2015

Epilogues

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

EPILEPSY
FOUNDATION
Minnesota

My Life’s Journey – April 17, 2012
by Robyn Alexander

Life is defined at the time from birth to death. We think of life as a long tour or journey through time.
I remember when I was young, my folks would show us home movies – that’s what they were in the old days, not videos or DVD’s. It sure was neat to see ourselves as we were, to see how we’ve grown and changed. It seems the video camera is a machine to record our journey through life – sounds like Star Wars. Of course we only catch the highlights, and usually only the good ones at that. But when we look back, the whole journey comes into focus, more like how the humanistic Lost in Space show was. We have our own video show running all the time and each person views their show differently, and even is influenced by the person’s mood at the moment of presentation.

The other day I noticed a gray hair and it just got me wondering what the next part of my life’s journey will be like. It’s been a round-about journey so far. I was born – crawled around, learned to walk, romped about, swam, jogged 10ks, skied, wind surfed and even skydived when I was a daredevil. All this happened in high school and then I journeyed on to college. I studied Aerospace Engineering in Florida and finished up at the University of Minnesota. From there I joined the U.S. Air Force and was stationed at Edwards Air Force Base in California with future plans to work at NASA as a Mission Specialist, but that changed in September of 1985.

I was hit by a semi on base.
I was in a coma for six weeks.
And the journey began all over again.

When I woke up six weeks later, I had to learn to walk, talk and think all over again. I even went through the “terrible twos,” but I was 23 years old, so I got really terrible.

I moved on, through the so-called teenager stage, where I started doing drugs – anti-seizure drugs! Everyone thought I was just being a “moody teenager” at first, until they noticed familiar irregular actions.

I went through a period where THEY had ME experimenting with new drugs. The drugs would even make me feel high at times. I got toxic one or twice – my boyfriend was reading from the Torah in the synagogue while I was in the congregation and I wouldn’t stop giggling and laughing, they tell me.
I think I’m finally growing up – I’m getting more okay with doing things wrong and accepting others telling that I’ve done things wrong. In fact, I welcome hearing people’s feelings about things and thinking of better ways to do things rather than finding a way to “attack back.”

On this new path in my journey, I’ve learned to write poetry – with or without rhyming – and journaling. Through this combination, I’ve found myself writing cards where I remember little things about a person to make things more personal. I find myself enjoying this. Those to whom I’m sending the cards to seem to enjoy as well (or they’ve learned to pull one over on me – I’m pretty short you know so that’s not hard to do).

My independent living workers have helped me develop daily living charts, needed because of my short term memory loss. This helps restore my confidence, making independent living practical: (display charts).
With my memory and reasoning loss, I find staying involved with other people gives meaning to my life. I can do this by involvement in Wilderness Inquiry, Brain Injury Group (BIG), different writers groups and activities with others with disabilities. The transportation services I use to take part in them help greatly like buses and Metro Mobility for evening meetings or when multiple bus routes are too detailed for me to follow.

I've found I still have my visual memory and that can help by writing things down because I can pull it out by seeing it in my mind. I've discovered rhyming to help me remember things and found positive rhymes are essential to my well-being. I've learned that if it arouses an emotion in me, it helps – which is why negatives are so easy to remember. I've learned to use the positives so I work hard at seeing the good in life which can be wonderful in turning me around when I have problems, especially from people being impatient with me since my disability is invisible now to those who don't know me well.

Singing songs can help me remember too, another emotion arousal technique. Exercising has helped greatly in my singing I've found and I've turned songs on to help my mood alteration. When someone says to you that you can't sing, remember that everyone can sing! Singing really helps folks feel good so next time you're feeling goofy – Let it out!

FEELING GOOFY – LA DI DA, DA, DA, DA – FEELING GOOFY!

For Cynthia

by Dennis Asmussen

In lucid times,
  with friends and
  Loved ones,
Spirit and energy,
Keen mind, and then,
I can only imagine this:
blue eyes deepening, softening,
that trip she takes
each time E claims her:
dreams, spontaneous arisings,
time out of mind.

Dennis Asmussen wrote this poem about his neighbor, Cynthia Rapacz, who is impacted by seizures. It portrays how he sees epilepsy in her.

The Story of My Life

by Cecilia Bergren

The first seizure I ever had was when I was FOUR years old.

After, that I felt very weird and I did not know what happened because seizures = knockout. My parents, did not know what was happening either so then we went to a special type of doctor that helps figure out what type or types of medication is needed. The first few types of medication, I kept having seizures whether I had them at home, school, or on vacation they just kept going and coming back.

In fifth grade I missed two weeks of school to go get my seizure alert dog, Mallo. At first, when we brought her back to the hotel, as soon as she jumped right on the bed that I was sleeping, I started freaking out like a lot. It took me time to finally realize that I do like dogs and that I never want to be scared of another one again, because dogs are a part of my life now! I for one, never want to let Mallo go ever! I love you Mallo!

Right now I have been seizure free for almost three years. I feel great that I have been given the chance to live seizure free. I love the freedom of a normal teenage life. I am also the Winning Kid this year. I hope I will get a chance to go to Washington D.C. to talk about how hard it is for anyone like me to be living with epilepsy. Although it has been hard for me to go through life I, for one, always push myself harder to get past obstacles. I just pray for people like Coach Kill to have control over their own seizures and control over life because this is how I think about life: “Your seizures do not own you, you are you!”

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Cecilia Bergren (age 14) lives in Chanhassen with her family, and has been involved in the Epilepsy Foundation of Minnesota for six years. She says, “Creating something that has my own style that no one else has – that inspires me.” Her hobbies are: drawing, basketball, watching football, dancing, theater, playing piano and gymnastics.

My Battle

by Kelsie Brandl

April 9th, 2001
Attempted homicide
Female. Poisoned.
Murderer still at large

Six years,
Since I was attacked.
A fluke, they said.
Nothing more.

But they followed me.
I was being stalked.

I could hear a shutter click.
Stare hard to find it.
Moments lost
Just staring to come back.
Moments lost in time.

I knew something was wrong.
I could feel it.
I was told I was fine.
So I must have been fine.
My reports went on ignored.

When they came back,
They would not go unnoticed.

Only I could see them coming.
And only I could see them there.
Others saw me staring.
So right back at me they would stare.

They kept me captive.
They kept me distracted.
They kept me quiet.
They kept me confused.

And then it happened,
And then it happened again.
Another attack.
And everyone knew.

Action was taken.
Long overdue.

At first there were 8.
“To protect and serve.”
Not soon enough,
But just in time

They kept me safe,
But the battle was ridden
With friendly fire.

The war went on
Until chaos subdued.
When defensive forces
Were taken from the feud.

Strategies were made.
And new measures put in place.
Hoping to be my saving grace.

I swear they still follow,
Just glimpses now:
Flashbacks to old attacks.
Nothing more than that.

It's true,
Isn't it though?
They do take my brain.

My senses,
My focus,
My reality, too.

Seizure, “Seize her”
They sound one in the same.

Kelsie Brandl recently moved to Saint Cloud with her husband, and her battle with epilepsy reached its eight year mark this past September. She says, “The support I've received from the Epilepsy Foundation of Minnesota as well my participation with them over the past six years has given me courage to reach out to help myself and others through writing. Writing, especially, is a hobby of mine, so why not use it to share my story with others?”

For the Mothers

by Audrey Colasanti

You know who you are.
You sleep with one ear cocked
to the bedroom door
and down the hall,

ever listening
for the sandbag thump
against plaster,
the banging of bed boards,

books falling off shelves
as if flung by fairies.
You know who you are.
You have attended

the dented
bicycle,
the chipped teeth
and bitten lips,

the broken arrow
of your child’s dreams.
You have watched the lion
on its hunt,

creeping through the grass,
waiting for the right time
to jump.
You have seen

the heat lightning
as it races across the prairie,
searching for a place to spark.
Yes, you know who you are -

counting out pills
from bright orange bottles,
wondering instead
about elixirs and salves.

You would give your child eye of goat
and leaf of lilac,
if you knew it would help.
For, of all the muscle

in your tested arms,
of all the sinew
thickened in your soul,
- you know who you are -

there is not a mother yet
who has not bled
at the sight of her child
in the grips of the lion,

getting struck again
by the lightning.
You would drive a pick
through your heart

to save your child
from *this*.
And for that, you are
remarkable.

NOM DE PLUME

By Audrey Colasanti

Why can’t they at least pronounce it “graaaand mal?”
Drawling out the A’s like British gentry
awaiting afternoon biscuits and tea?
Could you bring out the graaaaand mal, Jasper?

Don’t forget the marmalade.
It would sound so much more
dignified, wouldn’t it?
Graaaaand mal?

Said with a snooty upper lip?
My point is,
and this has just come to me,
perhaps there is no apt inflection at all

to convey what it is
and depict what it does.
This --- that comes exploding
in the middle of the night,

or while knitting at scarves,
or raking leaves by the fire pit.
One second, combing at dried sheets
of maple, and the next,

thrashing too close to the flame.
As sour aromas vex the nose,
spectacular satellites
rocket beneath your lids.

You have been visited
by staggering visions
and colors so rich and vigorous,
they do not even exist

on a modern-day color wheel.
You have said that you have seen God,
but not that God.
And this moment is not altogether

unsettling.
Your muscles have tensed
so very, very *graaaand*
they could crush steel beams

in your clenched up hands.
Yes, I am now sure of it.
There are no elongated vowels
up for the task.

No syllables … suitable.
No superbly rolled tongue
nor casual twang
could possibly deliver

the proper gravitas
and explanation of it all.
Grand Mal. *Graaaand Mal.*
As you plummet to the ground,

gripping at your rare Jehovah
to cradle the fall,
there simply are no words
befitting enough.

Mind-Body Healing Through Arts

by Derrick Dawson

Art Therapy Is A Great Way To Enjoy Being A part Of And With Others With Epilepsy. I Mr. Dawson do Enjoy The Groups Put On At Art Therapy, “I Also Must Share That Being With Those With Epilepsy And Parents With Young And Older Kids Are Much Easier To Clearly Communicate With.”

From Experience Attending And Being A part Of The Art Therapy Classes Is A Wonderful Feeling For Those With Anxiety, Stress, And Mood Swings, “Relaxation, Feeling Happy, Excited, Comfortable, Relaxation, “Most Of All Feeling Free.”

I Mr. Dawson Having A Computer Am Able To View The Art Work Made In Classes. I Mr. Dawson Found More Information On How Epilepsy Plays A Role In Many People’s Life. More Important How WE Find Different Ways To Not Allow Epilepsy To Get In Our Ways Of Approaching The Real World.

I Watch On Television And On Internet, “Two Church Programs Which I Come To Feel Are And Find To Be Really An Eye Opener In Many Ways In Touch Ministries W/Charles Stanley And Joel Osteen.” When Watching And Listening To Both, “They Help With Healing The Mind And Body” Art Therapy, Watching & Listening To Charles And Joel, My Psychologist, Psychiatrist, Neurologist, And The Epilepsy Foundation All Has Played A Big Roll In Me Learning About The Real World.”

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Derrick Dawson is 45-years-old. He has had epilepsy since he was seven months old, with complex partial seizures evolving to generalized seizures. He enjoys keeping track of his seizures monthly to try and make it to the next month seizure-free.

Epilepsy

by Caleb Foote

Once upon a time a very little boy
learning how to walk
felt a quiver start in his leg
soon it would drop him to the floor
His mom would pray a silent beg

and he would forget what happened before
while he was laying on the floor
Soon they found an epilepsy unit
And decided to go for it

Stinky glue, loud blow dryer, many wires
staying on the epilepsy unit, so tired
Pills, and alarms, falling and crying
Scared to go down a slide
felt the same
then the doctor came
He gave me meds that tasted yummy
and some to protect my tummy

I didn't fall unless I chose
And people started to see how much I know
I still hate to slide and I still hate to fall
Trampolines are the worst of all
It makes me remember a very odd world
I'd rather ride bike, tractor, or horse!
It's a journey and when I grow
I get more meds of course.
But, I am here and I am learning
And my heart is truly yearning
That others don't get scared if I fall
It's just a "brain fart moment"
That is all.

Caleb Foote is 13-years-old. This is his epilepsy story as told to his mom on his iPad using the Proloquo2go speech app.

Transformation

by Jerry Hartlaub

A fire rages in the forest
Glaring vivid red and yellows
Leaping from tree to tree
Like an Olympic broad jumper

Four legged creatures
Sniffing charred remains
Puzzled by it all
Like frowning grade school kids

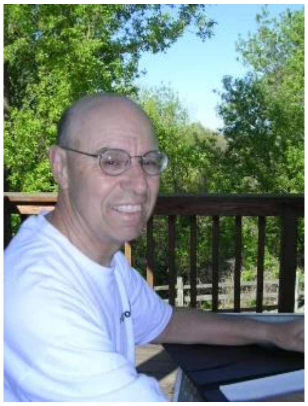
Ashes coat every surface
Food for the next gen of plants
Waiting for the next rainfall
Like sleepy children in a doctor's office

Torched pine cones spring open
Seeds burst forth
Looking for promising places
Like drunken ants

So I must spring forth
Grabbing for each new toehold
Tearing up the struggled past
My brain lightening subsided

There is no such thing as a free transformation
I too must burn to the ground
And wallow in the smoldering ashes
Of what I used to be

And go on from there



Jerry Hartlaub has volunteered at the Epilepsy Foundation of Minnesota for almost 15 years. He feels the Creative Arts Program, “demonstrates that folks living with epilepsy can be normal in every other way.” His hobbies include: harmonica, biking, teaching math, vegetable gardening and anything associated with technology. Jerry has two children and three grandchildren. Jerry's son has been fortunate to successfully treat his epilepsy over many years.

My Situation with Epilepsy

by Steve Ireland

First I don't regret my life, yes I know I might have liked to change my life's outcome somewhat.
Yes I've lived my life being worried, scared, regretful, thankful, & satisfied.
Finally I happily settled with being satisfied about having epilepsy.
I was tired of having epilepsy control my life.
I knew I had true epilepsy, yet I could not have epilepsy control my life anymore.
So I decided to enjoy the rest of my life, by taking back the control I gave to epilepsy.
Also my mother unfortunately died.
I only express this fact about my mother dying, this resolved much of my stress.
Why, she blamed herself for my having epilepsy.
And she didn't want me to go to any events, go to college, and finally she didn't wish for me to express to anyone that I have epilepsy.
Unfortunately I do have a tremor.
This situation is a result of both my having epilepsy & my taking medication for epilepsy for so long.

During my life I've been a blue baby.
I've also had many seizures, due to my having epilepsy, true epilepsy.
The medication & my viewpoints of myself, early in my life caused me to have many seizures.
Later, like today, I've had fewer seizures & for five years I’ve had no seizures.
This is due to my enjoying life more, less stress, my doctor, & my medication.

I first learned I had epilepsy, true epilepsy when I went to the Mayo Clinic.
The year was 1956-7 when I first saw doctors, nurses, and had a various battery of tests done.
This was the year I first was told I had epilepsy.
I was only seven years old.
I was referred to various clinics or hospitals by my doctor, located in Terre Haute, Indiana.
My local doctor expressed he couldn’t, with all his equipment as well as his staff, be able to tell me if I had true epilepsy.
He wasn't comfortable even ordering medication for me.
When I first saw the Mayo Clinic, I was 6-7 years old.
I was scared, as not only was this my first time & the building was so tall & I was so very small.
I went to the Mayo Clinic, year was 1956-7 where I first learned I had epilepsy, true epilepsy.
I was told by my doctor & I was 6-7 years old.

Since my 1st Mayo Clinic visit, & a battery of various tests, with other clinics & hospitals I was told my type of epilepsy was a lasting situation.
That I will have epilepsy as long as I live.
After living on two #23 floors (the epilepsy floor) in two hospitals, for six months,
I was told I had epilepsy, true epilepsy & that it will be a constant in my life.
How I deal with it is up to me.

Unfortunately I was disappointed a lot.
I put pressure on myself, so there was much stress in my life.
Yes I had many seizures.

I truly allowed epilepsy to control my life.

I've been told my epilepsy & all types of epilepsy shall be cured.
When? The late 60's or early 70's.
As you see both the 60's & 70's have passed & yet epilepsy is still a situation for many.
I've finally come to the conclusion that epilepsy will never be cured in my lifetime.

No, I may never like having epilepsy.
I've never felt comfortable with any person lying.
I do not appreciate various doctors or people saying there will be a cure for epilepsy in a certain time.
I don't wish to be treated as a 2nd class person because of my disability, epilepsy.
I don't need to be reminded that I do have epilepsy or a disability.
I've been treated in various ways, by various people, that I'm defective.
I've been told that if I was born in Russia, Germany, Poland, etc. during World War II, I would have been on a termination list.
I either would have been rescued or died in a death camp in one of their gas chambers, etc.
I've been told this more than four times.
Enough so you don't forget.

Yes I may afford my epileptic medication.
Also, I still can afford my hospital visits & doctor's visits.
The costs of the test are questionable, as I remember one of my test cost $5,000.
I'm certain that cost has risen.
I'm worried that someday I can't afford my epileptic medication, my hospital visits, or even my doctors' visits.
Like I pointed out, the cost of any of my tests may not be affordable at all.

People talk a lot about cancer & various cancers & hopefully a cure for cancer.
Do not people know that epilepsy & various epilepsy are just as bad?
The people with cancer are treated as a 1st class citizen.
I know I've been treated as a 2nd class person or person that is a nuisance.
Cancer is only one of many situations & sicknesses, we all, in this country share.

Since a more positive outlook of my life, having less stress, switching both my epileptic doctor & epileptic medication, my seizures are down.
For five years I did not have any.
Then I had 12 seizures in the next year, then 13 in the next year.
Considering I enjoy December, that is when both the 12 and 13 seizures happened.
Although this year I have had two seizures, one in June & one in July.
Yet my seizure situation has gone down.
At one time I had 140 seizures a year.
80 during all the months but December.
Then I had 60 seizures I always have enjoyed December.
It has been wonderful, having not only a five year record of no seizures & two other years of minimal seizures.
This has been better than many years of a 140 seizure count.

In spite of all my jobs and my epilepsy, I started volunteering when I was 15-16 years old and haven't stopped.
My 1st volunteering place was local Y.M.C.A.
I started at the boy's camp, located in Terre Haute, Indiana.
From this time on, I've volunteered every year, and enjoyed the various people and the various places, always.

I plan on volunteering until I've been told by someone & I see for myself that I can't volunteer anymore.

I'm proud of what I've done in my life.
I hope & pray that whatever my job was, it has helped someone, always.
I also hope & pray that my volunteering life helps people as well.

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Over the past 20 years, Steve Ireland has been involved in a variety of activities at the Epilepsy Foundation of Minnesota, including volunteering at the State Fair. What inspires him to contribute to the "Epilogues" writing collection are others who cannot for various reasons. He lives in Minneapolis and enjoys model cars and planes, music, movies and walking, in addition to expressing himself through writing.

Milestone

by Tayler Johnson

Another milestone met.
Six years of no white walls
and fluorescent lights.

Six years without
an IV
and a family in the waiting room.

The day is spent with hugs,
texts,
and a quiet dinner at home.

The night spent with my family
reflected a quiet celebration,
that ended with cake.

Red velvet cake,
always a family favorite,
was decorated with candles.

Six candles.

Six candles to represent,
every year spent
out of the ER.

The candles are lit,
my family smiles waiting
for me to blow them out.

I take a deep breath,
closing my eyes.

My eyes close and I
see the last nine years
flash before me.

From my first seizure to now
to nine years later.
Another milestone met.

My eyes flash open,
the flames now extinguished.
Laughing and cheers erupt.

I grin,
the countdown to another
milestone begins.

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Tayler Johnson is from Ramsey and has been involved with the Epilepsy Foundation of Minnesota since 2007. "I am inspired by what my family and I have gone through together since I was diagnosed. It's the way I perceive what is happening, and the way my family does – especially my brother. By sharing what I've gone through, then others know that they are not alone," she says. Her hobbies include reading, dancing, volunteering and spending time with friends and family. Tayler is involved in the dance team and Delta Tau Sorority at Hamline University and works in the disability resources office. In May, she will graduate with a Bachelor of Arts in Psychology and Religion, and then work towards a Doctorate of Psychology.

Getting on with your Life

by Debra Kammerer

Strange as it seemed, I was now the one giving advice that started, “don’t get tired, don’t get stressed…” Though I knew it fell on deaf ears, just as it had done on mine more than a decade earlier.

It started out as any other day, somewhat cool and crisp as a day in early October in Minnesota would be. Jackets in the morning, shirts in the afternoon. There hadn’t been a serious frost yet so people were still doing yard work. Gardeners were putting in bulbs, and lawn people were putting down fall fertilizer. It was the day of the Twin Cities and it just so happened that my sister was working in the garden when she had her first seizure. My brother-in-law saw her fall to the ground and ran over to see what had happened. When he saw her unconscious, he called 911. Thus began another chapter in my family’s journey with epilepsy.

My first seizure had happened on the Saturday before Thanksgiving, at the local grocery store. I had planned on just dashing into the store, grabbing a few things and being home within an hour. I felt fine in produce but by the time I got to the juice aisle, my vision went blurry. I can’t describe exactly how I felt, other than to say I felt bad enough to reach for my phone to call my husband. I never made the call, and instead woke up in an ambulance being told I had probably had a seizure. My shoulder was dislocated, and the paramedic was apologizing for having cut off my jacket so an IV could be started. I told him not to worry, because although I liked the jacket, truth was the color was out of style and I had gotten it at a garage sale for a few dollars. In the scheme of things it seemed like the least of my problems.

My first real thought was that I didn’t want to have epilepsy. But I shouldn’t have been surprised. My father and two of his siblings had their first seizures in grocery stores when they were each 56-years-old. My second concern was whether I had wet my pants. Happily I had not. They say you can learn something from every situation, and in addition to the routine advice about not wearing underwear with holes, now it seemed I was always going to have to make sure my bladder was empty before I went anywhere. I know an empty bladder is a happy bladder.

As a nurse, I knew the blue pads on the cart rails were there so I wouldn’t hurt myself if I had another seizure. I don’t know if the blue is meant to be calming, but I guess it didn’t hurt under the circumstances. As is typical after a seizure, I woke up at intervals, then fell back to sleep.

At the hospital I was taken for a CT scan. I was later told that when someone my age, 47, has their first seizure the concern is that they have a brain tumor. I am happy to say the CT did not show that. My husband arrived and I don’t remember much else. Contrary to what you hear about slow ERs, I was home four hours after I had been in the juice aisle. In the meantime, I’d had the CT scan, had my shoulder popped back in place and gotten a prescription to prevent more seizures. I was also given an appointment for more tests and one to see an epileptologist later that week.

After an MRI and an EEG, the doctor told me that usually epilepsy isn’t diagnosed until the second seizure, but my EEG showed I had abnormal brainwaves and he was confident in his diagnosis of epilepsy. It was a good thing my husband was with me, because I didn’t hear much after that. A diagnosis of epilepsy isn’t like hearing you have strep throat. My brain went off on its own tangent.
When I told him about my dad and his siblings and the grocery store he said, “We will presume it is hereditary then, yes some people tend to have seizures in particular environments.”
He told me to take two weeks off work. And that I couldn’t drive for six months. I was lucky that I had sick time coming, and a husband who could change his work schedule enough to get me to and from work.

The doctor gave us some pamphlets, told my husband that if I had a seizure he didn't need to call 911 unless I went on for more than a couple minutes, but that we should call for directions on medication adjustment. He gave me the following advice, "take these pills for the rest of your life. Don't get tired, don't get stressed, don't drink alcohol, don't skip meals, and get on with your life." But suddenly my life was different. I had epilepsy. And I was about to meet the good, the bad and the ugly.

A few days later a woman who had been shopping at the grocery store called me. I knew her from Inver Grove Heights and our kids went to the same school. She had been behind me in the juice aisle, and asked me gently how I was, and if I wanted to know what had happened. Of course I did. Like the majority of people, I had no idea how I looked when having a seizure and I had no idea what had gone on between reaching for my cell phone and waking up in the ambulance. She described how I had gone rigid and fallen over like a ton of bricks. I thanked her and added that I presumed she was the one who got my phone and coupons back into my purse. She hadn't called to ask questions about me, only to soothe me. The phone call from her was one of the kindest gestures I have had.

Having two weeks off work gave me plenty of time to search the Internet for information on epilepsy. The best site was the Epilepsy Foundation, and to this day I still check back there for information. The two weeks also gave me time to adjust to medication. Initially the doses made me dizzy and tired, but over time that has gotten better, though taking it on an empty stomach still makes me woozy.

Although I was aware of the stigma attached to epilepsy, I never tried to hide it. How could I when I was in a packed store where I probably knew at least a dozen people? Even my mailman had heard about it and a week later asked me how I was doing.

While we have learned a lot since the days when people with epilepsy were sterilized, or institutionalized, it is still frightening to see people fall to the ground and thrash about before waking up confused. Great people have had epilepsy: Socrates, Alexander the Great, Michelangelo. While I don't have much in common with them, I do share epilepsy with Jerry Kill, the Gopher's football coach. Anyone who talks about epilepsy helps acknowledge that it is an illness that crosses all ages and socioeconomic groups. As I often say, we don't get to choose our illness. If we did, we would all choose colds, or hang nails, not heart disease or epilepsy.

Getting on with my life was easier said than done. I was now taking medication several times a day which sort of kept epilepsy on my mind. I got a medical alert bracelet. And I constantly fretted about when the next seizure would occur. I worried about not getting enough sleep, which probably counted as getting stressed.

I returned to work and for the most part, people were very encouraging to me. People told me how lucky I was that I had not been driving when I had my seizure. I had to hold myself back from asking them that if I was so lucky, why did I have the seizure in the first place? On occasion, people would tell me I should never be allowed to drive again, and I was glad to have done enough reading to give them facts about reasonable lengths of time and predictors of therapeutic drug levels. And once when I asked a coworker for a ride to work, because my husband had to take his mother for cataract surgery, I was told it 'wasn't convenient for her.'

Over the next weeks, my neighbors offered to take me shopping at Target, family checked on me often, and a close friend brought me back to that juice aisle to "get me back up on the horse."

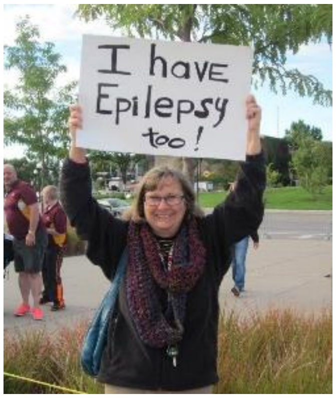
Over the past years I have tried to give back. I rallied for Jerry Kill. Many years volunteer at the state fair Epilepsy Foundation booth, which has been a good experience for me. I have met many people with epilepsy who look like they are coping pretty well. A person with a seizure-sensing dog stopped by the booth…interesting fact, canines have about the same incidence of epilepsy. I've had people ask me what I knew about dogs with seizures…I refer them to their vet. I met a couple who stopped with their teenage daughter who had just had her first seizure in the past month. I wished I could have done more for them than hand them a pamphlet and a pencil. My best advice to the girl, whom I sure viewed me as an aging crone, was to tell her to take her pills and get enough sleep.

But now my sister was 'one of us on the journey.' As I started off saying I am sure she didn't hear most of what I said about not getting tired or stressed. I hadn't even gotten to 'don't skip meals,' which isn't usually a problem for anyone in my family, 'don't drink alcohol' there again not a big deal, though I'll admit I do miss the occasional margarita. 'Take these pills the rest of your life' was doable, but the 'get on with your life,' in truth still rubs me the wrong way. The pills affect my balance. On one hand I didn't usually wear stiletto heels, on the other hand NOT being able to wear them irritated me. A small issue for most but knowing that wearing them was a sure recipe for a pratfall didn't seem like being able to 'get on with my life.' I haven't gone swimming since and at one point in my life I swam every day.

But I digress. I called or visited my sister every day that she was in the hospital, and she doesn't know this but when I woke up in the middle of the night I called the night nurse to see that she was okay. When I talked to her during the day I told her little things, like "find out if there are drug interactions you should know about." There is nothing worse than having heartburn in the middle of the night and not knowing if you can take an antacid or if you should tough it out for fear of a med interaction that might cause a seizure. I didn't think it was necessary to remind her about not being able to drive for several months. If she thought for even a few minutes, she would remember that she had given me rides during my non-driving times. I promised myself I would be there for her when she needed to get someplace.

I went with my sister to her first office visit after discharge. I encouraged her to bring a list of questions, but she told me she didn't want to ask anything. She just wanted to hear what the doctor said, and so I sat in the room with her and took a few notes (at my visits, I always went with questions). As I said earlier she was being seen by a neurologist, not an epileptologist. When I offered to this doctor that our father, an aunt, an uncle and I all had adult onset epilepsy, her doctor looked at me rather blankly. And that appears to be where the investigation starts and stops for people of our age. Some people inherit curly hair or money. In my family it seems to be epilepsy. Estimates show there may be hundreds of genes related to epilepsy. Funding for studying epilepsy is way lower than diabetes or cancer, so you can guess how long it will be before significant progress is made.

For me it has been ten since my last seizure. For my sister it has been three. For both of us and for all of you, I hope your seizure WAS your last seizure!



Since I wrote this in mid-October, I had a seizure last Thursday. And Jerry Kill retired. We get on with our lives.

Long-Delayed Resolution

by L.E. LaRue

I don’t make New Year’s resolutions. But recently I realized there were things besides epilepsy that I was ashamed of. I am still trying internet dating, and one of my matches spoke of her line of work being a program manager to help students become more college-ready. I was in two of these programs actually, Educational Talent Search (in high school) and Special Support Services (in college). I was told I qualified for these programs as I was from a low-income family. I remember this well because I was a first-generation college student. It is still a mystery as to how I qualified, as I wasn’t in the free and reduced price lunch program. It was likely due to my parents being divorced, and going by my mom and stepdad’s income (nurse’s aide, they don’t make much) and not Dad’s income (Maytag appliance factory, decent money). What little I had kept from both programs was buried in a box with the rest of my college papers. I went to the meetings as I was told I had to be there. Sound familiar? I said the same about going to appointments related to having epilepsy. I was ashamed of both and refused to admit either to most people. I must have been afraid of somebody telling me ‘you don’t belong here, poor boy. Go work in a factory like your dad.’ There were some benefits to the program of course, like fee waivers on college applications and mileage reimbursement on campus visits. We even saw the play ‘Government Inspector’ at Central College in Pella, Iowa, the school that administered the program. I was more annoyed with the college version, checking in with my instructors. But I did like the graduation banquet. As far as I know, all I kept was two newsletters from the high school version (where I spoke of being a football letter winner and planning to attend the U of Iowa) and the program from the college graduation banquet. Much like with epilepsy, it helped that I was willing to teach myself. And in the internet age, this is no problem whatsoever. I found the Wikipedia article that said both were part of the federally-funded ‘TRIO programs’ created by the Higher Education Act of 1965. And some famous people have been in the same program, such as basketball players Patrick Ewing and A.C. Green. As I have said before about having epilepsy, we shouldn’t ignore who we are or be ashamed of who we are. So I liked how I accomplished another resolution, albeit a long-delayed one.

It does remind me of how at times I have wondered how I survived my upbringing, with all of its obstacles, some of them self-created. I still think it is a miracle that I survived it all. I try not to think about how a few more wrong turns would have led to me being found at a drug treatment center, mental hospital, prison, or cemetery. I had also wondered, after seeing the movie ‘Running With Scissors’ (where the main character gets dumped with a legal guardian because the mom no longer wants to raise him) if I would have been more emotionally healthy if I had been sent to live with my ‘favorite aunt’, now an ordained minister in Wisconsin. But as I told a classmate, I would have had to leave my hometown of Newton, Iowa. Mom always told me how this aunt was in line to be my legal guardian, and I found this aunt to be easier to talk to and less judgmental. I also spoke of this to my then-lady friend, and said I could explore it through my writings.

I am also pleased with how I have been more active in the stand-up comedy community in the past year. I decided to become more serious about chasing down stage time after the loss of two of my comrades in December. It was bad enough to lose one, but two? I still recall having an ashen face after the second death was announced. I screamed a lot because of it. I spoke at the memorials for both, saying I was likely better known for documenting comedy than performing it. I cringed after saying this, and told myself I can change this. Now I am onstage somewhere in the Twin Cities at least twice a week, and it is nice to get stage time at more than just open-mics as well. I have had four ‘guest sets’ opening for my friends and aside from that I have picked up four more paid gigs. There was also performing on Zombie Night at a St. Paul Saints baseball game, and being in two more videos. One of them was part of the Loft Literary Center’s 40th Anniversary celebration. There was also more acting at a haunted house, which I enjoy as much as telling jokes. Just as important, I tried harder at finding stage time when I am out of town. I liked performing when I was in Toronto for the Pan-Am Games, then in New York City later in the summer when I was there for a writer's convention. Can't forget doing karaoke again, this time at Canadian Days in Little Canada, the town I lived in for a year when I first moved to the Twin Cities in 2004. Much like before, I chose a song I could sing with passion, it was 'Wonderful' by Everclear. 'Please don't tell me everything is wonderful now.'

Of course I still find enjoyment in activities besides performing. I liked dancing at my cousin's wedding in Wisconsin in June (where I caught the garter), it was 'Bust a Move' by Young MC. I said I had to as the song is in one of my favorite movies, 'Up In The Air' starring George Clooney, and I was wearing a hat that promoted the movie. I have found and taken pictures of many sites in and near St. Louis where the movie was filmed. Sadly I didn't see my friend that I knew from the Foundation's support groups during this year's St. Louis visit. Our schedules didn't match up. Even though I've cut back on traveling as it was getting expensive, I still go to St. Louis annually to see my favorite baseball team. I also do an annual visit to Chicago, to visit 'old haunts' as I once lived in the NW suburbs of Chicago for six years. I would have liked attending more of the Foundation's events but I happened to be out of town three times – the Twins game, Saints game, and the fall conference/seminar. I liked making it to the summer picnic though. I am thankful there haven't been any health problems, be it from epilepsy or the spinal cord condition, and I am hopeful this continues to be the case.

* * *

L.E. LaRue's inspiration for his written work is his own my life. He was diagnosed with epilepsy at age four on Dilantin until age 10. L.E. graduated with a degree in history from the University of Iowa, where he once received outpatient treatment for epilepsy. His seizures are rare now, less than once a year. He says, "It wasn't serious enough to prevent me from getting a driver's license. I still don't tell many people about my epilepsy, as I am afraid of being judged too harshly, or even losing friends or jobs because of it. I am pleased to have lived a fairly normal life, as I have worked for a finance company for 16 years."

Ultralepsy

by Mark Manning

Of course, you try not too hard to think about it, because thinking about it too much will drive you at the very least a little nuts, but thinking about it will also make you want to stop. I mean, when you are in mile two of the race and you realize “Holy Toledo! I’ve got 47 more of these to go...” you really begin to doubt yourself: “What did I get myself into? Why did I tell everybody I was going to do this?” But you try to push that to side and just think about the next 100 meters and the next hill, and the backs of the shoes of the person running immediately in front of you out on the trail, because if you think too much, you will stumble on some rock, or miss the importance of this particular moment. You have to live in that moment, which is a good thing here, because living too much in the past can leave you with regrets and living too much in the future just leaves you worried. So I recommend living on this trail, with these people, pacing yourself for the journey, confident in this moment, as if it were a religious pilgrimage.

Life can be so much like running an ultramarathon; epilepsy is an ultra.

My family thought I was a little crazy—no, more than a little crazy—to do this. At your age you should be in the stands, watching your kids, is the common refrain. What have you got to prove? Could you pick something shorter, something easier? My personal favorite: “Isn’t this a sign from God?” Now, you can’t let these voices rule your conscience. You have to pick and choose who you will listen to: a few loved ones who know you, and your coach, the company of those who train with you. And you train for this journey, this pilgrimage, by taking a small piece of it each day, and living it out. You train for it by living as if you were doing this race a little every day, experiencing this special moment a little every day. I guess this is sacred space and time, this race, because in it I come to understand the rest of my life beyond this moment; the particular becomes the general, and the metaphysical becomes the singularly physical. No cure, no miracle, just being who I am.

Life can be so much like running the epilepsy ultra.

Before you have too much time to think about it, you come to an aid station: there will be many more. You cruise in and meet your family or meet your “c.r.e.w.”—(Crabby Runner, Endless Waiting)—and they are glad to see you, and everyone is upbeat, and you are told to eat and drink, don’t wait, don’t put it off, don’t wait to get in trouble out there on the trail because it will be too late and we don’t want to come looking for you after you crash. So you shove stuff in your mouth and drink, and fill your bottles, swat you on the rear and send you on your way. “See you in a couple of hours...” Aid stations are wonderful, and they are manned by wonderful people, but they are also a break in the action, in the flow. I get into a pace, a rhythm, in this life and in this race, and breaking out of it can be annoying. But I have come to see that I need their help, I can’t carry enough food and water for 50 miles by myself. As the day wears on, these breaks will become simultaneously looked for and dreaded. Time distorts. The faces become more welcoming; or do I just need them more? The breaks grow shorter, or do I just get impatient? Yet without the aid stations, I am done. I can fantasize about not needing them, but truthfully, I need them as much as I need the stuff they have to offer.

The epilepsy ultra is my life.

At some point, I can’t be certain where or when, I will try to talk myself out of this. I will have “issues.” My self-confidence will lag, my blood levels will drop, or I will think I just don’t need help, that this whole enterprise was flawed from the start, and I will start to bargain and negotiate privately with myself. I may cry. I may have “dark thoughts.” I may just stop and say I can’t go on. I may argue with my crew. I will tell myself if I have another drink or gel or pill that I’m going to vomit it up. I will forget all the hours—hours and hours and hours—I spent training and living for these precious moments. I will forget all the self-discipline that got me here. I will forget that this moment will be followed by other moments, and yet more moments, and that I am not ‘stuck” in this moment permanently. The world and my life do not revolve around this one second. I hope that someone will talk to me with a mixture of comfort and authority, especially someone who knows what I am going through, someone who has been running with me, climbing the same hills, jumping over the same rocks, suffering the same stress and fatigue. I hope they will order or drag me into the next moment.

Epilepsy is an ultra.

At some point, if I stay true to the course, if I work through the issues, if I keep eating and drinking, and listen to my crew and coach, I may reach that flowing series of orange moments that mean that I have come a long way, and while I am not done, while I am not getting faster or better or energized or “winning” (for this is not a competition for me), I know that the end of this ultra is insight. Importantly, most importantly, of supreme importance is sharing this moment; if I have someone to run with me and share this moment with, how orange, how golden! If I have someone waiting for me at the end to share the trail, the journey, the life, the pilgrimage, than all is complete.

For a while it is complete, until I strangely realize that I must keep running these races, as awful and wonderful as they are to me. See? On my finisher’s medal: ultralepsy.

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Mark Manning is a Lutheran (ELCA) Congregational Pastor in Breckenridge, MN. He graduated from the University of Wisconsin-Parkside in Kenosha, WI and Luther Seminary in St. Paul, where he earned his Doctorate in Biblical Preaching in 2012. Mark has been in the ministry for 25 years, and grew up in Fergus Falls, MN. His wife is a public school Music Teacher and Choral Director. They have four children (two young women and two young men) ranging in age from 15 to 23. Mark is 54, and developed seizures after a head injury in 1996. He experienced grand mal seizures rarely and irregularly, but has been seizure free since 2009. He says, “After initially seeing a local doctor, I began receiving care from Dr. Gregory Cascino at the Mayo Clinic in 1999. I have been a nationally-ranked athlete in track, and gravitated to ultramarathoning after being diagnosed with epilepsy, and enjoying the life-slowing effects of Depakote!”

Sensory Overload

by Andrea Mercier

I am a 35-year-old mother, who had seizures but they looked different than what my son has, they started at a different age. My son's father had epilepsy that looked strikingly similar to what my son has now. My son has GEFS Plus. My education background as a nursing student, and as a college student prepared me for what to see. My working background in nursing homes, childcare, and hospitals prepared me for an experience. What happened with me and my life journey confused me, stressed me out, and drove me into a state of working away from others. Before I was driven away, I learned the depth of the human soul by the encounters with those I spent my time around. My background prepared me for the journey with my son but not the hurdles or feelings and experiences that come as part of the course.

In my experience just when I find that one medicine worked for my son, then it seemed it didn't or the side effects outweighed the benefit of its use. Then I discovered Keto and things seemed somewhat better. Then he enters school and things begin to change… again. Of course lately a large percent of the news I hear from the school is negative… like a ton of bricks on your heart. And while those bricks are piled on my heart now, I know that soon they will scatter out and he will walk on them in self-triumph. But one thing that keeps me positive is the impact that the Ketogenic diet has on him. Lately though, I have not seen what the education professionals have been seeing within my son because I had my "parent" blinders on and I had adapted to caring for him and had no idea (I already used visuals, breaking things down in to steps, patience, positive guidance, coaching through struggles, self-education of other special needs children). I was so caught up in managing epilepsy and everything else in life I thought his quirks were normal. I had no idea he was on the spectrum... And so another journey begins. My life is a multifaceted journey with him now, one with new meaning, new purpose, and maybe even better news from more professionals that know how to handle children like him. With the new journey comes new knowledge and new routines and maybe some not so new education to me, new struggles, and new challenges. I will be patient, I will be strong, I will teach his father, and I will be there for him.

And all the while this is happening, I rediscover (I go through periods of denying this) that I am either a highly sensitive person and or I am an empath (musing... maybe I am on the spectrum too...). I discover that the reason I am so sensory avoidant is because all of what is around me is over stimulating. I feel the emotions of others, I feel machines, and I sense things beyond what a "normal" level of sensing is.
When I stand next to someone, I can feel if they have psychological pain, I can feel their emotions, I can sense the full spectrum of their feelings. It is all so very overwhelming for me and I think that is why my life's self-journey was so difficult, because I myself am so very different. I don't wish this way on anyone, especially if you want to fit in, it is very exhausting. Some might think it is a gift, and it can be, but even more it is probably the reason I had seizures as a teenager and young adult because of the overwhelming stress I was taking in and not understanding what was happening to me.

Now that I have re-entered the crowded workplace, I am immediately feeling everything around me, and can feel the pain of others. I can feel the synergy or lack of synergy in the environment. I can sense and feel a toxic work environment. If someone works next to me I can feel their pain, pleasure, sorrow, mourning, loss, love, happiness, jealousy, hatred, and many more emotions. I can tell when I am being lied to. I can tell when a person is using me to get information to talk about me by the way they talk to me, the way their eyes move. I can feel people's energy. Now you add in the amplified noise of machines running, cell phones, colors, auras, and smells. Not only can I sense this in people, but I sense it in animals, soil, food, and plants. As a child I wore all black, I covered myself and no one ever understood why I did this in 80 or 90 degree weather. Looking back I get why I did it now. I was trying to block out the world I was feeling. I now know I was meant to be a healer and messenger. I hope that my son does not have my blessed curse. I also know things ahead of time sometimes, but I cannot explain in a logical or rational way to a typical person how I know them, so I remain silent.

I think that is why I have always felt a strong connection with those on the spectrum and those with epilepsy because I empathize with the strong sensory component of it and I sometimes wonder if there is more to it. I feel their pain in the trapped world of their diagnosis.

I had to laugh at some of the psychological diagnoses in the past that people tried to give me. I am who I am and I do things because of who I am, but not because there is something wrong with me. My post-traumatic stress disorder diagnosis was merely a symptom of myself trying to merge into a life and the many adaptations I have made to survive in a neurotypical world. I have been through some awful traumatic stuff not to mention. When I had those severely traumatic experiences, a higher being came to me and brought light back into my life. Even before those traumatic experiences occurred, those beings spoke to me in another plane. People are drawn to me and they tell me too much and it can be overwhelming at times, but I enjoy helping them if I feel up to it and ready to help them.

So maybe this is too much but I just want to say that no matter what our children face, keep searching for the answer. Look for it everywhere, think outside the box, go outside the known, dig deep, keep good records, notice patterns, cherish the good days, have fun, recognize when you need to let go of life's demand and spend time with your child, and also take good care of yourself. You can take care of yourself. Take care of yourself so you can be the best mom or dad you can be for your child. If you are like me, find healthy ways to re-charge your battery.

Thanks for listening to my strange journey and reading my story. In high school they always said I would most likely work for psychic friends. At the time I was not taking the comments seriously. My hope is that my 4-year-old son is not experiencing the sensory overload that I do. My gut is telling me though that he has some of my traits and he is too young for me to comprehend how I am going to teach him about this, so I am glad that the educators are placing him in an environment that works with children who have sensory adapting needs to function.

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Andrea Mercier says, "Here you will find a story about a different kind of mother and her perspective to a son with epilepsy and recently ASD. This perspective is coming from a mom who has been through, seen, and experienced a lot in her life." She lives in Mankato with her son and his father and has been involved with EFMN since 2014. "What inspires me to express myself artistically is to help myself and possibly others conceptualize, realize, and understand the experiences they might be feeling and or encountering in the real world. I want them to feel that there are others like them," she says. Andrea also enjoys working in the soil, understanding the many processes of nature and drawing. "Most of my time is lovingly spent working with my son and helping him achieve, adapt, and master the skills necessary for a functional life in this world," she concludes.

Battles

by Tessa Palmer

In life you will struggle with battles both within you and outside. It might be you having a disability like epilepsy. It affects people with it in many different ways from having grand mal seizures to a feeling throughout your body. Whatever you deal with “today you are you that is truer than true. There is no one alive who is youer than you.” Dr. Sess. Remember you are never alone, there are others behind you and in front of you that are dealing with the same thing or can relate in the closest way. You will have good times and bad ones, just love being alive and cherish being with loved ones. There will even be times when you have to spend time in a hospital but it too will pass. You too will be strong and will brave the rough and difficult even the best ones. Through God we will find a way and everything will turn out all right.

Tessa Palmer is 20-years-old and has epilepsy and TSC. She was diagnosed when she was a couple weeks old. Tessa says, “I enjoy life and cherish the moments I get with my loved ones. Over the years, I accomplished two 5ks, a 10k, a triathlon and went on four separate mission trips throughout my high school career.”

When I Grow Up

by Cynthia Rapacz

When I grow up
When I grow up, I want to learn as much as I can.
When I grow up, I want to travel the world.
When I grow up, I want to live in another country.
When I grow up, I want to change people's lives.
When I have epilepsy, I want to drive a car.
When I have epilepsy, I want to have energy to see my friends.
When I have epilepsy, I want to go to the grocery store by myself.
When I have epilepsy, I want to run again.
When I have epilepsy, I want to clean my house without having a seizure.
When I have epilepsy, I want to cook up a storm.
When I have epilepsy, I want to write and do art again.
When I have epilepsy, I want my beautiful smile back.
When I have epilepsy, I wish my husband didn't have to worry about me so much.

Cynthia Rapacz has been involved with EFMN for two years and lives in a houseboat with her husband Brian and two dogs. She has an undergraduate degree in theatre, masters in writing and art and hopes to travel the world. "I feel that I'm unstoppable," says Cynthia. Although seizures have impacted how she produces art, she's taking the opportunity to examine new mediums like digital imaging.

Capturing History Through Photography

by Kevin Reed

I am an artist with the Epilepsy Foundation of Minnesota's Brainstorm art program. As an artist I take pride in photographing nature in Minnesota, Wisconsin and beyond. It's important to accurately document the art captured to tell the story behind my work. For example, I took a photograph for my first art submission called "Presidential Resemblance" in October 2009. This photo was taken 200 feet above the St. Croix River located in Interstate Park in Taylor Falls, Wisconsin. This rock formation called "The Old Man of the Dalles" dates back to the ice age a billion years ago.

The Dalles of the St. Croix River is a geologic wonder of Interstate Park Wisconsin's oldest state park. "The Old Man of the Dalles" is an unusual rock formation with striking sculpted profile. This makes it a top Midwest tourist destination for people who enjoy nature.

In October 2009 I took a fall boat cruise along the St Croix River. I was enjoying the fall colors, when I looked up and saw "The Old Man of the Dalles" on the cliff above the river. I positioned myself on the boat with my camera in hand and took the historic photo. This was a difficult shot because I had to aim my camera and take the photo while being still, only my finger could move and any slight move would ruin the shot so it was a one shot photo. After we got back to the dock I checked my camera to see if the photo was clear and there were no errors. It turned out to become a masterpiece that was a must to submit. Five months later, I submitted the photo in the EFMN Brainstorms collections. The philosophy behind our art program is to keep the art as a permanent fixture to educate people about Epilepsy.

Acquired Idiopathic Absence Epilepsy

by Chris Sauer

The adage… Circumstances beyond our control really do control us. Our "acquired" epilepsy journey is one of those circumstances. May 2013 was a challenging month. On a dark night coming home from work I didn't notice anything out of the ordinary as I drove through our sleepy town of Roberts, Wisconsin. As I was falling asleep my EMS pager went off, "United Fire you are needed in Roberts at the St. Croix Central Elementary School for a structure fire. This is your first page." I jumped straight out of bed and swore so loudly. Who would start the school on fire. At the time, I didn't realize the extent of it until later that morning. At 6 AM the phone rang – St. Croix Central Elementary is closed for the day. My daughter was not so happy about that. We spent the day talking about what had happened. We cried. The next morning facts started coming out from the fire investigators as to what had happened. Not one cent of good news. School was cancelled for the week until appropriate facilities could be found for the kids. What a way to end her year of 3rd grade. At least one good thing was that her favorite book was recovered from her classroom. Everything else was sent to the trash. After a week the kids headed to Panther Camp and learned a lot about ticks, homework and community support.

That summer Anna and a majority of the elementary school kids attended summer school. Uneventful and she was always full of energy. In August, the remodeled school was almost completed. At open house, we toured the facilities and Anna, like the rest of the kids, were ready to get back to school. After the visit we headed out camping for Labor Day weekend. It was quiet for the most part except Anna changed – something wasn't right. She was starting to hear voices. When the first week of school started, the voices stopped but she would zone in and out. By the third week of school something was not right. I called and made an appointment with her pediatrician and wanted her to have some tests done. At that time, I was an ICU/CCU RN at the oldest hospital in the state of Minnesota and I knew she needed some neurological and lab testing done. She was tested for many things, including ruling out Lyme disease (school fire history Panther Camp). We were sent to the MN Epilepsy Group.

We met with the staff and after her first EEG, the doctor says "She is having seizures." I almost wanted to scream at him "Duh!!" Working as an ICU/CCU/Neuro ICU RN, I knew what a really bad EEG looked like and a normal one. The scary thing was that she was having more seizures then we thought. So the medication regime started. The Keppra slowed the seizure activity down, the Depakote slowed it down but she still had ten seizures an hour. She was losing time, 100 seconds each hour of classroom time. We were tutoring her throughout, allowing her to play sports, and being her support. She took everything in stride. Kids are really resilient. December was the turn key month. Anna cried she was tired of being poked and prodded. That Christmas I had the best gift of all, my daughter would like a good long life. The MRI/MRA showed no brain abnormalities or tumors. So the new diagnosis for Anna was idiopathic absence epilepsy. Per Dr. Frost, kids are able to grow out of this form of epilepsy. For our family, this was the best Christmas present ever – Life.

February 2014 was the turning month for us. We finally found a medication that completely stopped the seizures. We are now 30 months seizure free! We got Anna involved in the activities of the Minnesota Epilepsy Foundation, from Camp Oz, to baseball games to the MN Gopher games. Her dad is so happy to have someone go with him to these. We also started on the journey of being teased, made fun of people not understanding what epilepsy is about. Anna is bright and smart. We helped her to gain the strength and courage to stand up for herself and others and show that she can do anything a "normal" person can do.

We know now that epilepsy is a diagnosis. Epilepsy is a brain disorder but… Epilepsy is not a death sentence. There is always hope. Taking away hope from a person… from a family is not good. On this journey, I found new friends. I found people that I could cry on their shoulder. I found people that said “Anna go for it. We are there for you.” But most importantly I found that faith, hope, love and forgiveness is the key to survival of any diagnosis. I had to have faith in my husband that he wasn’t going to leave us. I had to have faith in my sons that if our daughter had a grand mal seizure they would follow my emergency plan for her. I had to have faith in my colleagues at the ambulance service that they would do exactly what I had written even though I was not present for her care. I accepted hope from the MN Epilepsy Group that our daughter can outgrow this thing. Love from our faithful community, family and friends were always around to allow us to vent, support and cry. Forgiveness… This has been a hard journey for me. The individual that started the school fire only wanted the prescription drugs from the nurse’s office. In his rampage, he destroyed 1/3 of the school with an accelerant fire, stole electronics and stole the sense of our kids’ security at the elementary school. Panther Camp was a good experience for the kids. The Girl Scouts of America allowed our school district to rent this to finish the school year. The parents were awesome between a snowstorm and spring temperatures, a retired closed Girl Scout Camp was turned into our kids’ school home for the remainder of the year.

I forgive the young man that started the school fire. He has helped to create a young lady that represents her community and school with the qualities of compassion that we learn as adults. Finally, I have taken on the role as a friend and supporter of a young family who is on this journey of their son with epilepsy.

* * *

Epilogue: In summary, Anna is in 6th grade now at St. Croix Central Middle School. She is on student council, she sings and acts, she plays a cornet, she is a member of the SCC Cross Country team, and has one of the fastest girls times. She is getting A’s and has adjusted well. Anna is off medications and has had no adverse effects and epilepsy is a thing of the past.

Dory - - Jerry - - Sarah

by Sarah Schmidt

Have you ever met a fish? There is a fish that we meet in Finding Nemo. Her name is Dory. Dory has memory issues. At one point in the movie she plaintively says,

> "I just remember things better with you.
> It's there. I know it is, because when I look at you,
> I can feel it. I don't want to forget."

Dory's vulnerability is somehow endearing. I am not, however, a fictitious fish. My own struggle with memory issues hardly feels endearing. Dory's last sentence strikes my heart: "I don't want to forget." Seizures, medications, and side effects cause increasingly more of my brain to resemble Swiss cheese. More and more of the real me keeps falling into those holes. In its wake seeps a heaviness that is hard to describe. There are days when I feel as though I am collapsing inside.

Maybe Jerry understands my feelings. The second name in this title belongs to a courageous highly respected Minnesotan. Jerry deals with epilepsy on a daily basis. In his emotional televised resignation announcement, Jerry Kill made these remarks:

> "My mom asked if I was OK. I told her 'No'."
>
> "I don't have any more energy.
> If I don't (change my life), I may be a guy
> that doesn't think too good down the road.
> I want to be able to think."

Jerry gets it. That last sentence also went straight to my heart: "I want to be able to think." Many times I've told my husband that I wish he and I could trade brains for just one day. Imagine an entire day of being able to think and remember. I am not, however, able to switch brains. Even this brain now realizes the wisdom of another comment from Coach Kill.

> "I never listened to my doctors, but I am now
> for the sake of my family."

Both my general physician and my neurologist have suggested resources to help manage the stresses in my life. In some ways, their directives have gone unheeded. I'm listening now when they recommend brain healthy foods, relaxation techniques, counselors, exercising, cultivating friendships, and making myself a priority.

By this time next year, Dory will still be Dory. Jerry Kill will be living the next chapter in his life. And I, Sarah, will be an even better version of myself. Stay tuned.

The Window

by Courtney Walker

Through that closed window,
A little girl looked out…
Into a world,
That she was afraid to even learn about.

So she grabbed her mommy and daddy's hand,
And we pulled her close to see…
That this truly was a place,
That she could also be safe and free.

So she fought hard and strong through the eye patch,
And a glorious victory was had through the leg brace years.
As she would drop and tremble uncontrollably,
We would stoke her face and wipe away the tears & fears.

Then, one day she would walk …
And one day she would RUN.
Despite the limitations that were set for her by others,
She certainly wasn't done.

She excelled in every aspect of life and school,
Even lettering in managing her varsity football team
She began to dream bigger than the mountains,
And then started living her dreams.

So, together we set out onto a big adventure,
And opened that window that was closed so tight.
Scared? Yes… Unsure? Yes but we did it together…
We held hands and together we opened it…

Through that wide open window,
She would look out and she is now sure.
That this is certainly a world
THAT BELONGS TO HER!

◆

Courtney Walker is the mother of Tiana, who was diagnosed with epilepsy at one-years-old and is now 16. "Tiana may have been born with difficulties right from the beginning, however they have taught her to become the AMAZING young woman she is today. She is kind, thoughtful, and she does not take any day for granted," Courtney says. The Walker family lives in Houston and has been involved in EFMN for approximately ten years.

Living with Hope

by Christine Woll

Isn’t life interesting? I think about that as I am writing. I write for specific reasons. I write because my road in life has been a bit rocky. I write because I have learned to live with hope. I write because I want each of you to live with hope.

When I say my road has been a bit rocky, this is what I mean. I was diagnosed with epilepsy at the age of 18 months. For years I would have 50-100 seizures a day. I wore a helmet with a face guard for 16 years to protect myself from the violent and unpredictable falls. In spite of the helmet, I have broken my nose several times. I have broken my jaw, my arm, and have chipped or lost several teeth. I lost count of how many stitches I have had. I have collectively spent months in different hospitals. At 12, I had brain surgery with ¼ of my brain being removed.

At 15, I had a VNS implanted. This is a Vagal Nerve Stimulator. I have a battery pack in my chest and a wire hooked to my vagal nerve. The VNS has been called the “pacemaker for the brain.” At 16, I threw away my helmet and began experiencing many days without seizures. I continue to seize every night as I am falling asleep – or early in the morning when I am coming out of a deep sleep. As of today, I have never had a completely seizure free day.

I do not have a driver’s license. I do experience some learning challenges. There are many things in this world I don’t have – or can’t do. However, I have come to realize that there is so much more that I DO have, and so very much I CAN DO.

Michael J. Fox, actor, lives with severe Parkinson’s disease. He has written two books about his life and how to be positive. He says the “the holes in his life” make him a stronger and better person. I like that. I think the “holes” in my life have made me a better person.

Now I ask you: What is your helmet? Maybe you don’t have seizures, but maybe something else sets you apart. What makes you different from the people in your life? What is your helmet? What is getting in the way of being the best that you can be?

Let me share some of the things I have learned while under the helmet. One, I learned that my enemy was not the seizure. My biggest enemy was the IGNORANCE of others toward the seizures. There was lots of teasing when I was in school. There were a lot of rude, mean and inconsiderate comments that were aimed at me. Well, I just had to chalk it up to people’s ignorance. Maybe even their fear. Maybe they were afraid of the helmet. Maybe they were scared because they thought I wasn’t “normal.” So my goal became educating others about seizures and to show them that people with epilepsy are still people.

Two, I learned that I could be as good as I was willing to think I could be. No other person could define whom I was going to be – helmet or no helmet. I was in control of my life and I was going to be the best that I could be. Again, my goal was to educate others about seizures and to show them that people with epilepsy are still people.

Three, I learned that I did not want to get stuck in the “victim zone.” I did not want the “poor me” thing going on. I refused to be who some people thought I was – the weird girl in the helmet. I wanted to be so much more!

I did not have a lot of friends in high school. It was a lonely time in my life. I did not have any dates. I did not have much of a social life. Maybe some of you know exactly what I am talking about.

No, I am not going to be the first woman President of the United States. No, I am never going to be a rocket scientist. No, I was never a straight A student. In fact, I had to work long and hard to get through school. And THAT is my reality.

As for HOPE? Well, I live with a lot of that! I hope for a life without nighttime seizures. I hope to get married. I hope to have a job as a motivational speaker and travel around sharing my life story.

You need to know something about me. I DO NOT want to have seizures. If I had a choice, this is not the life I would choose. But, this IS my life. This is my reality. And I will live it to the best of my ability.

Sure, there are things I can't do, but what I can do is ask for help. I need my friends and family for support. And, as I have been helped, I have learned what it really takes to help someone else. I am a very good friend and I am proud of that. I know I can help when many others can't. I "get it" when others don't. I can listen and really hear. I understand when life is not always as we had wanted or we had planned.

I also know pity is harmful. Pity actually hurts people. I can help someone in personal pain because I can feel it, I understand it, I have been there. I don't need to feel sorry for them, I need to support them. Just standing around feeling sorry will not get us anywhere. Listening, feeling, making a plan to move forward… THAT WORKS!

I have come to realize that when it comes to seizure disorders, I am somewhat of an expert. Now I don't know all the medical terms. But, I DO know about LIVING with seizures, about dealing with the emotional end of them. I know more about that than most doctors will ever know!

Because of your own life journey, your pain, your disappointments, think about how much you have learned and how it has changed you. You are probably an expert in something I know nothing about.

I get tired. I get sad. I get worn out. Then I work hard at building myself up again. This all comes with the challenges many of us face each day.

So my message for you is this: TRY TO BE STRONG. Be as strong as you can be right now on your journey. Personal strength will grow. Sometimes it grows very slowly, but it WILL grow through the passing days/months/years. I have had over 30 years to grow stronger – and I am not done growing yet! Don't let anyone ever convince you that you are not strong. Every one of us has the strength to survive and do great things! Feed the seeds of strength and let them grow!

TRY TO BE POSITIVE. Be as positive as you are able to be with your situation right now. WE cannot necessarily change our situation, but we can control our attitude toward that situation. That, too, takes time. Time to accept life as it is. I have had to practice that for many, many years. It is hard to rush it! Going negative is not going to get me where I want to go. All I really have to do is get through today – just one day at a time. I know I can do that! One day at a time.

TRY TO BE HOPEFUL. Consider the possibilities. Understand your restrictions. You may be surprised by what starts coming your way!
And lastly, I want to remind you to BE COURAGEOUS. This life is tough and it takes courage to get through each and every day. I would like to share a saying that speaks volumes to me about the life I was given. I hope

it will do the same for you. “Courage doesn’t always roar. Sometimes it is the quiet voice at the end of the day saying, ‘I will try again tomorrow.’”(Mary Anne Radmacher).

My wish for each of you is that regardless of what this day brings, regardless of what pain or sorrow or loss you are feeling, you will always be willing to try again.

Do not let someone else define who you are or what you want to be. Do not give any one else that much power in your life. Take control. Make a plan. Work hard. Be courageous. AMAZE EVERYONE – even yourself!

I love the Nike ad: JUST DO IT. And look at me. 16 years under a helmet, and here I am writing about my life. I am doing it!

Muster up enough courage and strength to try again tomorrow and the next day… and the next! I think each of us can do that. Just DO IT! Go out and make your life the very best it can be. Don’t just talk it – DO it.

And, like Michael J. Fox, recognize that it might be the holes in your life that are the very things that make you better.

Now, let me be the first to remind you: GO OUT AND MAKE IT HAPPEN!

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Christine Woll grew up in Eden Prairie with her parents and one sister. She graduated from Eden Prairie High School and studied Early Childhood Education at Hennepin Technical College. Christine lives in an apartment in Eden Prairie with her four year-old-dog, "Pippa.” She says, “I am a nanny for two remarkable boys (Jack 4 and Sam 2) who also happen to be my nephews and my Godchildren. I love walks to Starbucks, movies, the color pink and long talks with good friends. I am active in my church including teaching Confirmation. I always enjoy speaking to different groups about my life and my faith. My goal is to write a book and to do more motivational speaking.”

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