Epilogues

2007

A Writing Contest
Displaying the Talents
of People Affected by Seizures

EPILEPSY
FOUNDATION®
MINNESOTA

1600 University Avenue West, Suite 300
Saint Paul, Minnesota 55104
(800) 779-0777 • (651) 287-2300
www.efm.org

Our Mission

The Epilepsy Foundation of Minnesota will ensure
that people with seizures are able to participate in all life experiences,
and will prevent, control, and cure epilepsy
through services, education, advocacy, and research.

Educate · Connect · Empower

Introduction

Dear Epilogues Reader,

Welcome to the world of creative writing. This book of written works (poetry and prose) was compiled by the Epilepsy Foundation of Minnesota for the enjoyment and nourishment of the authors and their audiences. These written works were created by authors living with epilepsy or with a close relationship to a person with this disorder. The Epilogues Writing Contest Committee of EFM received the works during September and October of 2007.

The Epilogues contest was intended to provide a creative outlet for personal expression and to raise awareness of the disorder of epilepsy to the public. To give greater understanding and meaning to the works, the background information submitted by each author is included.

This first annual Epilogues contest grouped all written works submitted into three classes: **Judges' Choice**, **Superior**, and **Meritorious**. Additional author recognition includes a copy of this book, a few mementos, and possibly public readings or further publication on behalf of EFM.

Finally, congratulations to each author for creating their written work and then submitting it to EFM. They are the contest heroes, and we wish them well.

The Epilogues Committee

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Author Background

Elizabeth Jo Block-Kloss
age 50, person with epilepsy

1) What inspired my written work?
I'm working on a book about my dad and this is the start of the book. I was really close to my dad and had a hard time when he died. My dad was on board a Naval PBY and spotted the Archimede in the South Atlantic. With the help of two other planes, they sunk the sub. The Archimede was an Italian sub and it was fighting with the Germans in the 1940s. My dad received the Gold Star and the Air Medal from Eleanor Roosevelt at the Naval Air Base at Panama Canal a year later. The poems that I'm entering are about driving in a car – I'm on the road a lot with my job, seven days a week, and within a day or so, I came up with this rhyming story – and a story about mice at my sister's cabin on Peavey Lake in Minnesota.

2) How have seizures (mine or others') affected my life and my creativity?
It's hard to answer this question because I haven't had a seizure since June of 1998. I came close to having one a few days ago, but I asked for some Divine Interventions to keep me from having one. I asked my dad for some help and told him, "I can't afford to have a seizure right now, please stop this from happening." My dad died when I was seventeen years old. I felt fine after that and went on with my work. I just started writing different things not too long ago and recently won the Directors Award for lyrics to something that could be made into a song. It's entitled, "I'm taking your man, but I'm giving you life," and it's a quote from a woman that took my husband away from me. I entered the contest in Nashville, TN and the lyrics could go on to win the grand prize worth $1,500.

3) What is my seizure diagnosis or seizure frequency?
I have Grand Mal seizures, but they are medically controlled, and the last one that I had was June of 1998. I tried to end my life by overdosing on my medication for depression after my husband divorced me and then left me. I'm able to drive a car right now and I'm working three part-time jobs. I'm also working on books and lyrics as well.

4) Other information that describes me...
I'm 50 years old, divorced, and have a daughter, who is also gifted with talents. My daughter can paint drawings from regular pictures, make tie skirts, swing poi, with fire or without fire, and many other things. I have some lyrics that could be made into songs, and I'm also working on children's books and a book about my dad. I live in Hopkins, and I have a cat that shares my condo with me, and his name is Fonz.

The Auto Ballet

by Elizabeth Jo Block-Kloss

We drive our cars
to work everyday
when all we want
to do is play

Once on the highway
we either drive far
or we drive close
sometimes, just to be in our car

On the highway a
limo drives on
as we all holler out
“Please pass the grey poupon”

Cars pass on the left
then turn back into the right
as we pray to God
we make it home each night

A semi tries to pass
we give the driver the right
for, we just can't win
against something not light

When it's summer
we complain of the heat
that's when our pants
cling to the seat

When it's winter
we complain of the ice
and the cold
wouldn't it be great, if it was just rice

At the gas pump
we complain of the price
wouldn't it be swell
if it was always underprice

We get back on the road
and some people drive fast
or they drive too slow
while other people, just fly-past

We get on the cloverleaf
we start up high
then we go below
“Please, hurry, I'm late for my mother's pie”

On another cloverleaf
we start out low

and then we go up high
“Please, for Heaven's sake, don't go so slow”

When we drive in rush hour
we need to be careful, but fast
because, we really don't
want to be last

Some people cut in front
then holler and swear
oh Lord, this driving
just isn't fair

Watch out for drivers talking
on their mobile cell
they aren't looking
for, they're busy with mobile Ma Bell

There are people on a mobile PC
who look down when they drive
and don't pay attention
please make it home alive

If you should come across a
school bus with its stop sign out
you'll just have to stop your
car and pout

If the emergency lights
start flashing
you'll need to pull to the side
so there's no more crashing

The Auto Ballet is fun
on a very steep hill
for your tummy feels funny
like you've just taken a pill

There are others, who think
their cars are a plane to fly
God ends up taking them
up to the sky

Sometimes we drive
on roads with lumps
our poor cars just
can't take those bumps

We thank God for making
it home each night
only to do it again
when it's daylight

So, if you're wondering
“What's the Auto Ballet?”
Hop in your car and
drive the highway!!!!

The Mouse House

by Elizabeth Jo Block-Kloss

There's a cabin
on Peavey Lake
where the mice live-in
and leave us a little keepsake

There are three small mice
one wearing a red coat
which looks so nice
and causes all the mice to gloat

The other wears a blue one
which looks real cute
this mouse has a lot of fun
he plays the flute

The third mouse
wears green
he's no louse
he's made the scene

All three mice walk
on two legs, not four
they all talk
as they walk out the door

For, humans own
the cabin, not mice
it was well-known
they shared it, that's nice

But, in come the family, Clouse
as they walk in the cabin
all the mice run from the house
a Clouse says, "This cabin looks Lived-in"

A Clouse drinks from a plastic cup
while resting before they clean
the humans bring in a new pup
all the mice have now seen

In the morning in a jiffy
the youngest Clouse
had to use the moving biffy
later was found a very flat mouse

A couple days go by
and the Clouses leave
the mice see a small pie
and they get a reprieve

The mouse in red
says, "Let's have a party,

before we go to bed"
"Spread the news, now don't be tardy"

The three mice that walk on two legs
had way too much pie, and got sick
they felt like large pegs
and weighed like a brick

The mouse wearing blue
ate way too much pie
he got sick with the flu
the mice were afraid he was going to die

The mouse wearing green
was also too full
his coat needed a dry-clean
because it got a bellyfull

The mouse in red
ate so much pie
he was filled with dread
he also thought he was going to the sky

The three mice had to end the party
and told everyone to leave
all the mice felt hearty
but instead they were going to grieve

For the party was over
everyone was plum full
they were going to walk in the clover
as they gave the door a good pull

The mice that walk on four
went home for the night
as they walked out the door
it was such a funny sight

The three mice that walk on two legs
were so full and tired
one had a fat belly, that sags
two were so wired

"Let’s do this again,
when we have some more food"
One said, "Amen"
The other wasn't in the mood

So, if you're a funny human card
and you know the family, Clouse
be prepared to work real hard
when you go to The Mouse House

Author Background

Francine Coyan

age 54, person with epilepsy

1) What inspired my written work?
Poetry has long been a method of expression. When all else is crumbling around you, the need to convey that developed into a love, a need for poetic expression. My poetry's lure is its passion, whether it be sorrow, anger, or desire, the intensity of the emotion becomes entangled in my verse.

Inspiration is hard to nail down – fears of future and nightmares that haunted my past dreams. I think all of this contributed to a poem. "As Evening Falls" was created in 2003 when I had been looking for work as non-profit cut staff. I could add grief at no longer working for organization I admired and the fear of the unknown.

2) How have seizures (mine or others') affected my life and my creativity?
It has been a battle that affects employment, transportation, and lifestyle to a certain degree.

3) What is my seizure diagnosis or seizure frequency?
My first seizure happened when I was 28 years old. Apparently, a birth defect did not make its appearance until growing into adulthood. Now that CRT and MRI machines are available, they can know much more, and mine will require more medication in the future. For now, I have been seizure-free since 2003 and can stay that way with rest, watching out for stress, and looking for telltale signs when necessary.

4) Other information that describes me...
A five-foot, middle-aged brunette, born in Fergus Falls, MN. After enduring a traumatic childhood, I spent my free time in our school's art department painting. While visiting South Carolina, I was first introduced to contemporary poetry and was entranced. I began to create poetry with young southern poets guiding my attempts. Currently, I am with C.H. Robinson, an international commercial shipping brokerage. A great crew of staff headed by an exceptional manager – going to work puts a smile to the day. I am married and happy with my career. I can take the time now to work on other goals, publishing work, artistic, and poetic.

As Evening Falls

by Francine Coyan

As evening falls
So does the silence
Completing the isolation
From the living world
The plunge into silence
A hush that entombs me,
Unleashing a nightly struggle
In regaining some of the composure
That is necessary to endure.

Here is the moment
When madness seeks its entry
It hovers like a deadly vapor
Kept at bay by day
Pushed back into the corners
Its intensity replenished
Upon the descent of dusk
Seeking a flaw
It may penetrate

I feel its caress
As fragments of memories
Take flight through my dreams
Faster and faster memories flash
The night bursting with images
Of the past, nightmares of self doubt
Until serenity is sought after
Drawing my thoughts to safer venues
Until day returns

Earth Bound

by Francine Coyan

Earth Bound am I
But my true habitat
Are the summer’s stars
Revealed in the land of the Trinity,
I have traversed the universe
Yet, on Earth I remain until Doomsday
Until Christ returns in Glory

From the fruits of fruits, upon the world’s birth
From the soil’s essence, I was formed
Man is made, remade and made again
I was a Beast spellbound in a foothill
A serpent in a lake, a star, a lance in Arthur’s grasp
I was a flame in fire, kindling in a Beltane blaze,
Burned, yet not consumed,

A candle in a monk’s hand
A gentle light that glows in the night
I have wandered
I have called upon God’s forgiveness
To deliver me
Righteousness my only weapon
The Savior’s courage ablaze within my breast
Blood lust no match for his passion.

Realization

by Francine Coyan

Sitting here, passing time
While you’re away
It is suddenly clear the intimacy shared
The level of melancholy felt
In an evening’s time of absence
Has revealed the depth of ties
The strength of the bonds between us
Without you, there is a gap, a breach
The sense of a link missing so vital
Its loss is catastrophic
But, not from doubt or fear,
But, simply from missing your presence
Like chicken soup without the broth
No longer whole, life is truly lacking
Your closeness makes life complete.

Author Background

Lynn Deatherage

age 48, person with epilepsy

1) What inspired my written work?
I wrote this for a friend who wrote a book of poems. She and a son died in 1980.

2) How have seizures (mine or others') affected my life and my creativity?
My seizures affect my ability to work and go to college in order to find a career.

3) What is my seizure diagnosis or seizure frequency?
I have generalized and complex partial seizures.

Don’t Cry

by Lynn Deatherage

The time has come for me to leave-
God’s calling me.
Don’t cry
I’ve fulfilled my destiny on earth,
Which you have yet to do.
There’s things to be done
And people still need you.

We’ve given each other memories -
Hold on to them.
Don’t dwell on what could
Or should have been.
Remember I will always be where you are,
I gave you a part of me to keep
My Heart

Duty Calls
by Lynn Deatherage

Duty Calls
Once again my love is left behind,
But as sure as God is with me,
So, too, my love, are you.

Temptation may
In leaps and bounds
Shine bright before my eyes
Though quickly turns to ugliness
When fails to pierce my heart.

In trust that God shant let me fall,
In knowledge you, wait true,
I’ll fear no evil on the path
That leads me way from you.

Them as the moon shines brightly,
Through our lips be miles apart,
I’ll dream a kiss to you, my love,
To land upon your heart.

Author Background

Sarah DuCloux-Potter

age 28, person with epilepsy

1) What inspired my written work?
I wrote “Swallowing the Rainbow” when I was really frustrated because they kept adding pills and I kept having seizures. The pills were all different colors and I was nauseated a lot…along with some other side effects. After a while it really felt like I was ‘swallowing a rainbow’- a big nasty rainbow. Writing has always helped me get out the emotions I’m feeling. (By the way - my day to at least ‘like’ the rainbow is coming!)

“Stop” is really just about having seizures in general. The before (aura), the during (I don’t remember) and the after (I don’t want to hear about it). It helped me sort out in my mind what the heck was going on. And even though I’m still not comfortable hearing about what happened during my seizures - I don’t cover my ears any more.

2) How have seizures (mine or others’) affected my life and my creativity?
I’ve always written and drawn, but like probably most people, everything picks up when I’m upset or frustrated or angry. Having something that I can’t control makes me feel really mad, really lost, really frustrated. Writing gives me an outlet for a lot of those feelings and has helped me put it into perspective - that epilepsy doesn’t define me. It may be a teensy piece of me, a piece I have to be aware of, but really - it doesn’t control me. I control me. I just happen to have seizures every once and awhile. I ‘hand over the steering wheel’ in my brain to the backseat driver, I guess. I’m still in control of everything else about me.

3) What is my seizure diagnosis or seizure frequency?
Usually my seizures are in my sleep. I’ve had some in the daytime (very rare). Right now I think the medicines I’m on are working really well! Right now I’m only having about one seizure a month - and I even went a month without any.

4) Other information that describes me...
I have an awesome husband who teaches preschool and a really cool fourth grade daughter who is an amazing writer. We have a cat and two elderly guinea pigs. I work full time helping with research grants, running a website, and training people in HIPAA and data security. I’m proud of where my life is. I thought an epilepsy diagnosis would take the things I loved away, but it hasn’t. I just had to tweak a few things that I was doing and life kept marching on - ups and downs included.

Swallowing the Rainbow
by Sarah DuCloux-Potter

On my lap a rainbow -
sounds lovely
I'm sure.
Colorful and
pretty -
full of mythical
lure.
In my hand an ocean.
It sounds just fine,
I bet.
Sparkling and
pleasing -
the light and water
duet.
I'm not quite so happy.
In fact, I'm quite upset.
This task is quite
unpleasant.
You haven't heard it
yet.
I have to swallow
the rainbow.
Not pretty at all,
really.
I have to eat the
colors -
they all swirl up
in me.
I was told the many
hues would
chase away my storms,
but here I sit just waiting
for this rainbow
to perform.
I want to like
the rainbow.
I want to love
its rays.
I want to believe
the rainbow
will give me
better days.
When the lightning
hits though,
and I land
on the floor,

I want to throw
the rainbow
immediately out the
door.
When I see its colors,
my stomach starts
to churn.
My eyebrows bend
together;
my eyeballs start to
burn.
Still I sit and swallow -
because one day
I know,
the rainbow will
come through for me,
it will be a pretty
show.
I just grit my teeth
and bear it,
and hope that day is
soon.
Eventually, when the
storms are over,
I'll soar beyond
the moon.
I'll honk the horn
and steer my life -
I can already
feel the breeze.
The rainbow
just needs order,
come on rainbow -
Please!
Once again I'll
love the rainbow.
I look forward to
that day.
So for now I'll
sit and do my job -
willing my rainbow to
blow the storms
away.

Stop
by Sarah DuCloux-Potter

It's loud.
My ears, I think
are going to explode.
I want to tell the world to shut up
but I'm not sure how
and then I fall.
But I don't -
just my stomach does
as if I just dove off of the
highest mountain.
All while the world is
still screaming -
still amplified.
I think I am covering my ears, but
I don't know for sure.
And then it is all done.
At least it is for me.
Because I don't remember.
I don't remember.
Wait, I don't remember.
Why am I on the floor
and why are you looking at me?
Who CARES what two+two is
when I want to take a nap?
When I'm so
tired.
You make me mad
when you
keep asking me these
questions that I
don't understand.
I'm confused.
Please, just let me sleep.
I think I slept too long.
How long did I sleep?
Now I will be late.
Stop.
I don't want to hear you.
I don't want you to tell me.
I don't want to know.
Please don't tell me that it
happened again.
I cover my ears,
even though this time
the world isn't loud at all.

Author Background

Angela Halverson
age 35, mom

1) What inspired my written work?
My son and our journey together inspired this work. Being his Mom is a roller coaster ride and life seems to be full of both joys and sorrows that I need to channel somewhere. I don't consider myself to be all that creative. When I write, I just let it all out - whatever's in there, good or bad, it just comes pouring out.

2) How have seizures (mine or others') affected my life and my creativity?
My son's seizures have affected my life in many ways – I could write endlessly about this – but basically we literally lived the first 3 years of Evan's life with a bag packed by the door in case we had to call 911 or go to the ER. Evan's seizures have been just a part of the roller coaster ride. He has had periods of being seizure free and periods of 150 seizures a day. And when they are bad, they affect nearly every aspect of our lives. But we try very hard to not let them dictate what we do or don't do. We try and treat Evan like any other kid. Things have gotten a little better over the years. Evan is still seizuring 10-20 times a day, but we are handling it at home better now. I worry constantly, every single day.

3) What is my seizure diagnosis or seizure frequency?
Evan's seizure diagnosis is Lennox Gastaut Syndrome. He has several different types of seizures and has about 10 to 20 a day right now. He has had periods of time when he had 150 a day and he once went seizures free for 8 or 9 glorious months.

4) Other information that describes me...
After Evan was born, I became a stay at home mom. I like to read and write. In all I do, I am a Mom first - to Evan and also to our typically developing daughter, Ellie Mae, who is 15 months old. Seeing her grow and change each day is both exhilarating and sad, because it really shines a light on what we did not get to see Evan do. I am a wife of 10 years to Jeremy, the best Daddy in the whole world. I also work a day or two a week at a little shop in Spring Grove called The Back Porch. I like to read, write, spend time with my parents, "putter" around the house, and take care of my little family.

For Evan From Your Mum

by Angela Halverson

My sweet boy.
My always and forever baby.
So helpless and defenseless and sweet and funny.
You make me laugh
As my heart aches with love for you.

I fiercely wage battle each day for you.
Wanting only the best and
Not always knowing what that is.
Most days defeated and deflated and dog tired.
But still I battle on.
Knowing there is no end except the end.
Always fearing the end will come before it’s over.
Before I’m ready.

My head asks, “Is it really worth it?”
And my heart answers,
“Yes, hold him and love him because that’s what he needs.
The rest will fall into place. Have faith.”
And so it goes.
Day after day.
Some better than others
But always putting one foot in front of the other.
Even if I have to say it out loud.

No regrets now.
No “what ifs” or “only ifs” anymore.
This is it and it’s ok.
So much anger and hurt now turned to
Forgiveness and acceptance and thankfulness.
It’s about what we have instead of what we don’t.
It’s the appreciation of life
When other parents suffer great loss.

We do have what we’ve always dreamed of.
We just needed time to realize it.

Author Background

Jerry Hartlaub
age 67, father

1) What inspired my written work?
My adult son inspired this poem. He is an accomplished, gentle man. I am very proud of him. .

2) How have seizures (mine or others') affected my life and my creativity?
As a child, my son underwent a craniotomy to remove a tumor. The outcome was great and he grew to be a normal adult. He earned a PhD, is happily married, and teaches at a local college.

Recently, while changing his medication under a doctor's guidance, he experienced significant side effect complications, although no additional seizure activity. The complications were very challenging and disappointing. Over the past year my son has courageously overcome the major side effects while living his life very effectively. I have been an anxious observer, listener, and advisor. He has carried the burden with dignity, and I am impressed and humbled.

3) What is my seizure diagnosis or seizure frequency?
While in college he experienced his first seizure. Since that time (about 20 years) he has pressed forward with his life while using meds for excellent seizure control.

4) Other information that describes me...
When I considered entering this writing contest, I was again mindful of how proud I am of my son. This contest has provided an avenue for me to express my feelings.

Proud Father

by Jerry Hartlaub

A young man brimming with promise,
A rushing river has no boundaries.
Renaissance man, with gentle wit,
Not bogged in sand of a self styled pit.

Misguided synapses, prancing out of tune,
A burden not cared for, then likely a swoon.
Walking a med tight rope, outstretched arms,
An unhappy drummer, makes some days a bummer.

Whiz kid has laid a plan,
    Stress up, lie down.
    Bones down, weights up.
    Caffeine down, veggies up.
    Alcohol down, water up.
    Pop down, milk up.
    Feeling down, climb up.
    Friend down, listen up.

At the last curtain call, they'll play a neat tune,
All around him in life, felt good in his room.
Plying the high ground, there's no higher call,
He's moving about, mountainous tall.

I'm announcing to all, these happy tales,
Amid body trials, he's tough as nails.
Pleased to know him, so ring a bell,
He's my son, I'm proud to tell.

Author Background

Lorna Knight
age 37, mom

1) What inspired my written work?
Seeing my daughter deal with epilepsy every day.

2) What is my seizure diagnosis or seizure frequency?
She has partial onset seizures: focal seizures, complex partial seizures, and generalized tonic-clonic seizures.

Living with Epilepsy

by Lorna Knight

Living with someone who has Epilepsy has its ups and downs,
    Hoping someday soon there will be more smiles than frowns.
Changing medicines since six years old,
    Hopefully this one works, we're always told.
Now she's twelve, taking three different meds. Three times a day,
    But to get better, it's the only way.
This has been her worst year yet,
    Switching doctors was our best bet.
She feels sick every day,
    But she will tell you, "I'm Okay!"
Walking a lot, running, sports, biking, and anything with motion and more things that are fun,
    It gives her seizures, so she can do none.
She feels she's lost a few good friends along the way,
    They are active and into sports, none of which she can play.
Seizure free is our dream,
    And of course being able to play on a team.
She likes to draw, do crafts, play games and be outside,
    Sometimes she overdoes it, but at least she tried.
We still have fun and do lots of things,
    As we wait to see what tomorrow brings.
Going up North to her Grandparents' place,
    Always puts a big smile on her face.
She's smart, kind, happy and has a great sense of humor too!
    Those who know her will tell you it's true!
Epilepsy is "Annoying and stupid" are her exact words,
    And at times I agree it's for the birds!
It will get better someday I'm sure,
    And all the bad will become a blur.
We look on the bright side and hope for the best,
    To have her in our lives – we are blessed!

Author Background

Tamerra Levi
age 11, person with epilepsy

1) What inspired my written work?
One night I was laying in bed and outside there was a thunderstorm. I thought about what people had told me about what thunder, lighting, and rain meant. I knew that it was not true so I grabbed a piece of paper and wrote down what I thought each thing meant. When I finished I transformed it into a poem and the storm ended. I said thank you to God for bringing the rain so I could write this poem.

2) How have seizures (mine or others') affected my life and my creativity?
Seizures have not really changed my life. I don't let them, I have continued to do all the things I did before my seizures started.

3) What is my seizure diagnosis or seizure frequency?
I have simple partial seizures. I haven't had a seizure in two years, but I continue to take medication.

4) Other information that describes me...
I am in 6th grade this year. I love to play soccer and basketball. I love to read books of all kinds. I like to write poems, my friends and I wrote a play this summer, and I am starting a novel.

Have You Seen?

by Tamerra Levi

Have you seen lightning the way it flashes brightly?
That is God’s mighty power.
Have you heard thunder the way it rumbles loudly?
That is God’s happy laughter.
Have you seen rain the way it drips down your cheek?
That is God’s tear of joy.

Author Background

Roxanne Olson
age 32, mom

1) What inspired my written work?
My inspiration comes from my son. He is our shining star.

2) How have seizures (mine or others') affected my life and my creativity?
When he was diagnosed with a seizure disorder, we thought our life was going to crash. We did not realize that this was not something to fear or run away from. This is our son and the disease is no disease at all but a hurdle for us to challenge. Our son has learned that epilepsy is not a fear but a blessing. Many people do not know what is wrong with him and this is something we know we can deal with and work through no matter how long this is with us.

3) What is my seizure diagnosis or seizure frequency?
My son was diagnosed with partial epilepsy in June 2006. His seizures affect his left side of his body. He is unable to move or speak for a while after he has these partial seizures. Sometimes he knows he cannot speak well after a seizure but other times it seems as if he does not know what just took place and tries to pick up where he left off, but the talking will confuse him and he does not understand what has happened.

4) Other information that describes me...
In 1996 we wanted to have a son. We already had our daughter and really wanted to include a son in our lives. He was such an interesting little boy growing up through the years. He shocked us with his ability to excel in most anything he tried. We were so proud of him for everything he did until the one day we found out he had epilepsy. On that day we thought we lost him and what his life would be, but instead, we gained our son and a shining star. I find it beautiful to say shining star because when I look into the sky on a clear blue night, I think of my son on every star I see that night. He is a joy in our lives and being epileptic only makes him more interesting and a bigger blessing to us all. Thank you for all of your help and support. Your foundation has helped us see that he is just like everyone out there. He is not a special needs child, he is not handicapped. He is as special as all children are to their parents. As the author, this is what describes me: I am the luckiest mother in the world and nothing or no one could ever change that.

My Son, Just Like You and Me

by Roxanne Olson

A decade ago, I gave birth to a son.
A bouncing baby boy, ready to run.
From sitting, to crawling, to learning to walk.
He grew so fast and began to talk.

Five years passed and he started school.
He was excited and thought it was cool.
To make new friends and ride a bus.
He loved it all without a fuss.

As four more years passed and he turned nine,
All seemed well, all seemed fine.
Then one day he was playing a game.
Something happened, something was not the same.
He stood so still and started to shake.
This was real, this was not fake.
Fear had taken us over, as this was so real.
Our minds were confused; we didn't know what to feel.

Four months passed from that one day.
We dismissed what we saw, people may say.
But as our day began at the store,
My son turned and looked at the door.
Stiff on his left side, unable to show,
Mom, I have a problem, don't you know.
I cannot move, I cannot walk,
I cannot feel, I cannot talk.
I need your help, but cannot say,
Let's see the doctor, let's go today.
To the emergency room we went.
But they did not know, not even a hint.

A week had passed as we went for a test.
We hoped all was well, we hoped for the best.
The doctor came in with something to see.
He said, I diagnosed your son with epilepsy.
My heart sank as I became ill.
I felt like a rollercoaster going downhill.
Questions load and unload as fast as they came.
This had hit me hard, this was no game.

We chose to medicate and take it slow.
What his life would be, we did not know.
We isolated him from pools and all his sports.
Being with friends and even building forts.
This epilepsy name had us in a spot.
Scared he will seize or get hurt a lot.

Until we learned, we did not know,
Life will go on like a present with a bow.

Epilepsy is not what you are but how you see,
The world before you and how you view you and me.
Without this title, he is just like you.
He plays and lives like all of us do.
He is smart and gifted for a child the age of ten.
He runs and jumps, his minds wide open.
He learns and grows just like you and I.
He is no different than the normal little guy.

Epilepsy has changed our lives from here on out.
It taught us what our son is all about.
Smiles, laughter, love and running too.
He's full of childhood as we all once knew.
We are no longer afraid of what comes now.
We will face our fears and learn to know how.
We will face new and unfamiliar trails,
With our head held high, traveling miles.
No place is too far, no condition too deep.
The love for our son is ours to keep.

Author Background

Xandi Olson

age 15, person with epilepsy

1) What inspired my written work?
I wrote this poem as an assignment for English class. When we got the notice about the Epilogues contest, I decided to use it to enter.

2) How have seizures (mine or others') affected my life and my creativity?
I am a sophomore at Mahnomen Public School. I have had seizures since I was 6 months old. As I say in the poem, this is how I feel about my seizures. At 16, life seems terrible with seizures.

3) What is my seizure diagnosis or seizure frequency?
I am on 3 meds for seizures, plus I have asthma and allergies! Until the last med change, I was having 2 to 3 seizures a month – but in the last 2 months, I have not had any!

4) Other information that describes me...
My father John and older brother Jonathan both have seizures. Mine and my father's are intractable epilepsy – Jonathan has Lennox Gastaut. So I have a background/history of seizures.

My Life

by Xandi Olson

My Life
SEIZURES
Scary, often embarrassing,
Auras, headaches, tremors, vision,
Meds, too many, AWFUL side-effects,
Miss school, Doctors, can’t drive, no friends,
Protective family, watchful PCAs,
This is MY LIFE
Living with
Seizures

Author Background

Sarah Schmidt
age 54, person with epilepsy

1) What inspired my written work?
I wrote this for two reasons. I wanted to put into words the emotions of a seizure. I also wanted to tell my husband how inexpressibly grateful I am to have him in my life.

A seizure is difficult to describe. It simply happens no matter how much one may try to stay in the conscious world. A seizure takes me to a place where – for a while – I cannot feel, see, or even hear my husband. When I come back, the realization that I have had a seizure causes the feeling of worthless defeat. God has sent me an angel in form of my husband.

2) How have seizures (mine or others') affected my life and my creativity?
Marriage, children, and grandchildren have opened my heart to affect the lives of those whom I love. Music, art, writing, inspirational speaking, and volunteer knitting for charity have opened doors to let me reach out to others. Accepting the possibility of seizures has given me empathy for all of us who have some issue in our life with which to deal.

3) What is my seizure diagnosis or seizure frequency?
Seizure frequency is now gratefully controlled. I simply refuse to let epilepsy have a negative influence upon my life.

4) Other information that describes me...
Never once did I hear the words, "You can't do that because you might have a seizure!" Never once! This little city girl with epilepsy went on to grow up, fall in love, marry, and leave the city to start farming. As our family has grown through the years, so has my amazement for all of the blessings around me. I have gained so much myself when inspiring others to find their joys.

For a While

by Sarah Schmidt

I leave you.

And for a while, my world is without your touch
…your face
…your voice.

Time passes.

I return to see your smile
through my tears.

Your arms around me bring back
the self-worth that left with me
and somewhere stayed behind.

I try to remember how things were
but can find peace only in a long healing sleep.

I awake.

I thank God for you and go on living.

Author Background

Patricia Schultz

age 56, mom

1) What inspired my written work?
I think what helped me write this was the fact that I sat down and really thought about my son's condition and how it sort of runs a thread through everything in my life. It separates the important from the unimportant. The dos and don'ts of epilepsy kind of come to mind like the ABCs.

2) How have seizures (mine or others') affected my life and my creativity?
It was quite a shock when my son had his second seizure, because the first one was considered a fluke or something. He was 15 and I think they thought it had something to do with his age. With the second one, I remember talking on the phone to some voice and then standing next to his gurney in emergency. To this day, I don't know how I got the car and me to the hospital that day. Well, time and knowledge help a lot and lessen worry, but awareness always remains.

3) What is my seizure diagnosis or seizure frequency?
My son has been fortunate to have had 3 grand mal seizures. He has been on Dilatin for 12 years now and is doing okay. I am thankful that it only took one drug to control his seizures.

Life Happens

by Patricia Schulz

Epilepsy is a complex
Condition of the brain
That leaves the person
Sometimes drained
The different seizures that
Are called epilepsy
Can cause great strain
And sometimes great pain

When first diagnosed the
Person thinks
What is wrong with me
I feel so tired and drained
And why does everyone else
Look so drained

Then comes the questions
That tries to find the source
And sometimes it is
Idiopathic, of course

So what does one do?
Does one sit and stew?
No, one accepts, loves
And gets through it

This person is special
And has to get through it, too

Epilepsy teaches one much
To be thankful for that
Special person
To feel sad for the ones who
Don’t have a special person
Like this around
One learns compassion and
Great acceptance

One learns not to be too
Afraid of things (fear doesn’t
Totally go away)

One learns to keep on a straight path
One prays a lot to oneself
I have learned a lot because
This special person
Is my son.

Author Background

Lachelle Venenga

age 34, mom

1) What inspired my written work?
My son Joshua inspired this work. I have also been inspired by all the people on the e-communities at EFMN and the Epilepsy Foundation. These people are so strong! I am amazed daily!!

2) How have seizures (mine or others') affected my life and my creativity?
Joshua was diagnosed at age 2. Since then the longest time span we have had without a seizure is 14 days. I spent lots of time worrying and wondering about his future. Every time he stopped and stared, he would hear me asking if he was ok. Then one day he came up to me, placed one hand on either side of my face and looked me in the eye. He said, "I ok Mom." I just sat and watched him, happy and smiling, not a worry in the world. That is as it should be. All I want is for him to be happy – seizures or no seizures, kids deserve to be happy. We as a family are much more focused on the positive and enjoying the little things in life. Sure, there will be days that aren't so fun, but together we will get through them.

My son's seizures have affected the daily lives of our entire family, our circle of friends, and our day care. A year and a half after the diagnosis, I am confident there is still so much more to learn, so much more we can do to educate – ourselves and those around us. I talk about Epilepsy everyday. People who know me are very well versed in this disorder and I can only pray that they spread their knowledge.

I have recently left my job of 10 years to be home with our 2 boys. I pray that this will allow me to find a pattern or a trigger, or stumble across something that will make all the difference for Joshua.

3) What is my seizure diagnosis or seizure frequency?
Joshua has partial complex seizures with secondary generalization. He was diagnosed in March of 2006. He now has seizures an average of 2 times per week. We have failed on several medications and are still searching for that magic combination that will work for him.

4) Other information that describes me...
We have always been a Christian family, but Epilepsy has really given us the opportunity to learn and grow through adversity by relying on our faith constantly and meeting some truly amazing people.

We are parents who, like most, are determined that both of our kids have the happiest life possible, Epilepsy or not. Seizures may affect a few daily decisions – but they do not control us. We have a few more trips to the doctor and our 3 year old can swallow pills the size of a calcium supplement; but other than that, we are like every other family out there. Nothing will hold us back!

I Am a Special Child
by Lachelle Venenga

I am a special child. I can run and jump and play.
I play hide and seek and giggle through the day.

Sometimes I don't feel quite right and then I stop and stare.
My eyes are open but I won't answer, as if you are not there.

I may tremble or move my lips and may turn a little blue,
Soon it will be over and I'll be right back with you.

My seizures make this happen and it will be ok
I take my medicine to help me - each and every day.

Epilepsy is something I have, only one small part of me.
Let me help you understand, it's really simple you see.

Our brains are filled with tiny cells that tell us how to move,
Sometime they get all mixed up and they don't know what to do.

I stop and stare, I might twitch a bit and I even may fall down,
You can't catch it, don't be scared. Please help me to lie down.

A few minutes pass and I am back just as I was before,
I may be tired and want to rest or want to play some more.

There is no need to be frightened or to jump and shout.
Staying calm beside me is the best way to help me out.

I can do the things that you can do, just you watch and see.
You're my best friend and I pray, you'll do them all with me!

Author Background

Andrea Walker
age 23, person with epilepsy

1) What inspired my written work?
I woke up one morning with the first three lines of this poem in my head. The theme of the poem is following your heart and listening to your soul.

This poem was written as a commitment to myself to follow my heart. I was having difficulties with a friend; I thought she was being controlling. I knew I needed to listen to my instinct and stand up for myself, skills I had not used very well. So I wrote about not losing sight of where I wanted to be and what I wanted to accomplish. A few weeks after writing this I went to camp for the summer and did well believing in my abilities.

2) How have seizures (mine or others') affected my life and my creativity?
Seizures have given me the time to take for myself and to explore my creativity.

3) What is my seizure diagnosis or seizure frequency?
I had my first seizure when I was 20. Since then I've finished my Associate's Degree and have been able to explore other interests, especially art and writing. I have been on medications for over a year and they have controlled my seizures.

4) Other information that describes me…
I would rather have the poems speak for themselves.

I Pledge Allegiance to Myself
by Andrea Walker

I pledge allegiance to myself
That I become everything I can be
That I do what I believe is right
I stand up to my friends and enemies
And follow no one but myself

My heart, my mind, and soul
They know the way
Every day I ask for guidance
And they show me the way

For I am strong and I know what’s best
For me, myself, and I

While I look out for others
And care about humanity
This fight for freedom
Starts at my heart

I am my light, I am my truth
No one knows everything about me
No one knows all that I know
All my stories, my mark on life
Is so very personal
Yet others sneak inside

They come, they go
Leaving impressions on the soul
The others try to guide you
Tell you what’s right

But I am my own boss
I know the way
I will not let others blindly guide me
And try to lead me astray

If I follow my dreams
My mind, heart, and spirit
If I listen real close
To the voices called my soul
I will be guided
To my personal destiny

This is where I want to be
Where I may grow and flourish
My self is my only boundary
And I have control of me

Meaning
by Andrea Walker

meaning
deep personal connection
mind, body, soul
comes to touch me
keeps me going
radical acceptance
reach out
grab something
something to hold on to
does it touch me?
deep connection is felt
to the soul it goes
nourishing, soaking it in
touching all parts
reaching in, twisting, turning
nurturing, growing
is this right?
it’s what my soul knows
developing my Personal Legend
takes time, a patient ear
someplace to grow
a place to be heard
it may be different
but soul knows
where do I go?
only up, please
something better, something bigger
is not always given
set back!
step back
deep breathe, take time
different obstacles
require different skills
my Personal Legend knows
to the soul I go
searching for clues
what? how? where am I? lost?
not lost, but found
in the cradle of the world
I will not be forgotten, left to the wind
the wind knows me
will carry me home
up up away

Author Background

Dolores Warburg
age 60, grandma

1) What inspired my written work?
This poem was inspired by my grandchild.

2) Other information that describes me…
I live in Garrison, MN.

Untitled

by Dolores Warburg

At six years old I can’t explain,
Why epilepsy started playing its game.

My life was changed and full of fear,
I cling to my Mom, who is always near.

School is different and play time, too,
I even get tired just going to the Zoo.

The Epilepsy Foundation came out and talked to my friends,
That’s finally when most all of the teasing ends.

I’m twelve years old now, and taking my meds,
Hoping to outgrow this and the seizures all end.

I’ve been a Shining Star for over four years,
Now I’m full of hope and have a lot less fears.

Prose

Author Background

Mary E. Asp
age 29, person with epilepsy

1) What inspired my written work?
I wanted a chance to tell my story and what I have gone through. Dance has been a big part of my life and also gets me through some difficult times. If I did not have the gift of dance, I would not be here today. I think that it also helps to let people know where I am with my health. Having epilepsy is a part of who I am, but not who I am. It is something I have dealt with and there is a story behind how I have gotten where I am today.

2) How have seizures (mine or others') affected my life and my creativity?
I try not to let my seizures affect my life in a limiting way. If I let the seizures control my life, then they have won. I need to be in control of my life.

3) What is my seizure diagnosis or seizure frequency?
I have particle seizures. I usually have about 3 per month. Medication seems to be able to control the frequency and intensity.

4) Other information that describes me...
I work in a library and take an active part in researching the treatments that my doctor has prescribed as well as researching other treatment options. The patient needs to take an active part in knowing what is going on with the treatment and know how to ask the correct questions.

Release

by Mary Asp

Every life has a story to tell. Mine is told through dance and movement. Had dance not been there for me, I would not have made it this far in life. At different times in my life dance was the one stable guide that I could depend on to get me through and it has also brought me great joy to share my gift with others. Every time I dance, I thank God for the gift that He has given me, and how much it has helped me get though the trials in my life.

I grew up in a small town in Minnesota and took my first dance class at the local dance studio when I was four years old. This was a financial sacrifice for my parents because my dad was out of work at the time. I am not sure why my parents kept me in dance when their finances were so out of control, but they must have seen the joy that I was experiencing from it. Later on, when I was in fourth and fifth grade my mother cleaned house for the dance teacher to pay for my lessons. When I was in sixth grade I started to assist with classes at the studio, and as payment I received free lessons. When I started to assist in paying for my own classes, I took on the role of adult and paying for what I love - dance.

Taking on the role of an adult in sixth grade was not new to me, however. When I was in fourth grade, kids started picking on me and my parents brushed it off as “normal kids’ stuff”. I kept trying to tell them that what was going on at recess was not normal and I was hurting. I felt as though my parents did not care about me and they were not listening. Their actions forced me, at age ten, to take on the responsibilities of an adult. Writing notes to the teachers to ask to stay in during recess did not work. When that failed I felt lost. I remember bus rides with no one wanting to sit by me and praying to God to give me the strength to get through the day. God had helped Daniel in the lion’s den and I had my own lions to face. Surely, He could help me.

As the problems from late elementary school grew into new issues in junior and senior high school, I did not bother telling my parents. After all, they did not care about the name calling, why would they care about the depression I faced? I had dealt with the name calling on my own, I could handle this, too. Throughout high school I was depressed, suicidal, and felt alone with everything. Dance was the one thing that was constant and gave me hope. I knew deep down that I needed help, but I was not able to put it into words. Dance was a medium that gave me a way to express the anguish and abandonment I was feeling. When I was assisting with dance classes, the students looked up to me and that gave me the satisfaction of knowing that people did like me at some level. I felt so alone, but that was all forgotten when I was dancing. I could face anything then; nothing was too much for me. It was such a release for me to be able to express myself though movement and truly be myself for a few hours each day.

Through high school I lived behind a mask. Outside was a happy, normal teenager, but inside I was dying and depressed. I knew that something was wrong, but I was not sure how to help myself. During this time I started to develop these strange feelings – nothing I could identify, but a sense that something was physically wrong. I thought at first it was just my imagination, but the symptoms persisted. When I did tell my mother about what I was experiencing, she said it was sinuses and to just ignore it. When I saw a doctor, he did blood tests for a variety of illnesses, but everything was normal. There were no answers for what these strange feelings were.

My junior year of high school was the hardest year for me. I knew that if I did not do something soon to get out that place I was not going to make it out alive. What made that year so difficult for me was the fact that dance was starting to fail me as a release. The studio that I had been taking lessons at for twelve years could no longer advance me. The teacher had a difficult time admitting that, and I was just there taking lessons, without progressing in skill. Tension grew between my teacher and me in wondering why I was fighting to learn dance. The one thing that had been my sanctuary was starting to become a torment to me. Dance still made me feel free, but it was harder to achieve that feeling when I was fighting to learn more. At home, there were signs that my parents' marriage was starting to break up, even though they tried to cover it from everyone. They were absorbed in their own problems and did not seem to care about what was happening to me. Now that dance was not as stable, I had no place to turn to for support. There were nights when I would lie awake in bed thinking how easy it would be to kill myself. I would picture how my mother would find me in the morning when she came downstairs for work. What stopped me every time, however, was that I then would start to think about what everyone else in the town would think, and how surprised they would be. I was not your stereotypical suicidal teen. I was active in church, my parents we still married, I had good grades. Why would I have done that?

During that year I was able to convince my parents to let me audition for the Perpich Center for Arts Education – Arts High School in Minneapolis, a state-wide arts school for juniors and seniors in high school. I auditioned for dance, was accepted, and went there my senior year.

The summer before I went to the Arts High School, I stayed with my brother for a week to have my senior pictures taken. It was in that week that I had a grand mal seizure. When I was back home I saw my doctor and he did an MRI (magnetic resonance imaging) and an EEG (electroencephalography) however I did not find out the results right away. The strange feelings that I had been getting for years continued, only now they were getting worse. I was at the Arts High School and I did not know who to turn to for health information. In February, I saw my doctor again, but this time he wanted me to see a neurologist. I received a referral and made an appointment, but when I got there, the doctor refused to see me because of unpaid bills. I had to go back to school still, not knowing what was going on. At school I started to work with the health and wellness counselor, and with her help, I was able to finally see a neurologist and also found out the results of the EEG that I had had six months earlier. In April of 1997 I was diagnosed with epilepsy.

My year at the Arts High School was a year of growth and self discovery. I started to break free from the mask that I was hiding behind and learn to not be afraid of who I truly was. The dance classes that I was taking helped to expand not only my dance vocabulary, but also my personal vocabulary as to how I express myself. Living behind a mask, I closed myself off to what was happening around me and part of breaking through the mask was learning self expression.

The Arts High School helped prepare me for a college degree in dance. I went to Hope College in Holland Michigan where I studied a variety of dance forms as well as choreography. For my choreography class final project, I choreographed a trio that dealt with the peer harassment I faced growing up. The dance was entitled, "Just Like Me", and each dancer had a very specific movement style that reflected how I felt at different times in my life. The dancers were in separate quadrants of the stage for the beginning of the dance to represent the isolation that I felt in my life. Each dancer had a specific movement quality - small movements, large movements, and angular movements. Each one stayed in their area, almost afraid to leave it. The music built to a crescendo with a sudden stop that lead to a change in music quality; that change coincided with a unison movement for the dancers. They were now together as one. The movement also brought them to center stage where they had to rely on each other in order for the counterbalance movement to work. The dance ends with the three dancers in a circle, facing in, realizing that they all have qualities in common with each other. This dance not only expresses what I went through, but also the ideal that I would have liked to have grown up in an environment where you are not judged for how you act or look, but when you look hard, you realize that you need everyone to help make you better.

Part of the sound score included a poem that I wrote. The poem describes so much of how I felt when facing the peer harassment. The poem, like the dance, also describes the ideal that I would have liked to grow up in. I also express how my life will look without the peer harassment and what should happen in order to be free from hate in life. Here is the poem:

Why does life pass by so fast?
Life with all its heart ache and pain.
Life with nothing there.
All I want is to be seen for who I am,
not judged or laughed at because
I can’t afford the Z-Cavericis.
Not judged or laughed at because
I wear hand-me-downs or rummage sale stuff.
I want to be me.
I want to be free.
I want to escape the hate.

I want to shine like a star,
to be seen up there in the sky.
To have everyone watching me
and saying nice pretty things.
I want my life to change,
to go from this gray dismal color
to a beautiful shade of blue.
I want it now…
I don’t want to wait for those to remember
all the hate pushed on me.
I want them to feel my pain
and understand what I felt.
I wish they would remember
so they could say they’re sorry.
They really did not mean
all those cold and nasty things they said.
They just wanted to fit in.
Just like me.

I grew in countless ways during college. Dance was there to help support me and give me strength. I was able to face my past head on and I beat it. Now I had the strength within me to pull the mask off that I had worn for so many years and let the real me shine through. I can not tell you how freeing it is to be able to do that. I encourage anyone, who may be living behind a mask, to find the strength to dig deep, as I have done, and remove it. You will be glad that you did.

Author Background

Julia Auerbeck

age 38, person with epilepsy

1) What inspired my written work?
My short story "The Sensation of Spinning" was inspired by my grappling with some childhood traumas, including my mother's death, my epilepsy (that may be related to my mother's health issues) and my father's abandonment of me to be raised by my grandparents.   The title is both a reference to a side effect of Phenobarbital and to the spinning out of control when bad decisions start being made. My dad made some bad decisions that hurt me as a consequence; my grandparents made decisions that hurt him back on my behalf. In the end, though, I was right where I needed to be, raised by the people I needed to be raised by.

2) How have seizures (mine or others') affected my life and my creativity?
I would love to say that my childhood epilepsy has made me patient and strong, but I doubt that. I went through it because I didn't have a choice; the real strength was in those around me who loved me in spite of it and chose to care for me. My grandparents were heroes. They refused to allow me to be sent to an institution when a school district psychologist determined that I was retarded.

3) What is my seizure diagnosis or seizure frequency?
I've been seizure free since I was eight years old; it was another six years till I went off the meds (Phenobarbital and Dilantin) I'd been on since I was two and a half. I was "normal" finally and I just wanted to embrace that, to discover what normal was. As I got older I related my depressive streak to my dad's depression (he suicided when I was twenty) until a counselor suggested it probably had more to do with my epilepsy. I hesitated to research it, almost afraid of triggering it again. My grandfather had passed away and my grandmother didn't want to remember. My grandparents' next-door neighbor helped me fill in some pieces (including my mother's use of morphine while she was pregnant with me). I tried to write about it but it was far too painful. Eventually in my research I discovered that hypergraphia can be a side effect of epilepsy and I decided to stop writing. I doubted I would ever find an audience for the things I wanted to write about, including my epilepsy. Thank you for this opportunity to say what I needed to say.

The Sensation of Spinning

by Julia Auerbeck

He was getting his kids ready for bed when his grandmother called.

“You have to come. She’s had another seizure and I can’t lift her.”

“Where are they?” he asked tugging his daughter’s nightgown over her head.

“They had a dinner at church but no one there is answering the phone.”

He sighed. “I’ll send Lonnie to go get them,” he told her continuing to tuck Cindy in her bed.

“Roy, she’s your child. They deserve to have a night off. She needs you,” she said and hung up the phone settling the question.

His other daughter needed him. Her need was always too much and at the wrong time. He watched Cindy snuggle her stuffed rabbit and sing her ABCs softly to herself. His wife Rhonda, Cindy’s mother, was helping her sister for the weekend. It fell to him to interrupt his children’s routine to rescue the other one again. He plucked a string in him that still loved his other daughter’s mother and picked Cindy up to put her in the car with Lonnie.

The kids were asleep in the backseat in a heap, like warm puppies, by the time he pulled into his parents’ driveway. Roy had no siblings of his own and he loved watching the two of them together, fighting or playing. He considered it his duty to give his son the childhood he didn’t have. It was unfair to expect Lonnie to cope with a sick sister after he’d lost his sick mother. Cindy was perfect; he’d chosen her for his son as much as he’d chosen her mother for himself. He checked them again before he got out of the car. If he could be quick enough they’d never know they were at their grandparents’ house and he could avoid Lonnie’s questions.

His grandmother opened the door after the second ring of the doorbell. “I didn’t know if you were coming in or not,” she chided him. “You’ve been sitting in the driveway longer than it took you to get here.”

“I had to make sure the kids were okay,” he told her, pushing her rebuke away. The purest love he ever had was his grandmother’s, though his recent decisions had strained the bounds of it considerably. “Where’s Michelle?”

“In the living room.”

He let his grandmother lean on his arm, all the better to take the five steps to the doorway as slowly as possible. Michelle was curled up on her side sleeping, her head on a throw pillow from the couch as peaceful as he’d ever seen her. He would find her lovable if she could be peaceful like that more and patient in her affliction.

She was angry a lot. He still bore the scars of her rage from the time he told her to share the “tea” she poured him with Rhonda instead.

He picked her up off the floor carefully, her neck on his left arm and her knees slung over his right. His grandmother followed him down the darkened hallway to her room and switched on the nightlight. He laid her down and moved away. He watched as his grandmother pulled the blanket up to Michelle’s chin. She stroked the child’s forehead and mumbled a prayer. He strained to hear it but only made out the same few words he remembered from his childhood. He moved back into the hallway and waited. He could have gone then, his duty finished, but he owed it to his grandmother to see that she was all right.

She pulled the door closed leaving it open just a crack so she could hear. He held out his arm again and escorted her back to the living room.

“I’ll fix us some tea,” she said. “You take the chair by the window so you can see them.”

“Just some water for me,” he said as he settled himself where she’d ordered. He looked out the window at his car still trying to piece together the prayer his grandmother always spoke to “put out fire.” The first time he heard it she was whispering and blowing on his fingers after he played with matches when he was five. The pain was gone instantly. Her healing gift was handed down to her by her father and had to go to Roy's father as the next generation; his father had refused it and Roy wished it could come to him. It would die with his grandmother. He knew it was a Bible verse but he'd read the thing cover to cover and nothing ever jumped out at him.

She put the glass in his hand, startling him from his thoughts. "Was their car still at the church when you came past?" she asked.

"I didn't come that way. It was faster to go around the block."

She sat down slowly in the chair by the fireplace and covered her legs with an afghan Shelley had knitted for her. "I don't know how much time we have so I'm just going to tell you. They had a meeting at the school. The principal wants to put Michelle in an institution."

He nearly dropped his glass. He cried out and caught himself, biting his lip till he was under control again. It wasn't supposed to be like this. Their little girl was supposed to save Shelley, pull the cancer away. Instead the pain was too much for his wife and the morphine created a ruined life. Shelley died anyway. He took several deep breaths. "When?"

"The meeting was two weeks ago. Your daddy is calling in every favor he can and it looks like she's going to stay where she is. I just thought you should know."

His helplessness filled his lungs and fired his anger. "Don't I get a say? Maybe that's what she needs." His grandmother looked at him sadly.

"There's no fire in her head, you know," he spat. "Your mumbling doesn't work on epilepsy."

She shrugged. "A prayer is love, Roy. It's what I can give her. It's what your parents can give her."

"Don't I love her?"

"All you can, I guess," she nodded. "You have to let them love her if you can't. It's a poverty to punish her for something you decided."

He saw Lonnie sit up and look around. "I have to go," he said and ran out without kissing his grandmother goodbye.

He opened the passenger side door and laid Lonnie down again, rearranging the blankets so Cindy's head was uncovered. "Why are we at Nana's house?" Lonnie asked.

"Grandma Sarah needed my help," Roy told him. He shut the door and climbed in the driver's seat hoping that would be the end.

"Are we taking Michelle home?" Lonnie yawned.

Roy thought for a long time before he answered his son. "She is home."

He started the car and pulled out of the driveway.

Author Background

Elizabeth Jo Block-Kloss
age 50, person with epilepsy

1) What inspired my written work?
I'm working on a book about my dad and this is the start of the book. I was really close to my dad and had a hard time when he died. My dad was on board a Naval PBY and spotted the Archimede in the South Atlantic. With the help of two other planes, they sunk the sub. The Archimede was an Italian sub and it was fighting with the Germans in the 1940s. My dad received the Gold Star and the Air Medal from Eleanor Roosevelt at the Naval Air Base at Panama Canal a year later. The poems that I'm entering are about driving in a car – I'm on the road a lot with my job, seven days a week, and within a day or so, I came up with this rhyming story – and a story about mice at my sister's cabin on Peavey Lake in Minnesota.

2) How have seizures (mine or others') affected my life and my creativity?
It's hard to answer this question because I haven't had a seizure since June of 1998. I came close to having one a few days ago, but I asked for some Divine Interventions to keep me from having one. I asked my dad for some help and told him, "I can't afford to have a seizure right now, please stop this from happening." My dad died when I was seventeen years old. I felt fine after that and went on with my work. I just started writing different things not too long ago and recently won the Directors Award for lyrics to something that could be made into a song. It's entitled, "I'm taking your man, but I'm giving you life," and it's a quote from a woman that took my husband away from me. I entered the contest in Nashville, TN and the lyrics could go on to win the grand prize worth $1,500.

3) What is my seizure diagnosis or seizure frequency?
I have Grand Mal seizures, but they are medically controlled, and the last one that I had was June of 1998. I tried to end my life by overdosing on my medication for depression after my husband divorced me and then left me. I'm able to drive a car right now and I'm working three part-time jobs. I'm also working on books and lyrics as well.

4) Other information that describes me...
I'm 50 years old, divorced, and have a daughter, who is also gifted with talents. My daughter can paint drawings from regular pictures, make tie skirts, swing poi, with fire or without fire, and many other things. I have some lyrics that could be made into songs, and I'm also working on children's books and a book about my dad. I live in Hopkins, and I have a cat that shares my condo with me, and his name is Fonz.

My Hero, A Minnesota Hero

by Elizabeth Jo Block-Kloss

Everyone has a hero during their lifetime and my hero is my dad. He is no longer with us today because he died when I was just seventeen years old. For anyone that was lucky to have known him, or unlucky not to have known him, he became a hero, whether he wanted to be one or not. My dad wasn’t looking to be a hero and he didn't do what he did for the glory either.

Let me introduce you to my father, my dad's name was Earl J. Kloss, and he was the oldest of seven kids. My dad grew up on a farm near Royalton, Minnesota, during the Depression. Earl's parents were Julius and Helen Kloss, and when my dad was eleven years old, Julius had him running moonshine. One of his brothers died when he was only three months old, but the rest of the family pitched in to help with the farm chores. There was one day in particular that Earl had to milk the cows. He asked his sister, Rita, to stand in a certain spot by the cow and he would squirt her with milk, he would pay her for doing this. She did what he asked and she got squirted, but Earl didn't come up with his end of the bargain.

My dad loved to pull pranks on people, even before I was even born. There was this guy that admired Earl's eyebrows and asked him, "How can I get eyebrows like yours?" Well, Earl told this guy to shave his eyebrows off, and they will grow back, just like his. I think that guy learned his lesson after that, because it took a long time for his eyebrows to grow back, and they didn't look anything like my dad's. Earl was very smart when he was younger, he even skipped two grades in school. When he was in his twenties, Earl and his best friend Arnold joined the Naval Air Force. The United States was at war with the Germans and the Italians, and Earl and his best friend were lucky enough to be stationed together. My dad grew up near a small town, so it must have been hard for that community to have to see them go off to war, knowing full well that some men don't make it home alive when the war is over.

Most people don't realize just how close the Germans were getting to the United States during the 1940s. Hitler was using an Italian crew and subs to do his dirty work. In those days Hitler was just like the bad people that we have to deal with today. He didn't care how many people he killed and if some of his men got killed in the process, he still didn't care. I'm honored to know that my father was part of that history. He did his best, he also did what he was trained to do, at that particular time.

Earl and his best friend were stationed on a PBY Naval Plane, and on this particular day, Earl was assigned to be on look-out when he happened to look out this window and saw something on the ocean surface below. Earl noticed that it was an enemy sub and he didn't waste any time to report it to the Ensign. The Ensign took a good look at the sub and said that it was the Italian sub named the Archimede. By then they had gone over their target and had to circle around and come back again. The Ensign gave the order to sink the sub, and they did their very best to bomb the sub, but ended up having to call for the help of two other planes. Between the three planes, they tried something new and different that day. The pilots dive bombed the sub, going at a 60 degree angle and at 245 miles an hour, letting go their bombs and depth charges at the same time. Earl and his friend Arnold fired the machine guns towards the sub while it was sinking. When they checked for anyone that survived the shooting and sinking, they had to be very careful with the enemy so as not to get shot at by them, because they still had their weapons. I'm sure that both Earl and Arnold were really excited with what happened and couldn't wait until they could tell their family back home. If the war had gone on any longer than it did, the high ranking officers were about to train my dad to become a pilot. That's something I'm sure my dad would've done proudly, he was very smart and would've learned fast. When Earl was still in the Naval Air Force, he bought this flight jacket to give to his younger brother, Richard. My uncle still has this flight jacket to this very day, and even though it doesn't fit him anymore, he treasures that flight jacket, because it was a gift from my dad and his older brother.

A year later, my dad was given the Gold Star and the Air Medal from Eleanor Roosevelt at the Naval Base at the Panama Canal. My mom has the newspaper clippings from that day. She also has the medals and his sailor uniform. I really don't know how the sailors could wear those uniforms in those days or even today. They are very tight and must've been very uncomfortable to wear. I’ve written the lyrics to “The Ballad of Earl J Kloss,” but it needs to be made into a song.

When the war was over and they were sent home, family and friends were so glad that they made it home. My dad eventually met my mom, Shirley, and they dated and then they got married. Between the two, they had a family of four. I'm the youngest of the four, and the names are Diane, Tom, Debbie, and me, Elizabeth.

Before I was even born, the family moved around a little and the only places that I remember are Glen Lake, Dawson, and Brainerd, and then when I got married I moved to Glencoe and then back to Minneapolis, Minnesota. It was fun growing up in the small town of Dawson and we owned a Hardware store and a Carwash while we were living there. I would go on service calls with my dad a few times when I wasn't going to school. I was my dad's gopher girl, when he needed a tool, I would go for the tool and bring it to him. There was a service call that my dad went on without me and I wish that I had, my dad had to go to this bachelor's house, which was full of cats. The guy told his cats, "You better all hide, because Earl's coming." My dad didn't like cats and they seem to understand, because when my dad got in this guy’s house, not one cat could be seen.

My dad spoiled me when I was young and bought me whatever I wanted, within reason. The best birthday present he bought for me was a horse, his name was Sparky. I didn't find out until later that he already had a name, so I held a contest at school to pick a name for the horse. The winner of the contest was a classmate that came up with the name Sparkplug.

There was a lot of stress owning a hardware store and a carwash, so as a family, we would take trips together and go fishing together. There was one fishing trip in particular, where we had all the lines casted out, all of a sudden I blurted out, "What are we waiting for?" Everyone in the boat was laughing, but me. I still hear about that to this very day. My favorite time was when we had two nuns live with us for a short time. They were assigned to help with religion classes for our Church in Dawson, Minnesota. When we had some free time, one of the nuns would play her guitar and both nuns and our family would sing together and have a good time. My dad loved to take the boat out and pull some pranks on the water, he liked to chase the loons and get them to fly. On one of those days that the nuns were staying with us, my dad took them out for a boat ride and did his usual thing of chasing the loons, I'm sure that the nuns didn't like that very much. When they got home from their boat ride, the tv was on and showed someone out boating on the lake. One of the nuns made a comment like,"We're on tv already?" That was real funny, I guess that nuns didn't get out much in those days.

This doesn't involve my dad, but it involves my dad's son and my older brother, Tom. One of the nuns had a family emergency, so they needed to leave early. My brother was new to driving and didn't know his way in the cities very well. They stopped on the side of the road before Minneapolis, and what happens next, must have been funny to see. My brother got out of the driver's side and one of the nuns got out of the passenger side and it looked like they were chasing each other around the car, only they were just switching places.

My hero was born on April 5, 1923 and he died on January 9, 1975 of a massive blood clot to his lungs. He got diabetes later on during his lifetime and I've seen him give himself shots a few times, while he was alive. We were building a new home in Dawson, Minnesota and there were quite a number of panelings leaning against one of the walls and they fell on top of my dad and broke one of his knees. My brother tried to warn him, but it all happened way too fast. The force was so strong that it knocked my brother and a tank clear out of our living room window. I didn't hear about the accident until I got home from school on the day that it happened. My dad was in the hospital over Christmas of 1974 and they let him out on January 8, 1975, he had a cast on his leg. Being diabetic, any injuries that he had didn't heal properly, so my hero didn't stand a chance. He even knew that my mom would live longer and he even told her that she would live longer then him.

When my life is over, I'm going to be buried right across from my hero, at the Dawson, Minnesota Catholic Cemetery. Since my dad served in the Naval Air Force, he could've been buried at Camp Ripley or even Fort Snelling, but he made a lot of friends while we lived in Dawson and I'm sure that he would rather be buried with his friends.

Author Background

Stephanie Chappell

age 38, person with epilepsy

1) What inspired my written work?
The work was inspired by a recent ER visit. The story is a blend of fiction and fact. Unfortunately, some areas I've landed in are not accustomed to the recent medical updates of the decade and advocacy is becoming a monthly occurrence in places I never imagined.

2) How have seizures (mine or others') affected my life and my creativity?
My life has had several twists and turns in and around seizures. The scholarship mentioned in the story is true. In 1986, I was awarded a National Scholarship that I walked away from due to the description in the story. I'm hoping people will gain an understanding of more than just the seizures from reading this brief glimpse of someone's life with a seizure disorder.

3) What is my seizure diagnosis or seizure frequency?
I have a seizure disorder; the seizure type and diagnosis have changed.

4) Other information that describes me...
Magna Cum Laude college graduate.

Next Steps

by Stephanie Chappell

“Our ETA is six minutes. Female, mid 30s, in seizure for approximately four minutes. Uh, medical ID card reads seizures with meds of Lamictal and VNS.”

“Come back, VNS define.”

“Checking. Second med card, Vagus Nerve Stimulator, serial 64534 ER, procedure is fospheny IV drip.”

“Trauma 2 ready, getting Fospheny IV. Have you got vitals for Curt?”

“BP 168 over 90, pulse 71, oxy 89, seizing, pupils fixed and dilated.”

Don’t take the horses down to the water cuz I can’t drink that fast. There’s more Mr. Potato Head pieces in the 92-2137. No, that’s not what it’s for. I want to get the algebra done first. I need my VNS magnet!

“Emmalee, hang on. I’m trying the number you gave me, hun.”

No number in my name. I know there’s no number in my name. This is no time to try to trick. Who are you? Sue? Is that you? Sue?

“Emmy, Emm, they don’t know you at that 2137 number, do you have a different number I can try?”

Ok, how did she get my number from where I lived 20 years ago? I know she didn’t know me then? I sure did give it to her!

“Well, you’re comin’ back to us! I can tell by your eyes. Emmalee, you’re in an ambulance and we’re taking you to…”

“Owh swwitwhch, ma mam id epepee eee I caa er kk? U Hue whi?”

I sound like a babbling idiot!

“Sorry, Emm, I can’t understand you, your tongue is really bitten up and swollen. Can you try again? It’s ok.”

Ok, switch to charades. Think. Yeah, grab the cell phone…scroll to the number. Thank goodness that was in the pocket. Don’t knock yourself out, relax, just relax. Do I have my magnet bracelet on? Yes, I do. I hope they remember how to use it from when I introduced myself last fall to the First Responders. I’m impressed I remembered her name.

“No trouble, we’ll be at Heartland in about two minutes. You call, I’m going to chart your vitals – they’re much better! Try to keep your arms down now.”

“Mma ssesher, Harwan.”

At least Mom was home. One time she wasn’t, and it was a real mess. The doctors thought I was on drugs and had something in my system. I couldn’t reach my mom or talk well enough to explain I hadn’t and it was just a seizure. It’s funny how the medication can make you appear drunk sometimes to people. I’ve looked at the side effects listed and for any one who wouldn’t need the drug, I bet they would appear *to be high. For me, it's just mistaken identity. Seizures don't have any visible crutches or scars or distinguishing appearances to avoid that problem. My mom is really good with getting me home for what I really need after a seizure...rest!*

"Ok, I'll be there as soon as I can. Hang in there, it'll be about forty five minutes. Hand the phone to someone, Sweets. I'll be there."

"Swue…"

"This is Sue with Heartland Ambulance. Hi, Kate. Yes, we were called by Emmalee's neighbor after they heard some noises coming from her apartment and she went in and found her in a seizure. We're just pulling into Heartland Medical Center now. She doesn't seem to have hurt herself. Dr. Curt Enders is her attending. The guys have just rolled her in. They will probably keep her here for a few hours. Uh-huh. Ok. I'll let them know. Ok. Sure. You bet. Bye."

Sorry you caught me in a rush, it tends to get like this afterwards. I didn't expect a neighbor to hear. I moved into an elderly/disabled apartment building almost two years ago. I'm the first disabled dweller. I gained a bunch of grandmas and friends with advice, jokes, and great cooking! It's quiet and gives me a chance to recover from all of the changes in the past year and there have been a lot. Most of the changes are from side effects and not the surgery. That's the tough part. Disability terms consider side effects as secondary and not really a part of the disability. It's my catch-22. I either have to go through these awful seizures or the awful side effects – they both have a good and a bad side, but one definitely allows hope for a life without surprises. Usually, my Mom ends up dealing with the surprises. She's been through everything. Friends come and go like the side effects of each drug. Friends find it difficult to hang on through the tough times. My Mom would lose her mind but she's always there and understands in the long run. Speaking of tough times, I have to try to speak with someone here at Heartland with a chewed up tongue, I'll be back in a few.

"Hi Emmalee, I'm Tracy, and I've been ordered to take some blood, your sugar was really high when you came in so they want to get some more to take more tests."

"Diz ahrem bes fouwr bud an way owziwde wein."

"Gosh, I've never had a person from a seizure know exactly where to get blood before. That's amazing."

"I know."

"That's it, Emmalee. Thanks."

At least I avoided multiple sticks this time. My record is 13. It's not the number of sticks, it's when that little needle hits the nerve and you can't say "ooww" without hurting your tongue more – that makes it that much worse!

Where was I before?...oh yeah, surprises. Surprises don't work in life, so you're left with a double-edged sword. On one side, you find a job to fit around all the stuff that goes with the medication side effects (fatigue, thirst, weight gain/loss, moodiness, vision problems, coordination problems, word choice trouble, slowed thinking, memory loss, recall problems, sleeping issues, and even depression), seizures, and doing the job well, and the other side is meeting the needs of the employer without sacrificing yourself on the sword! Then there's finding time for a hobby, exercise, and a little family time. To upset that delicate balance, once you find it, an employer may unintentionally change a schedule or something, and you're forced to explain the 'sword' or just quit. If you quit, the bills pile up, and if you explain, it goes one of three ways: tiptoeing around you, no problems, or get documentation and the pressure starts and you can 'no longer do the duties as described.' There are great folks out there and jobs; it just seems the two are hard to find in pairs. Here comes someone else, be right back…

"Hi Emmalee, I'm Jeanne, I'll be your nurse. Since they took blood, I thought you might like a Popsicle to help with that tongue. I brought grape and orange."

"Can I hab boff?"

"Sure – take that tongue down to size! And here's the call button, just press if you need me. They're going to take some x-rays and a CT scan of your head because you have a really big bump on the front here. After that, we'll get some ice on there too."

"No M WR I."

"I saw the note about the VNS and put that on your chart – so no MRI. Don't worry. I'll dim the lights. Get started on those pops so we can talk more later, ok?"

Ok, I want a nurse like that every time I wind up in the hospital, clinic, or ER! A Popsicle should be mandatory for every sore tongue after a person regains eye contact! Heaven, this cold stuff is heaven. At least I won't sound like some fossilized caveman when I need to talk again. That nurse would be great paired up for that stuffed animal job I had as a kid but got fired when I mentioned I had epilepsy like the owner's son. Back then, there wasn't an ADA, just the Human Rights. Since then, the ADA has passed, but it still seems to take a back seat because of that double-edged sword of the side effects vs. the seizures. The ADA doesn't cover debilitating side effects, just debilitating seizures.

The new ADA Restoration Act (HR 3195) is working its way through Congress. So far, more than 200 politicians support the bill. This could make it easier for me if I return to work. With the ADA Restoration Act of 2007, I could work with an employer with more ease on both sides of that delicate sword I mentioned. HR 3195, The ADA Restoration Act of 2007, is a chance to bridge the gap for me in the workplace and even in my apartment.

I took a chance on the VNS implant and I'm glad I did. It's been a little over a year and it's been a rocky road. The device is different in everyone so I wasn't told a lot of things before the surgery. Another mistake was that I wasn't shown how to use it until nearly a year after surgery. Now that I have some options and confidence in VNS, I'm doing better with learning to listen to the unit and use it. Plus, I am down to just one drug! I was on as many as four, and all of the conflicting side effects that went with each made it hard to know when or if I should use the VNS device.

Unfortunately, many of the drug side effects are permanent or long-lasting. Between one of the drugs, I dropped 40 pounds and that gave me some hope that it can come off again. It went back on with the 'next drug – hopefully, it will drop off again.'

"Hurry, get her back in and hooked up. Where's Curt? Get him in here. Jeanne, do you need help?"

"Yeah, Chris, thanks. You got her back from x-ray fast. I could use some extra help. Can you start the Fospheny drip on her again? I don't know what made her drop off like that. She was fine in here."

"Jeanne, it was like night and day in x-ray. One minute she was sound asleep and then she said 'next drug' and it started – a full seizure. I got her back here as soon as I could."

"You did the right thing, Chris. She's coming out of it already – it wasn't that long or bad this time. Not bad at all."

"Shouldn't I have put a stick in her mouth and held onto to her, though, Jeanne?"

"Chris, those are just old wives' tales and things that people thought they should do. Really, they just do more damage for the majority of people. Well, look who's awake. Hi, Emm. How are ya feeling? Headache and a little foggy?"

"Yah, here."

"Oh for cryin' out loud! I completely forgot about this. Chris – there was something we could have tried."

"Now, peas."

"Oh, Chris, here, you try it. Emmalee will help you."

This nurse is great! She gives me credit for being human. And Chris is going to be the same way some day with those shoes to follow in. What a pair! I'll do the demo just like the charade in the ambulance with Sue and the cell phone. I bet Chris will be able to use my VNS magnet like a pro. Wait…I gotta point to the goose bumps. He sees them! I don't know why, but I get a ridge of goose bumps along my jaw line. It sure helps to show people that they've succeeded in opening the little gate on my device and how the electrical stimulation has gone to the lead wire in my neck and then on to my brain. Whew!

Granted, I had errors early on, and with the medication changes, like I'm in right now. Yet, if I hadn't hung on and tried the drugs and found a doctor who I felt comfortable with – I wouldn't feel comfortable participating in my care like I do. I'm starting to take the reins from my mom more and more. She's having a hard time because it goes back and forth. Before, I'd never show someone how to work a medical device. Now, I have to because people don't know what it is or mistake it for a heart thing and I wind up in a cardiac unit.

Where I am now isn't where I was. Things aren't what they used to be. I may not earn the perfect 4.0 that I did a year and a half ago or even finish my master's degree that I was working on. My goals have changed to daily ones for now. The future will hold better things. I just might hold on to my driver's license. Things always change. Now, colleges accept seizures. I'm the last kid who will ever need to walk away from a scholarship because the college didn't understand what stress did to seizures, and why three kids in a two-person dorm room would increase my seizures and cause more injuries. Now, kids – along with their doctors – can write a request for a double dorm room as a single to eliminate stress and injury, or request larger rooms or specific roommates for the same reasons. Those were the pre-Americans with Disabilities Act of 1990 days. What could the HR 3195 bring?

There's a new world of old possibilities for myself and others. Yeah, there's more things that need light, but for now a candle is better than darkness. I hear my Mom's voice. See you 'round sometime, hopefully not at an ER.

"Hi, Mawwam, I'm finge. Oozed magmut."

"Hi, Kate McCrory, I'm Dr. Curt Enders."

"Yes, I'm Kate. Thank you for watching Emmalee, please forward the blood work to this fax number. Did you take a Lamictal level?"

"Yes."

"Those and any other blood levels will be appreciated at this number. We'll be sure to follow up within a few days. Thank you. I can take her home anytime."

"Uhhh, I'll have the nurse get the paperwork ready."

I told you she was good. I'm working on it.

Author Background

Angela Halverson
age 35, mom

1) What inspired my written work?
My son and our journey together inspired this work. Being his Mom is a roller coaster ride and life seems to be full of both joys and sorrows that I need to channel somewhere. I don't consider myself to be all that creative. When I write, I just let it all out - whatever's in there, good or bad, it just comes pouring out.

2) How have seizures (mine or others') affected my life and my creativity?
My son's seizures have affected my life in many ways – I could write endlessly about this – but basically we literally lived the first 3 years of Evan's life with a bag packed by the door in case we had to call 911 or go to the ER. Evan's seizures have been just a part of the roller coaster ride. He has had periods of being seizure free and periods of 150 seizures a day. And when they are bad, they affect nearly every aspect of our lives. But we try very hard to not let them dictate what we do or don't do. We try and treat Evan like any other kid. Things have gotten a little better over the years. Evan is still seizuring 10-20 times a day, but we are handling it at home better now. I worry constantly, every single day.

3) What is my seizure diagnosis or seizure frequency?
Evan's seizure diagnosis is Lennox Gastaut Syndrome. He has several different types of seizures and has about 10 to 20 a day right now. He has had periods of time when he had 150 a day and he once went seizures free for 8 or 9 glorious months.

4) Other information that describes me...
After Evan was born, I became a stay at home mom. I like to read and write. In all I do, I am a Mom first - to Evan and also to our typically developing daughter, Ellie Mae, who is 15 months old. Seeing her grow and change each day is both exhilarating and sad, because it really shines a light on what we did not get to see Evan do. I am a wife of 10 years to Jeremy, the best Daddy in the whole world. I also work a day or two a week at a little shop in Spring Grove called The Back Porch. I like to read, write, spend time with my parents, "putter" around the house and take care of my little family.

Our 19th Hospital Stay

by Angela Halverson

‘In the hospital again,’ I think, as I sit on the side of Evan’s hospital bed, giving him his tube feeding.

There are some things a parent should not have to do with their child, and a hospital stay is one of them. Because, inevitably you know, at some point, you will be holding down your screaming baby (and by baby I mean the child you gave birth to, regardless of current age) for blood draws and examinations and procedures too horrific to mention.

As his Mom, I should be the one protecting him from hurt, but instead I forcibly hold both his hands down and lay across his legs so 20 or 30 electrodes can be cemented to his little head to monitor the 40 plus seizures he is having every day. I sing and dance and jump through hoops to try and distract him. He bites himself hard enough to draw blood.

We are here to do yet another medication juggle. We are always juggling, trying to get the perfect balance, as few seizures as possible without unleashing the nasty side effects. Evan has been on twelve different seizure meds over the course of his life, and all of them have had their side effects. From mood and behavior issues to drooling, lethargy, and weight loss. The worst was a life threatening drop in blood platelets. That was scary. But we keep trying because, well, what else can we do?

So, here we are, in the hospital again. I look at Evan and I have to laugh. Right now my boy is smiling wide because he just got his lunch tray. It’s pizza. He is such a trooper…and I am trying to be one too.

The Day of Acceptance

by Angela Halverson

It is Sunday morning and something wonderful happened this morning. Evan was up late last night – he is finally feeling better after his bad cold – and was in the best of the best moods. Jeremy and I decided to stay up with him instead of putting him to bed at his usual time so we could enjoy his good mood. It's been a while since he has been this happy and playful and responsive!

I fell asleep on the couch sometime after 1am to wake frantically at 9:30 am this morning! Oh my God! Evan's meds and first feeding are suppose to be done at 7am, and here I have missed it and I was freaking out. I ran to the kitchen and found the dirty syringes and med cups telling me Jeremy had done Evan's meds and feeding. So I went upstairs to check on my boys and here they were, both tucked in our bed, sleeping soundly. What a picture.

I sat down at the foot of the bed and just watched Evan sleep. The most amazing feelings came from out of nowhere. I noticed how perfectly shaped his head looks – no one would know that a good deal of his brain is not there, and what is there, has never and will never grow. I noticed how perfect his little pink mouth looked even though he can't and probably never will talk. I knew that under those little closed eyelids were the most beautiful blue eyes I have ever seen even though they don't work like they are suppose to and no one seems to know why. I looked at his hands and even though I know he doesn't have the greatest dexterity, his hands are beautiful and perfect and so tiny compared to his dad's. I looked at his little body and, watching him sleep so peacefully, you would never know that it just doesn't hold him up like it should. His chunky little legs will probably never carry him across the playground, but you would never know it by looking at them because they look strong and healthy and perfect. And then I looked at his sweet, angelic face again and instead of crying like I usually do, quietly and by myself so no one will see, I felt at peace that this beautiful child is mine. I wondered how I could love him so unconditionally when he has driven me nearly over the edge more than once, and even through the struggles and battles and grief – I would still give my life for this precious child if asked.

And in that moment I felt a peace come over me like I haven't really felt before – like all of the "what ifs" and "if onlys" and "I wonders" and "whys" flew right out the window. This IS what is supposed to be for me and nothing else – it is difficult and trying and tiring and hard. But it is also wonderful and lovely and peaceful and serene at times, too.

Now, I am not sure why I am feeling these feelings today – maybe because I am so relieved that Evan is feeling better or maybe I am still half sleeping or maybe I am getting my period. But it doesn't really matter. I am so in love with that child sleeping upstairs it makes my chest ache – and I thank God for giving him to me and not to someone else.

Author Background

L. E. LaRue

age 33, person with epilepsy

1) What inspired my written work?
The inspiration of the written work is my life, and how I've progressed while living with epilepsy. Hopefully, reading my story inspires people.

2) How have seizures (mine or others') affected my life and my creativity?
Seizures have affected my life and creativity in many ways. More likely in more ways than I ever fully realize. My memory is quite good, as many have said so to me. It might have actually improved. If it affected my creativity, it did so by making my writing better, since I was often more comfortable being alone than in social situations.

3) What is my seizure diagnosis or seizure frequency?
Since age 10, my seizures have been rare occurrences. Recently I had my first EEG in more than 20 years, and it was normal, which makes me feel good.

4) Other information that describes me...
I think what I wrote describes me well. Naturally, I feel fortunate to have lived a mostly normal life, as I know not all have. Not only do I work full-time, I have plenty of hobbies and interests going on in my life, besides my line of work, which includes traveling. Some family and friends say they envy me, which is definitely flattering.

My Life with Epilepsy

by L.E. LaRue

Do I look at the world differently since I have suffered from epilepsy? Probably. When looking at it this way, there have been two distinct segments in my life: before finding the Epilepsy Foundation, and after I found it.

I was diagnosed with epilepsy early in life, according to my mother it was at age four. I don't recall these first seizures at all, I was too young apparently. I was on Dilantin until age ten, and the doctors at the University of Iowa must have been satisfied with my condition after this visit, which included a brain-wave test (EEG). I can't recall how I really felt about having to be there, even if only as an outpatient, all I know is that I was a kid and I was there because I was told I had to be there. I told my fifth grade teacher I had to "go to Iowa City" but didn't say why, and would have to miss a day of school for it, since the University's hospital was 80 miles from my hometown. I know I wasn't thrilled about having the electrodes glued into my hair for the EEG, I found out they don't do it that way anymore. And I recall the Dilantin actually tasted good, sometimes pills can taste bitter.

I don't know if it ever was Mom's intention to make me feel ashamed about having the condition, but I learned to be. She told the story many times as to why I wasn't allowed to have a sip of my dad's hard liquor when I was a child, as she read it was fatal for a kid who had epilepsy, and didn't want it to happen to me. I really would have liked having Dad's input about this more often, but his job required him to work irregular hours, so he often was unavailable. He later told me how the doctors expected me to 'outgrow' it, and I have read some about how epilepsy is just a childhood condition for some. But it can be hard to know at times what can be believed, when I've read conflicting information. One book - don't know how old it was - said it cannot be completely cured. So I wondered, is that true for me? This might explain some of the things I've experienced over the years - like shaking for a second or two in the middle of a class in high school, possibly "petit mal" or "absence" seizures.

My mother's attitude about the condition may have been due to ignorance, or just being overprotective. I grew tired of hearing 'don't do this' and 'don't do that' all because of how I had seizures. I would much rather have heard about what I still could do. In high school, the matter was brought up three times in particular. The first was the school's blood drive, they had standard questions such as 'have you ever had seizures?' And I had to say yes, though it had been a number of years. I wasn't allowed to donate, too much of a risk. I told my classmates I couldn't donate for a different reason - a cold - because I was uncomfortable with telling them about having epilepsy. (Most of these friends probably still don't know to this day, as I have told only one friend - from work - about it.)

The second was when the school nurse called at the start of my senior year, saying she saw it in the health statement. Mom took the call, and she was obviously annoyed by it. She said I had been released from the hospital seven years ago, and to leave us alone. She was so disgusted that she hung up right away. The third was when the military recruiters called. Mom ordered me to turn them down, as there were other ways to pay for college besides the military. She also said the military wouldn't want me anyway, due to my history of epilepsy. What was my attitude about it? Thanks but no thanks, when told this was the one good thing about it as it still sounded negative to me. This wasn't entirely true, as my older brother had tried to pay for college with the GI Bill. He didn't even last through basic training, and received a medical discharge. He had epilepsy - not as bad as mine - but claimed it was recurring. The recruiters were informed about the history of epilepsy, and took him anyway, though he was borderline.

I had my reasons for refusing to tell my friends about having epilepsy. I was too afraid that ignorance would prevail, and I didn't want to lose friends over it. I wanted friends, who doesn't at that age especially? In addition, I thought it was better than being too open about it (wearing it on my sleeve) and forcing people to accept it, making it a litmus test. I know how many people have a closed-minded attitude about things they don't understand well, because they're afraid. It may explain why the school nurse called the house, afraid that it was a much more serious case than it really was, afraid that she may not be trained well enough to handle it. I just couldn't find a way to tell friends without them being worried about me. And I definitely didn't want their pity, or to be treated like a leper, or like damaged goods. What would I tell them? It's been largely nonexistent in my life since age ten, and was never serious enough to prevent me from getting a driver license. I figured that the attitude of some would be, 'Then why did you tell me?' I had a decent number of friends in school, but I was bullied at times as well and definitely didn't want to be taunted because of it. I did have problems with low self-esteem, possibly due to knowing relatively little about my condition.

In spite of all of this, I did do well in school, well enough to get accepted into the University of Iowa - the same place where I once received treatment. I graduated with a degree in history. This is what I would tell people who have epilepsy: it doesn't have to be the last word about your life, since it wasn't for me. It helps that there are public service ads to raise awareness about it. I recall one while in high school that began with "Bonjour, I'm a French teacher." It went on to say how many of those who have epilepsy can still lead normal lives.

Has it always been peachy living with epilepsy? No, especially when I know some people use it as an excuse to be mean, push people away. When my mother got remarried (my parents divorced) I was 15, and at the reception, the wife of my stepfather's friend yelled at me, saying, "Get away from me, you stupid kid." Her epilepsy was worse than mine, and most people didn't like her because she was mean. I was told that she would self-induce seizures to get attention, and use it to control her husband, which I always thought was wrong. Never saw any of these self-induced seizures, and I have no idea why anybody would want to do that - use it as a tool and as an excuse to be mean.

Eventually, I reached the second segment of my life, epilepsy-wise, which was finding the Foundation. I finally decided to educate myself more about epilepsy for some reason, maybe due to moving to a new state and feeling so alone. The support groups have been helpful, I feel more willing to share with others when I know I will probably be judged more harshly in the rest of the world. This segment began nearly three years ago, when I first shared my story on the Foundation's website. I spoke of how I called it "living with the secret" and referring to an episode of "Different Strokes" that dealt with epilepsy. I didn't think it was funny, as the main character (Arnold) said, "Hold my milk, I want to do a milkshake," after seeing a street performer suffering a seizure. Hopefully, what the show's producers were saying was how unfortunately there are some who don't understand it, and will just make fun of it. I'd like to think they were also saying this attitude is WRONG, because it is. But I can't recall every detail of this episode, as to if that message was conveyed before the show ended. We owe a debt to Tandem Productions for their willingness to tackle certain subjects that others wouldn't. This same company produced the TV show "All in the Family"- which showed how bigotry of ANY form is wrong, since Archie Bunker's bigotry often got him into trouble with somebody.

The support groups are a great way to educate, and find advocates, though at times I can be lost when others are discussing what medications they're taking, meds I'm unfamiliar with. But I'm listening and trying to understand as best as possible. The quarterly newsletters are great as well - annual events like the Stroll for Epilepsy, the picnic in July, and the Twins baseball game. I like the back cover's message on one of these, a teenager saying she wants her friends to know that epilepsy is something she has, not who she is. This is likely the reason why I was unwilling to share it with others - I didn't want to be known as the “seizure kid.” I know it happened to other classmates - those who had cerebral palsy or cleft lip and palate.

The conferences offered by the Foundation are excellent as well, they sponsor two a year. Hearing experts on epilepsy is helpful, as what they’re saying is likely applicable to your condition in some way, somehow. One memorable statement was made at a conference last year, about how those with the condition are less likely to be married and have kids. Sadly, this is true, and I know this personally as I haven’t dated much. The way it was worded is likely why: ‘those who epilepsy can have self-esteem problems.’ One example was given of an intelligent woman whose colleagues wanted to fix her up with some eligible bachelors. But she kept saying no, afraid of being ‘found out.’ That resonated with me, seemed to explain my situation a little better. I’d like to think that things are changing for the better in my social life, but it’s a slow process, slower than I really care for.

There of course are plenty of other events sponsored by the Foundation. Can’t forget a few of these other events I’ve been a part of so far, like the Lobbyist Day at the state capitol and the art contests. I was moved by one piece or art in the Foundation’s offices, using mostly orange, and mostly depicting the woman’s hair. I did enter the art contest, and called my artwork “Finally Over The Top,” but I’m better at writing than art. And an art display at a local college reminded us of famous people who have had epilepsy. More recently, this might include Supreme Court Justice John Roberts, and it wasn’t easy to hear how the media discussed his seizure so critically and even questioned if he was fit to serve. I thought it was absurd.

As a baseball fan I wanted to know if any baseball players have had the condition, but mostly had to look it up myself. There are some, including Grover Cleveland Alexander, whose life was the subject of the movie “Winning Team,” starring Ronald Reagan. I don’t know if Larry Dierker also has epilepsy, but it meant something to me when I heard of Dierker’s seizure in the dug-out as manager of the Houston Astros about eight years ago. If it was due to epilepsy, I had wondered if he had ever tried to hide it like I had, afraid of being judged by it and not by his baseball skills. I recall wanting to send a card saying, ‘I understand, since I have had epilepsy,’ but unsure why I didn’t. Maybe I was afraid of being unable to stay anonymous, which is what I wanted to do in the worst way since it was BEFORE I found the Foundation. If anyone is willing to expand it to other neurological conditions like Tourette’s Syndrome, it likely would include more famous people - like Jim Eisenreich, a baseball player. It was tough to read his story, about how he was called ‘Oddball’ in school due to his condition, as the tics from Tourette’s Syndrome are just as uncontrollable as epilepsy. Tolerance and awareness are what can break down barriers with any medical condition.

I know there might be other like me out there that are just like I was - ashamed of having epilepsy. But it’s been easier to live with since I’ve embraced it more than I had, accepting how it’s part of who I am, like it or not. There is no need to feel ashamed of it, because the feeling does you no good. There is hope, there are advocates, and there are people who understand and won’t judge you. But it means taking the first step - finding them - like I did.

Author Background

Mike Mielenhausen
age 14, person with epilepsy

1) Other information that describes me...
I am a Shining Star. The Epilepsy Foundation of Minnesota's Shining Star Program invites all kids with epilepsy to join and to connect with other kids who have seizures.

Living with Epilepsy

by Mike Mielenhausen

I had my first seizure when I was 4 years old. When I got a little older and knew more about my seizures, I was really scared that I was the only one. After a while, that feeling disappeared because of various programs at the Epilepsy Foundation. In 2003, I became a Shining Star. The Shining Star program is a fun way to get to know other kids with epilepsy. All you have to do is send in a form telling a little bit about yourself, then they send you a cool-looking certificate and the official Shining Star's medal. The Shining Stars all got to sing "Take Me Out to the Ball Game" at a Twins game and there are other cool and fun events that go on.

Another fun thing that the Foundation does is a program called the Winning Kid. Every year, one kid is picked to represent the Epilepsy Foundation of Minnesota. The Winning Kid gets to do fun stuff like: make speeches, throw out the first pitch at a Twins game, and go to Washington, DC to talk to the senators about funding for epilepsy research and events. I was the Winning Kid in 2004 and it was really fun! Another fun thing that the Foundation does is a fundraiser called the Stroll for Epilepsy. People raise money for the Foundation, and then we walk (or stroll) around a lake for a few hours. It's a lot of fun, and each year more and more people come. The cool thing about the Stroll is that there are 4 strolls: in St. Paul, in Rochester, in St. Cloud, and in Duluth. The best part is that no matter which one you go to, all of them will be a good time. *[The 2008 Stroll is also taking place in Fargo, ND. – editor]*

Aside from all the events and programs the Foundation has, you have to look at the staff behind the programs. As I mentioned, I was feeling really isolated when I first found out I had seizures. Once I met the staff at the Foundation, I felt reassured that it wasn't just me who had epilepsy. They really helped me to meet other kids who are in the same boat that I am in. The cool thing about meeting other kids who have epilepsy is that I'll always have my other friends who don't have epilepsy, and that's fine. But now, I know a lot of kids who do have epilepsy.

I also really like learning about famous people with epilepsy including: Saint Paul, Alexander the Great, Julius Caesar, Joan of Arc, Napoleon Bonaparte, Dante, Flaubert, Paganini, Tennyson, Byron, Charles Dickens, Fydor Dostoyevsky, Molière, Lewis Carroll, Agatha Christie, Handel, Beethoven, Vincent Van Gogh, Isaac Newton, Alfred Nobel, Richard Burton, Danny Glover, Elton John, and Neil Young. I would never have guessed that any of these people had epilepsy. I find it encouraging that such famous and accomplished people have had seizures – it proves that we can do anything we set our minds to.

Right now I feel hopeful for those of us with epilepsy. The reason is that we have plenty of good neurologists and research scientists who can try and figure out what causes a seizure and how to stop it. We also have the staff at the Epilepsy Foundation so until that does happen they will be there for us. One thing that I'd say to someone who just found out that they have epilepsy is this: epilepsy is just a series of seizures. Your seizures are not you, and you are not your seizures. I would also tell them to get involved so they can meet other people with epilepsy. When the Shining Stars started, I met a lot more kids with epilepsy and that's one of the biggest ways you can make friends who can understand what you're going through.

One final thing that I'd tell someone with epilepsy is that if anyone ever makes fun of you for having epilepsy, tell them it's too bad that they don't have epilepsy because you get to do lots of fun stuff and they don't!

Author Background

Marie Olson
age 50, mom

1) What inspired my written work?
I wrote this one day after hearing the school say he just had another drop. This happens weekly, but usually he doesn't get hurt. I guess being 6 feet tall will do that. But I want readers to realize that with a special needs child nothing is "JUST" - there is almost always more to it. I hope it helps people to understand that you never know what to expect with seizures - our normal is not like anyone else's normal.

2) How have seizures (mine or others') affected my life and my creativity?
I am the mother of 3 teenagers – 18, 16, and 15, two boys and 1 girl – Jonathan, Alexandria, and Matthew. Two have seizures and one we are still trying to figure out what is happening. My husband also has a seizure disorder. Son Jonathan is non-verbal and functions at a 2 year old level - he's mentally handicapped.

3) What is my seizure diagnosis or seizure frequency?
With 3 in this family having seizures, I've learned lots. It has made me realize that the normal day-to-day stuff is a breeze. I've learned to take life one day at a time. Like the drop seizures - you never know when one is going to happen.

Husband John (disabled) has 1 to 2 seizures a year. Daughter Xandi has up to 3 seizures a month with lots of behavior issues. She has intractable epilepsy. Son Jonathan has Lennox Gastaut - global delays. Son Matt has possible seizures or a cardiac disorder. We're trying to figure which. His spells are a couple times a year.

4) Other information that describes me...
I have 3 part time jobs – paramedic, swimming pool supervisor and teach lessons, and sub at school! I also help out at our church and teach community ed. classes in CPR and First Aid. I have my teaching license and sub at area schools. I teach CPR, First Aid, swimming lessons, and I'm a caregiver.

He "Just" Had Another Drop!

by Marie Olson

It's Tuesday, 8:30 am the phone rings, it is the school. Jonathan just had a drop seizure, and he is hurt. I ask a few more questions and find out that they really are not sure, but he either tripped or did a drop seizure, hitting his face on a nearby chair. He split his lips and is bleeding, and there is a piece of skin from his lip hanging. He is fighting their tries to stop the bleeding. He is tactile and doesn't like to have his face touched! So I let them know that I will be right there and hung up, stopping only to call the hospital to let them know Jon and I would be coming over in just a little bit.

Once in his classroom, I find a very upset young man, with a big, fat, bleeding lip and big tears! We head to the hospital to be checked out. After checking out the lip, it was decided it could not be stitched up and the hanging piece would have to be removed. It took 3 people to hold him down for the shots, so the hanging piece of lip could be clipped off. On further checking him over, it was discovered that he hurt his hand in the fall, possibly breaking bones, so x-rays were next. Not 1, but 2 x-rays were taken, as he didn't like holding still. After that we headed home, being told nothing looked broken.

After 18 years of seizure activity, about 10 of those with Jon having drop seizures, I thought I was ready for anything! This time was to be different. Later that day I emailed our Neurologist, and gave him an update, and explained the injuries, and the suspected drop. This was the first time in a year that we had to take Jon to the hospital for an injury due to a drop seizure. Thinking that I had done all that was needed, I mean he only had another drop seizure! Boy, was I wrong!

Two days later, on a Thursday, the phone rings, and it's our doctor's scheduling nurse, our doctor wants to see Jon in Children's Hospital in St. Paul, for a 72 hour Video EEG! "Because Jon had a drop seizure, and was hurt." Okay, I agree, and ask when does our doctor go back on hospital rotation, and was told in two weeks. So I agree to bring Jon in in two weeks. You know how we all want to have our own doctor, the one who knows our child!

I now started to plan out what I would need to get done before that date. I thought - I have two weeks, no problem! Little did I know! On Friday morning, before I could make any plans, the phone rings, it's Children's, our doctor wants Jon in the hospital ASAP! The nurse tells me there is an opening on Monday, but that is not going to work for us. My youngest has a doctor appointment on Tuesday in Wadena for a cardiac check up, and we need to keep that. Plus, I don't think I can get everything ready by Monday morning. We agree on Thursday! The plan is to be at Children's in St. Paul on Thursday morning by 11:30 am! My mind is spinning, it is a 5 1/2 hour drive from our home to Children's, so that means leaving home around 5 am that day!

Before I get hung up on the time, I have lots to get ready! First, I call the county and talk to Jon's worker and ask her to make arrangements for a 4 day stay in St. Paul, that means a place for me to stay and meals. She agrees and reminds me that she needs paperwork from admitting to say that Jon is being admitted. I quickly call the nurse back, to ask her to fax the paperwork, only to

find out, Jon needs to have cultures taken! Jon is a MRSA carrier, and we need to culture to see if the MRSA is active or not! A little later I find out we have to do another x-ray on Jon's hand to double check that it is not broken. Jon is not happy, we do the x-ray first, then take the cultures. ALL of this, and it is NOT even noon on Friday! Next, I work on finding people to cover my shifts on Ambulance, and as supervisor at the swimming pool. Both take a couple calls, but by supper I have my jobs covered!

Next, I contact my care attendants, the nursing service, and let them know of the change in schedule. I need to make sure I have coverage for my daughter, who also has seizures, and needs to be watched. I have to make sure all is taken care of at home, meds ready, meals planned out, and let everyone know what is happening. School is next, I let them know that Jon is going to be gone for 5 days or so, that means I am gone and Dad is in charge! That is a scary thought, as Dad also has seizures!

Packing is next, that and washing clothes, so we have enough clothes. By enough, I mean I pack for L-O-N-G stays. Jon has been known to go into the hospital for a 3-5 day stay, and he ends up there for 30 days or more. So I have learned to pack for long stays. Jon is on lots of meds, which I must bring, so all prescription must be filled. Jon is on lamictal, keppra, zonegran, depakote for seizures, plus periactin, caratine, and prevacid. That's 13 pills, and 15 capsules a day, along with 7 syringes of liquid meds a day. Also I can't forget the diastat, or the magnet for the VNS, and the formula! Diapers and diaper bag are also needed as Jon wears diapers. And any other stuff he may need.

Now it is my turn to pack my things. Besides clothes and personal things, I need to pack things to do each day. There are only so many movies one can watch! I always bring a photo album of pictures as we have been working with our doctor for 18 years. So we have lots of pictures not only for Jon, but of some of the nurses and the doctor. It is so much fun to look back at those pictures!

It is Wednesday, time to gas up the van, go to the bank for cash. Finally, double check the bags: 3 for Jon - one of clothes, one for formula, toys, and meds, and the diaper bag. I have 2 bags for myself. Hard to believe all this for a 4 day hospital stay! Now I pack the van, and we are ready to leave at 5 am!

The purpose of this stay, his second, is to monitor seizure activity, especially the "large" gasps seizures that he is having, those are the ones that are causing him to drop. The second purpose is to be evaluated to see if Jon is a candidate for the brain split surgery! This is our second try for this surgery. Back in May, Jon spent 4 days, but did not have any of the "gasps"/drops. Hopefully this time he will have the "gasp"/drops, but not get hurt! If there is enough seizure activity and he has a drop or two, all captures on the video EEG, his file will go before a board, so they can look over 18 years of medical information, and decide if the surgery is right for him. For me it will mean LOTS of research on the internet, so I have the knowledge needed about the surgery, and then with my husband and kids make a decision about Jon having the surgery!

SO, ONE DROP SEIZURE, early one morning at school, leads to a couple hospital visits and 6 days of planning, packing, and scheduling, all to end up in St. Paul Children's Hospital for a 72 hour Video EEG! This 1 drop seizure ends up taking 2 weeks from the drop seizure to the discharge from the hospital. We still have to wait to hear the results of the 72 hour stay, that will take a month or so. ALL BECAUSE HE “JUST” HAD ANOTHER DROP!

Author Background

Chris Poshek
age 36, person with epilepsy

1) What inspired my written work?
I was inspired to write this because I was excited about this contest and I wanted to share my story. I wanted to show what I can do and how epilepsy hasn’t changed my life. I may have epilepsy but I don’t let it run my life. I run my epilepsy.

2) How have seizures (mine or others’) affected my life and my creativity?
Well my daughter is the joy of my life and she inspires me every day. And I think having epilepsy has inspired to make sure I can educate every last person I meet that just because you have epilepsy or seizures doesn’t mean you cant be a successful active person in no matter what you do.

3) What is my seizure diagnosis or seizure frequency?
I have epilepsy. I have had two grand mal seizures but I haven't had one in nearly two years as they are controlled by medication. I do get regular blood draws to monitor my levels and yearly MRIs as well.

4) Other information that describes me...
I have been involved with the Foundation for over three years and I hope to be for some time. I have volunteered for three Strolls for Epilepsy as well as served on the Light Up the Night Gala committee.

Why Me - or Better Yet - Why Not Me?

by Chris Poshek

As I lay in my hospital bed with both my shoulders immobilized and in a half body cast many thoughts rushed thru my head. How was my wife? Was she holding up okay? What was I going to do for a job? I was supposed to start a new job today but I guess that is off. My main thought was - why me? What did I do to deserve this pain? My head hurt. My shoulders hurt. My back hurt. My eyes hurt from crying. Would I ever be the same?

That was after my first grand mal seizure. I would have a second one a year later and a year after that I would have a third seizure but these were just a few small ones. But by then I was diagnosed with epilepsy. I was scared. Would my wife think less of me? Would I ever be able to do the things I did before? I already had a sister who had epilepsy when I was kid so I knew about it but had no idea about the effect epilepsy would have on my life. In a few short months my younger sister would start having grand mal seizures and she still is battling them to this day.

I had controlled my seizures with medication and my wife and I decided to start a family and after two long years of trying we finally hit our lottery. We were going to be parents. And on that day in April 2003 my luck seemed to be changing. My daughter Hannah was born. She is the apple of my eye and there is not a day that goes by that I don’t thank the lord that my wife and I are blessed with her presence.

But then there was that day that turned black. The day Hannah was diagnosed with epilepsy. At 13 months she was having over 50 seizures a day! And I blamed myself. I thought - what did I do to my little girl? Could I have done something different? Did I pass this on? I was foolish because I know that is impossible because epilepsy can’t be passed on and even though it seems to run in my family there is no genetic link.

So after some more crying I came to a realization. Why Me - or Better Yet - Why Not Me? Hannah needed a voice. She needed someone to speak up for her and my wife and I decided to be that voice. But how? Where could we turn? That is when we discovered the Epilepsy Foundation of MN. Their resources have been invaluable. From every member of the office to the hundreds of volunteers. I have met so many people who are in worse shape than me or than Hannah. So I consider myself blessed. I have also have people I worked with or met tell me how they have a friend or loved one who has been affected by seizures or epilepsy in one form or another. And I stress that they need to get the correct information and knowledge to make sure that they don’t lose anyone to epilepsy.

My main focus is to raise awareness. Whether it be my being an active volunteer for the foundation or telling anyone I know that just because I have epilepsy doesn’t mean that I can’t do anything I did before my first seizure. And I will teach Hannah that as well. If she wants to be the first woman in the NFL, I want her to be that. Of course hopefully it will be for our favorite team…the Vikings!!! If she wants to be a future president of a fortune 500 company I know she can. In the coming months I hope to start an annual golf tournament and silent auction in her honor. Hopefully this will become an annual staple of ours to have some fun and raise more awareness. I think of myself as someone who never looks back. But I would not change anything that has happened other than having this happen to my daughter because she is just starting off in the world. But when I see how wonderful see is becoming I know she can handle it the older she gets.

I fully know that the battle is only beginning because so many people are still so closed-minded. So many people think if you have epilepsy you can’t contribute to society. Or if you have a seizure there are misconceptions on what you should do. That is because the knowledge isn’t other there. But the foundation is changing that. And I hope to help with that and I hope my daughter will continue that after I’m long and gone. It is amazing to me that epilepsy affects *more people than Parkinson's Disease, Cerebral Palsy, Multiple Sclerosis, and Muscular Dystrophy – combined***.** Yet somehow the word is not out there like it should be. But with the foundation important work and people speaking out I know we will change that. The simple fact is as I think back about my first seizure I think I am glad it was me and who better than me!!

Author Background

Lisa Renee Ragsdale
age 57, person with epilepsy

1) What inspired my written work?
"Perfect Seizure Weather" was inspired by the fact that stress "encourages" seizures and I have had more of the former then the latter, but I don't need any more of either. The brief satire "Errant Elliptical Epileptologist" was inspired mostly by the desire to write something humorous with the word "Epileptologist" in the title.

2) How have seizures (mine or others') affected my life and my creativity?
Seizures have had a profound effect on my creativity. Previously I could sit at my desk and piano and focus/concentrate on a musical composition and make progress within 60 to 90 minutes maximum. My ability to focus/concentrate has been severely limited since I started taking Dilantin in July 2007. I can, and do, sit at my computer and write some poetry, mostly prose based upon my life. Almost all of this is simply expressing my rage, only in a more artistic form.

3) What is my seizure diagnosis or seizure frequency?
My seizure diagnosis/frequency is actually questionable. I thought the diagnosis was primary generalized epilepsy, but I have only had four confirmed t/c seizures and the last one was in June 2006. The last jerk, oops, doctor I spoke with said the diagnosis was not a certainty.

4) Other information that describes me...
I am a 57-year-old woman, diagnosed at age 55; a composer of classical music with nine of my works performed since 1994; a published photographer (will have more photos published in 2008!); a writer of grant proposals, classical music reviews, business and technical writing, as well as humor and poetry; a trainer/educator; and a financial manager. I am originally from St. Louis, MO.

Perfect Seizure Weather

a story by Lisa Renee Ragsdale

Nice blue sky. A few white cumulus clouds drifting in from the west. Perfect weather for outside photography. Unless, of course, the desired effect was for less than bright sunlight. On the other hand… Wasn't it Harry Truman who was quoted as saying: "Always hire a one armed economist, that way he can't say 'on the other hand."

On the other hand I needed to find a job. I had recently left working in a typical cube farm performing icicle customer service. The company was not very friendly. They knew that I had epilepsy, but they had a pretty lackadaisical attitude. I had not informed any of my co-workers, they did not need to know. And only one supervisor knew about this. Then one day, they came up with a typical corporate non-excuse to present the front door to me requesting that I not return. They did receive a surprise at that time. As it was the beginning of the day, I told them I was not leaving until I could return to my desk to retrieve my personal belongings and to the employee lounge to pick up the lunch I set in the fridge. They looked at me like I had just broken the law, but allowed me back in.

No more cube farms, no more icicle work. At this time in my illustrious medical history, I had had but one major seizure, and it had happened ten months ago in the early morning hours. Today this wonderful weather made me want to go out with camera and photograph anything of my fancy: old buildings still standing with the names of extinct companies on their sides, people standing waiting for buses with the wide variety of people that ride the buses, juxtaposition of old and new buildings, the building cumulus clouds coming in, whatever I fancied.

So off I went with camera in car, most of a tank of exorbitantly cheap gasoline, and a few ideas of places to go. I had almost no money with me but I did have an emergency credit card. I also felt that getting out of the house and getting away would permit the aging brain to come up with new ideas for work. First stop was downtown. Found a cheap (no meter) place to park, and started walking. It was still mid-morning. I took a few shots with my twelve hundred dollar digital camera, and decided to head out for more spacious skies. It was just too nice a day to not take advantage. I grabbed a fast food lunch on the way out.

Only those photos can really describe the luxury of being out of a metro area and enjoying the scenery. I parked near a railroad track and photographed two trains with that nice sky in back of them. I took a brief nap, and decided to head back toward my sky-less home. About five minutes on the road, and my car made some strange noise. Next thing I know it just stops. Stops? My car? It just stops? Hey, I keep this thing tuned up. Is it mad at me for joking about cheap gas? I am trying to think, as clearly as I am able, what the best thing is to do. Hey, don't I have a cell phone in the compartment? Yes, I do. But it does not work. I forgot to keep it charged. So much for that idea.

I lock up the car and start walking toward the interstate. I think this would be the most logical thing to do sans (without either) operating car or cell. It takes me thirty minutes to get there. I am not certain what I am going to do when I get there having never been in this situation before. I stand on the side of the road hoping that even a state patrolman might pull over and tell me to get off the side of the road. Then I could tell him my car died and I needed to get a ride. At least I think that would work.

What happened to my fluffy white cumulus clouds? To the southwest they have started to clump together beginning to look like rain. Oh boy. I forgot; this is summer in the Mid-West. The weather can change in ten minutes or less. My thumb is out except for the semis and I am even looking in both lanes for state

troopers hoping for help. The only overpass I see is the one that leads to my dead car. I move toward this. Now I am even hoping for a semi and wishing I had a sign saying, “Have dead car. Please help.” By the time I get to the overpass the rain starts. The wind starts and soon I am soaking wet. Only then a state trooper pulls over.
“You should not be here. There is a forecast for severe weather with the possibility of tornadoes in the area.”
“Sir, my car died a few miles from here. Can you at least give me a ride into town please?”
“If you get in back, yes.”

Of course he would not want a soaking wet person with epilepsy in his passenger side seat. I glanced back at the sky and it was getting completely black. Then I thought of my car and camera. I was getting sick. Oh crap. The state trooper left me in a western suburb at a service station although I would have preferred to be closer in. The one thing I did have with me was that hidden credit card. I asked the person behind the counter the weather forecast, and the response I received was just “severe storms.”

“Are they suggesting tornadoes?”
“Not yet. The implication is it is possible.”
“Ok, next question. How do I get closer in to the city? My car died way out there, but I have a medical condition and need to be closer to a hospital.”
“Good luck.”
“May I use a phone?”
“Yea, ok, but make it short.”

I called a good friend who might be able to pick me up and was only able to get the voice mail. I tried two other people I knew. The rain was really coming down and the sky was pretty dark. No one was answering phones. Probably smart, but not for me. I had been shaking and experiencing other menacing signs for at least five minutes.

“How far away is the closest hospital?”
“Huh?”
“Hospital, where is the closest ………?”

When I woke up in an Emergency Department later, I was in a hospital I hade never heard of about ten miles east of the service station. There had not been any tornado. My car, however, was totaled. By hail. By some miracle, the camera and images survived.

The Errant Elliptical Epileptologist

a satire by Lisa Renee Ragsdale

Went in for my first appointment with the new neurologist. Said he was good. Told me he had been recruited away from some University. Trying to keep my expectations in line. After all this would be the fourth Neurologist in 18 months I'd see. Not much to expect after all this.

Had taken an older drug first, then put on one newer one. Said the newer one would be better for my type of seizure. Yea, ok. But the side effects of the newer drug were enough to make me prefer having seizures. Gotta accept they know what they're doing. Maybe I shouldn't be so easy going.

Show up for my appointment about 15 minutes early. By now they had seen me often enough to know my meds, my insurance, and me. Sat down with book I brought. Mystery novel. Waited and waited. Read at least 20 pages and looked at my watch. Been waiting for 30 minutes. Ok, so that's 15 minutes past appointment time.

Turned to start reading the next chapter but looked up. Same people were sitting in same chairs, still also waiting shamelessly. Maybe I should say waiting wantonly? Walked up to the young woman at the window. No one seemed to be paying attention to anyone else or to anything else. Were they on drugs?

"Hi. Yea, I have an appointment with Dr._____?"
"And your name again, please?"
"You really don't know who I am? I have been here at least five times just in the last year."
"Well, I have seen Dr._____, but let me page his nurse."
"Thanks."

Now waiting standing up. Not much different except my feet were not happy.

"Sir, his nurse said she saw him and she paged him for another patient. But ….."
"Apparently he slipped out for a smoke, huh?"
"What?"
"He snuck out for a smoke, slipped out for a smoke, or just left. He's just not here right?"
"If you will excuse me, I will page his nurse again."

I sat down again. Opened the book. Turned to the next chapter and started reading. Another 30 minutes and I was still reading. She was back in her seat. She had not called me over.

"Tell you what. I have been here for over an hour. I know you guys are busy. But I have waited over an hour past the time of my appointment. When I get home I will send you a bill for the time I could have been doing something productive. Oh, and if you ever find that guy, tell him to go back to that University where he came from."

Author Background

Barb Smith
age 56, person with epilepsy

1) What inspired my written work?
I would like to finally speak. The disabled are people, too.

2) How have seizures (mine or others') affected my life and my creativity?
Aiming for independence in a tight work market. Plus tearfully feeling family rejection.

3) What is my seizure diagnosis or seizure frequency?
I have been a partial complex epileptic for forty some years.

Channel #2

by Barb Smith

Eight hours job hunting finalized with an application at TV channel #2. They needed phone personnel during evening fund raising, so I stayed on location. Eight seconds before we went on camera, an aura briefly stopped my speaking capability. To compensate, I put my finger on the digit, the phone to my ear, and pretended to be talking to a donor. Amazingly, right on camera, only I knew of the seizure.

Walking in Circles

by Barb Smith

1.) Do you fear the unknown, or do you explore?
2.) I ask "why," then seek to learn.

Viewing out my window across the street, a middle aged man kept walking in circles. Drunk perhaps, I wondered? After a few minutes, he proceeded to the sidewalk, moving somewhat unstable. I went out following cautiously, feeling natural concern. Moments later I opened discussion. It had occurred to me, he could have experienced a partial complex seizure. After all, I walk around during mine.

Simple, but True

by Barb Smith

Conversation was going fine around the table when unknowingly, in seizure, Susan reached for the Starbucks cup. Not at all fond of coffee, she responded, "Oh pooowey."

Author Background

Lisa Stock

age 41, mom

1) What inspired my written work?
My son Tom inspired this written work.

2) How have seizures (mine or others') affected my life and my creativity?
Epilepsy has taught me how to be a better person. I manage stress much better than before, and I am a more giving and caring person. As far as creativity, through the foundation and being involved in many events, I am doing things I thought I could never do.

3) What is my seizure diagnosis or seizure frequency?
My son was diagnosed with epilepsy a little over 3 years ago at the age of 16. It has been quite an experience and has changed all of our lives.

4) Other information that describes me...
I am a wife and mother just trying to make a difference. I really enjoy being a part of and participating in the EFM events. I feel the more I can do whether it's working on the stroll, participating in events including this essay. It all helps in educating others and I will do anything to help my son and to make his life easier.

Epilepsy: What I've Learned, How I Cope, and How It Has Changed My Life

by Lisa Stock

Epilepsy, a rare disorder? No. A very misunderstood disorder? Yes.

How can there be such a disorder out there, in our world, that is so filled with uncertainty, helplessness, and lack of education. A disorder that - most often times with no warning - can leave a person unconscious on the floor seizing, sustaining injuries, perhaps multiple and even severe injuries, as they go down, their body losing total control of all motor skills. Do you ever hear anything about epilepsy? No. Why? People are afraid to talk about it. It is a secret to be kept quiet and behind closed doors, so many people think. I have made it my mission in life to help change that. All of the emotions that the person having the seizures, and the family go through, are numerous and the changes that a person makes mentally are either for the better or worse. You can either make it a burden or learn to deal with it. I have learned that the more a person is educated about the disorder the easier it is to cope. My son was diagnosed at the age of sixteen and that was a little over three years ago. That is when our life of uncertainty began.

You cannot imagine all that goes through one's head. All the questions, the wondering, the uncertainty, the helplessness. The nervousness, the studying and the learning, just to discover there is really nothing you can do.

The uncertainty and the wonder of it all. The uncertainty just kills me. How can there be such a disorder in our time with all the technology we have available to us. Not knowing what could happen from one moment to the next. As my son says, "It is like a roller coaster ride." How can the meds work fine for a long time and then all of a sudden quit working? Why does he have to have this? Why can't there be a miracle drug or cure, or more definite answers. All the questions that have no answers. Wondering and never knowing when a seizure will come. Wondering when a phone call will come that he has had a seizure and if he was injured and how badly. Will he ever outgrow it and be seizure free for the rest of his life? I don't know but I pray for that daily.

I have learned that the helplessness and the uncertainty are the hardest to overcome. I am the type of person that nurtures and "fixes" everything. So it has been extremely difficult, because the only thing I can really do is to take care of him when he is having problems and learn as much as I can about it. To cope with this disorder, knowledge, getting educated about epilepsy, is the key.

The helplessness is a whole other set of emotions. To watch your son have a grand mal seizure and not be able to do anything to stop it, is absolutely heartbreaking. The first grand mal I saw him have was terrifying. I could do nothing to stop it. I studied a lot after that and now when he has a seizure. I know in my heart that it is not hurting him. Sure, they are not very graceful to watch. But what I am trying to express is the knowledge of how a seizure happens and just to know it is not hurting him, makes it easier to cope and remain calm. Your children expect you to fix everything and epilepsy cannot be fixed in any way. To have to tell your child, "I just don't know," is very hard. I learned that epilepsy is, as I call it a "guinea pig disorder," if you will. No one, not even the doctors, know what will happen. Doctors can not give you definite answers about anything, not even the medications. They don't know if a certain medication, or the dosage, will work. Creating the proper medication dosage is a very trial and error procedure, and every person's epilepsy is different. You have to start it and get up to the dosage they would like you on, and wait and see if a seizure happens or if there are side effects. If a change in medication is needed, it is a long process. You need to wean up on one and when the dose is set, start weaning off the old med. It takes four to six weeks to adjust to the meds and then the wait begins. If a seizure occurs, they will keep increasing the dose until it reaches the max, or the effects start in. Doctors can only tell you the triggers of a seizure, but you need to see what the actual triggers are for yourself. You need to learn by what you are doing, and what is all going on around you, prior to having a seizure, to avoid a possible seizure the next time. You have to learn and investigate to figure out your own personal disorder, because everybody is different. There are no quick fixes with it at all and no long term fix or cure. Sometimes when you think you have it somewhat figured out, something changes and a new adjustment of meds or dosage takes place. As a parent I am on call twenty four hours a day. Everyone has all of my phone numbers and family's numbers in case something happens. I always need to be accessible.

Nervousness. I myself am far more nervous individual since this all began. I used to be laid back and not too much bothered me. Now at times my brain seems to be going 90 miles an hour. Am I nervous all the time, three years into it? No. In the beginning, before I learned to deal with it, I would make myself sick with worry. There are times when I get a bad feeling and just brace myself for something to happen. When that happens I will call my son and tell him to make sure he is getting enough rest and taking care of himself. I will do anything to avoid a seizure, if I could stop them it would be better, but that is not up to me.

I turned into a magnet for any information I could get my hands on about epilepsy. I studied and spent numerous hours on the internet hundreds of phone calls to his doctor just trying to figure it out. In fact, I am still trying to figure it out. When my son went through a rocky spot with seizures coming every month with partials, injuries, concussions, and side effects from the medication. I thought I have got to do something. I decided to call the Epilepsy Foundation in St. Paul. They were very helpful and put me in contact with Lori, the coordinator for the St. Cloud area. I decided I needed to get involved and contacting Lori was the best thing I ever did. The first thing I realized was that we are not alone and that was huge. I was astonished with the facts and figures as to how many people had this disorder. My son didn't have a rare disorder just a disorder that people are afraid to talk about. The myths and stigmas associated with it really upset me and I have made it my mission to educate others to make my son's life easier.

I still am a magnet for information about epilepsy. Whenever the opportunity arises I take advantage of what I have learned and our family's personal experience to educate others. I worked with his high school and his first job which happened to be at the plant I work and had a seizure that educated 100 people in one day. At an EMS meeting I did a little class about epilepsy with facts and figures and my son's story. I have found others who have had seizures either when they were a child or they have just had their first one. A lot of people were just curious and I took the opportunity to tell them all about it.

Through the foundation I have learned a lot. I have never been involved with anything like that ever. The many great people I have met to share the stories about the lives we all live has been very inspiring. The many family fun events that we have attended to connect all the families have been a lot of fun. The internet email support group we have put together called e-chat is a great help. You can ask questions about medications, doctors, diets, anything really, or just vent, and most importantly keep in touch. Just knowing you are not alone is priceless. Our family was also very involved in the stroll this year and that was the most satisfying project I have ever done. The amount of support we received from our community was phenomenal and a truly wonderful feeling. I really felt I was accomplishing something and educating people all at the same time. That is my mission. Just knowing that I had played a small part in such a successful event is something I will carry with me forever and cannot wait till next year.

Being a little over three years into this journey and with him moving away to college opened up a whole other set of emotions. The difference from the beginning till now is the knowledge we have gained. We understand what can trigger a seizure, what to avoid and know a lot more about the condition. How do we cope with it? I think part of us being at ease is the great attitude our son Tom has about it. From the very beginning we have never made it a burden or placed too many restrictions on him and I think that helped him. We don't tell him he can't do something we simply make a suggestion and let him decide. That gives him a sense of control over the condition. With him moving out he has even more control over it. It is his responsibility to take care of himself and most importantly to take his medication. We couldn't be more proud of Tom. We have learned a lot from him. His great attitude has given us peace of mind. He will not let it control his life. He continues to do the things he loves and is determined to make his life a success. The most important thing is he lives his life and is happy. What more could a parent want.

God has a special plan for him and I don't understand what it is yet. I thank God everyday that his seizures are controlled for the most part with medication and that it is not a lot worse and for him to keep him safe. I still worry continually about him. I would take this disorder from him in a heartbeat but that is not God's plan.

So now you know of our journey. Not only have we learned a lot about epilepsy but about ourselves. You know about some of the emotions and how I deal with it. We have made changes in our lives and the changes have been for the better. I went from having total control to having absolutely none and I can deal with that. I have met many great people and have a sense of accomplishment. Epilepsy is a very scary disorder but with knowledge, understanding, and a good attitude a person can overcome anything. As my son says, "When a person gets knocked down it's important to get right back up."

My goal in life is to educate others and give them an understanding about the lives, not just ours but the lives of all the wonderful people I have met. Understanding and knowledge is the key to help dispel the myths and stigmas associated with epilepsy. I will do anything to help my son and all the wonderful people out there affected by it. Epilepsy is a very deserving cause and I applaud everyone afflicted and affected by it. They are all very special people. It has changed all of our lives, for the better. It has opened up our minds, our hearts, and our souls. We are more giving, more sharing and more caring for all others, unfortunate or not. This has been and still is a very powerful experience. We are a closer, very fortunate family. If there is something I can do to make a difference in one person's life, my life mission will be complete.

Author Background

Krista Stotko

age 20, person with epilepsy

1) What inspired my written work?
I journal and listen to music when I'm having a hard time. Sometimes I even journal when I'm really happy. I have a hard time expressing my feelings to others, and asking for help. The number one reason why I wrote this is because I haven't expressed to Lynn how important she is to me. I'm planning on letting her read this, but I'm going to wait. She's really helped me out a lot and I really want to say thanks in a meaningful way. I also wrote it because I got some of my feelings out about how hard it is to make life changes. It helped me feel better and look at it with a more positive view. Writing things down is a good way for me to let some emotion out.

2) How have seizures (mine or others') affected my life and my creativity?
I had my first seizure in June and had to go through testing, and get in to see a neurologist to figure out why I was falling all the time. Then on August 2nd of 2007, I was diagnosed with epilepsy. I was having several seizures a week, and it was really hard. I was having them at home, work, school, with friends, and with family. I was no longer able to work, and was missing a lot of school. I'm a really good student and my education is so important to me, and I didn't want to take a break. The school supported me and helped me stay caught up.

3) What is my seizure diagnosis or seizure frequency?
I have grand mal seizures and the frequency has just started to become a lot less. I started a new medication recently and it appears to be working. I'm still on a small dose, so I'm hoping once it's increased I'll be able to return to work. I think this is the medication that will help me get my life back. If it's not, I'll be ready for whatever comes my way.

Fighting Epilepsy

by Krista Stotko

With frequent trips to the hospital and seeing multiple doctors, I finally hear my diagnosis. A few months ago, I was told I have tonic-clonic or grand mal seizures. I told myself, “This isn’t too bad, and I can get through this.” What I didn’t realize is that my life was about to change. They started me on Keppra, my body was not responding and I was having seizures weekly. I was trying to attend school and work, but I got pulled out of work and missed a lot of school, where I had a lot of episodes. The doctor added a medication called trileptal, which decreased my seizures, but I was still having a lot. The problem with this medication is that it made me extremely dizzy to the point I couldn’t get out of bed.

They decided to do in-patient treatment and the staff there were incredible nice. My favorite guy was the nurse practitioner, David. He was fun to talk to; he sat with me for a while and worked on puzzles. My favorite nurse was Lynn and she gave me treats. At the hospital, they changed my medication to depakote and I’m still having seizures, but a lot less often. I was hoping to go back to work, but I was told no. When I heard this, it really crushed me because right now I’m really struggling financially. I’ve been out of work for almost two months and have no income. If I’m doing well, I get to return to work in December. I thought about this and I told myself, “I didn’t think I could make it before and I did.” I just need to manage, plan, and work with what I have. I can and will do this one step at a time.

The hardest thing for me is not driving. I feel like my freedom was taken away. I’m 20 years old and can’t just get up and go meet my friends. I can’t afford public transportation and I hate depending on others. I’m not one to ask for help; I like to get by on my own. I think that epilepsy has been my biggest battle in life. I’ve struggled with fainting, tachycardia, having an ablation in my heart, and this is by far the hardest for me to cope with. My life is no longer my own. I’m not working, driving, or horseback riding. My life has changed greatly. I want my life back and I will get it back. This fight isn’t over and I refuse to lose. One of the nurses in the ER told me, “Every time you have a seizure, they kick your ass.” I said, “I’m little but mighty and I can kick ass, too.”

While trying to manage my seizures, a lot of people have been there to help - the doctors, nurses, paramedics, friends, and family. I would like to thank all of them. I’m a college student at the Minnesota School of Business and the person I want to thank the most is the dean of students. Her name is Lynn and she has greatly impacted my life. To be honest, when I first met her I didn’t want to know her. I was intimidated by her and I thought she was mean, but boy was I wrong. That was just my first impression and I hadn’t given her a chance. Now that I know her, I realize that she has a big heart and she’s kind of soft. I just know that she cares. I’ve had several seizures at the school and she is by my side with each one. She knows what to do and how to help. She understands when I miss class and is there to help me in any way she can. She’s also there just to talk to, whether it is good or bad. She’s always reminding me to eat, drink, sleep, take my medication, and to make sure I’m not driving. A lot of the time I’m like yeah, yeah, whatever Lynn. Even though I may not show it, I do appreciate her talking to me about these things. Sometimes she makes me mad, but I’m generally over it in 5 seconds. The instructors have all been understanding as well. They help me stay caught up, as I miss a lot of classes. I feel that the school has gone beyond what other schools would do to help, like helping me find rides to school. Our old dean of students, Milissa, is also a big person in my life. She even came to visit me at the hospital. I talk to her all the time and she reminds me to think positive. There are other important people in my life, but these two have helped me a lot through my journey with epilepsy.

I’ve had to make several changes in my life, and sometimes I really struggle with that. It’s really hard because a lot of things in my life have changed. It’s hard to stay concentrated and keep going. I figure when it’s well controlled and I can go back to doing some of my normal things, it will have made me a stronger person. I keep telling myself, “It will get better, just give it time.” Sometimes I just need to slow down, and take it one day at a time. The changes a person may have to make with epilepsy can be very hard. My advice is to make sure you’re talking. Don’t go through it alone, sometimes you need someone to lean on. Take it one step at a time, and remember things will get better. Oh, and listen to your doctors.