity; sometimes when something happens, he's afraid that Brock won't get the immediate treatment he needs or the care that is essential.

Brock has intractable epilepsy [also called uncontrollable or refractory epilepsy], meaning it doesn't come under control with treatment. Specifically, he has myoclonic-astatic epilepsy [*myoclonic* means muscle jerk.] The epilepsy has caused a learning disability and has also limited him physically, due to the severe fatigue from the seizures and meds. He has to be carried at times. Everything about our lifestyle has changed. Brock can't tolerate the heat, so outdoor time is limited. He has a special diet, which also dictates the environments we can be in. Brock loves to be around people when he can. He plays Wii, loves his small toys, and likes being told stories, but his lifestyle has been completely impacted.

The amazing medical team at UCLA, in the teen and adolescent transition program, has been helping us navigate his care. Slowly, over the years, continual modifications to multiple medicines have helped us find improvement.

Doose Syndrome is a genetic, intractable epilepsy and is similar to Dravet syndrome or Lennox-Gastaut, which makes it difficult to differentiate. As a result of this, Brock's diagnosis has changed since this story was written.

He currently has three medical supplements and a VNS. He's on the ketogenic diet, and he takes a lot of naps, because of the fatigue.

We're lucky to have found this amazing team to help improve Brock's health and give us hope, which is what we needed. We're beyond thankful to Brad and Candy Levy who helm EADDL and helped connect us to our team and resources. If it weren't for them, we wouldn't be where we are today. Continual awareness and education is the key. Epilepsy is a beast. As a mom who has a little one, we've been so blessed to meet people who've encouraged us and not let us give up the fight. So don't give up. As a parent, no one knows your child better than you; so never let anyone tell you differently.

Children with EMAS who have long seizures (generally considered five minutes or longer) may need emergency treatment with a rescue therapy, a quicker solution to stopping a seizure in progress.

WE NEED TO EDUCATE THE PUBLIC ABOUT EPILEPSY AND REMOVE THE STIGMA AND FRUSTRATION THIS INVISIBLE DISABILITY INFLICTS ON PEOPLE.

ED CRANE

Epilepsy is my invisible disability, and it became part of my life thirty years ago. I'm sixty-one years old, and for the first half of my life, I was healthy, active, and on a great career trajectory. I studied engineering in the U.S. Merchant Marine and traveled the world. Then, I worked as a field director in the insurance industry in New Jersey and New York, and for a decade, everything went well. In 1987, I was at a business meeting in Philadelphia, and I suddenly collapsed from a grand mal seizure. It was the onset of epilepsy, which changed my life forever.

I continued working for the next fourteen years, but my seizures, which only happened a few times the first year, became increasingly more frequent over the years—from monthly, then weekly, to daily. Eventually, they took control of my life. In August of 2001, I had to go on disability and leave my 24-year career because of my medical condition. This was a profoundly sad moment in my life.

In 2002, I had brain surgery on my left temporal lobe to reduce the number of seizures. It helped but also impaired my short-term memory. Life was still a major challenge for me, and I needed help. A friend had shown me a TV program about the non-profit organization Canine Partners for Life (CPL). It detailed the wonderful work assistance dogs can do for disabled individuals such as retrieving out of reach objects, opening and closing doors on command, turning light switches on and off, providing balance and support, providing stability on stairs, helping bed-dependent individuals move, assisting with dressing, taking purchases and wallets to a cashier, and alerting people to imminent seizures and cardiac events. This got my attention, and I contacted CPL to arrange an interview.

ED

I was introduced to a female black Labrador retriever who would be my home companion dog. Amazingly, at our first meeting, she warned me of an oncoming seizure twenty minutes in advance. I lay down on the floor, and she waited the seizure out lying by my side. I knew at that moment my life had changed for the better. It was a new beginning for me. Our relationship as a team was truly amazing, and my life seemed normal again. We were together for about eight years before she passed away in 2011.

Alepo was my next assistance dog. He warned me of seizures with complete accuracy and reliability. He wasn't satisfied until I lay down, so he could place his front legs across my waist. He wouldn't let me up until my seizure was entirely over and would lick my face to signal that it was safe to return to my feet. We were together as a team for six years before he retired.

My current dog from CPL is named Zern. He wears a harness, which I keep a good grip on to help with my loss of balance. Zern, and the other dogs I've worked with, made such a difference in my life that I founded a non-profit company called My Assistance Dog, Inc. We spread the word about the need for assistance dogs and the benefit they provide to disabled individuals and their families. We also hope to give support to the assistance dog community at large. We don't raise or train dogs, but rather celebrate the great work of the dogs and organizations that do and help them protect and advance our rights and promote awareness.

Epilepsy is a true battle in life, between the seizures, physical injuries, chronic head pain, frustration, and depression. I'm truly blessed that I have family and friends who have helped and supported me in so many ways. I am truly grateful to my sister and her hubby, who I live with, for being there for me. (May God bless them both.) Also, my service dog, who is with me twenty-four hours a day, helps me fight this battle, and I am truly grateful—to both Zern and Alepo for taking away the control epilepsy had on my life and returning a sense of normalcy to it. This has made a difference to me, and it is a true miracle.

Temporal lobe resection or lobectomy is a surgery in which a section of the brain is removed where seizures start. It can lessen or prevent seizures or make them less severe.

DAL

I A

I was born in April of 1997. I was a perfectly healthy child until 2008, when I turned eleven years old. About two weeks after my first menstrual cycle, I started falling for no apparent reason. When the falls increased to five times a day, I went to see a pediatric orthopedist. After trying different kinds of shoes without results, I started to feel sensitivity on the bottom of my left foot. The combined symptoms were not typical of a foot problem, so I went to see a neurologist. I was told it was a nerve problem and was given

medicine. Eventually, the sensitivity increased until it reached the point where I would fall whenever my shoe would come in contact with a rock or a crack in the road or sidewalk. My falls became more frequent over the next two years. My family and I had no clue what was going on.

In 2010, at age thirteen, I visited a neurologist in my home country of El Salvador, where I resided. I was officially diagnosed with clonic epilepsy. He prescribed medicine that only worked for two weeks. The doctor increased the dosage, but it continued to lose its effect. At age fifteen, my condition had advanced considerably. I felt a tingling sensation that ran down the entire left side of my body. This caused my left arm and leg to move involuntarily. I also started walking in a zigzag. When I realized I was walking sideways, I would try to correct it but couldn't. I wanted to stop walking, but I had no control; I would slide across a wall on my left side till my body stopped, using the wall as a brake. I realized I could no longer walk on my own. My mom would then accompany me everywhere, and when I wanted to stop walking, I had to ask her to stop me physically. On many occasions, I felt an accelerated heartbeat but could not figure out why. During my menstrual cycle, my symptoms would worsen until I was unable to walk for three or four days. I had sixty to eighty seizures a day. I could not use any walking tools because I would lose control of my left hand or it would shoot up. My left foot had become so sensitive I could not have any contact or put it down on the ground. I tried to hop on my right foot to mobilize, but that didn't last long before my right leg stated to get weak. I eventually had to stop trying to walk. I had too many falls and bruises, and it was impossible for anyone to help me, because they would also fall with me, as they tried to hold my weight in a split second fall. One day, I woke up and tried to get up as usual—only to fall to the ground. I attempted it a few times, falling every time. At that moment, I knew I wasn't going to be able to walk again.

When I was sixteen, I began to feel as if I was holding on to an electric wire with the sensation of being electrocuted throughout my entire left side. Over time, it worsened until it was a permanent sensation. My seizures would cause my left side to stretch out and force my body position to change. It would happen so quickly, it was impossible for anyone to hold me or to avoid a fall. Over the following year, the electric sensation amplified. The seizures turned from a stretch to an extremely strong sensation, as if someone was pulling my left leg and arm at the same time. I would shake throughout my full body. These seizures would last up to fifteen seconds, my breath would shorten, and my heart rate would spike upwards to 160/130. These continued to worsen to an unbearable level.

In those six years, while I was in a wheelchair, the electricity within my body was amplified to the point of hearing it run through my head. Others could feel it through the palm of my hand and described it as feeling popcorn pop. My ears became sensitive, and my own voice bothered me, making me feel like I was screaming, even though I wasn't. Insomnia was brought on due to the severity of the seizures, at times violently waking me. The seizures increased up to 280 or more a day, and the duration increased to forty-five seconds, leaving me with intense headaches. One time, I had a two-hour seizure attack of one seizure after another. I stopped counting after 1,000. I never once, during all of this time, lost consciousness.

Throughout these years, we saw specialists, tried medications, and had no permanently successful results. My aunt in the United States went online and found an epilepsy specialist in San Salvador at the Neurology institute of El Salvador. I was admitted for an EEG, which gave me a lot of hope. The doctor said we had to operate, however they were not sure what region of my brain the electrical discharges were coming from. We wanted to explore doing the surgery in the U.S., so the doctor told me not to come back to him.

Eventually, we embarked on the journey that has lead to proper diagnosis and treatment. After inconclusive tests, a magnetoencephalography (MEG) test gave our specialist the answer to where in my brain the surgery was needed. Two surgeries were done, one to install electrodes to map the discharges and pinpoint where they originated, and the other to remove the electrodes and the effected part of my brain. After that, the electricity and the seizures disappeared. After a third session of PT, I began to walk again with the assistance of a walker while trying to undo the years of trauma from the fear of falling. I went from being in a wheelchair to walking through an amusement park—12,000 steps in a day, without falling once. I visited family in El Salvador who cried at the sight of me walking towards them, because they never thought they'd see me walk again.

There are times you can get upset or want to give up, but those are the times you have to fight your emotions and push forward. I envied those around me that could so effortlessly walk up a flight up stairs, when I couldn't even take one step to get out of my wheelchair. Looking back at it now, I'm glad my family didn't give up, and I'm proud I didn't give up either, even after many doctors turned me away. No matter what you're told, keep your hopes up, and keep fighting. 2018 will always be an important year in my life.

A magnetoencephalography (MEG) scan is imaging (via a helmet with special sensors) that measures magnetic fields produced in brain neurons and can be used to pinpoint the source of seizures.


Service Dog


Convaid

SHAYNE

by MORGAN & SEAN TURPIN

Shayne's first seizure was at seven months old. We were told it was a febrile seizure, an isolated event, and it would likely never happen again. He was diagnosed with epilepsy at eight months old when he had two TC seizures in one day. He was hospitalized and had an MRI that came back normal. When he was fourteen months old, we received the results of his genetic testing, showing he has a mutation in the SCN1A gene. Finally, we had a cause for his epilepsy. At two years old, he was diagnosed with Dravet syndrome.

Dravet syndrome impacts every aspect of Shayne's life. His seizure triggers include over-heating and over-cooling, over-stimulation, illness, excitement, water, and sleep. These triggers are extremely difficult, and sometimes impossible, to manage. In addition to the forty to fifty seizures he has a month, he has significant cognitive delays and behavioral impacts. His seizure types to date include TC, hemiclonic, absence, complex partial, myoclonic, and focal.

He spends eight hours a week in private therapy in addition to being in a full-time special education program at school. He has developed a right-sided hemiplegia as a result of a very bad stretch of seizures, and he does aggressive PT and occupational therapy (OT) to help him regain his strength. He went from being right-handed to compensating with his left, after he lost his strength on the right side. He requires constant supervision due to the severity of his seizures and a lack of safety awareness. His full-time nurse attends school with him, since his seizures often require medication and oxygen administration. He also has a service dog that is trained in seizure alert, behavior disruption, and mobility assistance.

Dravet is truly a family diagnosis. Our life as a family evolves around getting Shayne the best care we can. We are limited in the places we can go as a family due to concerns over potential seizure triggers. His demanding school and therapy schedule limits the amount of time we have for other things. Last year, we traveled all the way from southern California to Ohio to get his seizure alert service dog. Our family vacations often involve traveling to epilepsy or Dravet syndrome events.

We have tried six different medications, including one that is in a clinical trial setting. We have tried many forms of cannabis, various supplements, the Modified Atkins diet, and even a specific type of filtered water that has shown to help some children with Dravet. We have traveled across the country to seek out trials and specialists' opinions.

In addition to Dravet syndrome, Shayne has also been diagnosed with autism spectrum disorder (ASD) and intellectual disability. Every day, we worry about Shayne's future. Dravet syndrome has a high mortality rate (one out of five children do not make it to adulthood). Individuals with Dravet often require full-time care as adults and are unable to live independently. We also worry about the impact of his condition on his younger sister. We pray for a cure, and we hope for a day where he no longer has to suffer seizures.

The best thing we have done is to connect with other families who are on a similar journey. These other parents have been the greatest source of information and companionship. This life can be isolating, but you do not have to go it alone. Find your tribe.

Shayne has taught us that life is truly precious. We see the strength he possesses every day, and we draw inspiration from that. He truly has a zest for life and loves to be out experiencing all that life has to offer. He has taught us to find joy in every single day and to live in the moment!

Dravet syndrome, previously known as severe myoclonic epilepsy of infancy (SMEI), is a rare, severe, and intractable form of epilepsy. It's the result of a genetic mutation that causes dysfunctional sodium channels (crucial pathways for sending chemical signals to the brain).

CAMERON

First, in my life, I am an athlete. I have been almost all of my life. I played semi-professional basketball, which took years of passionate training and extraordinarily hard work. In all that time, none of those hours were wasted.

Second, I wasn't born epileptic. I was born with undiscovered arteriovenous malformation (AVM) clusters that didn't manifest until later in life. I was in my late twenties when my AVM actually burst. That, of course, triggered an intense and dangerous brain surgery, followed by a few years of treatment, recovery and another brain surgery almost five years to the date after the first one. I wouldn't be diagnosed as an epileptic for another year and a half. Like many brain surgery patients, I was told that one day, the seizures would go away, and I wouldn't need the medication anymore. Unfortunately, that wouldn't be the case.

The process, in the beginning, was devastating. I couldn't speak. I didn't know who almost anyone was, including the person I saw in the mirror each day. One of the first things I remember a doctor telling me was that I couldn't do any sort of contact sport ever again. That didn't sink in right away, mostly because understanding anything was a challenge. Time passed, and I gained cognitive ability again. The realization of everything I was told before seemed to fall on me at once. It felt crushing. The thing I loved and worked so hard for felt further away than it ever had been. But I thought, "To hell with all of that!" I knew the doctors, nurses, and even some of my friends and family didn't know what I was capable of. They hadn't seen the hours spent each day pushing my body to its limits. They hadn't watched me pour my heart and body into something with every ounce of passion I have, and they certainly never saw me fail, only to immediately turn around and say, "This will not stop me. I will get better!"

So I started to push myself again in new and sometimes more difficult ways. Eat right, rest when needed, don't stop working out, have a seizure and take time to recover, smile on those hard days, fight, appreciate what you've already done and have, push-push-push, and never stop. None of it was easy. All of it was hard. I'd be lying if I said it wasn't the most difficult thing I ever had to do, but it was all worth it.

Epilepsy is the greatest challenge I've ever faced. It's the hardest thing to talk about and sometimes the easiest reason to give up. I've lost years of memory, the ability to play the way I'd like, and I have to take medications that sometimes slow me down for days. But one thing epilepsy hasn't done is define me. I am still the person I've always been. I still push every day to get what I want out of life. That will never change. One of the greatest quotes I've ever heard about epilepsy is this: "Epilepsy is just an f-ing inconvenience!" I wholeheartedly agree with that! It may hinder my abilities. It may slow me down sometimes. It may hurt me physically. It may upset me, but it cannot change who I am, and it will never break me.

Two years ago, I went to EADDL not knowing what to do or what I was looking for. I found hope, people who cared more than I knew possible, and new reasons to continue fighting. Amazingly, I realized most of the hope I felt came from a bunch of people with epilepsy. Just like me.

FACT: AN ESTIMATED 1 IN 26 PEOPLE WILL DEVELOP EPILEPSY OVER THE COURSE OF A LIFETIME.

EVERY MORNING YOU WAKE UP AND DETERMINE IF YOU ARE GOING TO BE A WARRIOR.

ALEXIS LEVIN

ALEXIS

When I was in third grade, a friend's mom noticed my eyes turning downward, as if I was falling asleep. She was a nurse and knew something wasn't right and told my mom. A few weeks later, I had an EEG at UCLA, and I was diagnosed with Jeavon's syndrome. My eyelids flutter, I have absence seizures, and I'm very light sensitive. Without medication, I was having over one hundred of these seizures every day.

Jeavon's syndrome is a type of idiopathic generalized epilepsy that can be characterized by combinations of eyelid myoclonia, absence seizures, eyelid-closure-induced seizures, EEG paroxysms, and photosensitivity.

I'm now in high school. Unfortunately, my epilepsy has made my processing speed very slow, and I also have dyslexia. I have an IEP at school, and my teachers are supportive, as much as they can be. Being in the sun is hard, and the heat affects me, too. I take Depakote and Onfi twice a day. This cocktail is working right now, but I'm constantly tweaking the dosage.

Over the last few years, I've learned a lot about how to manage my epilepsy and what my limits are. I wear sunglasses when I'm outside, which was hard for me to do in school, because other kids thought it was "weird". In elementary school, I was pulled out of class to get extra help, and people thought that was "weird". In sixth grade, my mom put me in a private school that specialized in teaching kids with learning differences. It changed my life. I gained the self-confidence I lacked, and I learned that "weird" was ok. It's ok to be who I am and embrace my differences. If you think about it, everyone is different. I found a hobby that I love—art, and I'm seizure-free when I do it. For exercise, I do indoor spinning. It's in a dark, air-conditioned room, and it's perfect for me. Reading takes me longer than most people, but there are so many apps that help with that. Plus, audio books rock!

My words of wisdom or warning to people newly discovering epilepsy are: Remember that you're not alone. People are there for you. Surround yourself with joy, and remember that a little self-care goes a long way. Don't be afraid to ask for help. It's a sign of strength not weakness. Every morning you wake up, you determine if you are going to be a warrior.

Cannabis is a complex plant. Cannabis *whole plant medicine* is terminology used to describe utilization of all therapeutic compounds the plant has to offer. *Isolate* is a term for a single compound extracted from the plant.

JAYDEN

by JASON DAVID

My name is Jason David, and pictured here is my twelve-year old son, Jayden. He has Dravet syndrome. Eight years ago, when Jayden was four years old, he wasn't doing well. He was on twenty-two pills a day—four different pharmaceutical drugs, and he was still having myoclonic events and grand mal seizures that were lasting an hour and a half every day. He couldn't walk well, chew, or comprehend anything. He was screaming in pain all day and night. So, I decided to try something new.

After doing my own research, we started Jayden on CBD, all on our own. No advocates. No medical help. We were just searching. The first day I gave Jayden the CBD was the first day he had ever gone seizure-free. Things progressed so well that after a month, we started to wean Jayden off some of the pharmaceuticals. This was a very hard process. We have now weaned him down from twenty-two pills a day to less than one pill a day.

The hardest part was the withdrawals. During this time, I left my retail management job that I was at for eleven years. I spent all of my time and all of my focus on Jayden. We introduced Jayden's Juice to the epilepsy community. As restrictions and laws fell into place in California, we quickly gained attention. In 2011, we were featured in a television series called *Weed Wars*. We also appeared on the front page of the *Los Angeles Times* and were featured on *CNN* and many other news outlets. I was one of the early pioneers that worked to create the percentages, ratios, and dosing that lead to low tetrahydrocannabinol (THC) solutions for a popular brand, also covered by Dr. Sanjay Gupta's television documentary special "Weed". Jayden's Juice is carefully formulated, non-toxic, and non-psychoactive. I need to feel good about giving it to my child and to others.

I have become an advocate for other children and patients that I know are suffering. I have been to meetings and conferences all over the U.S. for epilepsy, Dravet, autism, and rare genetic disorders. We have been trying to spread the knowledge about cannabis whole plant medicine. We promote one product, and we earnestly want to help families and children. Every child is different, and every child will respond differently to our product. This is our biggest concern and our biggest challenge with new families. People ask their friends for opinions, shop online, and then try a product. If that doesn't bring results, they generally give up on CBD altogether, rather than trying a new strain, brand, or supplier. Not unlike traditional pharma medications, it's truly all about trial and error. Now, as the face of Jayden's Juice, my goal is to educate people with real facts and resources for cannabis.

It’s helpful to find others with similar struggles, so you can help each other along your paths. Then, you will know that you’re not alone.

JACOB HICKS

I am sixteen years old, a sophomore in high school, and I am obsessed with computers and technology. My first few years of life seemed like any little boy's life. I am the youngest child in the family. Sienna is the oldest, and my twin sister Amber is only three minutes older than me. At age seven, we were on the couch watching a movie, and it seemed like I zoned out for a long time. My family didn't think it was anything until it happened again.

The pediatrician sent us to Harbor-UCLA, where I had my first EEG. I remember it was a little painful because the electrodes had sticky stuff, and it hurt when they pulled it off my hair. They started me on medication, and I had a bad allergic reaction and got a rash all over my body, so the doctor tried a different one. For a few years, we tried different medications, different doctors, and different tests, while my seizures kept happening. As I grew older, my seizures worsened and became complex partial seizures. Part of my brain and body would seize and shake, and I would blank out for thirty seconds. Afterwards, I would always feel really tired, dizzy, and confused.

I always loved playing soccer, and through all of this, I kept playing. Sometimes, I would have a seizure during a game, especially if it was hot, and I was tired. I was always lucky to have good coaches and teammates who would support me, and let me take a break from the game, and then cheer me on when I was ready to play again. My parents would educate everyone, so they would know what to expect and how to work with my condition. Nobody ever made fun of me. My mom remembers one game when I had a seizure and had to come off the field to rest, but when I returned to the game, I scored a goal, and everyone was happy!

The hardest part about having epilepsy was being partially disabled. I couldn't do any physical activity without being supervised, especially swimming. I was dependent on always having someone with me. There were other hard things. The medication made me more sensitive, lose my patience easily, and I'd have anger episodes. I had a lot of doctor's appointments and had to miss a lot of school to rest after a seizure.

In sixth grade, I met a friend named John, after he tripped on my chair. We learned we had something in common. We both had a medical condition that sometimes kids didn't understand. We'd look out for each other. When I had a seizure, he'd check on me to make sure I was okay. When kids asked him about Tourette's, I would speak up and explain why he twitches and would not let anyone make fun of him. We are still best friends to this day.

In 2015, I met with a pediatric epileptologist who convinced me to stay in the hospital for a few days for testing. They took me off of my three medications, which was scary, to locate where the seizures were coming from in my brain. After three days of seizures, the doctors came in the room rejoicing, "You're a surgery candidate!" They explained that all tests pointed to one spot in my brain firing all the seizures. There were possible risks, but they were confident brain surgery would heal my seizures. On June 3rd, 2016, Dr. Fallah did my surgery, and I returned home after three days in the hospital. My head was shaved, and I have a scar in the shape of a question mark on my left side. I'm seizure free, didn't experience any of the possible risks, and one year after surgery went off all medications. I feel I've been given my life back!

JACOB

by JESSICA CREEDON

When Katie joined our family on March 21st, 2012, we knew our family was complete. We spent the first twelve weeks loving on her, smelling her, and showing her just how happy we were that she was part of our family. On week twelve, just as we were getting ready to celebrate Father's Day at the lake, I was nursing her one last time to get her through the drive. I witnessed something I had ever seen before: her body went stiff and shaky, her eyes fluttered in ways that they aren't meant to, her diaper became saturated to the point where I felt like I was sitting in a bathtub, and the noise of fear that came from that baby girl is engrained in my mind forever. The emergency medical service (EMS) was called, and in several minutes, my baby girl was being whisked away in an ambulance, with people telling us this was common and would probably never happen again.

It did happen again. It happened two times on the way to the hospital, in fact. Her first hospital stay was a week full of lumbar punctures, EEGs, blood work, and sleepless nights. Suddenly, the joy of parenting our baby girl turned to fear and unknown. The next few months were a blur of referrals, appointments, and attempts to capture video of her seizures. We didn't ever get the answers we were looking for. We were told, "Sometimes seizures happen, and we don't know why." Katie was having dozens of seizures a day, and we needed to find an answer to that "why". We persevered until we found it.

Katie has a rare genetic condition known as CDKL5 disorder. The hallmark of this disorder is epilepsy. Katie has several seizure types and has never had seizure control for more than a couple of days. We're not sure if she realizes she has seizures, but her stamina and awareness does change after she has one. We have never let the disorder stop us from helping Katie be the best that she can be. She loves amusement parks and has the best belly laugh on roller coasters. She loves dogs and being outside. She has been on eleven seizure medications, a therapeutic diet, and has a VNS. We are currently raising funds for a seizure alert dog. Katie doesn't have any words and is cognitively at about fifteen to eighteen months. This doesn't stop her from loving life and people!

Our advice to people who are newly discovering their own epilepsy is to trust your gut and do your research. Don't feel like you have to take advice from the first doctor you see. Connect with others who understand what living with epilepsy is like. No matter how far away they may live, they always seem to provide the most comfort.

KATIE

The CDKL5 (cyclin-dependent kinase-like 5) gene provides instructions for essential protein generation for brain and neuron development. Most children with the disorder experience seizures very early in life. CDKL5 was identified in 2004 and is still being researched to determine the cause and incidence.

by SHARON & FRANK CANINO

Life started beautifully with the birth of our third child. I had decided to take some time out of my career to focus on our precious little family that had just officially become a family of five. Welcome beautiful, perfect, little Jessica Nicole. Four short months in this world, and Jessica's life took a terrible turn. Frighteningly, like so many children with epilepsy, Jessica hurled into her first grand mal seizure three hours after her second childhood immunization. This first seizure shook us to the core, but like typical parents, we hoped this was a febrile seizure simply caused by fever from the immunizations.

Less than two weeks later, that 911 call and hospitalization would seem mild in comparison to the next seizure that lasted well over an hour. Despite emergency room intervention and heroics to calm Jessica's seizures, she was eventually intubated and life-lifted to a hospital an hour's drive away. Frank and I handed off our precious five and three-year-old to trusted neighbors until Grandma and Grandpa could arrive. We drove silently, holding hands and praying that our beautiful baby girl would be okay when we arrived at the Loma Linda University Children's Hospital Pediatric Intensive Care Unit (LLUCH). It was at this point that life, as we knew it, truly changed, never to return to the pre-life-lift days.

Jess spent five days on life support, had EEG's, blood draws, spinal taps, CAT (or CT) scans, and her introduction to anticonvulsant drugs that would eventually rule every aspect of our daily routine and my nightly research. Fast forward twenty-eight years. We have spent these years as Jessica's warriors! Jessica has been on over a dozen antiepilepsy drugs and multiple combinations of polytherapy. Constantly searching for a diagnosis, Jess was treated at LLUCH, UCLA, and Children's Hospital of Orange County (CHOC) with consults and testing at some of the best pediatric hospitals in the United States. We searched for answers and tried everything to gain control of Jessica's seizures, which were spiraling out of control. We joined the first west coast group out of UCLA attempting the ketogenic diet, consulted a doctor from India, and spent a couple of years augmenting traditional meds with Ayurvedic medicine. We transitioned into Chinese medicine, utilizing acupuncture and Chinese herbs to supplement her ability to handle the pharmaceuticals required to keep her out of status. Alas, at twelve years old, we added the VNS implant and found our first step to some level of control. This magical little device actually stopped the status episodes for Jessica for the next eighteen years.

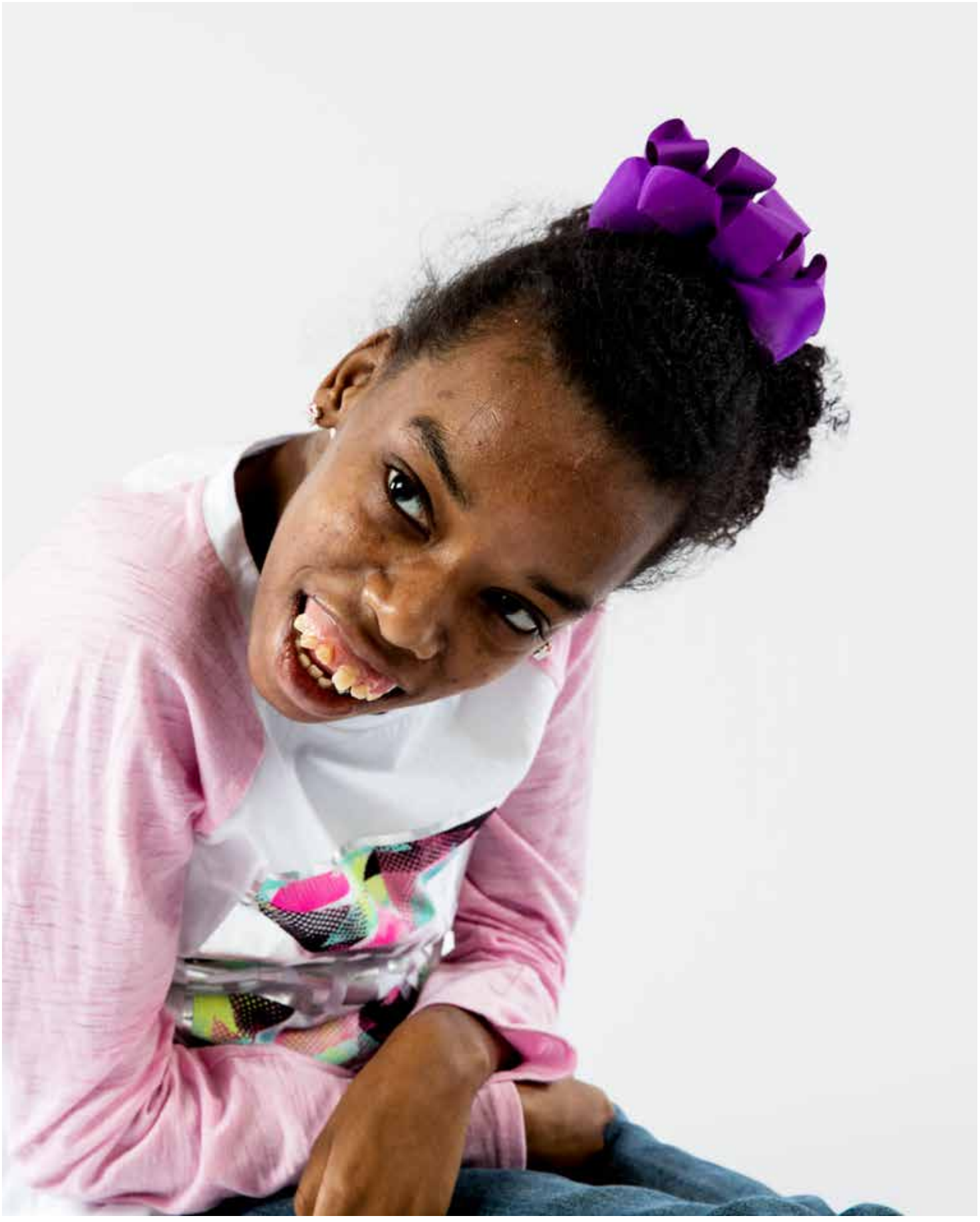
Feeling blessed, we continued life in a world of compromises and conquest. Jess moved from an inclusive elementary education in sixth grade into a special day class for junior high and a special needs department for her extended high school program. She has participated in therapeutic horseback riding for the last fourteen years and adores the interaction with her riding teams. As every child with a pediatric diagnosis will experience, we were challenged to find qualified doctors who wanted to work with Jessica.

Our second key in Jessica's journey came very unexpectedly during our first consult appointment with her new doctor. After a great deal of discussion around Jessica's first twenty years of idiopathic epilepsy, a new diagnosis was clinically considered. We were sent on our way to Google "Dravet syndrome", which was an unknown term to us at the time. We will never be quite sure how this was missed with all the genetic, metabolic, and systemic testing that our Jess had undergone, but her new genetic tests revealed a deletion of the SCN1A gene and a confirmation of Dravet syndrome.

This has resulted in heavy participation with a group of families, physicians, and researchers that has been amazingly uplifting and powerful. We were also blessed to meet Brad Levy, a tenacious advocate for epilepsy awareness. We have witnessed the successful introduction of CBD into mainstream medical treatment, have seen Food and Drug Administration (FDA) approval of Epidiolex (the first specific Dravet-targeted drug), and are on the cusp of completion with another promising trial. Some of these discoveries have been helpful with Jessica's polytherapy. Dravet syndrome is relentless, and although we've come far, last fall Jess was hit with two status episodes (after our eighteen-year hiatus), and she was hospitalized for multiple days in the intensive care unit (ICU). Reliving our fear of status hospitalizations has heightened our awareness of what so many families have to go through regularly, and our desire to make a difference continues to increase.

Yes, Jessica has Dravet syndrome, but she also has a mission and continues to touch the hearts of people in ways we cannot even imagine. Let us all think and dream together for just one second; that is what she would eloquently tell us if we could calm the seizure storms and let the beauty of her mind find words to share all that she has learned in her twenty-eight years.

JESSICA



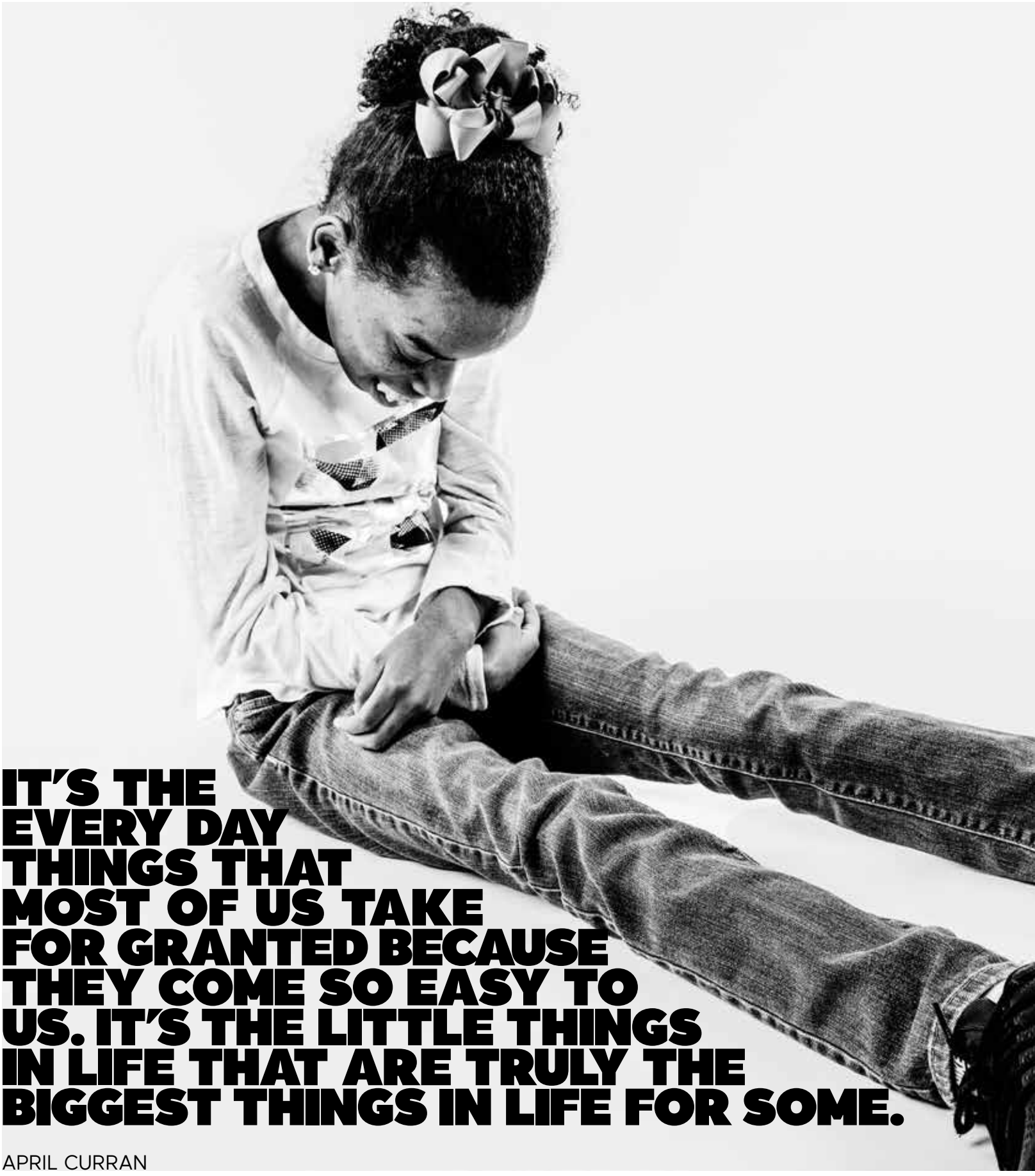
ZENAYA

by APRIL CURRAN

Zenaya had her first seizure at eight months old, due to a fever (febrile seizure). From then on, she struggled with seizures—and still does. Her current neurologist says she has multiple forms of epilepsy, and twenty-one years later, we're still learning what those are. She was diagnosed with Lennox-Gastaut syndrome (LGS) at age eighteen, and our neurologist says it's what is impacting her the most. She also has autism, and it's believed to be linked to her epilepsy.

A grand mal seizure, which lasted over forty-five minutes, caused developmental delays and the onset of cerebral palsy (CP). Over the years, from seizures and side effects of AEDs, she has also suffered loss of speech and all motor skills (gross, fine, and oral). Zenaya is currently on her third VNS and will soon receive her fourth. She has tried and failed with many AEDs. Her neurologist is concerned that she is running out of options (which is something a parent should never have to hear). She is now sensitive to heat and cold. If her environment is over eighty degrees or under seventy degrees, it can trigger to TC seizures for her. Everywhere we go, we bring a sweat jacket and her cooling vest with ice packs. I'm constantly monitoring her body temperature and the environment temperature.

Epilepsy has taken many things from Zenaya: her voice, her independence, her mobility, her knowledge—and it is stealing her ability to drink and eat orally and to feed herself. Despite that, it hasn't taken away the joy in her eyes, her love, her sweet soul, her infectious smile, and definitely not her fight and strength! No matter how many TCs she has in a day, she still has the most amazing disposition I've ever seen. There is just one percent of the time where she will bawl for hours after a TC and look me dead in the eyes, as if she's asking me to make it stop. That's when I break down. All I can do is hold her and try to comfort her. Every seizure and change seems to bring about more loss of skill, and I want to do something to stop this pain and damage, but I can't. It's hard to watch every muscle in your child's body tighten and convulse



IT'S THE EVERY DAY THINGS THAT MOST OF US TAKE FOR GRANTED BECAUSE THEY COME SO EASY TO US. IT'S THE LITTLE THINGS IN LIFE THAT ARE TRULY THE BIGGEST THINGS IN LIFE FOR SOME.

APRIL CURRAN

over and over again. Epilepsy has taken a toll, not only on Zenaya, but also on her whole family.

I work with children that have severe special needs, and that's how I met Zenaya and how she became part of our family when she was eleven years old. Because of her epilepsy, she was shuffled from one foster home to another. Every few weeks to a couple of months, she would change homes—but not just homes, her whole world would change. That meant continual change in her home, family, friends, school, and doctors. Most of her placements were not pleasant places to be. A child that doesn't understand why no one wants her...it's such a difficult thing to process. But we're grateful that she became part of our family, and it's made us all better people, even though it's not always easy. I really can't think of a way her life and our lives are not impacted by epilepsy.

One thing I've learned is to trust my gut. In the beginning, I just listened to the doctors because they're specialists in their field. Not anymore. They may be specialists, but you're the specialist in your child. If you have a question, ask it. If it's been bugging you, and you can't shake it, there is a reason it's sticking around. Try to catch anything that seems like seizure activity on video and develop an easy system of keeping a calendar. Take time for yourself, even if it's just for a few moments. I'm still learning that I need to take care of myself, or I won't be here to take care of Zenaya.

by KELLY BLOODWORTH

Ty Ezra Selik is two and half years old. When he was eleven months old, he started doing this sort of scream sound in his sleep. It was a cry I had never heard before. I didn't even look at the monitor; I just ran upstairs. When I got to his room (which felt like it took five seconds), Ty's arms and legs were moving, and he continued to make the sound. I scooped him up and held him until it stopped. It lasted a minute to a minute and a half and looked like extreme muscle spasms. I was about to set him back in his crib when I realized his body was limp, and this was just getting started. I couldn't get him to look at me, move, or do anything. That's when I knew something was really wrong. I ran downstairs to show my husband what was going on, and we rushed to the emergency room.

It never occurred to me that it could be a seizure. All I knew about seizures is what I had seen on TV—fast jerking motions and foaming at the mouth. This wasn't like that at all. His movements were slower. But it was the first question they asked us, and I said, "I don't know". It took about fifteen to twenty minutes for Ty to glance at me, but he wasn't able to hold the gaze. At about twenty to thirty minutes, he could solidly focus and look at me. When he first tried to move, it was awful. His head just flopped to one side with no control at all. At forty-five minutes, he could make initial movements.

Prior to the event, Ty looked like he was within days of taking steps on his own. He'd been walking to furniture and pulling himself up for a while. After the event, he couldn't sit without falling over. He looked like a Weeble Wobble. It took three days for him to regain most of his balance, and it would take a couple of months more for him to take those first steps. Ty's seizures happen about every thirty days and only happen about one and a half hours after going to sleep. Afterwards, it takes about three weeks for him to be fully himself.

Over the course of the next six months, we saw one neurologist after another. We were told it was everything from seizures to nightmares and, "He's so cute, he'll be just fine." He was put in leg braces and into PT to help with muscle weakness from his seizures. His seizures went from one and half minutes to three minutes in duration. Even though we were told he had seizures, no EEG could confirm that. After learning about EADDL, I decided to go and learn everything I could. In a session with one of the speakers, I broke down and cried for the first time. That day, we met the head of the epilepsy clinic with Children's Hospital of Los Angeles (CHLA), and our path would drastically improve.

We saw Dr. Lallas and tried our first seizure medication. This would be our first triumph. Ty went three months without having a seizure, and the break on his brain allowed his first real progress. He started learning new words and said "Daddy" for the first time. This summer, we had our second triumph. With a change to our medication, he went five months without having a seizure and literally flourished in that time. He graduated from his leg braces, PT, and speech therapy. He caught up in all areas he was behind. We were finally able to catch epileptic spikes with an at-home EEG monitor through EEG to Go, and we confirmed those results at CHLA. The findings point to focal onset seizures in the left temporal lobe. We still haven't caught a seizure on EEG, but the spikes suggest he has no other conditions causing his seizures except epilepsy. Our next step in management is to minimize the days of excitement versus adding more medication. One of us stays up every night to watch him for two and half hours after he goes to sleep to make sure he doesn't have a seizure.

The blessing we've seen through all of this is Ty's determination. He works so hard and doesn't allow anything to hold him back. He smiles often and knows how to celebrate his wins. Seeing a high level of determination and ability to work hard is an amazing thing to see in your child.

Technology now allows patients to remain at home or in a hotel room to record real-time video EEG data while being monitored live from a remote location.

OLIVIA

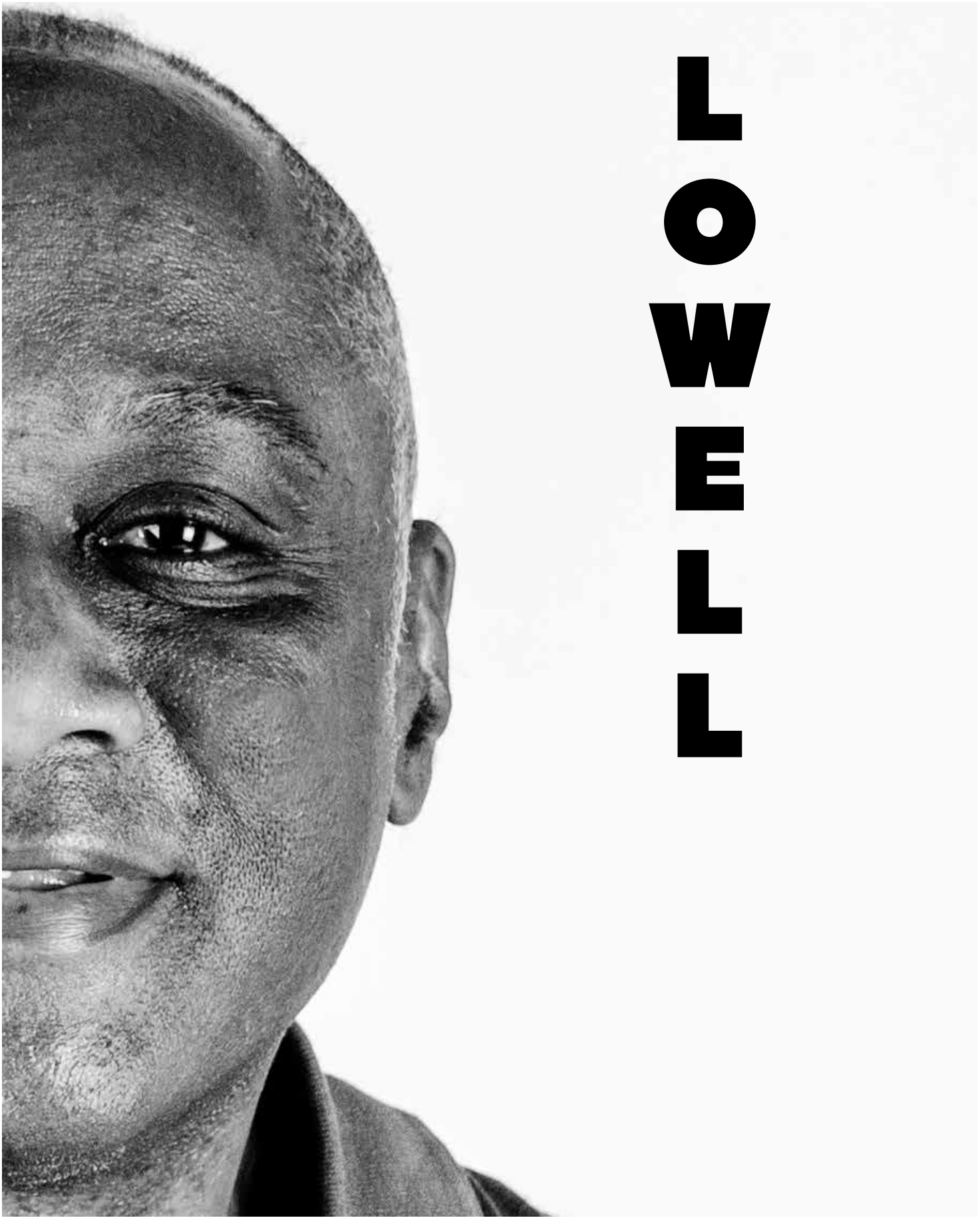
Three years ago, in January 2016, my life changed. I had my first seizure. At the time, I thought I had a nightmare. Weeks passed, and I didn't know a lot about it. In April 2016, I was sleeping at my best friend's house and woke up to her screaming my name with tears in her eyes. She looked at me and said, "I thought you were going to die", because she saw me have a seizure. Later that night, we told my parents what had happened, and they suggested it was probably sleep paralysis. However, I had a feeling it was something else, because I was tired all the time and didn't do well at school anymore. A few days passed, and I had another seizure. When I woke up from the seizure, I was crying because talking about the possibility of me being sick was scary. Later in the month, I hurt my foot and couldn't sleep because it was hurting. I went to my parents' bedroom and my mom said I could sleep in their room until my foot was okay. After sleeping in their room for a couple of days, I had a seizure. My mom saw me, and that is when my journey actually begins.

The hospital visits started because now they could explain to the doctors what it looked like when I was having seizures. Every week, it continued to worsen, and I wasn't put on any medication. I only had something to stop my more massive seizures when I had them. It was just a temporary fix, but you have to be thankful, even for the little things, right? I went from having one big and ten small seizures every month to one big one every week with five small ones every night. By the end of May, I was too tired to attend school. I barely slept at night and started to have small seizures during the day. There were many rumors at school when I got sick, and most of my classmates thought I was trying to skip tests, so I lost most of my friends at school. I still had much support from my family and also from a bunch of my dance friends.

When summer break came, I still wasn't on any medication, and I got worse than expected. I remember thinking I had a brain tumor, since we still didn't have any answers. I didn't tell anyone about that because I thought I needed to keep going, even though I didn't know who I was anymore, and no one recognized me. In August, I was told I would finally be admitted to a hospital the next month. Honestly, I couldn't have been happier; I would hopefully get the answers I had been waiting for.

But, the last weeks before I was admitted were the worst of my life. I had about eleven small seizures every night and a lot during the day, and the triggers to the small ones were unimaginable. I couldn't wash my face or take a shower. I couldn't be in bright or windy places. I isolated myself from the world even more. The last week of August I had the biggest seizure I have ever had. I barely got any air because I had a cold the week before. I remember there was blood on my pillow from biting my tongue so hard. Just a day or two later, I got a really high fever, and I had trouble. We went to our family doctor to find out I had pneumonia, and they gave me antibiotics, but I still had trouble breathing. We went back, and I inhaled oxygen, which helped for a while, but it got worse in the night. We had to go to the ER, and I was admitted. Luckily, I could leave the day after. I spent a few days at home, and then it was time to get admitted to the hospital again but this time for the seizures.

After the first night there, a doctor told me I had epilepsy and started me on medication right away. I have never been happier, but at the same time, I was scared, angry, and sad, because I was sick, and there was no cure. After a few days in the hospital, they did an MRI to check that everything looked right, and it did. One month after the medication, I was seizure-free for a year. Then I had another seizure, but I wasn't scared because they simply gave me a higher dose. Unfortunately, it didn't work. I had seizures back and forth. My last one was in March of 2018. At this point, I'm close to being seizure-free for one year again.


LOWELL

Growing up in a small town in the state of Virginia in the early 1970s, there was not much I learned outside of what I was able to see and what I was told. I had a beautiful life, as I was raised by parents who loved their children and were respected by everyone.

As a child, I never questioned what my parents told me. Whatever they said, I knew it was for my good and I felt they were smart. They were always working hard to take care of me so why would I doubt anything they would say or do? Once I saw a sick man and asked my parents, "Why is he acting like that?" Their answer was, "Oh, he is having one of his fits. He'll be ok." This was my parents' knowledge of epilepsy, and that is all I knew about the condition, until I developed it years later from a fall.

In 1980, I was twenty years old and fell while playing basketball in college. Three months later, the paramedics woke me up in my dorm room at 3:00 a.m. I didn't know what happened, so I asked my roommate if he was ok. He said, "They came to see you!"A paramedic said. "Mr. Evans, I think we detected epilepsy." I thought they were saying I was doing something illegal, so I raised my right arm in the air and said, "I swear to God, I don't smoke that stuff! You can check my drawers!" They asked if I had fallen and hit my head. I told them "No", but then I remembered the fall I had about three months prior. They took me to the hospital, ran several tests, and gave me a possible epilepsy diagnosis. They still had to explain it to me.

I didn't have another seizure for a while, so I was able to continue driving. The problem I had was this: the students at my college heard about everything. I was confronted with countless statements and questions. They suggested I'd have to quit school, quit playing for the basketball team, wouldn't be able to find a job, and even have a hard time finding someone to marry me. Some even thought they could catch the "disease" from me! My life was changing right before my eyes—and not because of anything I did. It was because of society's lack of knowledge about epilepsy. Initially, I felt I had to prove myself to everyone, and I worked and partied harder, but I grew to realize that wasn't necessary. My epilepsy was under control, and I graduated on time.

Growing up I had heard "It takes a village to raise a child." It wasn't just about helping another person's child—but people in the community helping one another. When someone needed a ride or a job, the community stepped up to help. Well, after having challenges with epilepsy, I couldn't even find people to talk with about it. I felt isolated. I had heard millions of people have epilepsy, but where were they? There was no "village" of support.

I later found people in support groups and on the Internet. I saw many people with epilepsy were facing the same challenges in life. There were problems with losing jobs and friends, self-esteem, discrimination, and isolation.

I decided to write a book called *The Village* about Kevin Bolden, a man whose life changed when he had a seizure on his job. He went from being an asset to a liability almost overnight, and now some people saw epilepsy before they saw him. In contrast, the people in his neighborhood "The Village" continued to see Kevin as the man he was. The book is the dream of all people who have epilepsy. The only way this dream will come true is with a "village".

Lowell authored the book *The Village*, a story about how one neighborhood's support transformed the life of a man with epilepsy.


KALIE
KAYLIE


be
free

by ANGELICA LOUTHAN

Our story began when Kalie was two and a half months old: We were out to dinner with family, and Kalie was sleeping in her car seat. We all saw her do a body twitch and thought it was odd, but we continued to eat. Later, around 2:00 a.m., I was feeding Kalie, and she began to twitch again. This time what alarmed me was that only the right side of her body was doing it. My husband and I drove her to the ER as fast as we could. They checked her out and did a spinal tap, blood work, and CT scan. Everything was coming back normal. We called her pediatrician, and between her and the ER doctor, they decided it would be best for her to go to CHLA. After what seemed like an eternity, we were finally on our way in an ambulance. My husband and I were so scared. She is our first child, and we didn't want anything to happen to her.

Once we got to the hospital, they wanted to do another spinal tap. Shortly after that, the whole team at CHLA came to check her out. Luckily, but unfortunately, Kalie had her third seizure right then. It was a very long seizure, and it was a lot more violent than the first two times. They immediately asked for a loading dose of Keppra. As she had more seizures, phenobarbital was added, and that seemed to shorten her seizures. We lost count of how many she had in total, but it was very scary. She was so sleepy from all of the loading doses that she slept through an MRI. My husband and I felt as if we were gong to lose her. Kalie was not her usual happy baby self, and she was very sleepy and out of it. The MRI was normal, and that gave us some hope. They had also done an overnight video EEG. We had to press a button every time she had a seizure. My heart would break into a million pieces every time we pressed it. The EEG showed she was having focal seizures starting from the right side of her brain and spreading throughout. They sent us home with Keppra and phenobarbital.

Learning how to give the medication was stressful. Luckily my mother-in-law found a pacifier from the company Frida, which made our

A loading dose is a larger amount administered at the start of a drug treatment, usually to effect a more dramatic change (with higher drug concentration in the system) before maintenance dosing.

life much easier. Kalie didn't have any seizures for one week, and then she began to have seizures in clusters on the 4thof July. This time around, her seizures were absence seizures. Her eye would go to the right for about thirty seconds each time.

We took her to the hospital again, and they gave her a loading dose of medicine. They didn't want the clusters to cause brain damage, so those doses were necessary. This time around, we were in the hospital for three long weeks. My husband and I took turns staying awake to watch her so we wouldn't miss a seizure. She was having about twenty to twenty-five seizures a day at the beginning of our stay. Kalie had a kidney ultrasound to check if a metabolic issue was the cause, but the results were normal. They added Onfi, which didn't seem to have an effect, and they added Vimpat, which immediately reduced her seizures from one minute in length to ten seconds. Eventually, instead of twenty a day, she was down to five. We went home after three weeks but stayed in constant communication with our neurologist. We had dosing instructions for seizures that seemed to come in clusters. Once home, the frequency kept decreasing.

Around August, the three of us had genetic testing done at CHLA. We were very excited that all our tests came back normal. This answered a few questions and gave us some hope. About a month later, on August 27th, Kalie had her last seizure. In October, we met with her neurologist and a geneticist, and it turns out that Kalie has a duplication in her second chromosome. They explained to us that because the study of genetics is so new, there is no guarantee Kalie will stay seizure-free. However, based on the other few cases like hers, it's likely she'll outgrow this. Once she's going through hormonal changes as a teenager, it could come back—but she could outgrow it again.

It was wonderful to hear this news! To this day, Kalie hasn't had another seizure. I wish I could go back in time and tell myself that everything is going to be ok—and not lose hope; even if her seizures don't go away, Kalie is a very strong girl.

SAMUEL & FINLEY

by CURTIS & REMIAH TOWNS

Our first encounter happened on an afternoon in August. Our three-year-old twins were playing hockey in the garage, when I noticed one of them, Sam, was lying on the ground and not breathing. After being rushed by ambulance to hospital, we were told they believed he had a seizure. Less than a week later, while driving in the car, Sam said, "Fin is making a funny sound." I looked back to see Sam's twin brother, Fin, having a grand mal seizure. The doctors said it was a febrile seizure, common in kids this age, and they would grow out of it.

That entire fall, the seizures continued for both boys and grew in length and frequency. We would often bring them into the emergency ward at hospital to hear things like, "That doesn't sound like a seizure", "Febrile seizures are common and don't warrant trips to the ER", and my favorite, "Maybe it was a night terror". Though I'm not a doctor, I have never heard of night terrors while awake and playing. We felt unheard and hopeless. By December, seizures and trips to hospital were almost daily. We still hadn't been sent to a neurologist.

We learned that the confusion was in our description of our twins' seizures. Fin and Sam don't go unconscious during their seizures, but instead, they lock their eyes on us and try to scream for help. We were unaware that this is very rare and made doctors doubt that we were seeing seizures. Finally, we were smart enough to film a seizure, and it was then that the twins were sent to BC Children's Hospital to be seen by a neurology department. Unfortunately, that was just the beginning of the crazy epilepsy adventure our family has walked through.

After multiple types of seizures, many unsuccessful medications, a lot of falling injuries, devastating developmental regression, failure to thrive, and a horrible bacterial meningitis experience, our boys were diagnosed with Doose syndrome. At the time, it was thought to be a regressive seizure disorder with very frightening statistics. Though our boys are still affected daily by their epilepsy, their seizures are now much more controlled, and the diagnosis is more hopeful due to more studies, new research, and education. Though our story reads as a frustrating fight of advocacy, we are forever grateful for all of the sleepless, fearful, and crying parents who ask the same unanswerable questions over and over again. We are also grateful for all the research, science, donations, and advocating parents who have gone before us, fighting for each child with myoclonic-astatic epilepsy (MAE), making each diagnosis a little more hopeful for the next!

Parkinsonism refers to a group of symptoms comprised of tremors, rigidity, bradykinesia, and postural instability.

ROBERT

by TRISH HUGHES

"Excellent". This is the attitude Robert has that makes his doctors adore him and makes caring for him and dealing with his physical challenges much easier. He loves to declare everything "excellent". I like to call this his "magic of excellent". Even in school, when kids would make fun of him because of his seizures, he found a way to talk to his teachers and classmates about epilepsy and educate them about the condition.

We are fortunate Robert is a very positive person; however, as a teenager, his medications and his frustration with his uncontrolled seizures caused him great depression. He even became suicidal. Robert's moods change when his medications change. He can go from a happy, content person to an irritable, demanding person, and that can be quite challenging for all of us.

Robert has medically refractory left temporal lobe epilepsy. He has about thirty or more focal onset impaired awareness seizures (also known as complex partial seizures) per month. Most of them come in clusters, which happen every couple of weeks. This has caused many other conditions. Due to the lack of seizure control and numerous concussions he has suffered in his life, Robert now has Parkinsonism, suspected chronic traumatic encephalopathy, recurrent aspiration pneumonia with restrictive lung disease, hypoxia, dysphagia, hyperammonemia (due to the high level of Depakote he takes), incontinence, and cognitive impairment.

Robert was most likely born with epilepsy, but he was not diagnosed until age seven. As a child, he was hyperactive and frequently reported seeing "cartoons" in his head and the colors red, blue, and green. When he was first diagnosed, he missed quite a bit of school in order to get the seizures under control. My parents even went so far as to take him to Switzerland to see a neurologist about whether surgery was an option. That neurologist could not help, but eventually, when he was in his twenties, Robert had two brain resections at University of California, San Francisco Medical Center (UCSF).

For treatment, has also used a VNS and is currently on five different anti-seizure medications. He's trying out a new medication, and he's being evaluated for a deep brain stimulator, now that it is FDA-approved. He sees two neurologists (one for his epilepsy and one for his movement disorder), and he goes to PT once a week in order to keep his movement disorder from getting worse.

There has been significant physical and cognitive decline in Robert's fifty-two years. Up until ten years ago, he was able to live independently along with some family oversight and financial assistance. Now he lives with me (his sister) and my husband. He needs to use a wheelchair and requires assistance dressing, bathing, and toileting. He has never been able to work; his medication affects his mood, cognition, and physical abilities. He goes to a fabulous Easterseals day program. He is very happy working on his word search puzzles and watching Family Feud, Jeopardy, and Wheel of Fortune.

He is also a man of deep faith and enjoys watching church on television every Sunday. As a teenager, Robert almost drowned while swimming. Ever since that incident, he tells me that God told him he was here for a purpose. I firmly believe that Robert is here to tell other people about epilepsy and about how to live with it in a positive and "excellent" way.

Hyperammonemia is a dangerous metabolic condition characterized by an excess of ammonia in the blood.

AS PARENTS OR CAREGIVERS, WE MUST KEEP FIGHTING FOR OUR LOVED ONES.

CATALINA STRAMAGLIA

GABBY

by CATALINA STRAMAGLIA

I remember the first time I saw her. It was during my second ultrasound, and the sight of her took my breath away. We were in love with her before we even knew her. There were no issues during the pregnancy or during labor. We had the most beautiful and perfect baby girl in December of 2013. When she was about four months old, I noticed she had been staring blankly at times, but we did not think much of it. About the same time, we started to hear her making loud noises with her legs—like dropping them. Again, we thought nothing of it, because we thought she was just kicking her blankets off. At five months, we took a road trip down to San Diego. On our way home, Gabby had about five jerky movements in both arms and legs. We watched and saw nothing similar for the whole next week. During the weekend of Memorial Day 2014, she had the same jerky movements. At this point, we became concerned. We called the advice nurse, and she told us to go into the emergency room to have her checked out. They scheduled an EEG first thing on Tuesday after the long holiday weekend. On Wednesday, we got a call from the neurologist that Gabby had infantile spasms, and she needed to be admitted for testing. After that phone call, our lives changed. Our lives became filled with appointments, therapies, medicine, and no clear answers. Gabby has had all available genetic testing done, two MRIs, and a spinal tap, none of which have been able to provide us with any sort of answer as to what is causing her seizures.

Now five years old, Gabby still has daily seizures. She has anywhere from five on a good day to forty on a bad day. For the most part, she is able to recover quickly after an episode, but there are times they take so much out of her that she just needs to nap. Gabby has been seizure-free on three different occasions. Every time they come back, our hearts are crushed. Her current diagnosis is epileptic spasms with tonic seizures. We had been with the same neurologist since she was diagnosed in 2014 until 2018. After we attended our first EADDL, we were encouraged to seek another opinion and to seek a doctor that would be more aggressive in the quest to find answers. We started to notice how her original neurologist had given up on Gabby. We are now with an amazing neurologist who wants to give her the best. He is doing astounding research that will hopefully provide more answers to families dealing with epilepsy. Her previous neurologist was treating her for the diagnosis of LGS, but her new neurologist wants to give her a diagnosis more indicative of her situation. Gabby has been on topiramate, prednisone, Onfi, and currently on Depakote along with a modified keto diet. Recently she was diagnosed with high-functioning autism.

Gabby is delayed across the board. She has fine motor, gross motor, speech, and cognitive delays. A few months shy of her third birthday, she started to walk. Until very recently, she mostly communicated with single words. She had a hard time interacting with her peers. We worry about her every day. Is she going to have seizures at school? Is she progressing? Are her seizures getting worse? How will her life be in the future? Who will care for her one day, if we're not around? It is very hard and stressful to watch your child seize, to watch them get hooked up to an EEG, to watch them have their blood drawn, to see them fall behind their peers.

We focus on everything great about her, and there is a lot. She is the sweetest and most loving girl. She amazes us every day with what she is able to do and grasp. Her teachers and therapist enjoy working with her. She is very determined and persistent. She loves to be silly! We see so much potential in her. She has this energy that draws people to her. To this day, she continues to take our breath away.

STACEY

I was four years old when I was first diagnosed with epilepsy after my parents noticed me staring off into space and not paying attention (well, at least more so than the average preschooler.) The stares continued until I was ten when my brain decided to raise the game and add myoclonic jerks into the mix. Life was cruising along until one night when the stakes suddenly got bigger. At the age of thirteen, I had my first grand mal seizure. The second occurred on a field trip at the age of seventeen, and at eighteen, all hell broke loose with my brain, and it hasn't settled down since.

My journey has not always been easy; it's often been painful, both physically and emotionally. I went away to college but was asked to leave partway through my first semester due to liability issues. I've had doctors tell me that I'd never be able to have children, tell me I'm stupid for wanting to take time to review information before changing medications, and refuse to continue treating me because their treatment plan didn't suit my life's needs and goals. I lost four jobs in a row due to my seizures and have been unable to work outside of the home in over twenty-two years. I can't drive. I have never had a license and likely never will. I've had people tell me that I'm faking it, that I'm lazy, and that if I'd just drink more orange juice, I'd be ok. I've had periods of time when I cannot bathe without supervision and am physically unable to leave my home for months. I often have sores on my tongue from where I've chomped down on it during a seizure. Let me tell you, you don't know how much your tongue moves until there is a big gaping hole in it! I have cognitive issues, bulging discs in my neck, and once my face was so badly bruised, that the bruises were still evident nine weeks later. Depression and side effects from the various medications have been a constant side battle that I have waged throughout this whole time. No, it hasn't been pretty.

You're probably thinking, "Dang, how awful. I would hate to be her." Stop right there. Let me share the beauty and blessings this broken brain has bestowed upon me. First and foremost, there is family, which does not necessarily mean you share DNA. A chronic illness will show you who the important people are in your life. My non-genetic sisters, "my girls", celebrate my wins, mourn my losses, and fight right alongside me every step (or fall) of the way. Marty, my husband, and I are high school sweethearts. He was with me "before" and has more than been with me in the "after" years. I've watched and marveled as he has grown as a man, learning compassion and sensitivity. He has become extremely efficient at work, since he never knows when he is going to get the call to come home. Let's face it: I'm high maintenance (but so worth it). He has maintained me, our kids, our home, his job, and everything else, when I can't do my part. Marty is my number one blessing. I don't know if I could make this journey without him. I do know that I don't ever want to find out.

If you have known me for more than four minutes, you'll figure out that I don't like to be told I can't do something. I definitely didn't want to hear that I couldn't have kids, the one thing I had always wanted in life. I was fortunate to connect with a neurologist who worked with Marty and me to achieve our goal of having children, and we were blessed with three beautiful, healthy children. My broken brain has helped them become more responsible at an earlier age, not judgmental of others' disabilities, and more sympathetic to the personal struggles of people with disabilities.

I'm forty-four years old, and Mommy and Daddy still haul me around. They take me to appointments, the store, the bank, you name it—they cart me there. As a result, we talk. I hear their stories and commit them to heart and mind. We laugh. We discuss. We (sometimes...rarely) bicker. We eat hotdog lunches at Costco. My parents attend more of the kids' school events than a lot of grandparents, because hey, they're taking me there anyway. Not driving is rough for an independent personality living in a very dependent situation, but even this has brought an unexpected and treasured blessing in a closer bond with my parents.

My seizures have shaped my personality. I've learned to let a lot of things go. You can't control everything, so make a plan, and then just roll and readjust as needed. Laugh, if you can't find the humor in a situation, you'll drown. Let go of your pride, it only stands in the way of blessings. Take the time to acknowledge all the little things that make life great. Delight in your morning cup of coffee, relish when you have a good hair day, and treasure when you sing a favorite song at the top of your lungs in the car with your family. Most of all, open your eyes and look around you to see those blessings. My seizures have been part of my life for forty years, but they have never stopped me from living my life. I may take an indirect path, and I will definitely stumble (and jerk, shake, and fall), but I'll live, savor, and celebrate every minute of it!

This photo was taken two weeks after Stacey received her VNS implant.


MICKEY

JERMAINE

by BRIAN BRISCO

Jermaine is our second born, and by all accounts was perfectly normal—until he wasn't. At four months old, we started to notice brief staring spells like he was falling asleep sitting up. The staring spells went from a few seconds to nearly a minute of two, and when we noticed his lips starting to turn blue from not breathing, we rushed him to the ER. After a litany of tests and countless follow up appointments over the next several months, we were given an epilepsy diagnosis with no identified cause, and a "play it by ear" prognosis. The seizures did not appear to be causing him pain, but we would not know for some time—years if there were any developmental or cognitive issues.

Much of our story is about managing medication and relationships with our providers. Jermaine was moved through several medications during the first year, one after the other, none of which decreased his seizures. We settled on a medication that we were told was the last option before moving on to "adult" meds. Jermaine was like a zombie. It sedated him heavily. He would sleep through the night, but in the morning, he would mope around and lazily play with a toy or two while lying down and then nap for an hour or so.

His seizures changed from what we would later know as absence seizures to head drop seizures. His eyes would roll back into his head, he would sit down, his head would drop to the left, and he would fall over. Three seconds later, he would sit up and do it again. Over and over. Some were in clusters. We recorded upwards of one hundred total drop seizures on several days. Frustrated, we demanded a 24-hour EEG, which his neurologist reluctantly approved. With the results, we received an apologetic phone call from him, and we finally had some vindication. We thought this would lead to meaningful progress in his treatment, but it didn't.

At our wits end, we cried to Jermaine's pediatrician and said we didn't want these meds anymore. The awesome pediatrician reassured us that as his parents, we have the right to make that decision. We had noticed once, when we were a little late with the dose, Jermaine's seizures decreased. So, on the day of his birthday party, we skipped them, and he only had three seizures that day! This prompted more conversation and a change to the "adult" meds but to no avail.

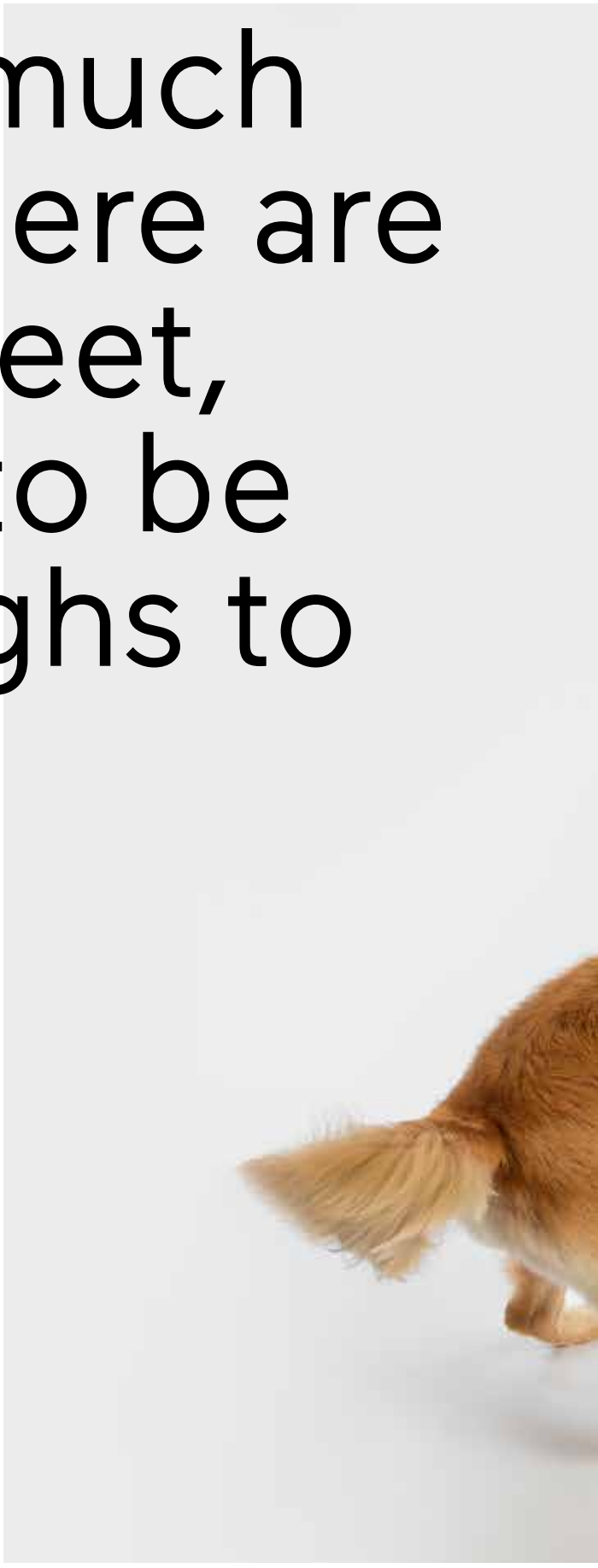
Then we sought out a geneticist who, through perseverance, discovered a very rare genetic mutation, POLG 268A. This helped confirm the medication we'd try next (Lamictal). However, after some time with no results, we sought a second opinion. The experience was terrible, and we left feeling belittled and ignorant. That drove us back to demanding more of our original team. Jermaine's epileptologist suggested we try adding prednisone to his medication. After three months it worked, and Jermaine was finally seizure free! Eventually, we were able to taper him off all the medication, and it's been over five years without a seizure.

We are fortunate that Jermaine began to experience these things at such at early age that it's his normal and quickly became our normal. Epilepsy has opened our eyes to other people with disabilities, physical or otherwise. We are in tune with their needs and aware of what they and their care providers may be going through. Through our story and experience, we want to encourage people to be the squeaky wheel until they get answers. Find the doctor and providers that will listen to you. Don't ever give up. You have epilepsy—it doesn't have you.

Jermaine's geneticist discovered the source of his epilepsy is a rare genetic mutation, POLG 268A, which is the cause of many of his medical issues (which also include autism, sensory processing disorder, auditory processing disorder, premature heart beats [ventricular contractions], eyesight concerns, and delayed speech.)

There is so much out there; there are friends to meet, adventures to be had and laughs to share.

AMANDA CHANTAL ROBAR



AMANDA

My name is Amanda Chantal Robar. I am from Aurora, Ontario, Canada, and I have had epilepsy my entire life.

When I was a day old, my blood sugar and calcium levels both dropped to zero, and I went into uncontrolled convulsions. I was rushed to the Hospital For Sick Children and stayed there for the first two weeks of my life while the doctors got me stabilized. I didn't have any more noticeable seizures until I was turning four years old. My younger brother came to my parents giggling and saying, "Mandy took a tumble!" I was rushed to the hospital, where I was officially diagnosed with epilepsy.

At nineteen, I had brain surgery to try and control the seizures. It took away the TC seizures. For a while, it even lowered the frequency of my simple partial seizures. I still have daily simple partial seizures that can turn into complex partial seizures, so I have a seizure response dog.

I have gained so much independence since having my first seizure response dog. I took my first solo trip to Mexico around 2011 with my first service dog, Kramer, and in 2015, I flew down to *Walt Disney World*® Resort with my current service dog, Kira. I currently work from home as an independent consultant for a company called Scentsy. I sell a variety of scented products including wickless candles, warmers, and diffusers. My first business trip with them is coming up, and I'll be heading to California.

I've also had an opportunity to speak with people about epilepsy. I always leave room for questions after my story. In one senior care home, I was asked if there was a cure, and more specifically, if there was one for me. This was a heartbreaking question to answer, since as of right now, the answer is no—not yet. However, who knows what thirty years down the road will bring?

I am now thirty-four and have been on seventeen different medications over the past thirty years. I have gone through determined times, I have hit the wall of no more meds to try (and hit the wall more times than I can count), and I've been depressed and even admitted myself to hospital, as life was not worth living.

I can tell you with certainty how wrong I was. There is so much out there; there are friends to meet, adventures to be had, and laughs to share. Despite all of my ups and downs, I have pushed through, thanks to the support of my family.

NOAH

by CHRISTINA CHEN

Noah was asleep in my arms when all of a sudden, he arched his back backwards, and his head went back. Noah did little jerks, and we noticed his eyeballs went backwards. He threw up towards the end of that episode. He was eight months old. As parents, we had no idea what was going on, and we immediately took him to his pediatrician. His pediatrician told us it was reflux, but we left the office with an uneasy feeling that this wasn't the case. Noah continued to have seizures, and the pediatrician and ER continued to tell us it was reflux. They suggested I stop breastfeeding him and get him on formula made for sensitive children. Our parental gut instinct told us otherwise, and thankfully, one of Noah's other doctors agreed and referred us to a neurologist. Noah was fourteen months old when he had his first EEG and was diagnosed with epilepsy. We still remember leaving the office in a fog. On one hand, we were thankful to have a true answer to what was going on, but on the other hand, we were scared and still didn't know what to do. As parents, we knew very little about epilepsy. That night we started to learn, and our journey began.

Noah has complex partial epilepsy with both daytime and nighttime seizures. His epilepsy is not caused by another condition, but his mitochondrial disease easily triggers it. Finding this key information has been a huge blessing, and we have been able to make sure Noah doesn't do too much in order to prevent back-to-back seizures. Before knowing this, he was rushed to the hospital in an ambulance and admitted on a monthly basis. We almost lost Noah twice during those years. In the last two years, we haven't had to rush Noah to the hospital, and his seizures have greatly improved.

Noah has never let his health conditions stop him. Since we have to limit his activities and outings, and he has to use his wheelchair more often, but he still lives his life to the fullest, never stops laughing, and continues to do what he wants to do. He takes three medications for his epilepsy, and we hydrate Noah through his G-tube when we do big outings, because he gets dehydrated quickly. The slow feed through the tube provides consistent hydration to prevent the back-to-back seizures. He still has seizures, but we've been able to manage them much better. Also, after six years of waiting, Noah was finally blessed with his seizure alert service dog, Dusty. Dusty lets us know before Noah has a seizure but also helps Noah by just being his four-legged best friend.

Emotionally, Noah hasn't been too affected, but as he gets older, we see moments where he notices how different he is from other kids his age. When he plays with other kids and needs to rest or use his wheelchair, we see his face change from a smile to disappointment. He tells us it does make him sad, but he also tells us his health conditions make him do things differently and make him feel thankful for the little things. As a family, each of us has been impacted differently and at different times. We've felt anger, sadness, and worry, but through it all, we've become a strong family. Our daily lives may be different from others', but we're so thankful and blessed to be such a strong and close family.

Epilepsy can be scary or angering at times, but there is help out there. As a patient, a parent, or a loved one, you are not alone in this journey. The diagnosis of epilepsy might change your life, but it doesn't define who you are. I asked Noah for words of wisdom or advice, and his response made me tear up. He said, "Don't let it stop you from living, don't let it stop you from laughing, and don't let it stop your dreams."

Noah loves to sketch, and his drawings are amazing. Most of his drawings are of planets he makes up himself, but he also loves to sketch people and animals. He is constantly reading and researching about anything related to space, and he knows about new discoveries and events before we do. His dream is to be a NASA astronomer and discover a planet. Noah says he will not let anything stop him from making his dreams come true.

A gastrostomy tube or G-tube is inserted through the abdomen to deliver nutrition directly to the stomach.

ONE WHO IS INTREPID WILL EXPERIENCE THE MOST IN THEIR LIFETIME.

CORBIN

I found out I had epilepsy as a freshman on the very first day of high school. It was during water polo practice. I have partial complex seizures, and I also have mesial temporal sclerosis (MTS). Two years after starting medications, I got a second opinion, which led to a right anterior temporal lobectomy. Dr. Aria Fallah at UCLA did my surgery in April 2017. Once I was released, I physically felt like one hundred percent.

I am on a lower dose of the same medication I had before the surgery. Before the surgery, I was fearful about whether I would have another seizure. After the surgery, my only fear is whether I will have another seizure if I ever come off my medications too early.

I tend to keep myself very busy. I like to learn about STEM-related concepts in my free time, and I am an Eagle Scout with the Boy Scouts of America. As an Eagle Scout, I've created pediatric imaging playsets for UCLA. The playsets are still in use today. They are made out of finished wood and are intended to reduce the fear that pediatric patients have in the hospital.

My view of life has opened up, and I feel blessed to be where I am today. People see me as a driven and intrepid teenager, and my main goal in life is to help establish a greater, more peaceful, and efficient society for everyone living in this world.

Mesial Temporal Sclerosis (MTS) is scarring of the brain tissue in the medial temporal lobe area.

LAUREN

by SHERRI BRADY

What I think was Lauren's first seizure happened when she was just a baby. It was before she had even gotten a diagnosis of Rett syndrome. I was on my way to her from work, and she was at daycare. They called and said something was wrong. I can't really say what happened after that, because it is all just a blur. I just knew that something was wrong with my baby girl, and I couldn't get to her fast enough. I took her to the ER, and I was in tears and so frightened that I could barely speak. I remember the admissions person telling me I had to calm down so she could help me. They determined it was a febrile seizure. I thought and hoped that it was a one-time thing that would never happen again. It wasn't.

A few years later, we were on a school field trip, and she had another episode. Thankfully, I was with her that time, but it was worse, and we were stranded at the Natural History Museum in LA, because we rode the bus with the class. As scary as it all was, it didn't last that long, which, I suppose, is why it didn't dawn on me to call 911. I eventually got ahold of someone to come pick us up, and I took her to urgent care. Shortly after that, Lauren was put on her first seizure med, Carbatrol. She's been on several since then, changing over the years for one reason or another. Lauren's seizures vary in type; she has small ones that she's able to bounce back from fairly quickly, large grand mals, and sometimes a combination of more than one. The frequency has varied as well. They typically range from once a month to several per week. She used to almost always have clusters and needed Diastat to stop them, but now it's usually only one at a time. The duration is less than a minute, but in the moment, it feels like an eternity. She is currently taking Keppra and Zonegran. There were actually times that I worried her meds were causing more seizures, but stopping them never felt like an option.

A few years ago, I started giving her various essential oils. I've never been sure if they've helped her seizure activity, but they've definitely helped her in other ways, so I continue to use them. In September 2017, when Lauren's seizures started to increase again, I decided to finally try CBD oil. I had been interested in it for a while but hesitated to try it, because I just didn't know much about it. I was concerned because there are several clinical trials going on for Rett syndrome, and I wasn't sure if giving Lauren the oil would disqualify her from participating. With direction from Realm of Caring, I started her on a very low dose of Charlotte's Web Everyday Advanced and slowly increased it to the recommended initial dose, which seemed to work. The results were fantastic, and Lauren went three months without any seizures. Unfortunately, I did have to increase the dose a few times since then. Overall, her seizure activity is still much better than it was prior to starting the CBD, but I wonder if I'll have to continue increasing the dosage, consider switching to a different brand, or try medical marijuana at some point. At the end of the day, I'll do whatever I need to in order to limit Lauren's seizure activity.

There are really are no words to adequately describe how it feels to watch Lauren seize. Gut-wrenching comes close, but it's so much more than that. I actually have a visceral reaction, and I feel completely helpless. Recently, a teacher sent me a message that Lauren had just had a seizure, and my heart stopped. She is typically with me or close by, and on this particular day, I was further away. The guilt I felt consumed me, and like that very first episode, I couldn't get to my baby fast enough. Each time she has an episode, in the back of my mind, I know what could happen. I know moms that no longer have their children, and the fear of that shakes me to the core. During times when things have been particularly bad, I have definitely cried myself to sleep.

Even though Lauren is unable to speak because of Rett, she is able to communicate, and she's told me the seizures don't hurt, so I'm thankful for that. I still hate the toll it obviously takes on her physically, and I hate that it interferes with her ability to enjoy life. I've chosen not to let the possibility of seizures stop me from making plans, but it's a terrible feeling to know one could happen at any moment and change everything. Lauren is the strongest person I know. She faces so many challenges because of everything she deals with on a daily basis, but she does so with strength, perseverance, and with a smile on her face—enjoying life in spite of it all.

Rett syndrome or cerebroatrophic hyperammonemia is a unique neurodevelopmental disorder caused by a genetic mutation. Epilepsy is a possible symptom of Rett (with a variety of seizure types) and is often associated with the less common CDKL5 mutation. Apraxia, inability to speak, and difficulty with breathing are among other usual symptoms of the syndrome.


MIRACLE FLIGHT
Family

AMANDA

by JOSE JIMENEZ

July 31st, 2010. This date would change our lives. This date was the first time we learned our daughter had suffered a seizure. Amanda, age two, had one seizure that day. We didn't know why this happened, and we were lost. Amanda went to the emergency room, was given no medication, and she was released the same day. We were told to follow up with a neurologist. Days after, we met with a neurologist, and we were told it might be a one-time thing, and if it happened again, she would need medication. On the second follow-up visit, Amanda suffered yet another seizure, landing her back in the hospital for a second time in one month. The neurologist suggested placing Amanda on Keppra, an anti-seizure medication. After the first dose, she became violent and completely turned into a different child. After this, Amanda was put on Depakote and did well for over a year. At that point, her EEGs were normal, and doctors said it'd be okay to take her off Depakote. My wife and I were confident this would be all over, but we were wrong.

During school hours, we got a call saying Amanda had collapsed in the classroom and started having a seizure. This began the hardest days of our lives. Amanda would start having multiple seizures every day, landing her in the hospital almost every weekend. Doctors put her on Depakote again, and throughout the following months, Amanda was on multiple medications that did not work. We also tried the ketogenic diet for over a year at UCLA, and after a year, her body started to reject the diet. Finally, we heard of a doctor in Palo Alto, CA, who might be able to help us. We live in Las Vegas, NV, so the question became: "How do we travel there?" That's how we found out about Miracle Flights. They offer free commercial flights for children in need to get specific care for their illness.

Dr. Porter at Lucile Packard Children's Hospital at Stanford was the answer. She placed Amanda on a very specific plan, giving us options every step of the way. Currently, Amanda's seizures have diminished to just three to five a year. After starting with Dr. Porter, she went seizure-free for a year and three months. Recently, Dr. Porter requested a genetic test, which found a gene mutation called CHD2. She also has been placed on a VNS implant to reduce or shorten her seizures.

Amanda is currently ten years old, and she is a very happy child. She's full of life and always has a smile. She is able to go back to school after three years of staying at home. Although she still has a hard road ahead of her, we are ready for it. My advice to any parent dealing with epilepsy is to get educated and do not ignore this condition. Ask as many questions as needed, attend conferences, go online, and join support groups. Most importantly, remember to be your child's advocate, because you know your child better than anybody.

Chromodomain-helicase-DNA-binding protein 2 (CHD2) is a protein-coding gene. This protein is found in cells throughout the body and plays a part in how DNA is packaged, which affects gene activity and possibly nerve cell development or function. CHD2 mutations are associated with epileptic encephalopathy.


RACLE FLIGHTS
Family

JANICE

In January 2014, one month after a surgery, at the age of sixty-three, I had my first known seizure. My entire life was turned upside down. I started having missing blocks of time, memory issues, daydreaming episodes, frequent falls, and waking up with missing teeth in my mouth. Did something happen to me during surgery? Did I have a stroke? Was there an anesthesia accident? What was this thing happening to me?

Thus, began my journey of many trips to the ER and urgent care, hospital stays, and specialist's appointments—each ordering multiple CAT scans, EEGs, and EKGs. I had three inpatient 24-hour multiple day EEGs at the local university hospital epilepsy clinic, and an outpatient 72-hour EEG. I had my whole genome sequenced looking for a genetic cause, and I had a heart loop monitor implanted to rule out syncope. The answer was allusive.

During my trip to receive a diagnosis, I drove my car off the road and into a deep ravine, losing my driver's license. I broke many teeth during sleep and received multiple concussions after falls. I had three TC seizures during simple medical procedures. My diagnosis went from simple partial seizures with nocturnal seizures to non-epileptic seizures, and lastly, to focal onset aware and focal onset impaired awareness seizures. I fired my neurologist when compassion turned to frustration for both of us. My new neurologist ordered a 72-hour EEG and sent me out into the world to live life. Finally, we had an answer, and he changed my medication to the fifth anticonvulsive drug I tried. Hopefully this is the one, and it will remain effective.

Prior to my first seizure, I was at the top of my game—employed as a Director of Regulatory and Quality at a medical device company. I rode hunter and jumper horses in my fifties. I did five three-day, sixty-mile breast cancer walks, Heart Association walks, Alzheimer's awareness walks, and autism awareness walks. I was active, traveled much for my work, and enjoyed life. Then it all changed. Suddenly, I was unable to keep up with the ever-changing regulatory standards, inspections and audits, and the stress of managing large teams. I stepped back from the management role, taking a senior staff position at another medical device company. The role change was the correct decision, freeing me to research seizure causes and treatments.

Using my research skills, I located foundations, societies, support groups, and discussion groups. I read National Institutes of Health (NIH) warnings and medical articles, and I attended the *Epilespy Awareness and Education Expo* and other gatherings. Through my reading, I discovered that epilepsy has perhaps been part of my life longer than I knew. I was the clumsy daydreaming child that fell often. I saw lights and auras in my teen years. Epilepsy may have been hiding for a long time.

I have learned to say, "I have epilepsy" without fear or shame. I have learned to ask questions but also to answer questions for others. I journal every day, which allows me to record details I may not remember later. I wear a helmet and use a walker, and that is okay. I dream of getting my license back. I have learned to do my own research before taking a new drug or having a medical procedure and know the language and terminology necessary to communicate with my physicians in order to give actionable information. I know which common drugs do not mix with anticonvulsive drugs and keep all of my doctors informed.

I have identified my seizure triggers and have learned avoidance techniques. I have learned to ask for help. I am in the process of receiving a service dog from Little Angels Service Dogs, so independence is in my future.

Remaining compliant to my drug routine allows me to stay seizure-free and live a normal life. I work for a compassionate company that is willing to make necessary accommodations, so I'm able to remain in a demanding field, which also gives me access to the latest genetic information. Data and information comfort me, so I continue my research. The cause of my seizures may never be known. I have epilepsy. That has changed my life, but it has not defeated me.

NIKKI

by BEC LARSEN ATTWOOD

An amazing man changed our daughter's life and gave her a chance at a completely different future. We went from hundreds of seizures every day to none. My sister had sent me a link to a talk by Dr. Gary Mathern from UCLA. In it, he said something like, "We have to stop thinking of surgery as a last resort. For some of these kids, it's the best chance they have for a future." Nikki had no triggers for her seizures. Her neurologist and we felt there had to be something in her brain causing them, but we couldn't find anything on scans. Surgery without knowing a specific spot was risky, due to the area the seizures were coming from, but we thought finding this spot was our only hope. I e-mailed Dr. Mathern to see if he would re-evaluate Nikki, and he responded within twenty-four hours. Three weeks later, we travelled to LA from Perth, Australia. Within two weeks, they found the spot, and Dr. Mathern removed as much of this area as he could without affecting Nikki's motor function. She was immediately seizure-free and remained this way for over four years.

Nikki's diagnosis was focal epilepsy caused by cortical dysplasia in the right parietal region of her brain. We first discovered her epilepsy just after Nikki turned two. She was standing in front of me and began flickering her eyes and tilting her head to the left. It was very brief, lasting about ten seconds, but it occurred every ten minutes. The hospital confirmed her epilepsy with an EEG and two days later, they admitted her and started her on medication.

For about two years after her diagnosis, she didn't have much of a life. At times, Nikki would have drop seizures and wear a helmet, at other times, she was so affected by medication she would just sit in her pram. She spent an average of one week every month in hospital for tests and trying new treatments. During this time, she missed out on development, in particular speech and gross motor skills. For over twenty months, Nikki had multiple MRIs, a PET scan, two single-photon emission computed tomography (SPECT) scans, lumbar punctures, and multiple blood tests. She tried over twenty-six medications. Some would provide relief initially, but her seizures always came back and would be longer and more frequent.

Nikki's surgery was truly life-changing for her and our family. The five of us were able to spend time together and do simple things like going to the park or beach without one of us holding Nikki. We always worried about her brothers and the impact it was having on them, as we really had limited time to spend with them. She did have another seizure in December of 2017 and only a few since then. It has taken more time for her to adjust and understand what is going on than when she was younger.

She still keeps a smile on her face and regularly tells us she is ok! She is in year four at school, and to look at her, you'd never know what she's been through. She is just like any other nine-year-old. She loves singing, dancing, swimming, gymnastics, and playing with her brothers and friends. Watching her tackle epilepsy has been an amazing journey, and to say we're proud of her is an understatement. Her strength and ability to take it all in stride is inspirational. We don't want epilepsy to define Nikki, as there is so much more to her. We know seizures may be a part of her future, but hopefully the knowledge that her parents will never give up can afford her the freedom to make the most of her precious life. There are so many different causes for epilepsy and so many opinions across the world—find the right one for you and your child. Never give up on hope; the hope for something better for Nikki kept us going. She would always say, "Don't worry, I'll be happy anyway."

Single-photon emission computed tomography (SPECT) scans show how an organ works. They produce 3D images, using nuclear image testing (a radioactive substance is given to the subject to allow a special camera to record the images.)

ERIC

My name is Eric, and I have epilepsy. I hate to say it, but I was embarrassed by it. I thought I would forever wear a scarlet *e*, and everyone would judge me. But now, I have come to embrace it as just part of who I am.

I found out I had epilepsy when I had a big seizure that I didn't know was a seizure. My behavior was odd, and my wife couldn't get me to communicate. I was just standing in our living room, waving at the staircase. I was already on the board of Sofie's Journey, so I mentioned it to Brad and Candy Levy. They put me in touch with Dr. Millet, who said it was textbook epilepsy. That was a year ago.

I have temporal lobe epilepsy. It may be due to four concussions I had before the age of thirty, but we may never know for sure. It's upsetting to know that I have epilepsy, but it has brought a whole new awareness of the disease and what it does to people that I didn't have before. My perspective has changed, and I want to share that awareness with the world.

I'm an attorney. I'm on the phone and computer all day long. I can no longer type like I used to, and my brain sometimes gets confused. When I have a seizure, I'm temporarily out of it, which makes my old hobbies out of the question. Epilepsy has limited my driving, and I had to give up riding my motorcycle and being a pilot. Now that I can't do either, I spend more time with my family and friends. I've completely eliminated any alcohol intake. I've also had to try several medications before finding ones that work for me, but Oxtellar XR and gabapentin, my current medications, have dramatically cut down my seizures and made it so I can work again.

If I had to give advice to someone newly diagnosed with epilepsy, I'd tell that person to never give up looking for answers. Pay attention and know what your body is telling you. Ask a lot of questions, and be your own advocate. Go after your dreams. Don't let epilepsy bring you down. Talk with a lot of people and stay active and productive for as long as you can.

All states allow people with epilepsy to drive, but each state has their own terms, which might include medical evaluations, a seizure or medication-free time span, a statement from a medical professional, and submission of periodic medical reports.

IT'S HARD TO EXPLAIN TO SOMEONE THE DAILY STRUGGLE OF GETTING SEIZURES IN MY BRAIN WHILE I LOOK FINE ON THE OUTSIDE.

THYARA HAAKMAT

by MARGARITA HAAKMAT

When Thyara was two years old, we discovered she had epilepsy. The playschool she used to visit called us. They said, "Thyara is not feeling well", and we went to get her. She was unconscious for several hours. We called the pediatrician, and she said to take her to the hospital. She was there for a few days. They did all kinds of tests and did not find out what was wrong. She was asleep when they did an EEG test, and discovered frontal lobe focal epilepsy on the right region. Her condition worsened, and she now has generalized seizures. After ten years, the EEG also shows both left and right seizures.

Thyara sees a neurologist on her native island of Curacao but went to Colombia for a 48-hour EEG test, because Curacao does not have the machine necessary for this test. The neurologist in Colombia said she has very active epilepsy attacks and prescribed 200mg of Lamictal. We also traveled to California to EADDL and did the Levy family's EEG to GO.

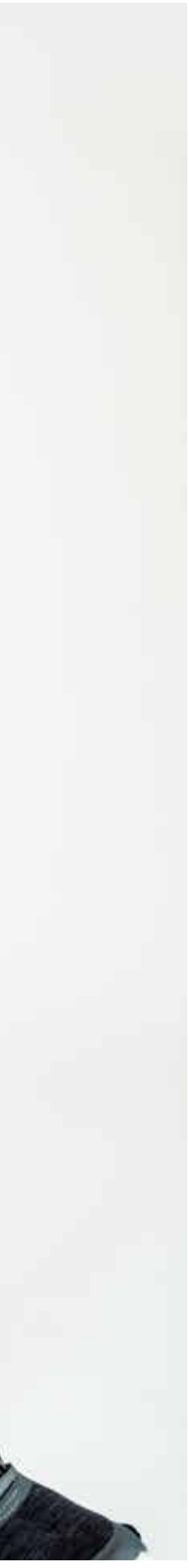
She is a very kind girl and loves babies and pets, but she has a lot of emotional and psychological problems. She is going to do a test to see if she also has autism and visits a psychologist due to issues like explosive screams, bursts of laughter, and concentration problems. She's often misdiagnosed with attention deficit hyperactivity disorder (ADHD) and a lot of other things. She does not get convulsive attacks, and you don't notice when she gets seizures. When she is excited, you notice her hand or neck get stiff. Due to that, people don't notice and see her seizures. She faces a lot of bullying at school and has a hard time making friends. They bully her because of her behavior and emotions. The whole family is suffering, as she continues to get worse.

On the island, we don't have help or special attention for epilepsy patients. We have a foundation that gives information, but the island is a hard place for people with epilepsy to be. The only help you can get is medication. I hope someday Thyara can get good tests and help for her epilepsy problems and consequences. When I asked Thyara for a few words regarding her epilepsy, this is how she responded: "If you have epilepsy, always know that you are special. God loves you and will take care of you. It's hard to explain to someone the daily struggle of getting seizures in my brain while I look fine on the outside."

THYARA

The things that make me different are the things that make me. Just like my glasses, my wheelchair, and my smile, my epilepsy makes me who I am. I might not like it, but it is a part of me.

PAIGE HILL



by MICHELLE & PAIGE HILL

Paige is seventeen. She is a junior in high school and is involved in band and drama. She is on student council and likes being social. She likes music and watching movies. She adores animals and being outside, is involved in 4-H, and shows a market swine project at our county fair and livestock show. She does these things despite the fact that she can no longer talk or walk. She is fighting a battle every day against her foe—epilepsy.

Paige started having seizures at age two. Her oldest brother was diagnosed with epilepsy at age five, so it was assumed that she was following in his footsteps. After MRIs, genetic testing, blood work, and a lot of poking and prodding, she was found to have a lysosomal storage disorder called MPS III or Sanfilipo syndrome (she has type A). This means she has an enzyme that builds up in her brain. Everyone has this enzyme, and we can eliminate it, but Paige cannot. It gradually crowds out areas of the brain so that she can no longer walk or talk or eat. Individuals with this regress and epileptic seizures are common. There is no treatment, such as stem cell transplant or enzyme replacement therapy, due to not being able to cross the blood brain barrier. Most people with this do not live to their teenage years.

Seizures interrupt Paige's daily life. They make her tired and have caused other injuries like broken bones, cuts, and bruises. Sometimes, it scares others around her who are not familiar with seizures. We have "Paige-proofed" the house to try to avoid injuries from seizure activity. Going to other activities away from home like school or church can put us on high alert. You never know when a seizure will happen in the middle of something. As a parent, I'm also tired from the constant care and worry. I think it has gotten harder, in some ways, over time because she has grown, and a larger child can be harder to manage. Paige has been on Keppra since the age of five. We're also interested in trying CBD oil. She takes her meds through a J-tube, since she can no longer take liquids by mouth. It's hard to find anyone besides her brothers to help out or babysit, because others are hesitant with tube use. She also likes to try and "help", so it is a constant watch so her tube is not pulled out.

Words of wisdom: Being differently abled does not necessarily mean you can't do the things you like. We adapt most activities for Paige, due to her physical limitations, so it doesn't stop her from having fun doing what the other kids are doing. Try something that interests you, sometimes you just have to try doing it in a different way! While epilepsy can be scary to you and others around you, it shouldn't deter you or destroy a can-do attitude. Be brave, because you are not alone. Many are fighting the "epilepsy monster". Some days we may lose a battle, but we are in it to win the war!

PAIGE

DANNY

by TOM STANTON

Danny lived a normal life. He played sports, went to pre-school, and was a happy kid. He was physically and cognitively on track for his age level. He had no conditions. Then, at age 2, he had his first seizure. After he had his second seizure a month later, he was diagnosed with a childhood seizure disorder. The term epilepsy was not mentioned. All of his five known seizures occurred during sleep. He was otherwise completely healthy.

Danny took medication daily. Aside from that, everything for him continued in a normal fashion. That wasn't the case with his parents. Like most parents in that scenario, they worried about Danny during the nighttime, which impacted their sleep and anxiety levels. That is exhausting. Often, Danny slept in bed with his parents because they were worried they would miss a nocturnal seizure. If he wasn't in bed with them, his parents would conduct regular bed checks while he slept.

Danny died from SUDEP at age four. The loss completely devastated his immediate and extended family. It is something we will never fully recover from. The best we can do now is to help other families in his honor. I serve as the Executive Director of the Danny Did Foundation. Our mission is to prevent deaths caused by seizures.

My advice to someone newly discovering their own epilepsy is to ask questions and be curious about what treatment options are available. Keep probing until answers are found that fit with the needs of your family. Sometimes parents or patients are afraid to question medical providers or to push for a new or different treatment path. It is so important that you advocate for what you need; no one else will do that better than you.

Losing Danny so suddenly, we learned about the fragility of life. Once we started the foundation, we met too many other families who suffered their own loss. Our message is: Enjoy your life. Enjoy the people around you. Seizures sadly can sometimes be fatal. Plan and take steps to minimize that risk as much as possible, but also embrace each day and live life with joy in your heart. That's what Danny did.

Family, friends, and caregivers of people with epilepsy should be informed of what to do during a seizure and learn the recovery position and cardiopulmonary resuscitation (CPR) techniques.

During our photo shoot, a grantee of the Chelsea Hutchison Foundation started to have a seizure, and we were not able to take other photos of the group that day. This was one of the few frames we were able to capture.

CHELSEA HUTCHISON FOUNDATION

by JULIE HUTCHISON

Chelsea was born on September 28th, 1992 and brought more joy into our lives than we could ever express in words. At the age of eleven, she began having occasional seizures until one night, April 19th, 2009, at the age of sixteen, she died very unexpectedly after having a seizure in her sleep. The Chelsea Hutchison Foundation was created in loving memory of her. No one had every told her family that a seizure could take her life. The term SUDEP is a term they would come to know well.

Chelsea loved life. She was as beautiful on the inside as she was on the outside. She never wanted to be limited to just one group of friends; she genuinely wanted to be friends with everyone. She loved who she was and even loved her name. It was important for her to be her own person and often proudly referred to herself as a "dork". Chelsea touched many lives, and we are amazed at how many she continues to touch, even after her passing.

The Chelsea Hutchison Foundation is designed to grant comfort and hope to those living with epilepsy. Funds raised by this foundation provide grants for seizure response service dogs, epilepsy monitors for those in need, wish trips, support, and public education about SUDEP.

One of our favorite projects is *Chelsea's Wish*. Since the start of EADDL, we have worked hard to bring as many families as we possibly can to this event. This isn't just a vacation for our guests, it's a valuable trip, where families have access to top professionals in the field, information on the latest treatment options—conventional and nonconventional, and the ability to meet and connect with other families that share similar stories, challenges, and concerns. The bonds made between the families are as important as the information they come away with. There is a support system that forms between the families during their days at *Disneyland*® Resort that lasts long after they return home.

Sudden unexpected death in epilepsy (SUDEP) is the leading cause of epilepsy-related mortality.

LITTLE ANGELS

SERVICE DOGS

by KATIE GONZALEZ

Our organization consists of professionals and volunteers working toward the common goal of assisting those with epilepsy through highly trained dogs. Our dogs respond by dialing a phone for help, retrieving medication or a loved one, performing deep pressure therapy, providing comfort, and are actively trained to alert to seizures through scent.

Katie Gonzalez founded the organization in 2006 to train assistance dogs for disabled children and adults throughout the United States. At that time, it was clear that epileptic patients greatly benefited when matched with a service dog, however few other organizations trained seizure response dogs. Katie had been doing this since 1998 and saw that many dogs could alert to seizures, and a select few could even alert in advance.

With her research, Katie found that dogs that were alerting to seizures in advance were naturally anxious in personality and demeanor and had a close bond with the patient. Furthermore, the patients of those dogs had seizure-related activity in advance of the actual seizure and had seizures that were distressful in nature. The dogs realized, through repetition, that they didn't like seizures and would show signs of distress when they know one was about to occur. The stress was demonstrated through paw licking, putting their ears back, pacing, shivering, barking, clinging or climbing onto a person they trusted to seek comfort.

Katie speculated that scent played a major role in this. Dogs have an incredible sense of smell, believed to be a million times stronger than our own. The dogs she trained usually paid special attention to the patient's face before, during, and after a seizure, sniffing and licking near a patient's mouth. She knew dog trainers throughout history had developed methods for dogs to search out explosives and drugs or to recognize and alert to the scent of cancer cells in patients. For many patients, seizure activity builds slowly. This is often seen in an EEG before the patient realizes a seizure is coming and before physical effects. Katie hypothesized that like an EEG, a dog would be able to use scent to detect an oncoming seizure and perform an alert behavior to allow for safety measure to be taken.

Katie's speculation proved to be accurate, and she put in place our current system for training our dogs. Since the inception of this method, every Little Angels Service Dog trained in seizure alert successfully alerts to seizures in their recipient. If there is not advance seizure activity before the physical effects of the seizure, the dogs are able to alert another family member that the seizure is occurring in the patient.

The first step is training the dogs to play the alert game. The dog is asked to paw at a trainer's leg, and in exchange, the dog receives a mouthful of delicious treats. This is very fun and motivating for the dog. Second, the patients are asked to swab their palms and the inside of their mouths with gauze right after a seizure takes place. Third, training magic happens, as the scent becomes the dog's alert cue. The gauze is placed in the room during alert game training. When the dog paws at the trainer's leg, a food reward is given. With weeks of repetition, in different training locations, we've seen that the dogs are consistently able to walk into a room containing the seizure scent sample and automatically paw at their trainer's leg without being asked to. From this point forward, our dogs await the scent of a seizure. They can't wait to play the alert game and receive their special treats! This has been life-changing for hundreds of people across the world.

We're an industry leader for seizure alert dogs, and the best place worldwide to educate the public on what these amazing dogs can do and show our love and support for these incredible families is EADDL. Brad and Candy, the event directors of EADDL, were aware of our work and invited us to attend, which we have been doing since year one. There is no other event quite like it on earth. The backbone of EADDL is individuals who have a heart for those suffering with epilepsy. They bring their experience and love for the community to everything they do. We will always be involved in EADDL, as we continue to train dogs for people who need them.

by BRAD & CANDY LEVY

It all started with the man in the middle, Dr. Gary Mathern. Without the great success he had on our own daughter, Sofie, we would never have been inspired to launch the first EADDL in 2013.

Dr. Mathern received his Board Certification in Neurological Surgery in 1996. He has had a long and prestigious career as the director of the epilepsy surgery program at UCLA. In 2016, he was honored by the American Epilepsy Society with the William G. Lennox Award for lifetime achievements in the field of epilepsy. He has been featured on multiple news programs and publications for his amazing success stories of patients who had previously suffered from uncontrolled seizures. In the academic world, Mathern has dedicated much of his life to furthering research and education for epilepsy professionals, including his time as the editor for *Epilepsia*, a worldwide journal established by the International League Against Epilepsy (ILAE) to publish the most current and groundbreaking research articles and papers.

Dr. Ed Bertram is the current Secretary General of the ILAE and a longtime friend and peer of Dr. Mathern. Dr. Bertram completed fellowships in EEG and epilepsy, and he launched the epilepsy monitoring unit and epilepsy surgery program at the University of Virginia. He has been a professor of neurology there since 2004.

EADDL grew, and around the third year, Dr. Mathern thought it would be mutually beneficial to partner with ILAE; A partnership would help the event gain notoriety, and EADDL's momentum would help ILAE gather input and data while furthering the joint mission to educate and empower patients. The ultimate goal for everyone, of course—to find the cure to epilepsy. Dr. Bertram took the idea to the league, and we have had their support ever since.

Enter Mr. Personality, Dr. Solomon "Nico" Moshé. Dr. Moshé wears many hats. He is the director of the developmental epilepsy division at Albert Einstein College of Medicine. He has an endless list of publication credits and currently heads up several task forces and committees for the ILAE. He is always smiling and interacting with families while continually in pursuit of better treatment and care for patients who suffer from uncontrolled seizures. Dr. Moshé also donates time abroad to care for patients in countries with no epilepsy care.

These three doctors have been with us every step of the way. In 2015, the ILAE decided to create the only International Epilepsy Awareness Day, which falls annually on the second Monday in February. (We know November is Epilepsy Awareness Month, but ILAE needed to select a day a globally moderate weather day. We used our *Epilespy Awareness and Education Expo* and event promotions to blast the international date across America, while securing a long-term relationship with our friends at the ILAE.

What began as a small show our family started has become an annual three-day affair, produced by our growing volunteer team and advisory board. We began with a few sponsors and non-profits, most of which have grown into powerful national partners. We are in the process of creating a permanent fixture in the epilepsy world to connect and support families in the epilepsy community worldwide: something forever—a legacy.

DR.
MATHERN

DR.
BERTRAM

DR.
MOSHÉ

CONCLUSION

by EDWARD H. BERTRAM, M.D., GARY W. MATHERN, M.D., & SOLOMON L. MOSHÉ, M.D.

We were asked to write the Conclusion for this book. In many ways, that request is an impossible task, because the experience that each of the authors has had with epilepsy is so different; there is no way to make a simple statement that covers the many ways epilepsy has impacted their lives. On the other hand, all of the stories emphasize what the International League Against Epilepsy and International Bureau for Epilepsy have stated for many years: epilepsy is more than just seizures. The authors, whether they have epilepsy themselves or are family members, write about a number of issues that we professionals do not always take into account.

When we see patients in the office, we're often focusing on seizure frequency and the possible side effects of medication. We also need to focus on how epilepsy might affect life's daily activities and how people with epilepsy might deal with the many challenges they face. Many of these challenges are a result of the unpredictable nature of epilepsy. Seizures happen suddenly, usually without much warning, and often occur in very public places at very inconvenient times. Were the seizures predictable, people could prepare and minimize many of the consequences. It is the uncertainty of all aspects of epilepsy that make it such a cruel disease. In many cases, as our authors emphasize, living with epilepsy is a day to day existence, and we need to be aware of this issue that is so important to people affected by the disease.

When something is wrong, we always want to know what is causing the problem, and we also want to know what the prognosis is. Epilepsy doesn't allow us to satisfy either desire. People dealing with epilepsy want to know what is happening, but they also want reassurance that life will go on as normal. We physicians often can't satisfy either concern, as our authors point out time after time. One of the unfortunate reasons for this lack of insight is the knowledge deficit about epilepsy in the general medical community, including many neurologists. Just as the knowledge about epilepsy in society is poor, there is little education about epilepsy during medical training. This knowledge gap was emphasized in the Institute of Medicine report on epilepsy in 2012, which indicated that most physicians receive no more than an hour of formal epilepsy training. These stories, which are all too common, should be used by the greater epilepsy community to emphasize that epilepsy requires much greater attention in the health care system.

Perhaps the greatest burden for those whose lives are disrupted by epilepsy is the overwhelming sense of isolation. One of the problems for people with epilepsy is that they often don't know when they've had a seizure or what actually happened during the seizure. They are told something happened, but they have no recollection of the event. Their lives are held hostage by these unrecognized occurrences. We all want to have control of our behavior, especially in public places, and

we don't want to attract unwanted attention. With epilepsy, control is taken away, which causes many to withdraw from public activities. This isolation is further enhanced by the stigma that societies place on people with epilepsy (and sometimes their families). Epilepsy is often erroneously associated with insanity, moral failings, or spiritual punishment; people with epilepsy and their families are avoided and isolated. Negative reactions to the admission of having epilepsy, voluntary or not, cause people to hide their disease and avoid situations in which a seizure may happen in public.

Because epilepsy is so disruptive for some people, and because the current accepted treatments may fail to deliver the desired control, there is an understandable desire to find something — anything, that will reduce seizures. Many will try a variety of measures that have no demonstrated medical benefit in the hope that this intervention will make the difference. As physicians we are very reluctant to support such measures, but we also recognize why people choose this path. We only recommend that people discuss these alternative approaches and consider the potential costs before starting.

Many people feel their experiences are one of a kind and that no one else has ever had to deal with all of the consequences of the disease. One of the great values of a book like this one and of gatherings like EADDL is that people learn firsthand that they are not alone; others are facing the same problems every day. Because there are no instructional manuals for families struggling to have a life that is not ruled by seizures and the many other issues that often accompany epilepsy, these events and books let people learn from one another; they learn how to minimize the many consequences of unpredictable epilepsy they live with. Stories such as these are also critical to the education of physicians and all of the professionals who try to help, often without success. The stories remind us that the solutions do not always come in a prescription or bottle of pills. There is a much broader support system of therapists, teachers, and devices that are key to a better quality of life.

This book is also a collection of profiles on courage. The people in these stories often have seemingly impossible obstacles thrown in front of them by epilepsy and its consequences. Many of us might have given up and accepted a terrible situation as a permanent reality. Our epilepsy champions did not. They continued to look for solutions and celebrated every victory that led to an improvement in their quality of life. In some cases, it was a reduction in seizure frequency, and in other cases, it was a change that reduced injury risk. Some people refused to have their lives controlled by seizures and challenged themselves physically or socially so they could live like others around them.

Perhaps the greatest message from these stories is to never give in and always look for ways to find your own sense of normalcy. This book and patient gatherings are important steps in showing us the way.

NOTES

The book includes commonly used statistics derived from the below sources.

p. 26 "Epilepsy is a common condition and affects at least 65 million people around the world."

Institute of Medicine; England et al., editors. *Epilepsy Across the Spectrum*.

Tomson et al. *Medical risks in epilepsy*.

p. 34 "Teen epilepsy presents unique issues that benefit from a holistic model of treatment; biological, psychological, and social support helps transition teens into adulthood."

Lerner, J. "About Us: The Biospsychosocial Approach at UCLA."

p. 63 "An estimated 1 in 26 people will develop epilepsy over the course of a lifetime."

Hessdorffer et al., *Estimating risk for developing epilepsy*

Institute of Medicine; England et al., editors. *Epilepsy Across the Spectrum*.

p. 135 "Sudden unexpected death in epilepsy (SUDEP) is the leading cause of epilepsy- related mortality."

Thurman, Hessdorffer, French. *Sudden unexpected death in epilepsy*.

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This list represents the origin of statistics referenced in this book. This list is not a complete record of all the works and sources consulted to considerately write and edit this book. Much of the information within this book is deemed common knowledge within the medical field and has been vetted by the book's expert affiliates.

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ACKNOWLEDGEMENTS

by BRAD & CANDY LEVY

A very special thank you to our hero, Dr. Gary Mathern, who changed our lives forever. It was just another day at the office for you, but for us, it was a miracle. You changed our lives and put us on our path as advocates. We will be forever grateful to you.

To our friends, family, volunteers, and board members (who are also friends and family), without you, none of this would be possible. Thank you.

To our physician mentors who have become friends and family to us, Dr. Ed Bertram and Dr. Solomon Moshé, thank you for the support and for always helping to keep our focus.

Sofie, thank you for being who you are. Your courage, strength, amazing heart, and soul makes us so proud. Watching you grow into you is the greatest gift. We love you.

Thank you to Karen, Amyliz, and Monty for making this project that was just a dream actually come to life.

Mostly, thank you to all of the families who sat for these photos, poured out their feelings and shared their personal stories with us. You are the heroes.

CONTACT

We welcome questions and comments about the book and stories we've shared, and we would be happy to connect the outside world to any of the participants in the project. For additional information, e-mail info@epilepsyawarenessday.org

ABOUT THE PHOTOGRAPHER

KAREN HABERBERG is a New York City-based portrait photographer and published author specializing in visual storytelling. Her photography has been shown in numerous gallery exhibitions, magazines, and newspapers including The New York Times, Wall Street Journal, The Daily News, Huffington Post, Time Out NY, Daily Mail, Cosmopolitan, New York Family, and Fit Pregnancy. Her first book, An Ordinary Day – Kids with Rare Genetic Conditions has been featured on ABC News , NY1, Out of Bounds Radio Show, among others. In addition, Haberberg teaches photography at the 92Y and JCC of Manhattan. Haberberg has also curated numerous exhibitions and collaborated with well-known photographers such as Annie Leibovitz, Elliot Erwitt, Joyce Tenneson, Gillian Laub, and Bruce Davidson. Haberberg holds a BA from Brandeis University and earned her MA in Art and Photography from the ICP. She lives in Manhattan with her husband and kids.

ABOUT THE WRITER

AMYLIZ PERA is a producer, performer, and writer. She's an executive producer with the commercial production company Twist, a company she has been a part of for over twenty years. Pera is a member of Actor's Equity Association and the Screen Actor's Guild – American Federation of Television and Radio Artists through which she's done stage, screen, and voice work. Amyliz has a professional choreography resume and enjoys working with teens, in particular. She studied music, taught piano for ten years, and also has a BA in theatre and dance. Her written works range from advertising copywriting to screenplays. She's currently working on her debut novel. Amyliz lives in Brooklyn, New York with her husband, Monty, and two kids, India and August.

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First edition, 2019

Library of Congress Control Number 2019939456

ISBN 978-0-578-48679-6

Designed by Monty Pera

Photo of Amyliz Pera by Mark Bennington

Printed and bound in USA