Epilogues
2013

a collection of written works displaying the talents
of people affected by seizures

EPILEPSY
FOUNDATION®
MINNESOTA
Not another moment lost to seizures™

Our Mission

The Epilepsy Foundation of Minnesota leads the fight to stop seizures, find a cure and overcome the challenges created by epilepsy.

Our Vision

A world where people with seizures realize their full potential.

EPILEPSY FOUNDATION®
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Table of Contents

Sustaining Ourselves - writings by people with epilepsy

Movements of Love - writings by family, friends and caregivers of people with epilepsy

The views expressed in these works are solely those of the authors, not those of the Epilepsy Foundation of Minnesota.

Dear Reader,

We are delighted to publish the seventh edition of “Epilogues,” a diverse collection of poems and narratives written in 2013!

This book of written works was compiled by the Epilepsy Foundation of Minnesota (EFMN). The authors are living with epilepsy or have a relationship with a person who has epilepsy.

2014 marks the 60th anniversary of the Foundation, which annually serves over 100,000 people who have a connection to epilepsy! The “Epilogues” collection is part of our Creative Arts program, providing opportunities to showcase the creativity and talents of people with seizures. The program also raises epilepsy awareness in our community through visual, performing and written works.

All poetry and prose submissions to “Epilogues” are grouped into three classes by a volunteer committee: Judges’ Choice, Superior and Meritorious. Each piece is reviewed and ranked based on the committee’s assessment of its emotional impact, connection to epilepsy and overall presentation. Background information is provided about most authors to give context to each piece.

The “Epilogues” collection is organized into two sections with works arranged alphabetically by author:

1. Sustaining Ourselves—writings by people with epilepsy

2. Movements of Love—writings by family, friends and caregivers of people with epilepsy.

EFMN congratulates these authors for their contributions, and for rising above seizures!

– The Epilepsy Foundation of Minnesota & The Creative Arts Committee

Sustaining Ourselves

writings by people with epilepsy

The Pulled Wires

by Robin Blaha

I have been asked many times throughout my life how I have overcome epilepsy and seizures: day by day. I am 39 years old and have had severe epilepsy for all 39 years. When I was younger, my parents taught me how to let it go: “Don’t hang on to what happened two days ago; don’t let it bug you,” they would say. In my head I couldn’t understand how they could just say “to let it go” when I was shaking on the ground, slower in school, teased on the playground, couldn’t find dates, had trouble communicating efficiently, or stared off into space. I simply had no control of my own body. Their persistence paid off. Now, I don’t worry about it until it comes up, and then I can let it go.

When I think of epilepsy, I like to think of my seizures like a computer, my brain representing the computer. A brain has many functions, makes many connections, and controls the body. A computer has many wires and complex technology to power the entire computer system. Each time you have a seizure it is as though one or two wires are being pulled from your computer (brain). Each wire pulled from the computer is essentially your memory, something you learned, something that just won’t function the way it should or used to. Seizures force your computer to dysfunction, burn out and run down. Sometimes the problems are repairable, sometimes they’re not, and sometimes that part of the computer ceases to work.

I first noticed the impact of epilepsy early on in my teenage years. As I became a young woman, epilepsy was a constant hindrance in my life. The seizures were a permanent reminder of my disorder and the difficulties that I had to face. My seizures became so severe that at times my parents had to bring me to the hospital to be sedated simply to stop the seizures from occurring. I have lost count of the number of times I was in the hospital. Some months it was as much as once a week, with multi-night stays. Each hospital visit was another plug in the computer. One day, my brain said, “I am not going to remember this,” or “I am not going to remember these words.” Despite so many missing wires, I have persevered into adulthood.

As a 39-year-old adult living with epilepsy, I have come to accept and let go of the hindrances epilepsy forces me to face. Day to day, I take many medicines on a strict schedule, and while the medications don’t necessarily stop the seizures, they make them less severe. There are also all the normal things that people with epilepsy struggle with: not being able to drive, anxiety about public seizures, those old worries from childhood that still linger. But now it is the fact that it’s difficult to find a job with all the doctor’s appointments, or worrying about performance as seizures have impacted my cognitive abilities! I think it is important to acknowledge all the difficulties people with epilepsy must go through and all the struggles we face. Anyone with epilepsy would agree it isn’t an easy thing to live with. Yet, most people with epilepsy are beyond resilient. Like a computer missing a few keys from the keyboard, pieces may be haywire, yet it still functions and carries on.

Despite the struggles of living with epilepsy, I have persevered and overcome so much, and I live a happy and fulfilling life. Some things that have helped my epilepsy are the Vegas Nerve Stimulator, which has decreased my seizures from 50 a month to only 20 a month. Additionally, I have been approved for a service dog, and I look forward to welcoming him/her into my home. I currently live independently with my fiancé, and continue looking for a job. Meanwhile, I volunteer with the Epilepsy Foundation of Minnesota, in our church, and Artist Mercantile in downtown St. Paul. My fiancé and I are both very active members in our church (Church of Acts) and look forward to our wedding June 21, 2014! Despite so many difficulties, it is possible to overcome epilepsy and live a happy life, in control of your own body. The small complex parts of living with epilepsy no longer control you. A wire may be pulled from the computer, but that one wire won't stop the computer from running!

Robin Blaha is a 39-year-old living with epilepsy. She was diagnosed at birth and has five different kinds of seizures. Inspired by her job coach and doctors, by hearing similar stories and by personal experience, she talks about her journey to help other people dealing with epilepsy reach their full potential. Robin crafts and meditates to help her relax before and after seizures. She acknowledges that seizures have had a major impact on her life, socially and cognitively, but she has persevered and now lives independently with her fiancé. Robin says, "I have overcome so many obstacles and don't let the challenges get in the way of my passions. Epilepsy does impact my life, but it doesn't control it or prevent me from reaching my full potential."

One Look

by Marvin Dale

Everywhere I go there are many things I see
I see all other things. I just don't see me.
I am somebody is what my mind keeps telling me,
but every time I look I just don't see me.
No matter how hard I look no matter how far I see
I see all other things I just don't see me.
You know you are somebody don't keep it held inside
Show yourself you are someone keep you head held high
Now the time has come to give yourself a guarantee
Take a look at yourself and tell me what you see.

Marvin Dale has had epilepsy for more than 30 years, and says, "I give thanks to God and Mincep Epilepsy Care for helping me to get and keep it under control. They are the best of the—best staff and all." He wrote a poem in 2009, but never thought of submitting it until he heard a radio spot about epilepsy and decided to act. He says, "I have been down a long road dealing with epilepsy, so I know how it is and where it may lead you mentally. Some children are being bullied and teased about it. I am 47, and I still keep mine hidden. It can take some into depression. This poem I dedicate to the Epilepsy Foundation of Minnesota. Once it's read, the understanding will all come into place."

Brian Dungan’s Story

by Brian Dungan

As a 37 year-old, I decided to head back to college at Winona State University and finish my degree. As a non-traditional student getting back into the groove of studying again, it was difficult. I also was suffering with epilepsy and was being seen at the Mayo Clinic in Rochester. Halfway through the first semester I was at the Mayo Clinic and my doctors recommended surgery to relieve me from my seizures and help me with my day-to-day life and studies. After struggling with my first semester from the headaches and poor concentration due to the epilepsy drugs, I decided to go ahead with the surgery.

In February I had my surgery. It was called a cranial ectomy (brain surgery). The surgery involved removing half of my skull for a period of seven days, then putting hundreds of EEG grids on my brain. Then they slowly took me off all of my medication and I proceeded to have seizures for an entire day; very painful. Once they found the focus of where my seizures started in my brain, they were able to remove that part of my brain to stop the seizures from starting. Then they removed the grids from my brain and placed my skull back together. It was quite a long recovery, but knowing that I had a goal of getting back to college to finish my degree gave me the determination and strength to get back on my feet.

I moved back home for a month after the surgery and then back to school. I finished the one class that I was able to maintain while I was in the hospital (I received an A).

Then it was time for me to go to work with speech therapists, physical therapists and a cognitive therapist. These therapies were very necessary, but at the time seemed incredibly frustrating. Every day was a challenge — a workout for my brain and my body. I was also taking one summer school class. So for me, this was more than a full load. Therapy helped me back to where I was when I first started school (and well beyond). When I first came back to Winona to finish my degree, I was at a 1.96 GPA. I will now be graduating in December with an overall 2.6 GPA. It was an incredibly long road with many obstacles; however, it was worth everything I put into it. I appreciated all the help I received from doctors and surgeons, and the wonderful staff at Access services. I also had wonderful friends and family who supported me along the way.

My major is Professional Studies, with a Minor in Political Science and a concentration in history. I created a class called “J.D. Rockefeller versus Henry Ford,” about how at odds these two men were about what would fuel our country. This class gave me incredible and unique knowledge into corn-based ethanol and biofuels. When meeting with one of the managers at the ethanol plant in St. Charles, Minnesota, he recommended that I become a lobbyist for the ethanol industry. This has proved much more difficult than I have expected. I’ve been looking for work since last December, not just in the ethanol industry, but in all types of environmental industries. Going back to college was not just a great challenge, but one of the most rewarding things I've done in my life. I'm so happy I made this decision.

The next step in my life will be to find a well-paying career, not just a job. I was very lucky to return to work at Interlachen Country Club in Edina, Minnesota. The management and staff welcomed me back and made it easy for me to return to work.

Brian Dungan grew up in Eden Prairie, Minnesota when it was a very small town. His graduating class was about 300. Brian loves sailing his 17-foot McGregor venture sailboat. Brian will be selling his boat to help pay back student loans, but says he can always buy a new one someday. The author loves being around people and is looking forward to his life beginning again. Brian has never felt better and has great admiration for the doctors and nurses at the Mayo Clinic for all the help they gave him. Brian also received physical therapy, occupational therapy and speech therapy at the Winona clinic; he says it was perfect. Brian was able to walk to therapy every day to receive wonderful help.

Tommy Tortoise

by Angie Freshwater

Tommy Tortoise was making his slow way along the shore of the lake when a thunderstorm took him by surprise. It had been a hot, muggy day, but as usual, Tommy had not been paying attention. Making his way along the shore of the lake was hard enough when it was muggy without having to watch the sky as well.

Being an old tortoise, Tommy moved slowly and took the easy way out on pretty much everything. When a thunderclap sounded overhead, Tommy knew he had to get to shelter. Being a tortoise, though, and an old one at that, he moved slowly, as was his custom.

As it happened, his home pond wasn't too far away. Tommy kept lumbering along, like turtles do, and was soon at his home pond. When he got there, he made his way to the watery nest that was his underwater home, and fell asleep. He was tired after such a long walk home. When he woke up the next morning, the sky was a clear blue, with not a cloud in the sky, menacing or otherwise, and no chance anywhere of thunder or lightning. It was a perfect day to go exploring once again.

Angie Freshwater has been writing stories of various types since she was 15. She finds inspiration for her written work everywhere: her personal life, world events, history, her imagination and more. She is 36 and has grand mal seizures. She was first diagnosed with a seizure disorder at eight months. She says, "I live on my own, and try to work on my writing as much as I can. I have lived for 8 1/2 years in an apartment in Sibley Tower in downtown St. Paul."

Among the Stars

by Heather Gilmore

When you walk among the stars
You cannot see the earth below
All its beauty, lost forever
Unseen, unheard amid the glow

You have to step outside yourself
Look around, breathe your first
There's so much more to be had
If you come down to the earth

When you walk among the stars
The glare is bright enough to blind
And you'll miss the wonders of the world
If you're stuck admiring your sky.

Fire

by Heather Gilmore

A dance of color, a twist of pain

Hope escapes on sweet silver wings

And dreams shatter amid the autumn leaves.

Dare I tarry long upon this lonely road

And wait, wait for the sunrise

To shed its light upon my soul?

Crisp and cold, it lingers long

Scars unseen but not unfelt

Fingers reaching, grasping, clawing

Tearing the very flesh of my heart.

A burning, searing heat

Sweeping through my entire existence

Illuminating the vast darkness

That threatens to destroy

My world, my heart, my soul...

Rainfall

by Heather Gilmore

Still my heart and slow my hand

Quicken my pace along this road

The end, ’tis now in sight.

Reaching with stone-cold fingers

I tremble and fall to my knees

Place my hands upon the ground

Feel the tears and see the rain

Silence surrounds as I weep

My tears mingling with the tears of the skies.

A moonbeam filters through the trees

Falling soft upon the waves

That stir the music within this time.

Standing to my feet,

Reaching up to the clouds

The rain falls inside my heart

Creating a soulful melody deep within.

Come and dance in the rain with me

Under the gaze of that sweet silver moon

That sings my soul to sleep each night.

Heather Gilmore has tonic-clonic seizures. She wrote “Rainfall” and “Fire” when she was just 18, creating the first poem when a relationship ended because the young man was uncomfortable with her seizures, and writing the second after she experienced a seizure for the very first time. She says, “With epilepsy come limitations, but that fact doesn’t make us less intelligent or less able to enjoy the beauty that life has to offer.” In these poems, Heather invites readers to “Dance in the rain. Laugh when fear is trying to control you. Enjoy every moment life gives you.”

Meditation

Excerpts from Tracy's forthcoming memoir, "Seized: Life as I (Mostly) Remember It"

by Tracy Gulliver

"Everyone sits quietly in the chapel and prays," I explained to our grandson. "Only we don't pray out loud. We talk to God in our heads." I let this sink in before delivering the final caveat. "And we do it for 20 minutes."

Blake sat deep in thought, a rare occurrence for an eight-year-old with ADHD. "That's a long time for a little boy to be quiet."

"Yes it is. It's a long time for a grown up to be quiet."

My husband and I had brought Blake to visit the place where his grandparents would be living for the next five months. We weren't sure how Blake would handle meditation. We were impressed by the amount of control he displayed as he managed to sit through the 20 minutes with minimal leg swinging and squirming. He went home to his normal routine of noise and activity while we began our stay as volunteers at a contemplative retreat center.

When we were occasional weekend volunteers at this spiritual retreat center, going to worship twice a day was easy, even relaxing. I looked forward to being part of the community now, but had reservations about getting through meditation over the months that followed. As the first week went by, those 20 minutes often turned into spiritual chatter. Like Blake, I found it difficult to be still mentally and listen.

Meditation felt like the equivalent of letting go of all thoughts, and I held onto mine with clenched fists. Even after being seizure-free for eight years, losing control was too familiar. The threat of being robbed of thoughts and actions without notice constantly lurked in the back of my mind. When I began to forget about it, a simple partial seizure would raise its head, sending bile to my throat and reminding me I'm still not immune.

I wasn't about to willingly release control.

After a week of daily meditation practice, I began to focus on my breathing instead of letting my mind flit from one thought to the next. I resolved to ignore all the tasks of the day. I'd have plenty of time to deal with those during my other 15-and-a-half waking hours.

For years I had practiced deep-breathing exercises whenever I felt the panic that often preceded a seizure. I believe it played a role in keeping my seizures at bay for many years.

I realized meditation was a way to calm the mind, not lose it. I put words to each breath.

On my inhalation, I thought: *My body is grounded.*

I assured myself that I wasn't going anywhere. I was in this room, physically planted on this chair. I envisioned a taproot connecting my body to the floor, developing a strong sense of where I was in space and time.

On exhalation, I mentally recited: *My mind is focused.*

I envisioned a point the size of a pin prick on the horizon of my mind—not a black hole, void of all thought, but a point to focus on. Like the eye of a storm where thoughts and worries swirl around. A nucleus large enough to hold tranquility sits in the center. This micro-space contains freedom from the day's chaos.

Inhale. *My body is grounded.* Exhale. *My mind is focused.* I practiced this for a week, until it seemed that it wasn't enough.

I am more than body and mind. I am spirit. I realized that this is at the heart of meditation. If I wanted to have a richer spiritual life, I must have an open spirit.

My body is grounded. My mind is focused. My spirit is open.

Open to what? a small voice asked. An open spirit is a willingness to listen, to be receptive, to hear a message that we might not hear in our otherwise busy lives. An open spirit explores life's possibilities, offers clarity, allows room for new ideas.

My body is grounded. My mind is focused. My spirit is open to receiving love.

These thoughts came spontaneously as a personal revelation with each breath. Twenty minutes was a long time to be quiet, but after months of practice, I was able not only to sit still, but to meditate in a meaningful and intentional way. But receiving love without sharing it seemed meaningless.

My meditation evolved into: *My body is grounded. My mind is focused. My spirit is open to receiving love. And sharing it with others.*

This became my mantra, and I became increasingly comfortable with meditating. To keep it from becoming a mindless recital, I replaced the word "love" with strength, peace, hope, and gifts.

I began to ponder my gifts.

Epilepsy popped into my mind like an invasive weed. Sharing my epilepsy? Seizures were not a gift! I yanked it out of my thoughts. Writing washed in as a gift, and I rode it in my mind like a gentle wave. Soon epilepsy floated beside it. Writing about epilepsy? I had been a freelance writer for 20 years. I had lived silently with epilepsy for 40. I hadn't talked about it with anyone except a few close friends and family. I quickly dismissed the idea.

As I continued meditating over the next few days, writing and epilepsy became inseparable. It became increasingly difficult to ignore their newly formed alliance and the feeling that I was being challenged to share my epilepsy through my writing.

Forty years is a long time to be quiet.

Office Dialogue

by Tracy Gulliver

For eight years, I experienced nothing more than simple-partial seizures—aura-like sensations that don't result in a full-blown seizure.

But last year complex-partial seizures took their hold on me. At first they were so mild that it was difficult to determine whether they qualified as a complex-partial. They began with a loss for words, which isn't unusual for me on a normal day. I wasn't displaying the typical fist-clenching and lip-smacking as I had in the past.

In an effort to distinguish whether I was having a simple or a complex seizure, my husband and I came up with a plan. Whenever Todd thought I was having a seizure, he would ask me some simple questions. How I responded would determine the seizure classification.

We were both working from home the first time I was put to the test.

* * *

I'm at my computer, silently debating whether to start taxes this late in the day, when I feel the usual panic attack coming on. I stop typing, look beyond the screen and start my deep breathing exercises to try and ward it off.

Todd turns from his screen when he hears me inhale.

"Trace?"

I look at him.

"Are you okay?"

I nod.

"What's your Social Security number?"

I struggle to come up with it. I know it has a 3-2-4 digit pattern with dashes between each set of digits. I know that there are supposed to be numbers in each blank. I think mine starts with a four. I know Todd's does. Finally, I grab any number. 987 . . . 65 . . . 4321.

It isn't until Todd writes them down that he realizes I'm guessing.

"What's our phone number?"

Again, I can see the number pattern: three digits, dash, four digits. All I can come up with is seven. I know that isn't right. I envision an area on the northwest end of Minneapolis, where the area code begins with seven.

Two . . . six . . . I fish for numbers. No, that's my sister's cell phone number, or maybe my daughter's.

Todd smiles and says, "I love you."

I look at him a little confused and say, "I . . . like you? Love you?" I'm pretty sure the second response is more accurate.

Todd presses on. "What is our address?"

I envision our large black mailbox at the end of our driveway. I see our neighbor's house across the road. I look for the gold numbers outlined in black that are stuck to our box, but they're gone. They must have fallen off. We should check to be sure, and replace them if necessary.

I'm still searching for the answer to the social security question, determined to get it right. I can never remember mine. I can spew Todd's number off my tongue faster than my own. Whenever anyone asks for my number as a security question, I always start with Todd's first three digits, then have to backtrack and retrieve mine.

All these things go through my mind.

It isn't fair that Todd asked for mine instead of his. I recite his now, quite certain it's correct. Then I remember our address: 3898 . . .

I even remember—but don't say—that it used to be 38 something eight, and am impressed that I got three out of four of those numbers right.

"Nebraska Trail, Chisago City, Minnesota." I add more information to prove to myself and to Todd that I am lucid.

"But we've been taken over by Forest Lake." I can't remember the word annexation.

I search my mind for our phone number. 436-9951.

By this time, it's over, and I have cognitively returned.

We discuss whether this counts as a seizure. Todd recounts our conversation and my responses. It matches my memory.

I tell him all I was thinking as he asked the questions. I ask how long it had lasted.

Todd guesses that it was about 30 seconds long.

I'm sure this is not a good time to work on our taxes. I close my Internet browser and shut down my computer while I give myself time to reboot my thoughts.

I gather our yoga mats so they'll be ready when we leave for class in two hours. Until then, I'll rest.

Tracy Gulliver's inspiration comes from seeing humor and significance in everyday events. Tracy writes to reach out to others and let them know they are not alone in their struggles, in whatever form those challenges come.

Seizures have affected the author in various ways and she has learned to pay close attention to her body's signals of an oncoming seizure. This practice has made Tracy more observant of the world around her, which has served her well in her writing.

Tracy was diagnosed with epilepsy when she was eight years old. The author experienced a wide range of seizures over the years, but deals most often with simple partial seizures. Tracy has been seizure-free for as long as ten years, but occasionally a seizure will show itself and remind her how important simple things like sleep, diet and exercise are to her health.

Tracy's work has been published in anthologies and magazines, including "Chicken Soup for the Soul," "Epilepsy USA" and "Minnesota Women's Press."

Clash
by Minden Hultstrom

Gradually burning, conflagration in waves of worry.

Eyebrows tense in aggravating fury,

In futile attempts to weaken the warrior.

Inhale.

He drills into the temples, the locus of anxiety.

Heartily bellowing, aggressive in a focus piously,

His laughter pours out throbbing, deafened ears.

Resist.

He clamps, winding twisted fingers in coils, drilling.

Blurring the eyes, consciousness spilling,

The room presents itself at an awkward angle.

Prepare.

Teetering to the side, heavy, tipping.

Knowing the images and insights are slipping,

As submission appears the sole conclusion.

Fight.

A sudden gale of chills, emerging to disable.

His clench is suffocating, but impotent to label

This fearsome moment as his victory.

Release.

Following a struggle with clonic tonic seizures as a teenager, Minden Hultstrom was diagnosed with epilepsy in 2000. She has participated in EFMN's Stroll for Epilepsy, and her poem, "In the Blizzard," was published in "Epilogues" and performed at the Foundation's 2011 conference. Her acrylic painting "Duality" toured with EFMN's Brainstorms collection and was the featured art work in October 2009. A high school literature teacher, Minden has degrees in English and Theater, and she is pursuing a Master's degree. She is the season coordinator for a community theater company and has been a theater director, actor and choreographer for 13 years. She says, "Epilepsy could have been a block in the path to my future, but I continue to use it as a stepping-stone for growth, expression, and inspiration."

Epilepsy: Just One's Disability

by Steve Ireland

Epilepsy does not judge anyone's life,
This disability may become anyone's strife.

We all do take pills each day to combat our epilepsy,
Various epilepsy, various pills, but one disability,

Just like all types of people and all kinds of situations,
May this one disability (EPILEPSY) never damage one's relations.

Life Full of Bumps & Bruises & People

by Steve Ireland

All life is full of bumps, bruises, & people.
It is what we do with all these situations that truly matters.
My life has been much like yours.
Epilepsy, Hospitals, Tests, Doctors, Nurses filled my daily life.
At one point epilepsy & seizures controlled my life.
After having many bumps & bruises & not many special people, I decided to take control of my epilepsy & not let epilepsy control me.
Now I'm blossoming out & having a blessed life full of many special & wonderful people.
I'm enjoying myself more, yet I still get bumps & bruises.
Some of those bumps & bruises I turn into times I will share, but share with less stress.
I pray & hope that these times, with less stress, may enter my life without a seizure.
No one can stop any of a person's bumps & bruises but with less stress, maybe there is a factor of fewer seizures as well.
Also how you act & what you do will decide if you find & enjoy various people in your life.

Over the past 20 years, Steve Ireland has been involved in a variety of activities at the Epilepsy Foundation of Minnesota such as volunteering at the State Fair. What inspires him to contribute to "Epilogues" are those who cannot for various reasons. Steve says, "I'm wired to accept the fact that whatever happens to all of us, we're all truly blessed." He lives in Minneapolis and enjoys model cars and planes, music, movies, walking and expressing himself through writing.

A Fear of Falling (Again)

by Tracy Jacobsen

For many, fear of falling is a physical fear that is associated with an actual phobia of being in a potentially unsecured/unsafe high place. A different example may apply to the person who has tried and failed so many times that they fear the idea of trying and possibly failing once again. This kind of paranoia keeps many people from excelling in life and convinces them to settle for less than might be possible in their lives. It also doesn’t help to have others constantly telling us that we will never succeed at anything we attempt.

Being a man with medical disorders, I have tried and failed at a lot of things, but I have also succeeded at a few too. Without a will to try, I might have never achieved so many things that I really did have the ability to accomplish. God wants us to do the most with what we are given, and the enemy tries to convince us that we are bound to fail (so why even try?) Obviously, we all have different levels of motivation within us, but most people can accomplish much more for themselves – and for God – if they simply try a little harder. If it is any consolation, I have failed at about 70% of the things I’ve attempted, but without trying I would have never known how great the 30% of success was for my overall morale.

Falling Into a Stove Pipe

by Tracy Jacobsen

You know how it feels when you look down a big piece of stove pipe? It's like a long, dark never-ending black hole that just keeps going and going. That's kind of what it's like when a person has a seizure. Even though the average grand mal seizure only lasts for 30-90 seconds, it seems like a lifetime for many as they continue to get drawn down into nothingness, floating through darkness. Then suddenly bang! They hit rock bottom like a ton of bricks and realize that it is finally over. The aftermath of this event can be an extremely difficult period that may last two to three days, and then another spell takes place. This seems like a continuous battle that has no real end. Whether we have epilepsy, alcoholism, drug addiction or are demon possessed, we often have to reach rock bottom before we can re-evaluate our situation and begin to start again on the road upwards.

God allows difficulties and struggles to have many similarities so we might have something to relate to when we get in these positions. He knows that we all need help and he provides it in different forms so we can have assistance available when we really need it. God puts people in our lives for specific reasons in order to help us. We need to be able to accept the help that he provides so we don't miss out on it. Being receptive to what God really wants for us will help a lot when we need assistance from other people or other sources for discernment. (Shown to me in a vision)

Tracy Jacobsen is inspired by Jesus in all that he does, and he says he has a need to relate to others who share similar experiences. His diagnosis is fixed cognitive impairment with damage on 50% of his brain. He says, "Until my seizures stopped, I didn't realize how much one spell a week for 40 years affected my quality of life in general."

Let Me Leave

by Tayler Johnson

The white room confines me,
there isn't much to do.

I stay in bed,
wires attached to my head.
We joke about how it looks like a tail-
a tail of wires.
The glue makes my scalp itch;
the wires have popped off in the middle of the night.
I hope to leave here soon;
I miss the pitter patter of my dogs running amok.
I miss their random barking at the sweet nothingness.
My schoolwork is
done;
I've watched each movie I brought more than I can count.
I can only smell the chemicals they clean the room with,
and the scant scent of my father's cologne.
It's been two days of
testing;
the lights
make my world disoriented.
I wish the lights would stop and let me be.
Dad is saying that they'll let me leave sooner
as long as I wear my helmet.
The nurses say it's just a precaution.
I only see it as a bother.

The glue is bothering me again,
I'm close to tearing my hair out.
I can't wait to take a true shower,
and feel the water drench my hair.

The doc is here,

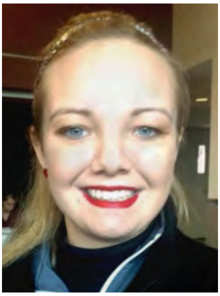
she needs me to take
another test.
Maybe she'll let me
head home…

Maybe…
just maybe…
They'll be content with letting me go...

The Same One
by Tayler Johnson

Throughout the years,
my mind wanders to
a certain night.
A cold October night
spent in the ER.
He sat with me.
I finally fell asleep
amongst the chaos.
He stood watch.
When I awoke,
I found him sleeping
sitting against a wall.
The buzzing I heard
came from his iPod.
It kept him busy while I slept.
I yearned to leave the small bed,
just to cover him up.
Yet the wires kept me tethered.
Tethered to a tiny bed,
wires and IVs encased me.
Hoping for release, I moved.
I finally heard the buzzing stop.
I knew he was awake-
knowing I finally awoke.
He moved to the chair
getting me talking,
even if it was about nonsense.
I finally ask for Advil,
the noises and lights burning my mind.
He ran out, in search of a nurse.
He returned, a nurse in tow.

Once she departed,
the room seemed like a dark abyss.
Over my eyes,
the cotton hoodie
blocked out any intruding light.
I finally was settled once more
my brother's hand in mine,
calming me into a doze.
The doctor finally let me go.
My brother was the first one to hold my hand
as I exited the ER.
My baby brother,
the same one
I promised to look out for.



Tayler Johnson's written work is inspired by her experiences since being diagnosed with periventricular binodular hetertopia in 2006. Much of what she writes is taken either from her point of view or that of her family. She says, "I write to express what I have gone through over the years with having five grand-mal seizures, and absence seizures daily. Since being diagnosed, I have discovered what I want to become. I am now a sophomore at Hamline University with a double major in neuropsychology and religion." Tayler is very active at Hamline as a member of the Sophomore Experience Council, the Dance Team, and is the student representative of the ADA/504 Committee. She hopes one day to work with neurologists, helping people as she has been helped over the past seven years.

Transition
by L.E. LaRue

This was a year with a big transition for me. I broke up with my lady friend of more than two years in early August. I took no joy whatsoever in ending the relationship, as I knew it was necessary. It was just a week after we traveled together to South Dakota to see Mount Rushmore. I spoke up and said we needed to talk when I realized I'd had enough. We spoke for more than two hours, and I calmly stated why I was no longer interested. Then I hugged her and left, and we haven't spoken since.

I don't wish to go into detail as to why it didn't work out, as some of these things should be kept private. When some of my friends heard about the breakup, they seemed to want to know why. I said how we didn't communicate well enough, weren't on the same page often enough, and I just wasn't happy enough with her. It seemed foolish to continue the relationship when it just wasn't moving forward. Our differences kept getting in the way, especially since we were from different religious and economic backgrounds. I liked how my history of epilepsy had nothing to do with why we broke up. I was honest about having this disorder and she accepted it. The seizures are rare now, so this likely made it easier for her to accept. I found that it was easier for me because I didn't try to hide it from her.

I learned plenty about myself from finally having a long-term relationship, and some of what I learned, I really didn't like at all. I didn't enjoy dealing with coworkers who kept asking why I wasn't married yet. It's because I wasn't ready yet. I decided to speak to these coworkers much less often, as I was getting annoyed with how they gave me plenty of unsolicited advice about the relationship. Going forward, I have no plans to talk about my relationships at work. I found out it really was more trouble than it was worth.

To anyone who wonders, I will say that I am doing fine after the breakup. I continue to do comedy here in the Twin Cities. Having this valuable social skill is helpful. The day it ended, I even told a college roommate how I would be fine because I have comedy. I like knowing I can turn to this talent of mine when I need it, as it is therapeutic to be able to release some of the pain in my life by telling jokes about it. I am thankful for the circle of friends I have because I do comedy. They can be a wonderful support network. I am also proud of having had my first-ever paying gig this fall, at a Minneapolis restaurant. The pay may not have been much, but I am still thankful for it. I also understand how with comedy as with any other interest in life, we must take the good with the bad. I've been annoyed with those who have done jokes about Minnesota Gopher football coach Jerry Kill having epilepsy. It is one subject that is definitely not funny at all to me, because I know personally what epilepsy is like. Sadly, it serves as a valuable lesson about how not everybody is going to be respectful.

I have dated some since the breakup, but nothing has advanced very far just yet. It meant going back to online dating, same way I met my ex. It requires some patience. I learned some tough lessons, and I know they will be applied. The most important one is that it is foolish to keep ignoring the warning signs when things aren't working out. I know I did, and there were many times when I could have ended it much earlier, but I lacked the courage to do so. Sometimes it is fine to let things fail, even if early on, if it wasn't meant to be.

Another notable event this year wasn't a transition, but it was welcomed nonetheless. I have a friend I met at the support groups sponsored by the Foundation that now lives near St. Louis. This is the same city I like to travel to annually during the summer, in order to attend a baseball game and visit some museums. During this year's trip in July, I included a breakfast with this friend in my itinerary. It was our first in-person visit since she left the Twin Cities, and much had changed in both our lives since our last visit a few years before. It was helpful to see this friend again as she knows me and understands me on many levels more than most. If she were a colleague at the office, she would be known as a "work spouse" for this reason. She was in agreement with other trusted friends and advisors on how I should end the dating relationship. I started to notice that they were right, as I wasn't saying enough positive things about my lady friend. I know full well it is best to listen closely to those who know me best when they have something to say. I ended it two weeks later. I wanted to be able to face all of my friends again and say I am truly living my life for me—and to make myself happy.

In this ever-changing world, there will probably be more notable transitions for me in the next few years. Since I have weathered some storms already in my life—be it coping with epilepsy or anything else—I am hopeful that I am not caught off guard.

L.E. LaRue's life is what inspires his written work. Diagnosed with epilepsy at age four, he was on Dilantin until age ten, and in time, earned a degree in history from the University of Iowa. He values his independence and is thankful that his epilepsy wasn't serious enough to prevent him from getting a driver's license. In fact, his seizures are rare now, occurring less than once a year. He says, "Finding the Foundation has been helpful, as I have been able to educate myself about the disorder, and that has made me less ashamed of having it. I still don't share that I have the disorder with many, as I am afraid of being judged harshly out of ignorance."

My Life With Epilepsy and Seizures

by Brian P. Lund

During the last 13 ½ years, epilepsy and seizures haven't affected me at all. But for my first 39 ½, they kept me from doing a lot of things unless I was with family. They even kept me from having many friends. Plus, thanks to the many years with seizures, I am not working in the field I would truly love to be in. However, I will not go back to college to renew my schooling because the brain surgeries have affected my short-term memory a great deal, and I fall asleep easily when reading a book today. I have to be doing something physical, like typing when reading or filling out papers, to stay awake.

But I look at the bright side: I am able to hold a job today that I never could for many years; I am happily married to the one woman who loved me even when I was having seizures; and I've had my driver's license for 12 ¾ years. So today, I am living a much more enjoyable and productive life, one that I couldn't for many years.

While enrolled in an online college course, Brian Lund wrote an essay on living with epilepsy. His instructor was impressed with the narrative and encouraged Brian to develop it further. The result is "My Life with Epilepsy and Seizures," published by Author House, available in paperback and as an e-book. He has also created a webpage to advertise his book and give people information about epilepsy and seizures. To access Brian's webpage, type: http://brianpl60-mybook.com. The entire page can be viewed by clicking the buttons in the header or footer of each page.

Family Tree

by Ethel Marx

A man I never knew died very young and was never mentioned again. He had four children who never knew him. He had a wife who missed him, but could never mourn him, would never grow old with him, and would never speak his name again. He had epilepsy and died in 1938 of a grand mal seizure.

The difference between living with epilepsy in 1938 and 1969 was life and death. In 1938 Dilantin had just been developed, and it was not widely available to most people with epilepsy. It wasn't approved by the Food and Drug Administration until 1950. I don't know if he had access to any anti-epilepsy medication, but there wasn't a wide choice available in 1938, especially to poor framers living in the Midwest.

The little bits I know about him were told in whispers when he was already gone. These are some of the things I do know. I know that people called him lazy and shiftless. I know he lived in the country, where being called "epileptic" was an epithet. He lived near the town of Cambridge, which housed an epileptic colony. People stood on the street, pointing and starting at the residents of the epilepsy hospital. People were ignorant, and that ignorance showed in unpleasant and hurtful ways. He was adopted. He always lived at home with his parents, but before he died, his adopted mother left home. Was it because of his epilepsy? His own children were told nothing of him when they got older, had never seen his picture. And none of his birth children have epilepsy.

I know that if this man had lived, I would not have been born. He was my mother's first husband.

I was born in her second family, and his seizures, though whispered about, were never spoken about out loud.

Then in 1969 I had a grand mal seizure, and it too was not talked about. Although there was medicine to keep me alive, I lived in denial of my epilepsy for years. No one knew about it except my husband, and thankfully I took enough medicine to keep the seizures mostly at bay. But gradually my seizures worsened, and eventually I had one in front of my family. No more denial. No more hiding. Still no one talked of the man who had died so young. I struggled with my control, anger issues, depression, taking more and more pills, still in denial to myself. But at least I lived because after 1969, there were many different medicines to try, and we tried a lot of them. I won't list them all, but every new medication that came along was going to be "the one" that made life easier. As life went on, I hoped that we could get a cocktail of drugs that would make my day-to-day life easier. And they have.

Now, in 2013, my seizures are somewhat controlled. And as I work on my family tree, I think of this man who died so long ago and wonder what his life was like. I sorrow for him and all people with epilepsy who have not had the help and understanding that we are getting today. Now my mother and all of her generation are gone, and I wish that she had been able to speak about him openly. I wish that I had asked about him when I had the chance. But she never would talk about him. I am full of questions about him as I work on the family tree. Did my mother love him? Why did she never speak of him? I know he was adopted, but cannot find any record of his real parents. Did he have sisters or brothers from his real family, and are there relatives out there now that we don't know about? Did he develop epilepsy like me, as an adult, or did he have it as a child?

He is like my epilepsy: always with me, unknowable, unreachable, just beyond my grasp. Although I am not related to him by blood, I feel an attachment to this man because if he had lived, I would not be here. And he had epilepsy, just as I do. Had I lived when he did, I probably would have suffered the same fate he did. He has made me think about myself and my mother very seriously and how my epilepsy has affected everyone around me. I cannot forget him.

Seizure Dog
by Ethel Marx

I’ve had seizures, and I’ve had dogs, but I’ll never forget my seizure dog.

He wasn’t a trained seizure dog, just my poodle Casey, who as I told everyone, would bark when I was going to have a seizure.

One day I awoke from a seizure, lying on the kitchen floor. My trusty seizure dog was nearby. His presence comforted me, and I called his name. I looked over and saw that he wasn’t guarding me; he was eating the food I had been preparing before I had the seizure. When I was able to fully comprehend his actions, I realized that he was only doing what this seizure dog needed to do, and that was not letting good food go to waste. Perhaps that was why he barked at my seizures—he wanted me to have them in the kitchen so I would drop food on the floor for him.

After that incident, I didn’t call him my seizure dog anymore. But dogs have been a big part of my life, almost as useful to me as the many medicines I take to keep my seizures under control. Dogs can make you smile when you are depressed, help you exercise when you would rather sit in a chair, love you when you are not at all loveable, and be a friend all the time. A good friend is rare. A good dog should be treasured.

Diagnosed with epilepsy at 21, Ethel Marx reports having had had varying degrees of success living with it for the last 45 years. She says she’s doing pretty well, having only a few seizures a year, taking about six medicines a day for refractory epilepsy. She says, "Seizures have been with me so long that I don’t really think about them much anymore, except that they are always sort of in the background." Her husband and sister are very supportive, but she admits to sneaking out to drive the car once in a while when they’re not around. Ethel has always liked to write, and since her family loves her work, she is trying to write more. She enjoys gardening, loves dogs and the history center, and is fascinated by museums.

Life!
by Marveil O’Neal

Life in Minnesota is what it is and what it will always be!

You know how that old saying goes, once a fool always a fool. Well that’s definitely true. I don’t feel there is anybody here in this state who really cares about you or anything positive that you’re trying to achieve to better yourself and your life. This state has all of these so-called programs that are supposed to be there for you to go to for help. Well that’s just a bunch of c---. The people who are supposed to be here for you don’t have time to listen to what you have to say. All they want to do is let it go in one ear and come out the other. Everybody starts from the very, very bottom and then once they get into those types of jobs, they seem to forget all about you just because you’re not like them and you didn’t fit in. Now that, my friend, is what you would really call being very discriminatory.

Do you know what is more messed up is not only just being black, but also being a black, blind and innocent man. These important people, in this system, would rather you not think for yourself. They want to do all of the thinking and make all of your moves for you and not with you even if you’re handicapped and eligible for these programs—especially people with low-income assistance and with disabilities. They just treat you any kind of way; they won’t and don’t care, especially legal aid. If you needed a lawyer and went to legal aid for help, they wouldn’t help you at all. The only thing that they would do for you is just tell you we can’t help you with your cases or they don’t handle those types of cases. But in reality they have their favorites, and those who aren’t their favorites, they won’t help.

Also, the education programs that are supposed to be there for the people with disabilities as well as everybody else, they’re just not happening. Let’s just take state services for the blind for example. I had six counselors who didn’t help me for anything in the world, and the bad thing of it all is that they want you to look like you’re the wrong one. When you sign up for their services, you get what’s called a counselor and this counselor is supposed to be there for you and help you to set your goals and accomplishments with your life. But then when you set out to do all of this, all of a sudden they just s---- you right over with no problem. They say that they will help you, but I never received any.

I’ve been here in Minnesota for 13 years, and I had never ever, ever found myself with this many problems before, in my whole entire life. I came to this state and was almost beaten half to death by a janitor. For what? I had never seen this guy before in my life, since I had been living in that building, and then after all this had happened, I wound up with epilepsy. I still haven’t received any kind of help or any kind of explanations about what had happened to me or why it happened. And to make it worse, nobody had ever even tried to find out what really went on in this situation. I found myself being involved with a lot of fraudulent things against me, even fake police reports that don’t even exist and never did. Then after all of this had happened to me, some years later my girlfriend and I had wound up being involved with another fraud situation. We had a fraudulent mold inspection report that said that there was supposedly nothing wrong with the apartment that we were living in. which there really truly was. I mean it was so bad that we had no other choice but to break our lease in the middle of the freezing cold winter of last year, 2012, and move out. We were getting very sick and being very badly mistreated. Also the people who were living above us assaulted my girlfriend and threatened me, which caused me to have a lot of seizures. I wound up being in the hospital for a while, and nobody had done anything to take any kind of interest in what was or still is going on at all.

A landlord poisoned me and my girlfriend with mold when we had moved into one of their apartments back in 2009. Everything started out being okay at first, but before we even got to move in at first, they had told us that our apartment wasn't ready. When we finally did get to move in, we had made the biggest mistake of our lives possible by telling them on the application that we were legally blind/visually impaired, and then they just took a great big a-- advantage of us. They just lied to us and had us living in this molded apartment, and we didn't even know it was there for a few months. Then they said they were going to fix up the place. They messed up everything and that's when mold started setting in. We told everybody from management to the public health department and a lot more, and they didn't do anything. They weren't even trying to help us or get us out of this place that was infected so badly, and I mean very, very badly infected. I mean this place was so bad, and it was making us so sick, that we had no other choice but to break our lease and move out on our own.

The so-called Section 8 inspectors came out to our apartment, and they even saw the mold that was in the apartment, but that didn't matter to them at all. They had even seen the mold and the pictures while they were in the apartment, and they just lied to us and told us there was nothing there. And they had claimed that nothing was ever there, and it really was right there, in their faces. We even tried reporting this whole thing to the public health department, better known as OSHA, and they didn't even come out to take a look at the apartment or even take us seriously about this whole thing at all. All they told us was that they were just going to stick with what the landlord's private contractor report said after they had gotten it from the landlord, and that was that. Now this was the public health department that we had talked to. Then after that we even tried going to the news about this, and they were more concerned about their taxpayers' money instead of being concerned about us telling them about the mold where we were living.

When we started getting sick with this mold, we had to go into the emergency room and had to take all kinds of medicine and shots, stuff that you don't normally do every day. The doctors still kept misdiagnosing us, and right now today, they still keep sending us to the same places that we had started from in the beginning. They still won't refer us to someone who knew about mold exposure or even how to treat us for this type stuff that we were dealing with. You know even after going to these doctors, they were still just wasting our time instead of trying to help get us better, and it's just not happening, you know? It's like they just don't even care about how they treat you or if they misdiagnose you, especially when you have U CARE and don't have all of the better expensive medical insurance to maybe get a good thorough check up, and get your health back to normal and feel a lot better. It's like that's just not happening. I mean we are still going back and forth to the doctor constantly for all of these same illnesses, and we are really still suffering from mold. A lot of these doctors were very rude to me just for going in and telling them about how I was really sick. I was having really bad chronic aches and pains, sinus infections, migraine headaches, and I still have all kinds of rashes all over my body and so on. I am still having all of these sicknesses and infections.

After being beaten almost to death and then winding up with epilepsy, and after that literally having mold poisoning, we still haven't gotten anywhere, but when this one guy had found out that he had mold in his apartment, he got the royal treatment. We just got completely s--- on period by everybody. Who really does have constitutional rights in this state or in this world? Is it just for people who have the money, or is it really for everybody no matter who has what? I feel like it isn't for me or the people who don't have money. I believe that God is more powerful than any money or anybody or anything, and no matter how much of a struggle we all go through, God is always right there for everyone. All we have to do is just believe in him, trust in him, pray each and every day and be thankful that you, I and everyone are still on this earth, waking up and going to sleep each and every day. I sure do, and I hope you do to.

I've been racially discriminated against. And no type of justice was ever done, not even an investigation of this very dangerous hate crime that happened to me. This crime could have killed me, and it has done damage to me for rest of my entire life. Not only was I already born blind, but also no one really seems to care about this. This is how I wound up with epilepsy, and not only that, now I have mold poisoning this very day! You know the only thing we would always get from doctors is that you're supposedly crazy and that there's nothing wrong with you. But that's just not true, and they just don't want to admit it or try referring me to someone who knows about mold exposure, how to treat it and how to get this stuff out of my system. But then that would be taking money out of their pockets. Moving here is the biggest mistake I have ever made in my life. So be it. I guess, as that saying goes, you got to carry your cross and bear it as well. Well I'll be out of here after my birthday, and I'm never looking back because there isn't anything positive here for me at all, you know? When you think everything is just about to go well for you, and then as soon as you are just about to start accomplishing all of your goals and everything, all of a sudden everything that you had started putting together just all of a sudden starts to go right down the toilet, and it just stays there for as long as you live here in Minnesota. Just like my first story; I mean it took a long time to write that story, and nobody ever paid any attention to it at all just like this story. But you know what? To me it seems like when everyone else who's important has a story to tell, everybody will sit and listen, and then give him or her all of the help and moral support possible; but me, I'm just out of my rabbit a-- mind. Well I'm out. PEACE!

Borders with Epilepsy

by Tessa Palmer

Seizures trap me in my mind of the outside world

Not letting me in to do any sports or be with any of my friends.

I still strive to do what I want even though I have seizures.

I live life to the best of my ability and love every minute of it.

Tessa Palmer is 18 years old. Having had seizures since birth, she is diagnosed with tuberous sclerosis and complex partial seizures, and has adjusted fully to her condition. She says,“I am no ordinary girl who goes to school. I like being active, running, swimming and biking somewhat.” This past year, Tessa ran two 5K races and competed in a triathlon with a friend. She says of her family, “I have two sisters, one 20 and one 13, and they are important to me. I also have parents who love me.”

Solid Foundation
by Kevin Reed

I started working with the Creative Arts program at the Epilepsy Foundation in January 2010. I submitted my first photographic work of a rock formation taken at St. Croix Falls. I worked with Stephanie Kolari, the former creative arts director. I showed this work at the Minneapolis Government Center where I set up and curated the Brainstorms Collection. Throughout my working with the Foundation, I have had the opportunity to create a visual database of submitted artwork. I have received strong support from all the staff to make the Creative Arts program a success.

I appreciate the fact that the program helps people learn about epilepsy through art. People express strong interest in the arts program and share their own stories about knowing someone who has epilepsy. The mission of the Creative Arts program is to show the world that people with epilepsy can succeed in life and live their dream.

The entire EFMN organization has been the foundation of my success, allowing me to teach people living with epilepsy that it is not a barrier to reaching their goals in life. With the Foundation's support, I can now reach people and share what I have learned, so in the future, they can continue the strong legacy of EFMN's Creative Arts program.

17 Centimeters

by Sarah Schmidt

It all became clear as I stood at the foot of my father’s grave. Since my last visit, the date of his death had been chiseled into the solid granite of his gravestone. There was no denying the finality of his death.

In between the date of his birth and the date of his death was a line just 17cm in length. Every event and every emotion of his 91 years, four months and 16 days were now condensed into 17cm.

The realization flooded over me that I, too, would someday have a 17cm line. Condensed within my line would be every emotion and event of however many years I had been given to live upon this earth.

My father’s and my lines will have some things in common: the family members we loved, the places we called home, the jokes we thought were funny, his walking me down the aisle, his holding my daughter, who had now made him a grandparent.

Our lines will also share, however, the emotion of hearing a doctor’s diagnosis: “Your daughter has epilepsy.” At another time, our lines were a testimony of unconditional love and dependence as his arms held me during a seizure.

Although his line has ended, my line continues. The majority of my 17cm line will have been unavoidably affected by epilepsy.

Affected by? Yes. Surrendered to? No. How much should any one part of a person’s life be “line consuming”?

As I walked away, I turned to look at his gravestone once more. This time, the date of his birth and the date of his death seemed to hold less significance. My tear-filled eyes saw only that short line.

The importance of filling that 17cm line was his final gift to me.

The relationships Sarah Schmidt shares with others inspire her work. In the past, she had written pieces from her or her husband's perspective, but this time wanted to write from her father's perspective. She feels that it is now her role to wear epilepsy well, despite the unsteadiness, insomnia, blurred vision or memory loss. Sarah counters those negatives, saying, "I have a job that allows me to work as well as I can. I have those who love me and a God who protects me." Her seizures are now controlled, and she expects they will remain so. She says, "With one husband, three married daughters, seven grandchildren, 400 cows, little calves, and crops, my life is busy" – and clearly fulfilled.

Trust—On the Floor (song lyrics)

by Gregg Schreiner

Feel it coming on
Try to hold it down
Look for the door
Anyone around

To help if this one
Pushes through the drugs
Life goes on you hear
You hear so much

Put the past behind
Took off you see the dust
Moving so fast then you wake up

You watch their lips
You nod you feel you must
Agree or disagree
Matters only to the one you trust

Nothing keeping you down
Symptoms you describe
Keep you medicated inundated never come back around

Agree or disagree
Matters only to the one you trust
When that one arrives
Please tell me—be one hell of a surprise

Gregg Schreiner has daily complex partial seizures due to a brain tumor (oligodendroglioma) that was found in 2002. At that time, he was married, had a good career and was earning an MBA at night. The stress of his condition overwhelmed the marriage, but he was able to work until 2009 when an MRI showed new growth, requiring radiation. Use of several medications and a VNS device garnered little improvement. Gregg admits that dealing with it all "is an emotional rollercoaster," but he has found a creative outlet. "One of the few things that allows me to release my frustration is talking to others with epilepsy and writing songs about its toll on my life. Writing songs has been a major part in my battle to accept the problem and move forward."

Movements of Love

writings by family, friends and caregivers of people with epilepsy

Living His Life to His Full Potential: Christopher Michael Ferron

by Barbara Ferron

When the little silver car pulls into the driveway in the afternoon, all you need to do is look at the expression on Christopher Ferron's face to know how happy he is to see his dad get home from work.

When his sister, Renee, comes to visit, there is no mistaking the laughs and excitement, the abundant joy that those most familiar to him bring. His quality of life is enhanced in ways that words aren't necessary to express.

Christopher was born in 1985 with an unspecified severe disability that limits his communication and physical mobility. He also has epilepsy, which became life threatening in 2009 when he developed aspiration seizures. He was hospitalized a dozen times between 2009 and 2010. Palliative care staff was brought in to see us in 2010. However, since 2010, a very dedicated team of individuals have helped keep Christopher alive and free of aspiration seizures due to a strict eating/sleeping schedule he must adhere to.

A key player in this team has been his day program, Achieve Services, in Blaine, Minnesota. Christopher attends Achieve Monday through Friday, where he spends his day in the work room. He participates in several jobs brought in from the community, including shredding paper, assembling gadgets and putting together cards. Christopher is allowed to work at his own pace, and he receives a small paycheck based on the physical weight of the jobs he is able to complete. Some days he has the stamina to stay on task for a long period of time; other days he isn't as strong. In either case, he is given the opportunity to complete the tasks at hand to his ability.

While at Achieve, Christopher also receives non-work-related programs, such as occupational therapy and opportunities to maneuver his walker or wheelchair throughout the facility to strengthen his muscles. He is given the self-help care needed to maintain his strict eating/sleeping schedule and meet his significant habilitative care needs.

Once a month, Christopher uses his paycheck from Achieve to take his family out for pizza. Before working at Achieve, he had never been able to earn enough money to do this.

When his mother's little blue car pulls into the parking lot at Achieve in the morning, all you need to do is look at the expression on Christopher Ferron's face to know how happy he is to see the buses arriving that bring his friends to work alongside him—to see the abundant joy that those most familiar to him bring. His quality of life is enhanced in ways that words aren't necessary to express.

Barbara Ferron's son, Christopher Michael Ferron, is the inspiration for her written work. As his mother and primary caregiver, Barbara has for 28 years made sure he receives his daily medication, caring for him on his good days and his less good days. She has also educated many individuals at his schools and day programs, and has promoted epilepsy awareness throughout most of his life. Christopher's grand mal seizures artially controlled by medication, averaging four to five a month; his aspiration seizures are controlled by a strict eating/sleeping schedule. Barbara hopes her son's story inspires or provides a model for anyone who develops aspiration seizures, and says, "If our story saves one life, it is worth sharing."

The Good News Is

by Jerry Hartlaub

Well the good news is
The seizures have moved on
Ambushed by powerful meds
Maybe forever, good riddance
Gone to pasture.

The bad news is
A new affliction has caught him
A pedental nerve attack
Unanticipated, unwelcome, unnerving
He didn’t need a new challenge.

He will do what is needed
Not just a flanking maneuver
But a full frontal attack
To overcome big ouch symptoms
And claim, "I’m back!"

Effective life style tactics
Will rule the day
Like an ice breaker in the Arctic
He will create a pathway
To comfy, normal land.

Jerry Hartlaub’s adult son inspired this poem. As a child, his son underwent a craniotomy to remove a tumor. His son experienced his first seizure about 25 years ago when he was in college, but is now doing well. Jerry proudly says of his son, “He has pressed forward with his life while using meds for good seizure control, and he has courageously overcome major drug side effects and other health challenges. I have been an anxious observer, listener and advisor. As a husband, father, college professor and very compassionate person, I am impressed with him.”

You Are a Hero Too

by Mariah Mrotek

I'm going to tell you a story,
Not about a bunny, a puppy or a teddy,
But about a handsome sock monkey,
Who is my brother, Eddie.

Brave, strong and proud is he
He always has a smile for everyone to see

Eddie is a hero
For lending a helpful hand
To a friend in need
Who had a seizure that wasn't planned

Eddie is amazing
But how did he know what to do?
Eddie knew just how to help
Because Eddie has seizures too!

Eddie says:
"Never panic, because you can help too
"You will always have a friend,
Who knows what to do."

By becoming seizure smart
You will know what to do
With this knowledge and an open heart
You can be like Eddie too.

Mariah Mrotek's sister, Tehya, is the inspiration for Mariah's work. Tehya was diagnosed with epilepsy after having grand mal seizures about two years ago, and Mariah says their family had to adjust immediately to this unexpected change in their lives. She says, "We had to be with Tehya at all times and adjust her classes and schooling. She had to accept it, but her ability to do this and still show a smile kept all our hearts uplifted. We as a family grew together in the process and became stronger." On the challenge of writing this poem, Mariah says, "I didn't think it would affect me the way it did until I wrote the last stanza. I realized how easy it is to learn about epilepsy and to know what to do when someone has a seizure. It's simple to learn, and to put it in terms for a young child made it that much easier to understand. Anyone can learn. Anyone can know. Anyone can help."

Dear Hannah

by Chris Poshek

Dear Hannah,

One day, you will be grown. You will leave home, make your own choices, maybe fall in love and start your own family. You are growing up so fast, and I am loving watching you grow up into the person you are becoming.

Please always know that you are bright, beautiful, and strong. Never ever forget that your future is wide open and full of possibilities. Never let anyone disrespect or treat you any less than what you deserve. My hope for you is to achieve your dreams and be anything you want to be. I hope you know how incredibly special you are. You may have epilepsy, but epilepsy doesn’t have you because your mother and I will always have your back. I love you.

Love,

Dad

Unconditional Love

by Chris Poshek

To my loving wife,

You have been the love of my life ever since I first laid eyes on you. You have been with me through lots of joy and lots of pain. You pick me up when I need it. You were by my side through the seizures. You were there when they cut off the casts. You are my rock, and I want you to know that you mean the world to me. Our first year of marriage was full of medical tests, body casts, and an unknown future. This was in part due to epilepsy coming into our lives.

Love is a wonderful and powerful thing, and I feel lucky that I have felt true love – I am sure not everyone has or ever will experience it fully. I feel so lucky to have known what it is like to love someone more than anything else in the world. And you gave me another person to share that love with—our daughter. She makes us laugh every day. I'm amazed at the wonderful girl we are raising. Thank you for making me realize what unconditional love is.

More than anything, I wanted to thank you for giving me the best 12 years of my life. If my life was a flat gray plane that never ended, then the 12 years with you are like a landscape with bright colors. If I never knew what it was like to be with you, then I would never have known that a world full of beautiful colors was possible. I would have never known what it felt like to love so much, to feel so happy, to feel that my life was complete. Thank you for loving me, standing by my side and showing me what unconditional love is.

With all my love.

Chris Poshek's wife and daughter are the inspiration for his work. His diagnosis is grand mal seizures with partial complex. He says, "The seizures have forever changed my life. They actually showed me what true love is. They have given me a voice for those who may not have one." He shares his story so that people who are uneducated about epilepsy learn that those with the condition are capable of doing anything they set their minds to.

Jordan

by Lisa Riley

When you left at eighteen, I knew I'd see you again.

You were gone for years, serving our country with honor.
My pride for you was immense, and I worried you would go to war.

You called me with the news, a disorder that would send you home.
I wanted to come see you, but you said you'd be okay.
The medication they gave you took the seizures away, but they came back with a vengeance and took your life away.

Now all I have is memories of that young boy I knew. I missed out on the years you served and while you grew.
From child to the man that you became, my pride for you was just the same.
I had a year with you, then came a knock on the door.

The officer said you died, and so did I that night. My tears will not stop flowing. I know that you are safe. With Jesus you spent Christmas as I just sit and wait. For one day I will see you. It can't be soon enough. For Jordan, you're my son, and my heart is filled with ache.

The Perfect Storm

by Lisa Riley

Who knew, except God, that the baby born on a cool, crisp autumn day would be taken by the perfect storm.
Who could believe that the chubby-faced toddler, who gave new meaning to the terrible two's, would succumb to the perfect storm.

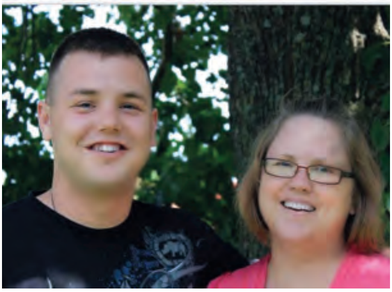
Who could see that the boy with the youthful exuberance and smile, where the corners of his eyes squinted over an embarrassed blush, would someday see the perfect storm.

Who could look at the strong handsome man that he grew up to be, who raised his hand and took an oath to stand and protect our United States, would soon be battling the perfect storm.

Then it happened, the perfect storm, where everything aligned perfectly on a cold November night. No one was ready, least of all his mother, who had nurtured, loved unconditionally and gave life to this child.

The perfect storm is SUDEP or sudden unexplained death in epilepsy. It took his life swiftly before anyone knew what was taking place. Everything had to be right for the perfect storm to hit.

On Mother's Day, I ponder if anything could have protected my son from this perfect storm. Can anyone stop this from happening to others? We will forever be affected by the perfect storm. It took my son, and it's a battle too big for me to take on today, Mother's Day.



Lisa Riley is the mother of a young man who had left temporal lobe epilepsy and tonic-clonic seizures, and who died from SUDEP on November 26, 2012. Her son is the inspiration for her written work. He lived with epilepsy for just three years, and his death has been devastating for her and her family. She says, "Losing someone and not knowing we could lose him from a seizure was a shock to our family. We're still reeling from the loss." She explains that her son's seizures "began as nocturnal, but he died when they broke through his medication."

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