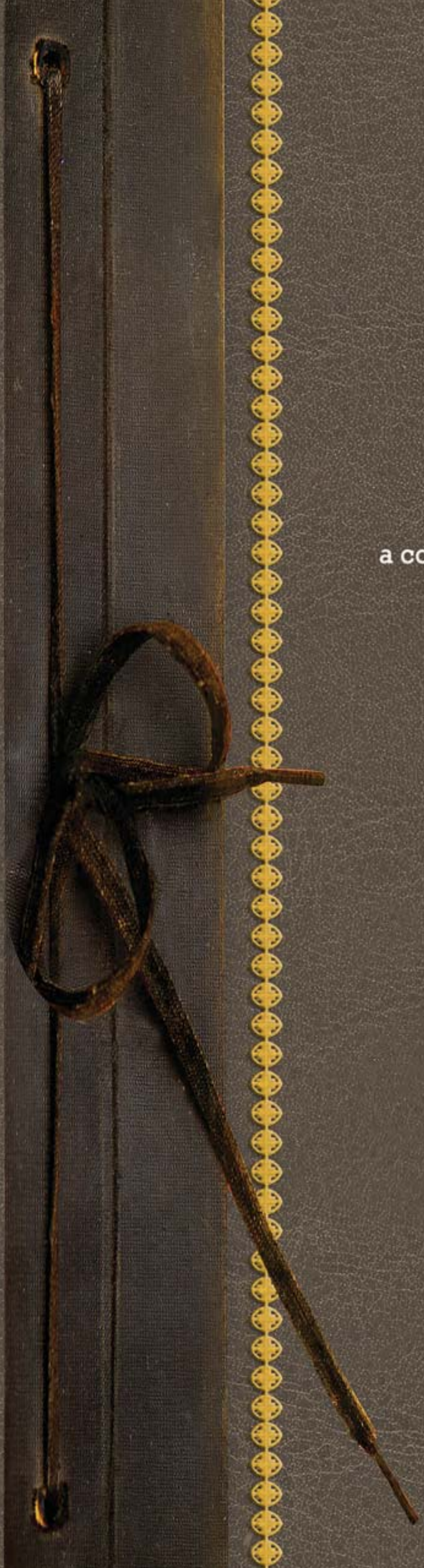

Epilogues
2012

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.

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Dear Epilogues Collection Reader,

We are delighted to publish this 6th edition of Epilogues! This book of written works, including poetry and prose, was compiled by the Epilepsy Foundation of Minnesota (EFMN).

The authors are either living with epilepsy or they have close relationship to a person with the disorder. The Epilogues Collection provides a creative outlet for personal expression and raises epilepsy awareness.

All written works are grouped into three classes – Judges' Choice, Superior and Meritorious – in a poetry category and a prose category. Members of the Creative Arts Committee read and ranked each work based on their understanding of the author's emotional impact, connection to epilepsy and presentation. Although the categories are intended to reflect skill, we recognize each author's contribution as valuable.

The Foundation extends a special thanks to Tracy Gulliver for editing this book. Epilogues is organized into two sections:

> *Sustaining Ourselves - writings by people with epilepsy*
> *Movements of Love - writings by family, friends and caregivers of people with epilepsy.*

To give greater understanding and meaning to the works, a short biography of each author is included. Poems and prose pieces are in alphabetical order within each category.

It is our honor to congratulate each author for their creative work! Some authors have submitted writings in the past, and others are new. We wish all authors well and are thankful for their contributions. This book's words not only raise awareness about epilepsy, but also connect our community.

The Epilepsy Foundation of Minnesota & Creative Arts Committee

Sustaining Ourselves

writings by people with epilepsy

Do you know Who you are?

by Kyah K. Altiere

I've been asked several times how I have overcome epilepsy and seizures in my life. My response is simple. I haven't. Epilepsy and seizures are a part of my identity but not "who" I am. I tell people that it basically comes down to two things: 1) know "who" you are and 2) identify your "quality of life".

I have had seizures all my life and was diagnosed with epilepsy when I was 8 years old in 1979. I was fortunate because my seizures had been controlled growing up, except when I forgot my meds one weekend. When I didn't have a seizure, I decided I no longer needed meds and stopped taking them. Big mistake, huge. I still cringe at the memory. Status Epilepticus for 30 minutes and my dad was terrified because this was the first time he had ever seen me have a seizure. After a long, one-sided discussion with my mom (an LPN), I immediately got back on my meds and seizure control returned.

I left for college in 1989 and I had a GTC three times my freshman year in very public areas. I hadn't had a seizure since that weekend when I stopped taking my meds. This couldn't be happening, I told myself. I could not, (would not) accept that seizures would be a part of my life. I deluded myself into believing that if I was a really strong person, I could prevent those seizures from occurring. It was "mind over matter". When I felt the aura coming on, some part of me said, if I just close my eyes for a few moments, the seizure will go away. Strike one. If I take a nap, the seizure won't happen. Strike two. If I do yoga and find my happy place, the seizure will just go away. Strike three, thank you for playing the game but the seizure is starting. I have to admit that I also tried those techniques with medication side effects with similar unsuccessful results. My husband is always happy to remind me of them.

When I last lost my driver's license, my goal in life was to get my driver's license back. Epilepsy was not "who" I was and seizures were not going to stop me from driving. My pride and ego saw that by accepting seizures as a part of my life, was letting epilepsy win. Every time I had a seizure, I would get so angry and depressed. I also got very good at self-pity. My husband and family/friends will testify to that. For some inexplicable reason I still believed in "mind over matter" - having seizures was something I could choose not to do. I have to shake my head. Seriously, if that was the case, why are people choosing to have seizures? "Geez I'm bored today. I'll have a seizure to shake things up a bit". Crazy.

It's taken me 23 years of soul-searching to recognize and accept "who" I am. My name is Kyah Altiere. I'm happily married and live in Duluth, Minnesota. I am a licensed hospital social worker. I have completed two Master's degrees and I am still paying back college loans. I take the city bus, saving a lot in gas money. Epilepsy and seizures are just a part of my life. My hobbies include: being with friends, reading, running, watching action/sci-fiction movies (have to wear sunglasses because of flashing), and of course, volunteering with the Epilepsy Foundation. I am very proud of “who” I am.

Identifying my “quality of life” has been integral to knowing “who” I am. At every MINCEP appointment my epileptologist tells me about new anti-seizure mediations that have come out. He also asks about interest in possible brain surgical procedures. My responses continue to be “no” across the board. Firstly, I fall into the lower percentile where the more types of anti-seizure medications one has taken, the less likely a new anti-seizure med will control one’s seizures. I am not seizure-free but my quality of life is not hampered.

I love my husband, and I have a home and a job. More importantly, my seizures are significantly decreased and are manageable. Why should I go through the process of weaning off my current medications and start a new med, plus have to watch out for potential side effects? I mean, it’s so much fun and hasn’t affected other aspects of my life at all.

In 1995, a neurologist managed my epilepsy care and felt I was a candidate for surgery. He didn’t know that I was overdosed on my anti-seizure medications that were causing me to have uncontrollable seizures daily. I was so scared when I was sent down to Abbott Northwestern Hospital for two weeks. My husband drove back and forth from Duluth every day and my mom was there with me. I was so relieved to learn that surgery was not needed. My anger of betrayal toward that neurologist was tempered by my introduction to MINCEP. Needless to say, I never saw him again. Although I am terrified of any surgery (which is funny considering I work in a hospital), I will still discuss the pros/cons of various surgical procedures at each appointment. I respect those who have chosen to do so. I know it can lead to successful life-changing results.

But, what if it doesn’t work for me? The odds are not in my favor in trying a new anti-seizure medication, and I cannot identify a valid incentive to “go under the knife” so to speak. What am I missing in my life? Driver’s license? Yes, not having one is an inconvenience at times, but we have an efficient bus system in Duluth and my home and workplace are on the bus route. I’m saving lots of gas money, too. Children? My husband and I decided not to have children long ago. And we thoroughly enjoy our roles as aunt and uncle to our family and friends. We have been discussing being host parents for the foreign exchange students program. I am pleased with my “quality of life”, and my epileptologist supports my decisions. Granted, should I start having uncontrollable seizures, etc., and my “quality of life” changes, I would be open to further discussion.

I can honestly say that I’m feeling pretty fulfilled right now, and I’m proud of “who” I am. What is your “quality of life”? “Who” are you?

Kyah K. Altiere
Age 41, person with epilepsy

I was at two minds of submitting this work. One, people don't need to hear about me again. I've been involved with the Epilepsy Foundation since the late 1990's. Then my husband asked me, "Wouldn't you have wanted someone to talk to and know that you aren't alone?" He knows me so well. Those sentiments are my inspiration for submitting this work. We may be strangers, coming from all walks of life. But we share a bond, a part of "who" we really are. Please read my epilogue and you will know how epilepsy and seizures have affected me. At age 8, I was diagnosed with generalized epilepsy. Today, I still have the diagnosis of generalized epilepsy and my EEG supports this diagnosis. However, I no longer have GTCs, instead I have complex partials.

Head and Tongue Fight

by Sonya Boeser

My tongue and head are not agreed
On what to say and what to do.
My tongue is a fiery dart,
A speeding bullet,
A shooting devil with no brain-
When I become annoyed.
My head is a lingering angel
With a conscience, and regret
For what my stupid tongue has said.
They don't mix, head and tongue.
My unruly tongue first shoots out
Words that I will regret before
My head can block the ruthlessness.
My head must come up
With ways to cope with
What my acid tongue has done.
Once my tongue has made
A decision, there is no going back.
Actions speak louder than words,
But words cut the pain
Of actions deeper.
And my head's conscience knows
That my tongue must learn
(With no brain)
To control itself.
Situations of annoyance and
Situations of inconvenience
Can make my tongue
A shooting rocket.
Before my conscience can decide
That something is wrong to say, it
Spills out onto my tongue, offending many.
My head must outsmart my tongue
And be ready to block it
In these times.
I must consider the effect
That the impulse to comment will have
On others; whether acquaintance, friend,
Family, or pure stranger.
My tongue resides in my head.
My head holds my tongue.
They can either fight
Or be forced to get along.
The head can hold the tongue back
Before it strikes - I know it is in my power.

The Garden of Trust

by Sonya Boeser

Can you trust me?
Yes, here you must
Because we are in
The Garden of Trust.

There is no hatred,
There is no lust,
When we are in
The Garden of Trust.

When we are here,
There are no lies.
Only the truth,
From which no one can hide.

The flowers sprout faith.
The trees branch out trust.
When the wind blows,
Love comes in a gust.

There's no one who'll harm you,
And there is always pity.
Don't be afraid to say
That you have a disability.

No one will judge you;
Here, that's not how we think.
Trusting each other
Is like a soothing warm drink.

When we're here together
Our friendship can thrive.
To trust is to know
That you're truly alive.

To come to the Garden
Is all up to you.
Plant one seed of trust,
And the Garden will bloom.

Living with Epilepsy and Asperger's Syndrome

by Sonya Boeser

Being a person with seizures since I was about twelve, I have still lived a fairly normal life. My life is, undoubtedly, much less predictable at times because I have epilepsy. This is something my family knows. These are words taken from my prose piece; just read the whole thing and the answer is there. I graduated from the University of Minnesota with a Bachelor's degree in Art History. I want to go back and earn a Master's degree, and eventually maybe even a PHD in Art History. I want to be a teacher or museum curator. I have loved art and being creative since I was very little…not just due to having Asperger's, but because creativity is a part of who I am as a person.

Every day, I am a person with epilepsy and Asperger's Syndrome.

I have epilepsy, yet I can still get up and out of bed in the morning. I am a person who has occasional seizures, but I can still dress myself.

I sometimes have seizures, and outbursts from my asperger's, but I got through elementary school with a lot of high honors.

High school was difficult as a person with epilepsy and asperger's, but I graduated near the top of my class with a letter on my jacket for academics.

I now have a Bachelor's Degree in Art History. I have loved art, as a person with Asperger's, since I was very young. Asperger's makes me more creative.

I am a 25-year-old woman with friends, and they know about my epilepsy. They know to sit me down and watch me when I have a partial-complex seizure, and when and if I have a grand mal seizure, I need to go to the hospital.

I have seizures occasionally, and also trouble controlling my temper at times. This is something my family knows. My family loves and cares about me and my friends understand me and want to hang out with me even though I have epilepsy and asperger's syndrome. I just have to be careful how I react sometimes.

Being a person with seizures since I was about twelve, I have still lived a fairly normal life. My life is, undoubtedly, much less predictable at times because I have epilepsy.

In most of the ways that people my age do, I know how to have fun and like it, too. My seizures have not gotten rid of the fun person inside of me.

My epilepsy does not impair my sense of fashion, confidence, self esteem, or right versus wrong--as long as I think before I act.

I know that I have epilepsy, and yet people understand me and accept me as a person. They know I have Asperger's, and yet want me around me as long as I can control my temper and act respectfully toward them.

I know and accept that I have epilepsy and Asperger's, and have lived a fairly normal life knowing these things. I only want to be around others who will accept me for who I am; and that these disabilities are part of who I am, but do not make me in any way a lesser or weaker person; they make me a stronger person in multiple ways.

I am a person with epilepsy and Asperger's, proud of all my accomplishments.

Sonya Boeser
Age 25, person with epilepsy

The poem "Head and Tongue Fight" reflects how I am in social situations sometimes. I want people to understand how I feel and what it's like to live as a 25-year old woman with epilepsy AND Asperger's Syndrome. "The Garden of Trust" is probably my dream world, where no one hates, hurts or insults each other, and doesn't lie or judge. I have loved art and being creative since I was very little…not just due to having Asperger's, but because creativity is a part of who I am as a person. Being a person with seizures since I was about twelve, I have still lived a fairly normal life (although much less predictable at times because I have epilepsy).

Seizure

by Sarah DuCloux-Potter

Ears covered,
in a futile
attempt
to wall it off.
The noise!
Amplified and screaming,
echoing and splitting,
booming and piercing.
Please just make it stop.
Then-
the rise
and fall,
the empty space,
a gap in time,
a lost place.
The unknowing,
of the known.
Confused,
alone,
with salty mouth,
and tired
bones.

Happiness and Epilepsy

by Sarah DuCloux-Potter

I wrote this essay because I would like people to know that it's okay to be happy when you have epilepsy and why. I have run the gamut of emotions-anger, sadness, irritation and acceptance. Now I'm good, happy and advocating for others! I do still get irritated once and awhile when it's cold and I'm waiting for the bus, but I think a lot of people without epilepsy do too. The Foundation has been a fantastic resource for my family and me. Thank you. I hope I can give back as much as I have received.

Someone asked me the other day how I can be happy and have epilepsy. I found that to be an odd question and wasn't sure how to respond. I actually had to pause for a minute and formulate my answer so as not to offend them for asking an innocent (if somewhat ignorant) question.

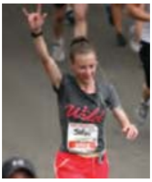
Epilepsy causes episodic loss of control, it can potentially take your ability to legally drive if you are refractory to medication, it forces you to take medication that comes with some annoying side effects, and it carries with it a stigma that is unfortunately taking time to overcome.

Epilepsy does not take away my ability to live a full and happy life, it does not take away my ability to have a family, it does not reduce my good fortune in love, it has not stolen my capability to run long distances, it will never take my smile, it has not taken my capability to attend and do well in school, it is not allowed to stomp on my passion for life, it has not impeded my realization of my goals.

Epilepsy has taught me compassion towards others. It has taught me to slow down once and awhile, it has given me the insight that good friends will be there no matter what. It has taught me to take care of my body, it has made me an advocate for myself and others, it has given me a challenge to overcome and smile when I do.

The answer is how can I not be happy when I am so very lucky? I have epilepsy but in reality that is so minor in the scope of my life. I am a mother of an amazing teenager, a wife of an incredible husband, an employee of the University of Minnesota, a student getting a degree in Health Care Management, a runner, a genealogist, and so very much more. If I allow seizures, not driving or medication to hold me back, I will not accomplish the great things I intend to do with my life. I am happy. I will continue to advocate for others with epilepsy so they can feel the same. Epilepsy shouldn't rule how you feel, you should.

Sarah DuCloux-Potter
Age 34, person with epilepsy



The poem “Seizure” is written to describe a seizure. I have run the gamut of emotions-anger, sadness, irritation and acceptance. Now I’m good, happy and advocating for others! I do still get irritated once in awhile when it’s cold and I’m waiting for the bus, but I think a lot of people without epilepsy do too.

A Different State of Mind

by Heather Gilmore

Whispers of a soft summer's rain
Dance wildly on the edge of my dreams.
Soulful melodies echo across the sweeping plains
Ringing out among the rocks and rills that cover the earth.
Time standing by, ever watchful, waiting for something
Coming soon and swift as light.

Rushing rivers, flowing streams
Rare to find the unbroken dreams
In a world torn by hate and sorrows filled
Where words sting and tears are spilled.
Time standing by, ever silent, waiting in patience
For something comes on silver wings.

Put a smile in my heart and a song in my mind
This ever-present stillness surrounding my soul
Will sing evermore of troubles untold
Stirring feelings of what, I ponder it long.
Time standing by, ever doubtful, waiting in silence
For something is coming in dawn's first light.

Something, something, what can this be?
A nightingale calling sweet songs in the night?
A dream soaring high above the stars?
Perhaps a spirit of something unclean
Or is it my heart, returning to me?
Long shall I wonder until it arrives.

Something, something, invading my mind
Calling my heart, my existence and time
Can it be, oh my soul can it be
An echo of love on a warm summer's breeze?
Hopeful in heart, body and mind-
Long shall I wonder, for the rest of my life.

Words and Dreams

by Heather Gilmore

The ancient blood of bards
Flows within these veins
Whisp'ring words alive and thriving
Straight into my heart, my soul.

Hope soars high above the clouds
Caressing the face of the silver moon
Flying ever higher, to a place unseen
A place on the edge of dancing dreams.

Does happiness move like clockwork?
Does Time ever stand still?
When hope has escaped and love, a mistake
Can these jaded dreams survive?

All this and more make me who I am
My world, my existence, purely combined
Words and dreams serenade my soul
As I am carried off on the silver wings of Time.

Whispers

by Heather Gilmore

Calm as the colors of the dawn
Cool as the crisp of autumn’s touch
She sweeps through the trees-
Even the stars gaze in wonder
As she dances to a song left unsung.
In the air, in the fields-
Birds and beasts stop to listen
As she whispers
Whispers of a wrinkled page in the book of Time.

On through the city streets
Her aimless waltz carries her
Past a forgotten forlorn house-
As Time is knocking on the door
She tiptoes to an open window
And beckons to one little boy-
In the dark, he strains to hear
As she whispers
Whispers of coming summer days.

Into the park her endless dance leads
A choir sings, songs of life and love
Voices rising as the sun-
All of nature pauses to listen
To the melodies soft and sweet.
In their wake, she carries on-
Yet none will turn their ears to hear
As she whispers
Whispers of a jaded heart as Time slips away.

Heather Gilmore
Age 27, person with epilepsy

I've always enjoyed writing. I just get this sense, what I call "the itch" to write, and put pen to paper. Writing has been my outlet for many years. I began to write poetry after a student in my high school died…I wanted to find a way to console my classmates, and poetry was the only way I could think of. In the thirteen years since then, I have written hundreds of poems and short stories, and am attempting a novel. I was diagnosed with absence seizures twenty years ago, and eventually it developed into both absence seizures and generalized tonic-clonic (also known as grand-mal) seizures. Epilepsy is part of my life, but it does not define who I am, nor does it detract from my livelihood. I am determined to enjoy every day and to bring joy to those around me.

A Good Day

by Tracy Gulliver

Today

I was present in every moment

Today

Clarity reigned

Words arrived on command

Thoughts marched in straight lines of logic

Knots of confusion loosened

Fear was held at bay

Today

I didn’t have a seizure

A minor inconvenience

by Tracy Gulliver

Laura is driving and I'm in the passenger seat as we approach the Highway 8 Bridge when that familiar sense of dread washes over me. I feel my chest tighten as I try to breathe slowly and methodically. I look over at Laura. She must see how panic stricken I feel. I want to get out of the car, run as fast as I can to escape this fear that warns me I'm about to be carried off to that other world again.

"Mom . . . are . . . you . . . all . . . right?" Laura's voice sounds too deep. Her long drawn out words echo as if they're coming from the far end of a cave. And her face looks distorted as though I'm watching her underwater. She looks like she's swimming toward me, trying to rescue me from this drowning sensation as she reaches over to take my hand off the car door handle. Like a puppet, I watch her guide my hand to my lap.
"I'm fine. Don't worry about me. Watch the road." I try to say. But all these words stick in my throat, refusing to pass over my tongue. I want to flee from this moment and get on with my life. By the time it's over we have crossed the bridge and are on the freeway. I take a deep breath and lean back against the head rest.

"Are you okay now?" Laura's voice sounds normal again.

I nod. Keeping my eyes closed I take inventory of my surroundings. I'm riding in the car. Laura is driving. We're going to the mall, her second home. I live in Chisago City now, not Lindstrom. We moved 15 years ago. Todd is working from home today. Jenny is in college now. My seizures have returned. Collecting these fragments of information, I gradually reassemble the pieces of my life.

"What did I do?" I ask as I open my eyes and look at her. I always ask.

Frowning, she assesses my condition with furrowed brow. I remember that she wants to be a nurse.

"You were moving your feet a lot. I thought my driving was upsetting you."

"It probably was," I tease, "I'm sure I was telling you to slow down." I smile and she laughs. "Did I say anything? I was trying to tell you that I was okay." In the thirty seconds it took to cross that bridge the seizure leaves me feeling as exhausted as a marathon swimmer who just completed her final lap and stands at the edge of the pool trying to catch her breath.

"No you didn't make any noise. Why don't you rest for a while?"

"Then who would tell you how to drive?" I say as I close my eyes and let my body go limp.

I'm relieved that we were in the car when this happened and not in a public place. My seizures are usually mild, and they come and go so quickly that most people, even my family, rarely notice that I've had one. But I worry about whether my behavior during my next seizure will cause strangers to question my intelligence because they've witnessed 30 seconds of erratic behavior. I've had too many embarrassing moments.

I wrote about my bridge experience for class assignment. A woman came up to me later and thanked me for sharing it. Her husband had seizures but never talked about it. Hearing my experience helped her understand what he went through. I understood her husband's reluctance to talk about epilepsy. People's misperceptions of the disorder can be more debilitating than the condition. But hearing her words of gratitude made me wonder if it was time for me to speak out.

When my husband's coworker learned I have epilepsy he asked if I'd be willing to talk to him and his wife about my experience. Their eight-year-old had epilepsy and getting the seizures under control was a challenge. My heart went out to them. I remember what it was like to have to deal with seizures at that age. During a time when wearing the wrong color shoelaces can summon the ridicule of your peers, having seizures in school can be off the charts on the humiliation scale. Of course I would talk to them. I didn't know what I could say to help them, except that they weren't alone.

Growing up, my parents treated my epilepsy as they would any other daily routine. Morning conversation included, Did you brush your teeth? Did you take your medicine? Dinner conversations included: How was your day? What did you learn about? Did you have any seizures? Please pass the potatoes. It was a part of our lives but not the only part. I'm grateful for my family's acceptance of epilepsy as a minor inconvenience, something to be worked around. Not everyone sees it that way.

I'm told that my doctor was more upset about telling my parents I had epilepsy than they were at learning it. They were grateful for a diagnosis that explained what seemed like inattentiveness and excessive daydreaming; and that there was medicine to treat it.

Unlike diabetes or high blood pressure, epilepsy is not a popular disorder. For as old as it is, it's still misunderstood. For many, there's still a stigma attached to having epilepsy. Children still taunt those who are different. Some kids who don't understand what a seizure is or why it happens grow into adults and employers who continue to have misconceptions about seizures and the people who have them.

People with the best of intentions have suggested that I might be possessed and have offered to exorcise any demons that might be controlling me. Others who don't know I have epilepsy have questioned the intelligence of people who have seizures or whether they should have children. Until now, I never pointed out that I have managed to raise two healthy daughters and complete four years of college in spite of a seizure disorder.

My life has been occasionally interrupted by seizures and I've been inconvenienced by them along with the trial and error process of finding the right medication. While I'm mildly affected by epilepsy, today it's really no big deal. I'm more open about my epilepsy now: with individuals, families, even my state representative.

Just as my class assignment described my experience on a bridge between realities, I want to help build the bridge that will lead to a better understanding of epilepsy. I want to encourage those who are still struggling; advocate for those for whom seizures are still a major hurdle; and affect new laws that could help them transform a major distraction in their lives into a minor inconvenience.

Tracy Gulliver
Age 54, a person with seizures

My inspiration comes from seeing humor and significance in everyday events. I write 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 me in various ways. I've learned to pay close attention to my body's signals of an oncoming seizure. This practice has made me more observant of the world around me, which has served me well in my writing. I was diagnosed with epilepsy when I was eight years old. I've experienced a wide range of seizures over the years, but the type I deal with most often is simple partial. I have been seizure-free for as long as ten years, but occasionally a seizure will show itself and remind me how important simple things like sleep, diet and exercise are to my health. My work has been published in anthologies and magazines, including *Chicken Soup for the Soul, Epilepsy USA and Minnesota Women's Press.*

Seizures Don’t Stop Me! I Have a Brand New Life!

by Dora Haugen

I was diagnosed with epilepsy a few weeks after my first birthday. I don’t remember a time when seizures have not been part of my life, although there have been stretches of time when I was growing up that it was very well controlled. I have tried 10 different medications. I cannot recall a time when taking medication was not a part of my life. That’s just the way life is.

On November 7, 2011, I underwent brain surgery for epilepsy.

My neurologist began talking about the option of brain surgery probably 10 years ago. I wasn’t a big fan of the idea. I decided to keep trying different medications. Oftentimes, there was a honeymoon period on a new medication when it seemed like it was working well, no seizures and then… a seizure would breakthrough. Finally, after being in a car accident not seizure related and then the seizure becoming less predictable, I decided to give the idea of brain surgery a chance.

It took a long time to go through the various testing that was needed to ensure brain surgery was a viable option. When I finally found out in March 2011, that brain surgery was an option, it was such a relief!

Surgery was planned for April 2011. I was so psyched and ready to go. It ended up being cancelled 3 days prior to surgery. I was devastated! It takes a bit to psych up for brain surgery. It was rescheduled for June since my neurologist would not be making hospital rounds or in the OR, things we both wanted. On July 7, 2011, I actually made it to the hospital, through most of pre-op only to be cancelled the morning of surgery!

People say, “You’re so brave to have brain surgery.” I don’t think so. Brave was being willing to undergo one more test, seek out one more referral to a specialist or get a second opinion. As I look back, maybe brave was just agreeing to withstand the drama that went with having brain surgery cancelled and rescheduled. Was it ever really going to happen?

Finally, November 7, 2011, arrived. I left the house and I remember looking at my cat, thinking, ‘I’ll be back.’ Surgery had been on and off so many times. When my neurologist and neurosurgeon arrived in pre-op and talked with me, the tears just flowed. It was so hard to believe I was actually going to have brain surgery that day. What a relief! They were tears of joy. I was able to return to the comforts of my own home November 10, 2011.

Life is different in so many ways since the surgery. I believe I’m more creative. I love photography and painting, scrapbooking and writing. It’s been a long road but I know I have more energy to enjoy life now. My life is incredible! I’m so thankful for all that has occurred.

Life has also been challenging at times. Returning to work as an occupational therapist was one of the greatest challenges. I was off for 10 weeks before returning part-time for two weeks. For the first year following surgery, I worked four days a week. My job is demanding and as an occupational therapist, I am constantly on the go, working with patients throughout the day. The biggest challenge was overcoming the fatigue associated with returning to work. It took so much longer than I ever expected to be able to get through the day and then still have some energy left to do something in the evening. I truly love my job and am thankful for the patience and support on behalf of my co-workers and supervisor.

One thing I learned following surgery and over the course of the past year, is that I truly love my time. As a result, I have decided to continue to work four days per week in order to have some additional time to enjoy the simple pleasures in life.

I am able to drive again. I had not driven for a year and a half and I am thrilled virtually every time I am able to walk toward my car and hop in the driver's seat and go wherever I want, whenever I want. I have been given a brand new life and I am so grateful!

* * *

Dora Haugen **(pictured at left below)**
Age 40, person with epilepsy

Having brain surgery for epilepsy has changed my life in more ways than I could have imagined. I have been given a brand new life. Who gets a brand new life?! I did after having surgery. I love it! I know each day is a gift and to treasure every day with family and friends. I have gained a new perspective as it relates to my work as an occupational therapist. I regularly work with people who have had some type of surgery. I can tell people, "Your body needs time to heal and recover. Surgery is a big thing." I can say this as I truly know what it is like to go through a major surgery.

Yesterday, Today and Tomorrow

by Steven Ireland

Anybody reading this has a life. How or what we do with our life, of yesterday, today and tomorrow is up to us.

Due to the fact I have a disability, epilepsy, my life has been full of various and interesting hospitals (clinics and satellite hospitals). My life has been filled with multiple, various types of medication and drugs, and various and interesting doctors. As for tomorrow, God knows, this time not only will my future but an interesting future as well.

Even though I was a blue baby who needed oxygen and an oxygen tent, in and out of local hospitals, had various tests done, seen various doctors, and had convulsions, no one knew I had epilepsy! After being referred to a specialist and a special hospital, and having more tests done, I was diagnosed with epilepsy.

No one, not my family, myself knew I was born with epilepsy until I was six years old!

Besides various tests, going to various hospitals, being prescribed with various medications and drugs, I was also being introduced to various pharmacies, medication and drug plans. I also was introduced to various hospital plans as well.

I've been introduced to many facets of what my life with epilepsy has to offer me. One facet of my epileptic life was an ambulance ride to the ER. As for tomorrow, I leave this in God's hands. I truly pray that all people, with or without a disability, will enjoy a much better life than mine.

We all want a perfect life, including me. This includes a good family life, a good school life, and a good network of friends. Finally, a career that would enable us all to reach our goals and have our dreams fulfilled. Even though my career, and thus my dreams, couldn't be reached and fulfilled, I've been blessed in finding and having a great life.

Yesterday has gone in one direction. Today, my life has gone and is going in a new direction. Tomorrow, my life, due to new and old situations, will go another way and a new direction.

In spite of my having epilepsy, I try hard to have a positive outlook, a cup half full on life. I have felt this way yesterday and today! I truly feel that I will feel this way tomorrow as well.

I had some wonderful moments in yesterday. I know that I have had a special today. I'm certain that my tomorrow will be interesting and enjoyable as well.

In spite of my having epilepsy, I feel blessed in many ways. Due to this disability I have become more sensitive to all people and their situations even though I don't feel I am there yet, I've tried to attain or care about all people, always.

Even though I haven't found my goal, I've attained a mental ability of not allowing various people or situations to get the best of me. Mentally, I feel that epilepsy has made me a stronger person. Finally, good or bad, I know that epilepsy has made me the person I am today.

I do not regret my life of yesterday!

I do not even regret my life of today!

Also, although it has not happened, yet, I truly doubt I will regret tomorrow!

What I would not feel right about, is if any one of you would have to go to the same stop signs I went to.

Any one of you would be temporarily slowed down by what I call speed bumps in the road to your life.

I truly wish that there will be fewer or different ones for you. I pray that my life had some hoops to get through or more bridges in it so your life may show more enjoyment sooner than mine.

I don't regret my life at all!

I don't wish much of what I went through on my worst enemy.

Epilepsy is not an enemy but a condition. At first I didn't know I had it at six years old. Then I knew about it and let it have control.

Now I've got control – five years.

I pray that you all find peace of mind sooner than just five years.

* * *

Steven Ireland
Age 62, person with epilepsy

Many people have given me the inspiration to send in my written work this year. Most notably, various people at the Epilepsy Foundation of Minnesota, friends and family. Seizures have affected me since I was born. I've been told that without use of my medication, I will have seizures for the rest of my life.

Epileptic Artist
by Tracy Jacobson

Vincent van Gogh, one of the world's most appreciated artists, was also was a man who suffered his short life from a disease called temporal lobe epilepsy. This was supposedly passed down through his family from father to son. It is also the reason that most people who knew him assumed that he was mentally insane. He did not have much luck at keeping friends and ended up putting his energy into a variety of art/art forms (approx. 2000 prints). Neurologists today can prove that all of these traits he possessed were in fact a part of his sickness. Even his ability to create extravagant forms of art, all came as a side effect from the brain damage that he suffered. He was not insane! He was simply mentally tormented from a number of instabilities caused by this form of epilepsy. He was actually a highly intelligent man who spent his life trying to sort this all out. His death was originally considered a suicide, now there is proof that he was actually shot accidentally. When he was near death, it is very possible that his thoughts were delusional and it was common knowledge he was tormented by local children and townspeople. They made his life more difficult because they didn't know why he was sick. I often have to wonder why a man of great genius ended up with such a short, unhappy life. He needed Jesus in his life and was never able to meet him. Even though his father was a preacher, his family literally disowned him and called him crazy. I too have this same kind of sickness that he (Van Gough) had, [an artist without a home] and only because of God's grace am I still alive. We all need Jesus to help us get by in this screwed up world that we live in.

Don’t give up

by Tracy Jacobson

Here’s a short story about my battle with epilepsy and paralysis and overcoming trials in life that might otherwise destroy someone.

By the time I was one year of age I had contracted a disease called encephalitis that left me paralyzed on half of my body. I had also gone through a form of brain surgery that wasn’t very successful.

My mother told stories that I was some kind of a miracle baby. Somehow after all of this, my body didn’t give up. I began to move and talk again.

At ten, I began having grand mal seizures as a side effect from the disease. They attacked my body for the rest of my life. Still, I didn’t quit going.

My wife Gwen married me knowing full well that I had a very unique and serious condition. She also knew I had special gifts and a love for God. We went on to have a loving family with kids, pets, etc. She didn’t give up. My goods somehow outweighed my bads.

When we came to the North Shore of Minnesota, my employers also knew about my conditions. They knew too that my skills as a chef and entrepreneur had great potentials. They took me on and gave me a chance. I became one of the best chefs in Minnesota and helped to make Bluefin Bay on Lake Superior a premier resort restaurant. I also created a line of gourmet food products for Bluefin Bay. People believed in me and I also believed in myself. With God’s help and direction I beat the odds and made it.

Now I have been chosen to take on a totally different challenge. Lots of people have a variety of life altering diseases or sicknesses like me, and my job is to educate them on how they can respond to mental or physical disabilities so that people like them and me can have a somewhat normal life

Currently, I am in the best condition [mentally or physically] I have been in for at least 30 years. My overall health and mental status continues to improve by leaps and bounds. Interestingly enough my seizures have all but stopped entirely. I take care of my body and God in return takes care of me also.

Obviously this has not been an easy forty year ride. My biggest mistake when I was younger was simply a lack of knowledge. This has put me in some pretty rough situations including a couple near death experiences. The fact that I could not have a brain scan until recently caused me a lot of unnecessary suffering. Understanding our brain and body is a huge part of having a somewhat normal life.

Tracy Jacobson
Age 49, person with epilepsy

Jesus has always been my rock and always will be. At six months old I was not expected to live, but he is not finished with me yet. As hard as I tried to ignore the effects that seizures had on me, they just kept on trying to get in my way. Overall I feel that I won. I have fixed cognitive impairment that occurred at six month of age along with partial paralysis. Currently, I am classified as mentally disabled. God allowed me to achieve all that I hoped for in life. It all happened a lot quicker than I ever considered possible.

Overcome

by Tayler Jean Johnson

Today I will overcome
the frustration.
I will overcome
the hurt.
I will overcome
the medications.
I will overcome
the anger.
I will overcome
the side effects.
I will overcome
the absents.
I will overcome
the stigma.
Today I will overcome
Epilepsy.

Tayler Jean Johnson
Age 18, person with epilepsy

The piece I submitted, “Overcome”, was inspired by the ups and downs in my life since I was diagnosed seven years ago. I have gotten through every obstacle I have been faced with and continue to overcome many obstacles daily. While I haven’t had any tonic-clonic seizures in the past three years, I still have absence seizures daily.

No one likes to be told no

by Corrine Jordahl

No one likes to be told, “No…you can’t…you shouldn’t...be careful…”, least of all a 17 year old who has just experienced one the most terrifying and confusing moments of her life. I have never been one to let the “no” rule my life, including as a child (ask my parents), and this was no different. In fact, I think that possibly somewhere in my subconscious, even during that first ER visit after my first seizure, I knew epilepsy wouldn’t stop me. I wouldn’t let epilepsy be “THE NO” that would stop me from living my life.

And it hasn’t, not for one day. Not when I was on my college swim team and the doctor told me I shouldn’t be swimming in water, just in case I had a seizure...I just made sure my coaches and team mates knew what to do if I did have one.

Not when I moved to Boston to get my Masters Degree in Child Life and Family Centered Care….I always carry identification and information regarding my medical history, and I use my personal medical experiences to help me better relate to and care about the children and families I encounter.

And, most recently, not when I signed up for my first triathlon this summer, despite my doctor responding with a sideways look and, “Really?”… I had “EPILEPSY” written on my arms during the race so there would be no question of what was wrong in case I did have a seizure, as well as an amazing support team along the way who knew my background.

Granted, I have had my share of ups and downs, doctor appointments and tests, medication side effects, hospitalizations, and yes, seizures. And I have been and will always continue to be smart about taking care of myself and making sure those around me are aware of my epilepsy. However, I have yet to find something I CAN’T do, and I’m not expecting to.

Through the past 18 years, and all those to come, there is no way I could handle all this by myself – it’s way too much for one person to comprehend and maneuver alone. I have been hugely blessed with amazing, supportive, and loving people who are always here for me. I always thought of their support affecting my life and bringing encouragement to me each day, but little did I know I have done the same for some of them, as I recently read this part of a piece my dad wrote:

“Thru it all she has persevered and kept her spirits up and always bounces back when she is down. My daughter is my hero and has shown that living with epilepsy doesn’t have to slow you down or place limits on your life.”

Overwhelming emotions come over me when I realize that epilepsy, which I initially thought of as a negative in my life, could also bring positive into my life and those around me, all because I didn’t let it be “THE NO” that stopped me from living my life. I hope you are also enjoying your life and not letting any “no” stop you.

Corrine Jordahl
Age 35, person with epilepsy

Be There When Needed
by L.E. LaRue

When I was trying to think of what to write for this year, I said I wanted to find the booklets from previous years to see what I had written. I found three of the five, at some point later on I may find the other two in my home. But when I was searching I did find more from the Foundation. I also found the calendar from the national office (yes, I did send the donation to them as requested) as well as the quarterly magazines from the local office. In addition, I found the folder from the November conference. It all reminds me how the Foundation is there when needed, even though I haven't been to the monthly support groups much lately.

First, I will start with the calendar. I thought about making this year's theme 'hope' as I liked seeing how the calendar was called 'flowers of hope'. I will admit I don't look at it very closely most of the time. But there is plenty of information given to help those who need it, like the resource center, along with research grants and fellowships, and Social Media. But just as important, there is the section called 'Ways You Can Help'. At times I am not sure what I can do, but I've done volunteering at Camp Oz before, so I know there are various ways to help. Some can still help out greatly with giving of their time, which can be just as helpful as giving their money.

I liked the mention of the National Walk in Washington, DC, since I participated in this event in 2009. I titled that year's piece 'Turning a Corner' as it was beneficial to be around others affected by the disorder. I had really turned a corner by being brave enough to share my story on camera. I like how it also includes 'First Aid for Seizures' on this page. It is a reminder of attending the November conference, as some public service ads from the Epilepsy Foundation's Canadian counterpart were shown.

Next, I will cover my thoughts on the conference. My notes are kind of sketchy, but I wrote down a few things from the speakers that I agreed with. One of them was that if epilepsy were predictable, it wouldn't have such a negative stigma attached to it. This makes it hard to compare with diabetes. Another was to 'channel fear, advocacy, still afraid of having one'. With the last of these three sentiments, I said 'I understand' but in many ways I understood and agreed with all three. But the first two help with minimizing the third.

The toughest thing about the conference was when I had to choose one of their two tracks. I chose Individuals and Families over the Professionals. Life is all about choices, but at the time I was left wondering what I had missed in the other track (I read a little further and it looks like all of it is available online). I had to remind myself how I skipped last year's conference due to a scheduling conflict. It was nice just to be back there again.

I am still a little surprised when seeing some of the art I did for the Foundation continuing to go on tour. One of them was at the conference, and it may have been the same artwork I saw at a community center in August when searching for a Charlie Brown and Snoopy statue with my lady friend. I say this as I see myself as being better at writing than at visual art. But even with my blog, I can be surprised about what people like to read. I am truly thankful that some read what I write and some like the art.

The art event was held the same weekend as the conference. I did attend the art event and said I can be one of the speakers at next year's art event since I am just as good at public speaking as those I saw this year. Since I continue to perform comedy, I've proven how I'm good enough at public speaking. Then there's the quarterly magazine or newsletter. For me, the features called 'Seizures Don't Stop Me!' are most helpful. The problem I had when dealing with epilepsy as a child was feeling so alone, so isolated. Hearing the stories of others is the best way to combat those feelings. Also notable was the mention of some famous people with epilepsy. I had previously written how I thought it was absurd that some had questioned the ability of John Roberts to serve on the Supreme Court due to having epilepsy. It looks like some still look at him differently, according to the recent article, which is sad.

In the case of Justice Roberts, and with Minnesota Gopher football coach Jerry Kill, I would expect that all who needed to know were fully aware of the disorder when these two men were hired. I had previously written how there seems to be a need for a flag bearer to prove that epilepsy doesn't have to prevent success in life. But when I see famous people having to deal with the naysayers, critics, and haters, I seem to understand why there is no true flag bearer. It can be hard to deal with being famous, even harder when a chronic medical condition is part of the equation. With those who wish to debate Coach Kill, my response is his epilepsy shouldn't be a factor in whether or not he is retained. This is especially true if it doesn't interfere too much in his ability to serve as the coach.

I'm sure there are many things I can look forward to in the upcoming year. Besides the Twins outing, there is the Foundation's Awareness Day at the Capitol. Meeting the elected officials who represent me each year is great. I like participating in the process, as I've said before how democracy is not a spectator sport.

I like knowing how my epilepsy and my spinal condition are manageable, neither one has slowed me down at all in life. It is comforting that I don't have to battle the fear of the unknown like I was before. And I can count on knowing the Foundation will be there when needed.

* * *

L.E. LaRue
Age 38, person with epilepsy

I was diagnosed with epilepsy at age four and was on Dilantin until age ten. Seizures are rare now, less than once a year. The inspiration for my written work is my life. Epilepsy has affected my life some, but it's hard to say how much. Thankfully, it wasn't serious enough to prevent me from getting a driver's license. I value my independence. Finding the Foundation has been helpful, as I have been able to educate myself about the disorder – and it 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 too harshly because of it due to ignorance.

Living Well with epilepsy

by Sylvia Nelson

One seizure comes now, another comes later;
God knows about each one, He is always there.

My story is my own, I've shared it with many,
There have been days and years between seizures
I'm thankful I'm steady.

I love life! I walk, talk and write; there is music in my soul and sleep at
night.

How can I help you? What can I do?
I want to support you and help you through.

Epilepsy is amazing! I look forward to what will be,
When the sun comes up tomorrow, there's another day to live well with
epilepsy!

* * *

Sylvia Nelson
Age 72, person with epilepsy

I am 72 years old, and have had epilepsy for 49 years. I was Inspired to write because of encouragement from the Epilepsy Foundation of Minnesota. I have tonic clonic and complex partial seizures. By the grace of God, the seizures have been controlled for 2½ years.

A girl’s best friend

by Kristine Novotny

A magic pill that causes weight loss without lifting a finger or counting a calorie? A middle aged girl’s best friend. I was thirty-four years old and my metabolism was slowing down. I had been gaining weight over the previous few years. It was a slow but steady rise. However, over the course of six months, I lost fifteen pounds and I wasn’t even trying. I could now list my real weight when I renewed my Minnesota ID Card instead of my real weight minus ten pounds. The scale was now my friend instead of the high school bully that I tried avoid when I got on the bus. When I stepped on the scale, I felt joy instead of anxiety. The magic pill could not be purchased at a grocery store and was not advertised late at night on an infomercial. It was an anti-seizure medication prescribed by my doctor.

The side effects of a medication can sometimes be more debilitating than a seizure itself; however, I was happy with my suppressed appetite. Friends and family were taking notice of the weight loss but said I appeared “too thin.” All I saw in the mirror was a woman who could fit into a pair of size three jeans she bought in college. But a whole host of unwanted side effects included diarrhea, irritability, speech and cognitive problems. I would find myself snapping at my husband even thought I was normally even tempered. I would open the cupboard to take out a coffee cup only to find a cucumber. I constantly struggled to find words during a conversation and I would wake up every morning with severe stomach cramps. All this for fifteen pounds? My seizure control was no better or worse than before I started taking it yet I resisted changing medications. I was willing to cope with the unwanted side effects just to take advantage of the one that actually made me feel better about myself.

After one year, I finally decided to change medications. By that time my doctor indicated that my general appearance was abnormal and she saw at “very tired, thin woman intermittently tearful throughout the exam.” Nine years later, reading those words are difficult because they bring back painful but necessary memories.

* * *

Kristine Novotny
Age 42, person with epilepsy

The inspiration for my written work is my desire to express my creativity by drawing on my life experience. Epilepsy is just one facet of tha0.t experience but it has a significant impact that is both positive and negative. I was diagnosed at the age of seventeen with generalize tonic clonic, absence seizures, and later developed myoclonic seizures as an adult. Although my seizures are well controlled today, there is never a day that I forget about being a person with epilepsy. I am fortunate to have family and friends that have supported me throughout the years.

Marveil's life in Minnesota
by Marveil O'Neil

It all started back in 1981 when I was living in Chicago, Illinois. I signed up to join the job corps and was accepted. The place was called Joliet Job Corps Center and when I started there, everything was going pretty good, I was getting to know a lot of people and making new friends. I was just getting started with my G.E.D and doing as much as possible. I was close to home and could always go home on the weekends. Until one night the place had caught on fire and thank God that everyone was safe because it turned out to be just the lunchroom that had burned down. The very next day we all had to pack up and leave that job corps center and transfer to another one called ATTERBURY Job Corps Center.

Some of the people that I knew came with me and a lot of the other people went to different job corps centers. I mean boy was it really hard to deal with new faces and new places, but I had done it and after that I got started working on my G.E.D and my trade, which was plumbing. Within the two years that I was there, I had completed my plumbing trade, but the bad thing was I didn't get to finish my G.E.D. because my time had run out and it just had to end way.

Then some things had went wrong in my family and somewhere along the way, my mom and some other family members had passed away, so I still didn't get to finish my G.E.D. However, somewhere in 2000, I found out about a plumbers union that I could join in hopes of completing my apprentice and journeyman's license. I joined the Minnesota Plumbers Union and I got my plumbing certificate registered. After that I found out about this program called State Services for the Blind and it all sounded pretty good, so I filled out the application and was accepted. I was assigned a counselor who helped me enroll into a school called Blind Inc. I had to go through learning how to be blind for two years, wearing a blind fold for eight hours a day, Monday through Friday, which was one heck of an experience!

I learned how to read and write brail, travel with a cane, cook, clean. I also learned how to use a talking computer. In 2002, I graduated and earned my certificate in the blindness and training program. At that time, I met my best girlfriend while I was staying in one of the school's apartments.

This school had given me some insight on the ups and downs of being blind in life. I was born totally blind and a few years later, I had to go through eye surgery in order to get the vision that I have right now today and I am very thankful to the Man above, for blessing me with the gift to see.

After finishing the program, a few months later my girlfriend had told me about this place called Mears Park Apartments shortly after she moved in. After so long I applied for an apartment, was accepted and moved in as I was getting everything together and going back to school to finish my

G.E.D. Everything was going smooth, I mean it was easy to get around, the transportation was right there and the whole place looked really nice (but the carpet in my apartment needed shampooing).

This one particular night I had told my girlfriend to come down to my apartment, after she was done with washing her dishes. As soon as I had walked right out of her crib, there were these two security guards just standing right out in the hallway a door away from hers. As I walked out they whispered to each other and where pointing at me. I had no other choice but to pass them to another because the elevator in front her door out of order. I went to the other elevator and got in and made down to my apartment and I had my door opened waiting for her to come down.

As I was waiting for her, I had started shampooing my rug and all of a sudden, one guard and the building maintenance man walked in to my apartment. The maintenance man started tapping me on my shoulder while I was shampooing and he told to turn off my darn machine. I asked both of them what the heck are you doing in my apartment and then they grabbed me and forced me out of my apartment into the hallway and down to the elevator. Once we got into the elevator, the maintenance man ripped the buttons off of his shirt as he was putting it open to make it like we were struggling in the elevator.

When we got outside, he forced me from behind face first down to the ground and put his knee and all of his weight into my back and just started beating my head against the concrete tile surface and the only thing I could do was just yell as loud as possible for help, but nobody came. Then all of a sudden I heard a police walkie talkie and all they did was just turn them down and just stand there while this man was just beating my head against the ground and then he had dislocated my arm so I couldn't keep trying to get away. While all of this was going on, my girlfriend was trying to get down to my apartment, but the other security guard told her to go back to her apartment and she had thought that was strange but did so.

It was a hot summer night and everyone must have had their air conditioners on, because no one came to my rescue, except these fake cops who took the employee's side and dragged me down the stairs and threw in me the back of a squad car. The last thing I heard before passing out in the back of the squad car was the cops saying to the security guard and the maintenance man, "don't worry we'll take care of this."

Then all of a sudden, when I came to, I found myself in a detoxification center with blood still gushing out of my forehead and my shoulder still dislocated. I was in a lot of very serious pain. I kept telling them to get me to a hospital but all they did was put a bandage on my forehead and put me in a quiet room. I had passed out and didn't come to until the next day. That was when they had decided to take me to the hospital. There, I found out that I had brain damage. My shoulder was dislocated and I lost an awful lot of blood.

Now when I came home from the hospital the very next day, I wasn't in my right mind and the building maintenance man kept telling me, 'remember I am the one who did this to you.' Can you believe this? Also, in the early morning of June 21, my girlfriend looked for me everywhere and I was nowhere to be found. She spoke with another tenant that told her, "baby girl I got you. I'll take care of you now. Marveil went off in ambulance." That made my girlfriend start to worry even more. When I made it back, she was so happy to see me, that I was still alive. That was when we had requested a videotape of the crime that happened on June 20. The building had a full security camera system, yet they made sure everything was shut down and removed, and made sure that there were no videotapes or anything to look at.

After all this had happened they came to my apartment and gave me an eviction letter stating that I was disturbing the peace along with another letter also telling me that as of June 30, Mears Park no longer had a security video system or a videotape for me to look at period. I also found out that one of the guards who was involved with this incident quit and moved out of town. The maintenance man still had his job and had to scrub up all of the concrete, but when the stain wouldn't come up, they built a statue of two kids playing leapfrog over my bloodstain.

Mears Park told me that I could never ever step foot on their property, but why would I even want to after all that happened to me there? They made it hard on my girlfriend to live there, because they would always harass her and she felt very sad without me being there. Two years later, we moved into an apartment together that was very dangerous and unsanitary to live in, because we had no other choice thanks to Mears Park putting falsified information in our rental history.

Since that summer, we have moved several times due to getting very sick in bad apartments and building managers and caretakers bullying us. For example, the apartments had lice, mice, roaches, bugs, mold, and my girlfriend had suffered from pneumonia, bells palsy and developed asthma. Also, I developed seizures as the result of getting beat up. My seizures increase in these bad apartments, but what do we do when the odds are stacked against us? We are both visually impaired, are different races and have a big age gap between us, but we are together and will always be together no matter what anyone thinks.

We are seeking justice and want something done about the state system and how the little people get mistreated and misrepresented. We have a long paper trail that links to every apartment that we have ever lived in and it seems like the people with power are all working together to break us up, but like I said, that will never happen.

Marveil O'Neil
Age 48, person with epilepsy

Seizures

by Tessa Palmer

In happy times, in sad times I never can forget you. You help me decide what I can do and can't. I can go day by day like everyone else but, I am not like anyone else. I'm unique. You made me able to do most anything with you that others can't do. You might be annoying but, I will have you stick around.

* * *

Tessa Palmer
Age 17, person with epilepsy

I'm Tessa Palmer and I have suffered with Tuberous Sclerosis my whole life, which means I have had seizures my whole life also. I have had many different types of seizures, but right now I have complex partial seizures. I wanted to write this poem because of my feelings towards seizures. It shows people how every disability has ups and downs but we can still find a way to work around it. I always remind myself that no matter how bad my seizures get, God will always be there to catch me.

CONTROL? WHAT CONTROL?

by Lisa Renee Ragsdale

Once upon a time, no wait.
Twice upon a time, I had
what they call a seizure,
specifically what is called a
tonic / clonic seizure, formerly
known as a grand mal seizure.

Actually, I had four of them altogether,
but two of them happened either while
I was eating breakfast or after I had completed
my first meal of the day and the result was
only a few dishes on the floor, a wrecked
TV table, a burned muffin and a scalded pot.

I called those two “mini-mals” instead of the
grand mals. After the second tonic/clonic, they
found I just didn’t have enough of the drug in
my system to prevent the seizures and upped the
dosage from 750 milligrams to 1000 milligrams
every night before going to bed.

I’ve been on that dosage of Depakote ever since
10/18/08 and the side effects are taking over
and wreaking havoc on day-to-day life and the
possibilities of gaining employment. There are the
tremors in my hands that are unpredictable and
can even mess up my typing on my computer keyboard.

Just as bad, if not worse are the times I lose my balance,
walk into a wall, a door, or start to fall for no reason
whatsoever. Am I to believe that I will become employed,
not to mention these flaws, and then get fired for not
disclosing that I have epilepsy? Or disclose I do have it and
not get a job? And I was comforted, once, that my seizures
would be under control, and I could get back to leading a
“regular life.”

* * *

Lisa Renee Ragsdale
Age 62, person with epilepsy

The inspiration for this year’s poem is the numerous side effects of the medication I take to control my seizures. Although I would rather have the side effects than the seizures, I would prefer neither. I keep doing things that I want and need to do as best as I can, without owning a car or having even a part time job in the hopes that I can “get back” as much of my life as possible. To paraphrase Winston Churchill: “I will never give in to epilepsy.”

Ambassador of hope

by Kevin Reed

My name is Kevin Reed and I was diagnosed with epilepsy in September of 1995. I was attending Minneapolis Community College. I had a grand mal seizure in the student lounge. I took a year off from school to recover from my seizure.

I had to start over and regain my strength and to admit I was to live with epilepsy for the rest of my life. I accepted this and once I got back up on my feet I decided to go to the Epilepsy Foundation's monthly meetings. I went to all the events and got involved to see how I could make a change while living with epilepsy. I don't allow myself to be defined by epilepsy.

In December 2010, I was given the opportunity to join the Creative Arts Program which allows fellow artists to show and express who they are living with epilepsy. I was given an opportunity to take photos of all the artwork in our collection. I took my time to photograph each and every piece of work. Then I contacted different colleges, coffee shops, doctor's offices, etc. to promote the Creative Arts program. I made phone calls, set up and was asked to curate at the different sites. I spoke about our program and being the voice of the Creative Arts Program and sharing our work and lives with Greater Minnesota and the world.

Our work is on our website and in newspapers etc. My role is to be an Ambassador of Hope and the voice to make the change we all deserve to hear. I will strive to include everyone in the education about epilepsy and keep the flame of our Foundation burning to provide the light that is important to reach our goal and to continue fighting and finding and cure for epilepsy.

Kevin Reed
Age 39, person with epilepsy

My name is Kevin Reed and I am a photographer and a spokesperson with the Creative Arts Program. My mission is to educate people about epilepsy through the Creative Arts Program here in Minnesota, and around the world.

Mile Number 17

by Sarah Schmidt

For 16 miles, my run had gone smoothly. The sun warmed my shoulders while a light breeze cooled my face and tousled my hair. Running felt good.

At mile 17, I tripped on an unexpected rock. There I was - face down in the middle of the pathway. It wasn't that rocks hadn't been in my pathway before. Insignificant ones had simply been ignored. Others were easily tossed aside. Without breaking stride, I usually ran around the larger rocks.

This rock was different. It would not let me step over it. When I tried to run around it to the right, it rolled to the right. When I tried to run around it to the left, it rolled to the left. It stubbornly filled my pathway.

While it did allow me to pick it up, it would not let me toss it aside. Whether I liked it or not, this was my rock. If I wanted to continue running, I would have to carry it the rest of the way. No one else could carry it for me.

Mile 17's rock was now part of my life.

It definitely did not fit in my pockets. Admittedly, it was not attractive. In fact, for a time, I did not want anyone else to see my rock.

Then I looked at the other runners. All of us were carrying rocks of some kind or another! Some rocks were simply more visible.

Most of the runners put their rocks into a backpack and kept on running.

I had been taught at an early age that there was one who knew both my pathway and my rocks. He controlled what kind, how many, and how big my rocks were going to be. He gave me just the right size backpack. That backpack let me focus on what lay further down the pathway.

For many miles, I ran alone or alongside others. Just before mile 21, I met someone else running on my pathway. He promised to stick with me until I reached the end of my run. He couldn't carry my rock. Besides, he had enough rocks of his own!

By putting my rocks into a backpack, my hands were freed to do other things. They were free to hold a child in my arms at mile 22, again at mile 27, and finally at mile 29. And, oh! The joy of holding their little sweethearts began at mile 52.

Now the miles seem to go by more quickly. There are still hills and valleys that all runners encounter. There is no guarantee how long I will have a running partner. Because of mile 17's rock, I always carry the chance of falling face down in the pathway. I will, however, always fight to get back up and continue running.

At mile 60, the sun now warms my aging joints. A light breeze cools my face and tousles my graying hair. Running still feels good.
and against my will

Sarah Schmidt
Age 60, person with epilepsy

We all have issues to deal with-or as portrayed here-we all have rocks to carry. One of my rocks is epilepsy which I have carried since I was a teenager. For some reason, God has allowed epilepsy to be a part of my life. It is now my role to wear epilepsy well. There are, however, the difficult days of unsteadiness, long nights of insomnia, bout with blurred vision, or frustrating memory loss. To help balance the negatives, I have a job that allows me to work as well as I can. With one husband, three married daughters, six grandchildren, four hundred cows, little calves, and crops, my life is busy. In my spare time – who am I kidding? What spare time? I dream of having spare time.

A seizure doesn't mean you have to park it for three months

by Anonymous

Last year, there was a shift in the framework of Minnesota's driving laws for people with seizures. The wait time for driving after a seizure went from six months to three months and all exceptions were left untouched. It's the exceptions that continue to cause confusion for drivers, doctors, and state employees. If you have a seizure and a driver's license in Minnesota, you need to know Administrative Rule 7410.2500. (The Office of the Revisor of Statutes, 2007)

The nutshell of Administrative Rule 7410.2500 – The state's definition of a seizure

- Applies to any loss of consciousness/voluntary control (with or without an aura/warning, happening day or night).
- Definition of "loss of consciousness OR voluntary control"

1. "inability to assume and retain upright posture without support or
2. inability to respond rationally to external stimuli"

With the state's definition, the medical field is no longer the interpreter of a seizure. This is where your first role as your own advocate starts! The state's definition doesn't match the medical definition of a seizure. Check out the examples below to get a better understanding:

- ➘ Example 1. Sarah has complete awareness of her surroundings, can communicate and respond to questions and maintain her posture yet her right arm twitches and jerks uncontrollably for 45 seconds to two minutes three to five times per day. By the state's definition above, Sarah's seizure type does not fit the state's definition of loss of consciousness.
- ➘ Example 2. Tim loses awareness of his surroundings for 15 seconds but has no recollection of this loss of time. It was captured during an inpatient stay on an epilepsy unit. Tim's losses have gone on for more than six months without any other medical conclusions. His episode fits the state's definition.
- ➘ Example 3. Kim has a seizure every four years due to juvenile myoclonic epilepsy. Due to the time between seizures, Kim qualifies under the exceptions of the administrative rule.
- ➘ Example 4. Logan was doing okay on monotherapy (one drug) but under doctor's supervision began a second (add on) drug for better control of side effects and had a seizure. Logan's doctor's determined the seizure was due to the adjustment of the new medication and agreed that Logan was qualified to drive with positive long and short term prognosis. Logan's license was not suspended for three months per the state form Logan turned in. More later on this example.

The Nutshell of Exceptions:

If Administrative Rule 7410.2500 ended with just the definition and a three month waiting period after having a state defined seizure, Ex. 1, Sarah wouldn't legally be required to stop driving under the Rule; Ex. 2, Tim, would; Ex. 3, Kim, would have to stop driving for three months every four years; and Logan would be penalized for the three months for trying to improve seizure control under the doctor's supervision. This is where the exceptions start. In the four examples, the exceptions change the outlook for Kim and Logan. First, check out the exceptions.

Here are the exceptions in a brief outline, note each exception is WITH the State issued waiver form PS31015 (Minnesota Department of Public Safety Driver and Vehicle Services, 2010), signed by your doctor and yourself:

1. Doctor ordered removal or change in medication and doctor does not recommend driving cancellation.
2. First seizure
3. If not the first seizure, and alcohol or controlled substance is involved, the cancellation will be 1 year from the date of the episode.
4. Copied as it appears from Administrative Rule 7410.2500
   (The Office of the Revisor of Statutes, 2007)
   "The commissioner shall not cancel or deny the person's driving privileges if the driver or applicant submits a physician's statement indicating:
   (1)
   that the episode was the first episode experienced by the driver or applicant in four or more years;
   (2)
   that the episode was due to intervening and self-limiting temporary illness, treated by a physician, or to the driver or applicant forgetting to take the medication; and
   (3)
   that the short and long term prognoses for episode free control of the person's condition are favorable."

Bullet 4 above has three subsections separated by semicolons. The definition of a semicolon is to join two independent or complete sentences. Using this basic grammatical definition, bullet 4 of the Rule could be to read in this manner:

Bullet 4 (rewritten with author's influence using above definition of semicolon)

4. The commissioner shall not cancel or deny the driving privileges if the driver or applicant submits the state's form where his/her doctor indicates the long and short term prognosis for episode-free control are favorable and the seizure was due to either of the situations:

(1) The episode was the first experienced by the driver in four or more years
(2) Or, the episode was due to intervening and self-limiting temporary illness, treated by a physician
(3) Or, the episode was due to the driver or applicant forgetting to take medication.

When dealing with the State of Minnesota Department of Public Safety it's always better to arm yourself with the rule, the facts, and be prepared. But first, remember the examples of Kim and Logan? Here's how the exceptions apply to them.

Kim has Juvenile Myoclonic Epilepsy. In this example, it means that there's a seizure once every three to five years and medication is still required daily. The exceptions allow Kim to continue driving. Kim has become an advocate when it comes to dealing with Minnesota because the mailbox has contained another form that starts, "Under the authority of and as directed by the laws of the State of Minnesota your Minnesota driver's license or privilege to operate a motor vehicle is hereby canceled effective…" Kim has received the canceled form by mistake a few times over the past 25 years. Kim has also learned the phone representatives at the State of Minnesota may be difficult to deal with and some do not read the form when it's received. Instead, only the date of the seizure on the form and the date of the seizure on the state's computer are compared. Advocating at this level has become time consuming and frustrating, but it's the difference between working and having a home and homelessness.

The other example was Logan. Logan was adding a new medication under doctor's supervision and going down on the other medication. There was a brief seizure. Logan's epileptologist didn't feel there was a need to discontinue any activities including Logan's newly earned driver's license. Logan's mom brought the state form for the exception, Seizure/Loss of Consciousness Waiver, to the appointment and the epileptologist completed it after reviewing and discussing the exceptions. The waiver can be found on the link in the bibliography. Although many epilepsy centers claim to have the same form, it is not the waiver form, but rather a blank form that is sent for renewals from the 'driver evaluation unit'. The two forms are very different.

The nutshell forms and the Rule:

From my personal experience, the Driver Evaluation Unit sends a cover letter to drivers that have identified seizure activity upon application or renewal. With the cover letter is the renewal form and it's neatly divided into three quarters:

The first quarter is a brief informational notice: it's the driver's responsibility to report a seizure; the report must be made within 30 days of the episode, and the state's definition of a seizure.

The second quarter is the driver's completion: name, birthdate, date of last seizure, reason, and other loss of consciousness (which is asking the same question again per the state's definition on the first section), and the driver's signature.

The third quarter is to be completed by the doctor and asks questions related to years of treatment, date of diagnosis, medication, result of treatment, patient cooperation, prognosis, qualification for motor vehicle and commercial vehicle, review time, and doctor's signature.

The form that is mailed to the driver for renewal purposes doesn't take into account or allow for any discussion or explanation of seizures under the exceptions of Administrative Rule 7410.2500. (The Office of the Revisor of Statutes, 2007) Its sole purpose is renewal.

On the other hand, when dealing with seizures and long term diagnosis, the waiver form is a valuable tool. The waiver (Minnesota Department of Public Safety Driver and Vehicle Services, 2010) is more concise and divided into three parts:

The first part includes instructions, a statement of Minnesota State Statute 171.13 (The Office of the Revisor of Statutes, 2011) where the focus is on subdivision 3 regarding the examination of licensed driver – it says if an examination gives the state reason to believe a driver cannot operate then the license can be cancelled. The section completes with the state's definition of loss of consciousness, the driver's duty to report within 30 days and a phone number for more information.

The second part is for the driver. It asks for the license number, name, birthdate, date of last episode and signature. That is all. Yet, you may want to consider including which exception your seizure qualifies under. This is a personal choice. Some examples might include, missed dose, hospital out of brand and substituted generic for 3 days, titrating under doctor's supervision (a situation that happened to myself), Admin. Rule 7410.2500 Subp. 3 B, or first time.

The third part is for the doctor. The areas required include time under care, diagnosis and date, medication and result, yes or no to cooperation question, separate answers for short and long term prognosis, yes or no answer to operation of motor vehicle, review selection, and signature. This area may need the cooperation or the documentation support of multiple doctors if you were treated for illnesses that suppressed your seizure medications, made your normal (brand vs. generic) medications temporarily unavailable, or somehow affected your medication or your body – in this case, be prepared to have documentation and/or additional signatures on the page. On a last note for this section, be sure to include implants and other devices that you use to control your seizures.

The nutshell about advocating for your driving exception

But wait! You need to advocate. Here's a list to help when you advocate. One last thing, I know driving is a big deal, especially in isolated areas. The Minnesota Department of Public Safety trusts drivers with seizures enough to report themselves. Trust yourself more. Driving isn't worth a seizure on the road.

General

- Keep track of who/when
- Write down questions beforehand
- Don't use the word 'you'
- Repeat what the person said for clarity
- Always get a copy
- Even if it doesn't happen, say thanks

Phone conversations

- Use speaker so you can write/type
- Don't get into a shouting match
- Don't cry
- Use a checklist
- Get the person's name, extension
- Stay calm

Dealing with the Driver Evaluation Unit

- Have in front of you:
    - Administrative Rule 7410.2500 -Highlight the exceptions for the Rule
    - Statute 171.13 subd. 3
    - Copy of the forms and fax confirmation causing the issue
    - Most recent renewal
- Ask to speak to the Medical Evaluation Unit
- If it's due to a "cancellation in error" - ask if the waiver form was received and give the date and time of the confirmation. The representative may not understand what you mean by "waiver form" you can mention PS31015.
- Keep your cool and stay friendly.
- If you feel you're going to lose it, take a deep breath and relax – it won't get you anywhere to lose it. If the representative you get is really nasty, just say thank you, be sure to repeat what they say to you to be sure you get the information correct. They can say really stupid stuff! It is rude, inconsiderate, and may even make you cry. It is based on something, information from a computer, training, lack of training, ignorance, or a combination. Try to blow it off. Say thank you. Compose yourself and dial again. Eventually, you'll get someone that can help you.
- If writing, thinking, responding, and conversing seems mind blowing (I understand), have a second person with to help record the conversation, even let the representative know you may need to ask them to repeat things and thank them for their patience. Most

times dealing with Public Safety is via the phone; however, with the time issue of mistaken cancellations, it might be easier to just go to St. Paul with your documentation.

Dealing with a physician

- Your physician is not a philosopher, lawyer, or judge.
- See your doctor in person as soon as possible after a seizure if you believe your seizure fits one of the exceptions – you need to report the seizure within 30 days of the event.
- Crying won't help in a doctor's office.
- Doctors see too many patients to be able to remember everything. Help them help you.
- Prepare a list for your appointment – type it if you can so it's easy to read and organized.
- Detail the reasons you see the seizure fitting the exception, get records and bring medication bottles if needed, also bring lab records to show blood levels.
- IF taking antibiotics for a temporary illness, bring it with you to your appointment.
- If you can't see your seizure doctor, see the doctor you feel prescribed the medication that caused the seizure, the doctor who treated you for the short term illness that you had when you suffered the seizure, your family doctor, etc. and note the 30 days – doctors may be able to get you in to see your specialist sooner.
- If you have to do a phone message, fax the waiver form to them and have the office mail the completed form to you so you can review it first. Sign and complete section 2 of the driver's portion only after you receive it from the doctor's office. Or, go to the clinic to have it done and pick it up.

Make sure your doctor knows about the exceptions. The chart below has ideas to see how exceptions apply to some seizure situations and what doctors can do to help improve communication within the state's renewal and waiver forms.

DECREASE, INCREASE, OR CHANGE IN MEDICATION AS ORDERED BY THE PHYSICIAN

Admin. Rule 7410.2500 Subp. 3 A
Avoid medical shorthand (arrows, mg, test results, plus, minus, etc.)
Write out all terms related to medication changes/treatment
Include all treatment methods (deep brain stimulation, VNS, surgery)

FIRST OCCURRENCE

Admin. Rule 7410.2500 Subp. 3 B
Note seizure was first occurrence

FIRST IN FOUR YEARS, PROGNOSIS IS "FAVORABLE"

Admin. Rule 7410.2500 Subp. 3 C

Note date of last seizure in form’s exception area

OCCURRED DURING ILLNESS UNDER DR’S TREATMENT, PROGNOSIS IS “FAVORABLE”

Admin. Rule 7410.2500 Subp. 3 C
State dates or number of appointments, phones calls from patient and other doctor if treated by another physician, and dates of hospital or emergency room (if contacted during stay)
State specific illness and how it compromised medication level, ability to take medication, changes in medication (i.e. metabolism, dehydration)

FORGOT TO TAKE MEDICATION, PROGNOSIS IS “FAVORABLE”

Admin. Rule 7410.2500 Subp. 3 C
State last time patient forgot to take medication
Indicate extenuating circumstances surrounding incident

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Anonymous
person with epilepsy

I’ve dealt with seizures and the additional stresses, challenges, and successes that come with each one for nearly 30 years. After suffering through society’s ignorance, intentional or unintentional, there are skills and small tidbits I’ve learned that others may benefit from and bypass the tears and frustration. If one person can take just one skill or tidbit from this piece and apply to their own situation or that of a loved one, I’ve accomplished a success from a seizure and that’s the drive behind the writing. My ability to drive was delayed due to my diagnosis at the age of 14 and seizure activity. Before graduating from high school, I was able to get a driver’s license. With fewer and fewer interruptions from seizures, I continue to drive today. Driving is a responsibility that society sees as a right. I don’t. Society needs to learn about the privilege.

Movements of Love

writings by family, friends and caregivers
of people with epilepsy

Ben’s Music Performance

by Beth Bacon

Kindergarten Music Performance

The children all sit in a circle

Eager faces full of light

Checking to make sure their
parents are watching

On the bleachers to the side

The bleachers are yellow, red and
blue

The room is energized with
excitement

Anticipation

They sing and dance

Play instruments with enthusiasm

As we all watch avidly

The world’s greatest performers

On our stage

The moment is fleeting

You may have missed it

Circle time –

My son left us –

Just for a moment

In case I had forgotten

My child has epilepsy.

That fleeting moment

Followed by his confusion

It’s hard to remember what happens
next

When you don’t know what just
happened

All of a sudden I am transfixed

Wanting to run to my son

Shelter him from the next minutes

Where he will stumble through the
rest of this performance

Instead I sit still

Applauding all the children

That are singing and dancing

Watching silently

As my child reenters this group

Following along Like nothing ever
happened.

Ben's Evening

by Beth Bacon

Tonight a crabby four year old
Easily hurt
Fighting for independence
Control

I wonder as I watch him
What it is he is feeling
Is his body betraying him
Setting his mood

These difficult times
Hard for every child
Trying for every parent
We want the same

How it must feel
To be jumping and bouncing
On a neighbor's trampoline

And then...Accidents happen
But they are not suppose to
When you are finding
A bright spot

The one who stormed down
The middle of the road
Not needing
Or wanting to hold hands

Gently crying
Hiding his face
Carried in his mother's arms
So saddened

I wish I could protect him
Follow him down the center
Of the street again
Dreading the independence.

Beth Bacon
Age 44, son has epilepsy

These poems were inspired by my six year-old son, who has had focal seizures since he was two months old. Having three kids, I realize that every child has his/her own challenges, some we can define and some we cannot.

Epilepsy Won’t Make You Famous

by Susan Caskey

In 2002, our life changed as we knew it. Seemingly already complicated by our daughter’s autism diagnosis, we were blindsided by the events about to occur.

Our family of five pulled up roots after 18 years in Chicago to relocate to my husband’s and my birthplace, Minnesota. Kevin had a promising opportunity at a dot-com startup which subsequently went belly up after six months. Being near our aging parents and children’s grandparents made the risk seem worth it. That decision changed our life forever.

I was happy to hear there was an autism clinic at the University of Minnesota. I added Claire to the waiting list. Six months later, we were in.

It was a Tuesday in January, l was getting our three children; 11, 9 and 7 ready for school. Kevin was boarding a plane to California for the week, orienting for his new job. At 9:00 am l received a phone call. Most days I would have let it roll in to voicemail, but the caller-ID said “University of Minnesota-Fairview,” maybe I should take this one I thought, so I answered.

Claire’s new neurologist had requested a baseline MRI and was calling with the results. We had never had one in Chicago. Claire was so tactually defensive that she would need to be hospitalized and put under anesthesia to tolerate the machine and the I.V. contrast. She was older now and we hoped she’d allow it with only an oral sedative.

Well, my trooper went through it without any medication. The first of many amazing episodes of courage and trust Claire demonstrated.

The doctor asked me if my husband was home, she wanted to see us as soon as possible. When I told her that he was on his way to California, she said he needs to come home, “Claire has a brain tumor and I would like to see you both in my office tomorrow morning”. I told her I’d have to call her back and hung up the phone in shock.

I was granted a special grace to get through the next 24 hours; acting calm and collected so the kids wouldn’t suspect anything was wrong.

After making two routine bus stop runs, I called the airline and asked if Kevin’s plane had departed yet. The plane was on the tarmac ready for take-off. The Delta agent contacted the flight crew and returned Kevin to the gate.

After what seemed like the longest day of my life, we were sitting in the neurologist’s office the next morning. We met with our doctor, a neurosurgeon, and oncologist. Surgery was scheduled in 3 weeks. Claire’s brain was housing a “low-grade Glioma” for God knows how long. In three weeks it would be removed and examined to determine the treatment plan. Our experience with epilepsy was about to begin.

Claire had her first seizure the night of March 8, 2002, the day of her tumor resection.

I have this image of a roller coaster in my mind. The neurons firing in her brain, like the wheels grinding the rails. Rapid highs and lows, rendering her body with fatigue; if not from the seizures, from the medications to control them.

The experience of this new life, was about to take us hostage with EEG's, MRI's, blood draws and medication trials, forever. Amidst all these trials, Claire still held on to her dreams.

Claire loved acting and planned to be an actress. With her amazing memory and ability to recall complete chapters of books, it seemed like a logical way to use her talents.

Now navigating the stage was nearly impossible. Claire has vertigo and open spaces-particularly high ones-cause her to hit the deck. Few roles require lying on the ground throughout the production, at least speaking parts anyway.

Claire's challenges acclimating to her huge, unpredictable, highly stimulating world became harder with each passing year. Her love for scripts, stories and escaping into character would unlikely materialize into a career.

It seems funny that unless a person with epilepsy falls to the ground and contorts their body, somehow it isn't authentic. Many individuals who experience seizures don't present this way. Frequently there are no visible signs. They can occur during sleep, or so subtly that you have to really be watching for it.

I remember an occasion when Claire and I were riding a trolley on the streets of Chicago gawking at the sights through our open-air window; I turned to Claire pointing out the horses and carriage decked out for the holidays. She didn't turn her head, didn't answer me, I might as well have been talking to a tree or a fourteen year old. I spoke in her ear, touched her shoulder, nothing.

Invisible to the rest of the riders, Claire was having a seizure. No acting here and yet people will never see the fireworks going on in her brain or understand the effects of the aftermath.

Try living in a world that gets faster with every new invention; it already takes longer to process information than your family, friends or neighbors. In a society that values "keeping up," this is a struggle people with seizures face every day.

After a seizure, Claire is very tired and anxious. Our fun was cut short, back to the hotel so Claire could rest.

Claire's brother and sister became accustomed to having what most kids look forward to as being fun, turning into anything but fun. Countless times plans are derailed because of unannounced events.

Seizures rock the world of a person with epilepsy and affect the entire family. Despite the fact an event is often invisible, it is no act. Epilepsy should be treated with the same importance and public awareness as all health initiatives.

Having epilepsy won't make you famous like an actor, a rock star or athlete. In our family, it will get you admiration, for courage, perseverance and a "kick it" attitude.

* * *

Susan Caskey
Age 54, daughter has epilepsy

I live in Eden Prairie. My daughter, Claire, experiences absence seizures in addition to managing a brain tumor, autism, diabetes and vertigo. Before raising my children, I worked with young adults as a therapeutic recreation specialist. I have a special interest in travel. Inspired by Claire, I am currently writing *Autism Travels: How to successfully travel when you have Autism.*

You Don't Know

by Les DuCloux

You don't know what it's like to
wake up lost, scared, aching, with a
stranger hovering above you telling
you that everything's going to be
alright, but who are you and where
am I?

You don't know what it's like to be
scared, helpless, a stranger to your
best friend who even though you
tell that everything's going to be
alright, you just don't know.

You don't know what it's like to take
this poison, swallowing each pill
knowing that it will try to fight its
way out, gnaw at your stomach, or
attempt to strip away everything
that makes you, you.

You don't know what it's like
to watch you take that poison,
knowing that I'd take it for you if
I could, for a day, for a week, for a
month, for a year, forever, just so
you could be you again.

You don't know what it's like to
depend on someone for so much,
so much that you used to depend
on no one but yourself for, so much
of that lost independence that your
confidence and happiness were
rooted in, and to be overprotected.

You don't know what it's like to
depend on you for so much or how
much of who you are intertwines
with someone else, how much
your happiness depends on
their happiness, and how fragile
happiness really is so you do
everything to protect it.

You don't know what it's like to
utterly appreciate someone for
everything that they do, to know
exactly how comforting and
reassuring the gentle hug of love
really is, to know that you're loved
unequivocally and unconditionally.
Then again, maybe you do.

Les DuCloux
Age 34, wife has epilepsy

I thought of the concept of this poem after my wife had a seizure and looked at me like I was a stranger. I realized that although I'm sympathetic, I don't know what it's like to have epilepsy. I do know that my perspective as a spouse of a person with epilepsy is a unique one. I think it's caused me to be much more appreciative for what I have and all that I'm able to do. I've had the opportunity to meet many people who deal with more difficult situations in their lives and they always seem to smile. Oh yeah, I got to marry a special lady with epilepsy too!

Rewards

by Jerry Hartlaub

Do for doing, or do for others,
Or make a list, doing for self.
Is personal reward usually smothered?
Or do we always build our wealth.

A fleeting moment here in passing,
We float in cosmos everlasting.
To make a difference is a motive,
But will anyone here really notice?

A lonely stone someday will mark,
The journey's end. Was it a lark?
A place unvisited, who can recall.
Appearing to have come late in fall.

Gratify the soul and the mind,
Viewing others, there are all kinds.
Give words of praise for gifts observed,
There seems no meaning to be a nerd.

Searching for purpose, I am seeing,
Only the journey has import.
Perhaps solely with fellow beings,
Where is found the lasting resort.

Attitude seems your finest tool,
Rewards a plenty, no broken rule.
Sensing and kind, the message you send.
Proud I am, forever your friend.

Jerry Hartlaub
Age 72, son has epilepsy

This poem was inspired by my adult son. As a child, he underwent a craniotomy to remove a tumor. The eventual outcome was good and he grew to be an accomplished normal adult. While in college he experienced his first seizure. Since that time (1967) he has pressed forward with his life while using meds for good seizure control. However, he's had big complications while switching meds. Through it all he's carried the burden with dignity. I am impressed and humbled. When I considered entering this writing contest, I was again mindful of how proud I am of my son. Writing this poem has provided an avenue for me to express my feelings.

My Daughter has epilepsy

by Kay Moran

I said, “My daughter has epilepsy.” Usually the response I get is silence or “don’t you just take a pill for that and everything is back to normal?” How I wish with all my heart that was a true statement. But nothing could be further from the truth.

The seizures started over 29 year ago, just out of the blue one August morning. My daughter was up getting ready to go to the first band practice of the upcoming school year. She was in the bathroom curling her hair. I was in the next room and we were talking back and forth to each other. Suddenly I heard just noises coming from the bathroom – like a loose board banging from a sudden gust of wind. When I turned to look into the bathroom, I saw my daughter in the bathtub, in what appeared to be a semi unconscious state. Blood was coming from a cut on her forehead, saliva and blood from her mouth and her arms, legs, and body were thrashing about.

Fear registered first. I could hear myself screaming her name over and over again. Instinctively I tried pulling her out of the bathtub and calming her down. I had no idea what was happening. Finally, I did get her out of the bathtub and onto the floor and the strange movement stopped. She was not coherent and did not seem to understand me. My mind was racing. What happened? Is she going to be ok? What can I do for her? What do I do next? I’m all alone here! Can I call a doctor at 6:30 in the morning?

Of course I could call a doctor or doctor’s service at that time of the morning. I was advised to get her to the hospital as soon as I could. By the time we arrived at the hospital, she was able to stand on her own but her speech was incoherent and she was exhausted. After an examination, the doctor said it looked like she had had a seizure, but more tests and more time was needed to figure out what caused it. He said he did not want to call it epilepsy because it was a label that once was put into your health information could never be erased. It wasn’t until later I learned how true that would be.

The seizures continued. We were sent to see a neurologist and prescribed medications. Soon we would learn about the horrific and life changing results that would happen because of all the seizure medications that would be prescribed in the years to come.

My daughter was fourteen that day and her world and mine changed forever. The next few years were filled with seizures, doctors, all sorts of tests, fear, looking for someone or something to blame for this epilepsy because surely we hadn’t caused it, or had we? Fourteen is an age that has many challenges and adding epilepsy to this mix just added more challenges. People, classmates and even your own family can be so cruel in their words and actions. We searched and searched for answers but never found any because doctors and/or neurologist don’t know the answers. New drugs and procedures are constantly being offered.

There is no cure just the hope of being able to control the seizures and try to have a life. Try to have a life…what a statement that is! How does she have a life when everyday she has to wake up and think did I have a seizure or am I going to have one? Am I going to be able to function in the fog from horrible side effects from these high potent drugs I have to take to supposedly control the seizures? And I became overwhelmed with fear and guilt. I did not protect my own daughter from this. How could I as her mother let this happen to her? All my hopes and dreams that I had already formed in my mind for her died and now all I could think about was, how is she going to live with epilepsy? How are the seizures going to affect her quality of life? Well we would soon experience what kind of life you can expect if you have epilepsy.

My daughter did graduate from high school and college with awards and many outstanding achievements. And she went on to become a teacher. But she was plagued by side effects from the drugs and recurring seizures. She even had one in her classroom. Her behavior can change, she has sudden outbursts, confusion, memory loss, depression and many other side effects that other people can't understand. Our lives revolve around seizures and doctors. She has been fired from jobs because once the "normal" people out there find out she has seizures they don't want to be around her. There are laws to supposedly protect her from that, but you and I both know they don't work. The world is full of ignorant people even hospitals and nurses who lack any knowledge about seizures and what to do to help someone having one. All we can do is keep trying to educate and inform the public about epilepsy.

My daughter looks as normal as anyone on the outside. Family and friends don't remember that she has special needs and sometimes needs special consideration. So it is always easier to just avoid her and go on with their lives. Of course I realize that is true for all of us. If you don't have the special need yourself it is very hard to understand what that person with on a daily basis. Alone my daughter and I ended up trying to deal with all the problems that come with a person having epilepsy. Probably most people with seizures do feel alone, confused and depressed. My heart breaks over and over again when I see the hurt caused to my daughter by the lack of understanding by employers, friends and family members.

As my daughter has gotten older she seems to be able to fight for her rights and try to live her life to the fullest as best she can. But sometimes in trying to express her views or thoughts she becomes confused and repeats herself and people lose patience with her. It took years and years to find a neurologist that would actually listen to her explain about how the seizures and drugs were affecting her life.

I, on the other hand, have been overcome with fear and depression. I worry about what is going to happen to her if I die first. Yes, she does very well, but the memory problems are increasing and some days are better than others. The frustration and loneliness of trying to explain her situation to others in hopes of gaining acceptance from them is never ending. And of course we know that there is no cure for epilepsy, only trying to find the best way to treat it that will give her the best chance of “getting a life”. She lives day to day until the next seizure happens hoping against all odds that she will become seizure free one day.

I am proud of my daughter everyday and love her more than words can say. She has more determination and more zest for life than some “normal” people”. In spite of the epilepsy, she faces each day with determination to go out there and be a part of this world we live in. I applaud her for that and I am in awe of all that she has accomplished. The hopes and dreams I had for her when she was born have been replaced with my wish that she be able to live every day seizure free and be able to find happiness and self-worth in all that she can and has accomplished.

Just take a pill they say……..oh how I wish that was true because you see my daughter has epilepsy.

Kay Moran
Age 66, daughter has epilepsy

My daughter started having grand mal seizures when she was 14. We have spent the last 29 years trying to figure out just how to live in spite of the seizures. It has been a constant uphill battle to gain understanding and acceptance. The side effects of the seizure drugs take top billing in the struggle to figure out the best way to live your life to the fullest. I am hopeful that one day my daughter will be able to live seizure free.

The Meaning of Love

by Chris Poshek

You have never been like other kids in our eyes,

And God knew early on,

You would need a family strong enough,

With all the love in the world to give.

And so our own lottery pick was sent to us,

And as luck would have it,

You haven’t been a challenge,

But a blessing in disguise.

The way you see the world,

The laughs you give us,

The pleasures you see everyday,

Far outweigh the special needs,

And will melt the coldest of hearts.

We will always be proud that we were chosen,

To be your parents and help you achieve your dreams,

The gifts you give us everyday,

Are more than you can know.

A precious gift was sent to us,

You are a treasure from above,

A child who’s taught us many things,

But most of all what the meaning of love is.

My Hero

by Chris Poshek

When you were just an infant

And you couldn’t sleep,

I would set you on my chest.

I was the one protecting you,

Keeping you safe from harm.

I would look up into your eyes,

And I could see how much love

You had for this guy you call dad.

How did I get so lucky?

You were the princess chosen for me.

There is something special

About a daughters love.

Seems it was sent to me

From someplace I couldn’t believe.

My love is everlasting.

I just want you to know,

As you grow older,

That you are my hero,

And you always will be.

Chris Poshek
Age 41, person with epilepsy, daughter has epilepsy

My inspiration is my daughter, Hannah and wife, Sheila. I am amazed how far my daughter has come since she was first diagnosed. My wife is my rock. She has been there since my first seizure and through all of Hannah's seizures. I don't think seizures have affected my life. I work full-time and am in school full-time. Everyone who has epilepsy is the part of the same family. Our families have ups and downs, but we are never alone. My wife and daughter are my heroes. I know one day we will cure epilepsy.

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