# Epilogues

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.efmn.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

# Table of Contents

*continued*

Table of Contents *continued*

# Introduction

Dear Epilogues Reader,

Welcome to the world of creative writing. This book of written works, including poetry and prose, was compiled by the Epilepsy Foundation of Minnesota (EFM) for the enjoyment and nourishment of the authors and their audiences. These written works were created by authors living with epilepsy or having a close relationship to a person with this disorder.

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

The Epilogues Committee of EFM received the works in this book during September and October of 2008. The Committee grouped all written works into three classes - **Judges' Choice**, **Superior**, and **Meritorious** – in a poetry category and a prose category. Author recognition includes a Certificate, Letter of Appreciation, copy of this book, and possible public readings or further publication of works on behalf of EFM.

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

Epilogues Contest Committee

# POETRY

Bill Aleshire
age 34, person with epilepsy

I have had seizures for most of my life. They became most noticeable when I was 4 years of age. Right now I'm employed through the city of St Cloud at the local athletic complex called The Mac. I've worked there for over 16 years and I'm proud to have such a job working as custodial engineer for them.

## sonnet on music
**by Bill Aleshire**

music.
i love that it's for me.
for it is nothing to blame.
it can help us to be what we want to be.
nothing a person says can ruin a person's name.
music is for us all.
it can make us cool.
music can make us stand tall.
for it can make anyone feel blue.
music will help you stand up.
it can also let you down.
but it sometimes makes anyone feel like a pup.
it will also make you frown.
music will always be fun for me.
so just let it be.

Connie Binsfeld
age 48, person with epilepsy

I was diagnosed with a seizure disorder after I had been involved in an auto accident in 2001. It is under control now with medication. Every time I start feeling like, "why did this have to happen to me," I remember my father-in-law who suffered and died with Lung Cancer and also my dad who died of a Heart Attack. It makes my disorder small compared to the loss of two people who were a very important part of my life. I wrote this poem when we knew that my father-in-law did not have much time left to live. I have used it to remember not only him, but my dad also, and all of those who were close to me and had to suffer before an illness had taken them from me.

## Remember Me Not
**by Connie Binsfeld**

Remember me not in my moments of strife,
Remember the many good times of my life.

Remember me not in my times of pain,
Remember the wonderful things I've gained.

Remember me not in sorrow and in tears,
Remember I'll be there to calm your fears.

Remember me not as being forever gone,
Remember I'm in a place where I belong.

Remember me not with the darkness of night,
Remember me with the warmth of sunlight.

Remember me not in the many rough times I've had,
Remember me as being a great husband, grandpa and dad.

Remember me not as being down and feeling blue,
Remember that I'll always love each on of you.

Remember me not with sadness on your mind,
Remember the love I have left behind.

Remember me not as being away and apart,
Remember me please......in a place in your heart.

Karin Corbett
age 39, daughter has epilepsy

Living in St. Paul, MN, I am a mom to 9 children. They range in age from 22 to 7 years. Our lives began on a path with epilepsy on July 4, 2007, when our now 12-year-old daughter, Marielle, had her first series of grand mal seizures.

## Beginning of Epilepsy
**by Karin Corbett**

E….. EVERYTHING STOPS !
P….. Perplexing questions and confusing answers.
I ….. I wonder why. What did I do wrong as a mom?
L….. Learning is the key of medications, triggers, and safety measures.
E….. Eventually we adjust to our new life.
P….. Periodically I cry (alone), periodically we cry together.
S….. Seizure after seizure, you may seem far away...but I wait patiently for your return.
Y….. Yes, Life does move forward, and our dreams can be rekindled.

Francine Coyan
age 55, person with epilepsy

What is the inspiration for my written work?
Poetry's lure is its passion. Whether it be sorrow, anger, or desire, the intensity of the emotion becomes entangled in my verse. I have written poetry since the 1970s, and poetry has long been a method of expression. When all else is crumbling around you, the need to convey that develops into poetic expression. "Life's Tapestry" was inspired by complex cultures in the world – the intricacies that abound around us. "If Only in Dreams" started as a dream after looking at some old photo albums, and in them all of a sudden there they were, beside me as if to reminisce of old times. We lose track of people even when we try to stay in touch, it's sad.

Other information?
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. Married and happy with my career, I am trying to work on other goals, publishing work, artistic, and poetic. I am happiest creating or listening to music. Success is being happy with what you are, now.

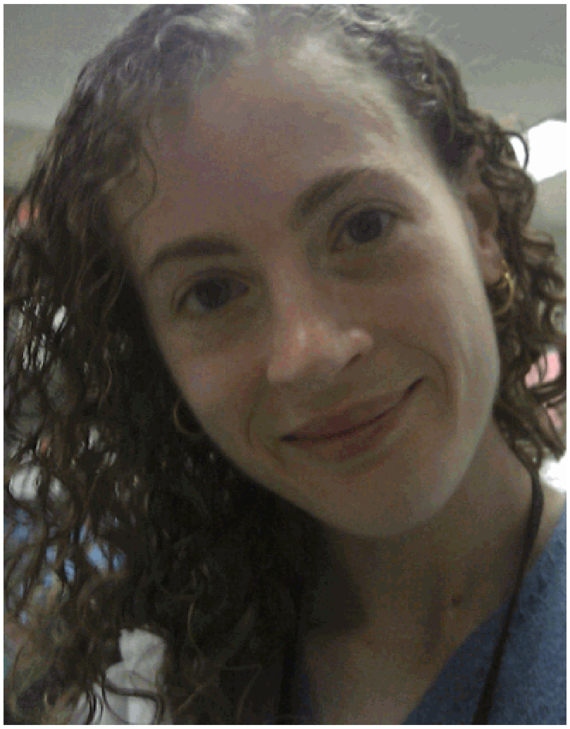
## Life's Tapestry
**by Francine Coyan**

Life, woven: in a weave that reflects our culture
Past, Present and Future
Our lives are the threads
Creating the patterns of the weave
Its colors reflecting our souls' substance:
Much of the cloth is embroidered
As we shape our dreams
While the rest remains pure
Colored by joy brought forth
As the embroidery's hues
Adorning our voices
Influencing the choices made
Embellishing our beliefs
While the rest remains pure
As the expression of its Creator

## If Only in Dreams
**by Francine Coyan**

In my dreams
What seems hard to express
In the light of day
Makes perfect sense in my dreams
In dreams you are back again
Back from old photos of laughing friends
To stand beside me now
Filled with delight and admiration
To hold you in my heart once more
If only in dreams
To have those times recovered
Days spent with you revived
If only to remember
What memories can not uncover
No more tears for what has been lost
The chance to talk with lost friends
The chance to relate insights discovered
Would it not be profound?

If only in dreams;
Walking through the past
With you again
Life is new and strange
A sensation of buoyancy
As if the air is too thin
Or too little gravity to hold me
Extraordinary the taste of freedom
With the promise it holds within



Sarah DuCloux-Potter
age 29, person with epilepsy

### What is the inspiration for my written work?

Both "Medication Mumble" and "Magic Potion" are inspired by my medications. One of my most hated side effects has been word loss. I can still write fluently, but if I try to say what I'm thinking out loud, it comes out as mumbo jumbo and I feel like an idiot. It's very frustrating because I know I'm literate and intelligent, and I want to **sound** that way, too!

Other times I can't recall a simple word – as simple as "apple" – just because I want to say it. It's maddening. There are so many side effects, sometimes I've considered quitting the medicine over and over and over, just to see if the increase in seizures would really be worse than being tired, nauseated, and sounding stupid all the time.

"I Am Me" was written quite a while ago after I had a seizure at work and people were treating me funny. I'm not sure what inspired it other than the fact that I was trying to make myself feel better and take the focus **off** my seizures and back onto **me** as a person.

### How have seizures and epilepsy affected my life?

At first epilepsy affected me a lot because I was afraid of it. Now I don't really think about it anymore, it's just become something that I deal with once in a while. The driving thing bugs me the most – that still affects me a lot.

### What is my seizure diagnosis?

Partial complex with rare secondary generalization. Mainly during sleep.

### Other information?

I'm married to a super cool pre-school teacher and have a daughter in 5th grade this year. I work full-time and also have some fun hobbies. I'm really a lucky person.

## Medication Mumble
### by Sarah DuCloux-Potter

The microphone is turned on,
I can hear my
voice
being blasted out the speakers.
All eyes are turned
on me.
My upper cheeks have taken on
a crimson color.
I must admit
quite unbecoming,
as I stutter out the words…
The words that flowed so
freely
when I practiced
in front of
the moving crowd of
stuffed creatures
last night.

Chin up,
move on.
Speak clearly –
flow, rhythm, wax and
wane.
Out of the comfort zone,
I'm not at home.
Make them disappear –
those black pupils
I sink
so
deeply
into.
Those colored corneas
surrounding red-ringed
black holes
veiled in
mosquito-bitten
flesh.

Speak-UP!
Chin-UP!
Rhythm, hips sway,
sashay,
mouth move, do your thing,
you know this.

BEAT BEAT BEAT
tap
tap
tap
hear the drums!

Forget the pucker
of the mouths,
the movement
of the hands,
the eyes,
the brows,
the foreheads wrinkled
bite.
Don't sink into the crowd,
they're stuffed,
just like
last night.
Don't let the crimson
eat you.

Blind voice
Blind voice…
Where have you gone?
Twinkling lights…you're so pretty –
why are you
hiding my sight?
Plastic people,
plastic ears,
blind voice…
Where have you gone?

I turn the microphone off,
a deafening
squeal.
It doesn't matter.
They were deaf
before
it let out its
groan of displeasure
anyway.

Ceiling shatters.
It falls upon my
head.
No microphone,
my voice can see
again.
Where did the crowd go?

## Magic Potion
**by Sarah DuCloux-Potter**

Magic potion,
Cure to all that ails.
You seem to have made
A horrid mistake.

I simply must insist
This be worked out.
This miscalculation has
Caused clenching in my fists.

Sure, I am on the mend.
But what is this that
Has now transpired?
I just can’t comprehend.

Angry as I seem,
I ask for just what’s fair.
Do just what you’re meant to
Without the added scheme.

For every ail you mend,
You can’t add on three more.
Completely unacceptable,
This you simply can’t defend.

It’s not right to question
That the choice of fix is
Worse than the complaint.
A joke to the profession!

Magic Potion,
Cure for every ail.
Aren’t you supposed to fix me?
Not cause all this commotion?

## I Am Me
**by Sarah DuCloux-Potter**

When I speak…I talk too long and everything(one) fades away.
When I write…I ramble on and the blank paper becomes
speckled with ink…in time, it, too, fades away.

When I listen, I hear too much and faces melt…
they, too, then fade away.

I am impulsive, resistant, and me.
Not many people can handle my changeability.
Blindly they stumble upon me expecting me to be
the same
the same
the same
as society.

I am not.
I am,
got it?

I speak – quietly when I am to be loud,
loudly when I should be quiet.
I believe – but not in the mainstream beliefs.
I don't have favorites.
My favorite book is different every week/day/hour.
TV? Oops, I forgot to watch it.
And I can't recall the latest song.
What brand are my shorts today? I dunno.

Tell me.
Who are you?
I can tell you – once I meet you –
whether I'll like you, or dislike you.
I am not nice, I am too nice, I am charitable, I am selfish.

Sometimes I feel like a shell that lost its insides…its meat.
Floating out to sea, with nothing.
Sometimes I feel like I am whole, alive, vital…
like I could conquer the world if I wanted to.
Sometimes I feel that I don't…feel, that is.
Sometimes I feel too much,
overwhelming sensations that threaten my sanity.
Sometimes I question.
Sometimes I hold answers and refuse to give them.
Sometimes I lie. Sometimes I am too honest.

Really I just am…Me.
The half-Whole-partitioned-defragmented-contradictory-
human…Me.
Know what, though?
Me and I are extremely lucky.

Lisa Edelbrock
age 45, son has epilepsy

The inspiration for my poetry is my son, Shelby. He had seizures when younger and still is at risk. Shelby had petty mall seizures. Shelby also has autism and is non verbal.

## Over the Years
### by Lisa Edelbrock

The early years were difficult
Each of us learning our part about
Medications and the implications
On him, on us, on life in general.

The seizures taking their toll
On a small boy, who also did not speak.
The heart wrenching idea
That all I could do was watch.

Over the years
We have learned.
Same brain, same child.
Older, stronger, wiser.
Him and I.

The early years shaped us.
They made us stronger for the struggles we endured.
Wiser, for today we have deeper appreciation
That we at least have today.
And smarter, for we learned how to cope
And find the child that reached out.
We found life can be sweet and love endures
And yes, love does conquer all.
We made it through together with a bond tighter
And love deeper, and knowing that
We have been deeply blessed.

Pam Farr Seals
age 48, niece has epilepsy

**Who is the inspiration for my written work?**

My niece Kayla Marie Borman has lived with epilepsy since the age of four and is the source of inspiration for my "Seussian rap."

**How have seizures and epilepsy affected my life?**

Her chronic condition affects my life minimally, but I know that epilepsy and seizures remove any normality from doing the multitude of things that people usually take for granted. That abnormality has become normality, and Kayla is learning how to focus on the capabilities she has, like playing hockey, raising money for the Epilepsy foundation, and maintaining her progress in school at the level that's exactly right for her.

**What is the seizure diagnosis of my niece?**

In the beginning, the doctors thought she would outgrow her seizures in 1 – 2 years. But, she was not so lucky. We continue to work with our current Neurologist to try and find the right fit for all of her medications. We will be seeing an Epileptologist, on our doctor's advice, this week to see if he has any other ideas. Right now we try to live each day to the fullest, hour by hour. Things can change like the wind and you really need to learn to adjust to that. We continue to pray for a miracle.

**Other information?**

Keep pushing for a breakthrough. Kayla has been granted a wish to visit Disney World in February 2009 by Wishes and More http://www.wishesandmore.org/ located in Fridley, MN. We are hoping to have her seizures under better control so she can really enjoy this special experience.

Kayla Borman, the writer's niece

## Stick With It
**by Pam Farr Seals**

We speculate
2008
will be great
as you calculate
and eliminate
(at an accurate rate)
from your plate
each carbohydrate
that would complicate
and aggravate.
You shouldn’t hibernate
in the Gopher State.
Wise to associate
-- instead of vegetate --
with an increased heart rate,
so you chose to skate.
(Got Dad to officiate,
Mom to orchestrate).
We’ll all appreciate
every date
you’ll skate.
The team will congregate,
your body, activate;
your legs, accelerate;
your wrists, cooperate;
your stick, detonate;
the puck, reverberate.
Everything will coordinate
the more you participate.
Face-off? *Concentrate!*
Cold hands? *Insulate!*
Saturday morning? *Can’t sleep late!*
Soon
you’ll dominate
and annihilate,
obliterate
and asphyxiate,
decimate and
gladiate.
Opponents will wait,
not anticipate.
They’ll hesitate
and agitate,
hyperventilate
and hallucinate,
about meeting their fate
with “Kayla the Great.”
WE CAN’T WAIT!!

**Kacie Finley**
**age 20, person with epilepsy**

My life and my experiences are the inspiration for my writings. I am lucky that my seizures are controlled. I do have to take meds, but I can live a fairly normal life. Nevertheless, epilepsy has affected most aspects of my life in some way. I am not very confident or outgoing, partly because of my childhood seizures. I have some difficulties with the way I learn, so I have to work really hard to do well in school. My epilepsy was diagnosed when I was 4 years old and was caused by a stroke I had before I was born. Besides causing me to have complex partial seizures, the stroke left me with some relatively minor physical issues that I have learned to overcome or compensate for. I will always have to take meds. Because of my experience, I am studying to become a nurse and hope to someday work with children who have epilepsy.

## Out of the Shadows

**by Kacie Finley**

Shaking
Out of control
At church
At burger king
At school
Everywhere
Nowhere is safe
Rain obscures my view
Meds
Breakthroughs
Add meds
Change meds
Fear and frustration
Nothing works for long
Fog surrounds me
Hospital stays
Tests
Surgery
Infection
Back on meds
Control at last
The Sun shines

## Camp Oz

**by Kacie Finley**

Cabin in the woods
Wooden
And Stuffy
And buggy
And a lake
Deep
And blue
And cool
And kids like me
Cooking outdoors
Canoeing and swimming
Taking their meds
Here, we are normal
Here, we are all the same
Kids with epilepsy

Angela Halverson
age 36, son has epilepsy

Mom of two, Evan is 9 and Ellie is 2. I like to read, write, spend time with my family and putter around the house and yard.

## Hindsight
### by Angela Halverson

"Brain surgery."
I am gripped by fear when the doctor says it.
My heart pounds hard in my chest.
"…2/3 Corpus Callosotomy..." he continues...
The hair stands up on the back of my neck and my stomach twists.
I begin to sweat.
"Isn't there anything else?" my voice catches and I suddenly feel like I've swallowed an apple whole.
I tell myself not to cry.
"....medications haven't worked...."
The doctor goes on, but I can't really hear him.
I find myself spacing off toward the nurse who is sitting to my right.
She has little Dr. Seuss heads all over her scrub top.
"....our best option at this point..."
Sam I Am, Sam I Am...
Don't cry. Breathe. Don't cry. Breathe.
"...by cutting the two hemispheres..."
Sam I Am, Sam I Am, I do not like green eggs and ham...
"So, what are your thoughts?" the doctor asks.
My thoughts are, I'd rather die than let somebody cut my baby's brain in half.
"We'll have to think about it," I say weakly.

One month later..............
Evan is having 30 to 40 hard seizures a day and is now on regular doses of Valium.
We took our second ambulance ride this week and I am constantly terrified he is going to die.
I am ready to consider surgery.

Three months later................
The night before surgery and I want to back out. I am beyond terrified.
I want to turn back, go home and hide.
I cannot do this - cannot make this decision, cannot put my baby through this, cannot risk losing him.
I beg and plead with God throughout the long night.
I am not ready for Evan to leave this earth.......don't you take him from me yet.........please.
The alarm goes off and I awake to the day that I've been dreading for months.

Hindsight is always 20/20.............
My sweet and funny boy is home 4 days after the surgery.
...back to school 7 days after that
...the surgery is a success with no complications
...Evan made it through and so did I.

Jerry Hartlaub
age 68, son has epilepsy

With a son who has experienced seizures, I tried to role play in my mind an experience he might have had. It helps me to understand some of the challenges he's faced. There is always a continuous low level concern for the health of child who has a chronic condition, no matter how old he/she is. And there have been very scary acute events. My son had a craniotomy as child to remove a tumor. The outcome was generally good. The first seizure activity occurred in college. With careful life style management, the past five years have been seizure-free.

## I'm Pretty Good
### by Jerry Hartlaub

I fear each day an episode,
In fact, I feel one coming now!
Gotta lie low.
Maybe outside.
Hey, there's a chair.
I'm breathing deep and slow.
Like I told myself I should.
Seems to reeeeelax my brain.
Oh, steady as she goes.

Seems to have passed.
Hope nobody noticed.
I look around.
I feel just fine.
Shall I tell what happened?
Maybe a little tired.
Could do whatever on time.
But others may have their doubts.

Even if days or weeks
or even years have passed.
They might remember.
Raise an eyebrow.
An episode taints me.

But I know the triggers.
And I know the onset.
And I know how to be free.
It's just, I'm not perfect.
Well, who is?

Oh, I wish this would all pass.
And I could be absolutely normal.
Fitting in everyday.
But nobody's absolutely normal.
Soooo, I'm pretty good.
No matter what they say.
In fact.
I'm very good.

Barbara Hueston
age 42, person with epilepsy

I wrote this poem the day my dad was buried. I have had seizures as a child that were thought to be outgrown but came back to haunt me approximately five years ago. I had two grand mal seizures and several simple partial complex, absence, and complex partial particularly to the left temporal lobe. I have been seizure-free for almost three years but suffer from anxiety and depression.

There are times at work that it is very hard to cope; stress and lack of sleep are what cause my seizures, so I can't take on a job where I work overnights or too many hours in a row. I have also been fired from my job this past year after disclosing to a co-worker I have epilepsy. I have a wonderful husband and two boys age 18 and 13 that are all very understanding of my epilepsy and some of the emotional moods I go through having to take medications.

## Eagles' Wings
**by Barbara Hueston**

As they were preparing to lay you in the grave,
I could not turn and walk away.
There was something I was seeking and longing to see.
I needed to see an eagle, God's messenger today.

I looked up in the cloudy sky and the sun was shining,
yet no sign of an eagle in sight.
Then I looked again and one came into flight.
His wings soared toward the sunshine and heaven
as the eagle disappeared from sight.

At that very moment the sun shown down toward my husband, boys, and me,
and there was a very bright light.

It was the brightest sunlight I have ever seen on this green earth.
Now I know my dad's soul went to heaven with God and his angels
and there will be rebirth.

Lord Jesus, watch and care for him in heaven.
Let him know I love him now and forever. I will forget him never.

One day on eagles' wings, I will also soar. I love you dad forevermore.

Lorie Jensen
age 35, foster children and patients have epilepsy

As a foster mom, I have parented many children who suffer from seizures. I am also an RN with extensive experience with Seizure Disorders.

## The Seizure
**by Lorie Jensen**

It comes quickly,
          Ripping him from me.
Separating us with its great trembling energy.

It swells through him,
Leaving him a small twitching mass,
Unaware of my presence or the soothing hand I offer.

It recedes gradually,
          Allowing him to return again,
                    To my ever open arms.

**Tayler Johnson**
**age 14, person with epilepsy**

I had my first Grand Mal on 12/26/06, and I have not had a seizure in 7 months. I am a freshman at Anoka. I love to read, write, and dance! I am on the Anoka Twisters Dance team, and I am loving it!

## Epilepsy? No Excuse!
**by Tayler Johnson**

I may have epilepsy, but it doesn't have me.
Sometimes I wonder, how can this be?
I have no memories of the big ones,
Sometimes I wish it could be un-done.

My family says it's no excuse,
Sometimes it feels like a noose.
In the end, it doesn't matter,
Although it makes me mad as a hatter.

The EFMN has opened a lot of doors,
With friends like Nikki, Mike, Matt, and more.
I threw the first pitch at the Twins game this year,
I even got some official gear.

The world has opened its doors to me,
And I will be able to be all that I can be.

Andrea Jones
age 35, person with epilepsy

I am a wife, mother and teacher who happens to have epilepsy. I have had seizures since I was a child and my frustration with the condition was my inspiration for writing this piece.

## My Little Green Man
**by Andrea Jones**

I stroll through life taunted by a little green man.
He greets me each morning with a cackle. I reply in disgust, turning away and rolling my eyes.
That tiny man constantly plays with my mind; then laughs as I struggle to free myself from his relentless evil.
He lurks in barren, midnight shadows and hides behind each promising sunrise.

My little man is immensely threatening though he stands a mere inch and a half in height.
He glides smoothly throughout my body but is nice and cozy nestled behind my nose.
He is more than content pinching my cheeks and shooting arrows at my eyes.
On a whim, he fills my head with a smothering poison, such as an over-pumped rubber ball, ready to explode.

My discussions with myself, conducted once out of shear terror, are now simply routine.
"Am I shaking or twitching too much?"; "Where is the baby?"; "What time is it?"; "Sit still!"
With clenched fists and focused efforts, I continue my nervous dialogue, alert to my circumstances and to my surroundings.
"Don't let yourself be taken over by this craziness!"; "Fight it!"; "Be strong!"; "Be willed!"

Then my troll starts answering back in all his glory and his splendor.
"Just you watch this," he says, as I find myself up and twirling out of control.
For his next trick, my twitching becomes a rare sight, my throat a clicking novelty.
My bodily functions give out; the clock skips over time; the whole episode takes its toll.

My green friend does not discriminate: my physical, emotional, professional, social lives are all fair targets.
And he has no problem dropping in at multiple or even dangerous times of the day.
I am determined to go on despite him though. I am stronger than he and his games.
For my family, for anybody else with a green man dilemma, but especially for me,
it just has to be that way.

Lorna Knight
age 38, daughter has epilepsy

My daughter inspired me to write this. She's 13 years old. Epilepsy changed her life when she was 5 years old.

## My Daughter
**by Lorna Knight**

September 2008,
Was when she discovered something great.

She went out to play with the dog,
She threw the ball and started to jog.

She also gets seizures when exercising, biking and running around,
But now she was running all over the ground.

She stopped and looked confused,
But THIS TIME she was AMUSED!

No seizure, didn't feel sick, no funny taste –
Mom, I only got a headache, she yelled and off she raced!

She told me it was the first time in her whole life she could run,
She was having so much fun.

Activities we take for granted
Give her seizures and make everything look slanted.

She's not seizure free,
But we are happy as can be.

So RUN, BIKE, SKIP and JUMP!!!
Enjoy your new life without the speed bump!

Kay Irving Kramer
age 69 ½, person with epilepsy

*I've had epilepsy all of my life and have proved at every stage of it that with a positive thought and the desire to be and do like others, you can attain unprecedented goals in your life.*

## Epilepsy

**by Kay I. Kramer**

To those with epilepsy, I do say it's merely a disability for you or me,
It's not the end of our abilities to enjoy life to the fullest,
and only a hindrance if you let it be;

You are a person, whether a boy or a girl,
And epilepsy simply occurs when our brain waves become
unstable, or out of control;

It's but another of the many disabilities that people face in life,
And when we come to understand its triggers and causes in
each of us we'll be much happier than full of strife;

Following our doctors' advice and taking our medicines on time is another key,
Since doing that, as well as getting adequate rest can help
both you and me;

So, when the day is over, be thankful for your accomplishments,
So that when the next day comes you can pursue them in full
and feel great instead of nil.

## I Believe
### by Kay I. Kramer

Throughout my life, I’ve sought many things,
From which have come both good and bad tidings;

Yet, I’ve never lost my faith or hope,
In that they’ve been essential in helping me to cope;

I’ve learned a lot over my life’s many years,
The happiness has brought me joy and the sadness tears;

These teachings I’ve used much like stepping stones,
Moving through the elements life brought with each one;

Since learning is a true virtue of life,
If used effectively, it can often remove life’s strife;

Faith and trust in The Lord’s actions is the most essential key;
For He’s always with us and knows what’s best for you and me.

## Our Golden Years
### by Kay I. Kramer

As we grow throughout the various times of our fruitful life,
Be they education, family, or work, there is one thing we'll all
come to face during our older age;
They’re known as The Golden Years of life and they’re supposed to be
filled with love and joy, or so we hope;
Yet, as we grow older we come to recognize that such isn't so;
We lose a spouse, retire from work, and our bodies lose the energy they
once had,
Our entire system seems like it's beginning to fall apart and we
don't always know why or how;
What happened to Our Golden Years, many people will often come to say,
Sometimes it's just plain hard to make it through the entire day,
without coming to face some form of pain, I do say;
Socialization and Friendship with others has become important to all,
For with its use, games we play, and other types of participation,
they can often come to ease the items of depression and stress;
And at the conclusion of each day, "We should thank The Lord for another
day of life in Our Golden Years, be they filled with joy or even cheers."

C.A. Lancrain
person with epilepsy

Inspired by a friend, Betty J., and kindness in others, especially my children. No concrete diagnosis, dealing with Epilepsy since 2006. Frustrated by fear, sometimes self, more often others.

## Contemplating
### by C.A. Lancrain

Was it a blow to the head or a poison to the flesh?
What started this painful misery I can only begin to guess?
The pounds from a sibling?
Physician pills from a shelf?
I can't figure it out and I'm searching for myself.
Am I still smartened from my degree?
Beyond these chains can someone see me?
Where can I go from here, with a mind sometimes adrift?
Will someone see beyond it and let me share my gifts?

Galiena Lind
age 40, daughter has epilepsy

Who is the inspiration for my written work?
My 18-year-old daughter, Ashley, is the inspiration for this poem.

How have seizures and epilepsy affected my life?
My daughter has had epilepsy since she was a very young child. Epilepsy has not only impacted my life, but it has touched my family and many of Ashley's friends. I have become educated over the years about many types of drug therapy, diets, and surgery options. I have grown as a human being and have a respect for those who face challenges/disabilities in their lives. I wouldn't be the same mother/individual if I had not had to walk this road with Ashley. I am very blessed and thankful for her life, and no matter what life may bring, that will never change.

What is the seizure diagnosis of my daughter?
Grand Mal seizures

Other information?
I feel that my daughter is a better person because of this diagnosis. She is strong and brave, and I admire her.

## Ashley’s Poem

**by Galiena Lind**

I watched in disbelief as it gripped you wave by wave.
I felt alone and helpless against the pain.
Why the suffering, why, I asked,
And no good answer came.

You graduated kindergarten, then
On to first grade.
You were such an outgoing person,
And you were so brave.

I admired your spirit,
Tried and so true.
I began to notice,
I’d been learning lessons from you.

You taught me to smile again,
You taught me to dance in the rain.
You brought so much sunshine into my life,
That I forgot about the pain.

Before I knew it you were standing before me,
In your cap and graduation gown.
I knew it was time to let go now,
As I watched a woman cross that stage and I didn’t utter a sound.

My baby girl is all grown up now,
And I celebrate her life.
It all happened so fast,
Despite all the strife.

Now when I look into her eyes,
I see confidence and bravery.
She faced her disability head on,
Without ever wavering.

Mosmi Malhotra
age 28, person with epilepsy

My inspiration comes from the past 7 years of my seizure disorder. I was feeling down for the first couple of years. But then I realized that I have control over myself, not the seizures. Seizures have affected my life in a few ways. The most important thing is that it made me realize not to feel sorry for myself. There are other people in this world that have more to worry about than I do. Epilepsy is just a part of my life, it is not who I am. I am diagnosed with having complex partial and simple partial seizures. I am so grateful of the love and support my family gives me each and every day.

## Who I Am
**by Mosmi Malhotra**

People think epilepsy
Is who I am
That is not what defines me
Some still don't
Understand
I am a
Teacher
I am a
Daughter
I am a
Wife
Seizures are just a
Small part of my life
My life is normal
I have fun
Just like you
Nothing can stop me from
Doing what I want to do

Laurie Olmon
age 41, person with epilepsy

I have had epilepsy for the past 30 years. I am married to a wonderful man and have a beautiful son, who love me for who I am.

## My Definition
### by Laurie Olmon

The word “Epilepsy” is derived from the Greek word “epilepsia,”
which means “to take hold of” or “to seize.”

Epilepsy: A disorder characterized by
transient but recurrent disturbances of brain function
that may or may not be associated with impairment or
loss of consciousness and abnormal movements or behavior.

Seizure: A sudden, excessive discharge of nervous-system electrical activity
that usually causes a change in behavior.

Here is my "thesaurus" version:

Eminent
Lurking
Panic
Everlasting
Possession
Steal
Rob
Pilfer
Capture
Arrest
Snatch
Confiscate
Yell

This is but 2 minutes of my life,
but herein lies the rub,
which 2 minutes when.

So how do I move on, you say?
I am not an epileptic....I am a mother, wife, and human being that happens to have epilepsy, only the world chooses to make it a big deal.

Carol Ann (Oxborough) Olson
age 56, person with epilepsy

The fall season was my inspiration. I was diagnosed with psychomotor seizures at age 14. I have had to learn acceptance. Now I am a school bus aide for special education. At times I can draw on my own experiences to help the children.

## September
### by Carol Ann (Oxborough) Olson

While lounging in my lawn chair
Enjoying what the petunias vent to the air
I watched the perfectly round orange sun set
Over the housetop across the street.
I'm grateful for the sweet
Breeze
Gently gusting and rustling
Some early colored leaves
Already fallen from the
Trees.
Caterpillars have merged into butterflies.
Many baby toads hop helter-skelter,
Seeking some dark cool shelter.
Grasshoppers always skipping along.
Crickets with their constant, tedious song.
Moths in a silent, jittery flight,
Ever flitting toward the light.
I so treasure moments like
These.
Darkness creeps earlier on now.
Days have grown shorter somehow.
I didn't notice right away
Until there were less for the day
And more hours of night.
But again, it all seems right.

Annaleigh Petrun
age 14, person with epilepsy

I had my first known seizure at school when I was 8. I have been with the Epilepsy Foundation since 2001, when I was the winning kid. EFM really helped me and my family in so many ways, and we have had a lot of fun with everyone from EFM, too! I've made some really great friends. I have been going to Camp OZ for 7years and this year I will be a Junior Leader for training to become a counselor. I am now seizure- free since the winter of last year. It's so exciting, and I'm so glad not to be taking pills anymore! I attend the St. Paul Conservatory for Performing Artists (SPCPA) for dance and am in 9th grade. And I am also on the EFMN Advisory Youth Council (YAC).

## My Shadow
**by Annaleigh Petrun**

It follows you like a shadow,
lurking at your side.
I used to be ashamed,
and blame it on myself,
but it's something I just couldn't help.
It creeps up
at the most unexpected times.
Just when you thought finally it would leave,
it takes over your body,
and controls your mind,
makes you go away for a while,
and then it leaves,
and just follows behind.
Finally.
The day had come,
quiet and calm,
it stays in control
and doesn't come alive,
but still,
always by my side,
following my every stride.
It's gone to sleep,
at rest for good,
never knew it really would.
It has left me alone,
let me live my life,
with no interruptions,
me and my shadow are at peace.

Lisa Renee Ragsdale
age 58, person with epilepsy

Unfortunately this poem was "inspired" by a recent seizure that was worse than my first one. Seizures have affected / impacted all aspects of my life from my creative endeavors (e.g. composing music and photography), mobility, having any kind of social life, etc.

## A Poem of Hope
### by Lisa Renee Ragsdale

I've been asked to describe
What happened, yet all I know
Is waking to a scene of chaos
And physical destruction in my
Bathroom. My glasses in two pieces
And two places; one lens bloody;
My forehead open and bloody and painful;
No doubt indicating the strength of the force
That my face hit the floor; I can't go on with this.
I will need stitches in my forehead,
An increase in the dosage of my medication,
A tetanus shot, and fluids, of course, for all the blood lost.
What I think I need the most
Is the will to go on living.
Not because I don't want to live,
But because my resources have been
So depleted and there is
So little left and
Fewer and fewer options
To restore them.

Vesper Fe Marie Llaneza Ramos
age 26, patient had epilepsy

My inspiration for this work - and many more in my life - was a patient of mine I met while I was in surgery rotation as a medical student. He was diagnosed to have marjolin`s ulcer secondary to severe burn. He had generalized tonic-clonic seizures since childhood, and he had an unwitnessed seizure while burning leaves in his backyard. My encounter with him left such an impression on me. He gave me such a vivid account about how seizures affect lives. I am now going into residency in adult neurology, hopefully to make a difference, in what way I can.

## Gardening
**by Vesper Fe Maria Llaneza Ramos**

I still remember
Melted skin
Like candle wax
Upon a face
Recognizably human
On a head bowed down.

I called his name
His eye met mine
Or maybe because
He could not really close
His eyes at all.

I asked him how
How this happened
His voice was soft.

He had epilepsy
But he was living through
He got used to the episodes
Brushed them off
As little moments
Of occasional spotlights
And people whispers.

He could take those on.

He took those on.

But this, how this?
What this? Why this?

He was gardening
A proof to himself
He could lead
A normal life.

Gardening.
Grow flowers, plant a tree
Start a life
Gardening.

Of all the moments
In a lifetime,
Why?
While he stood upon
Leaves burning
He seized
And fell.

On the pile.

This time
No whisperers
No 911 calls
No "are you okay?"
No horrified looks
Other than
Other than
Other than
What was happening
To his own.

His face was on
The burning bush
Of dead leaves and dirt
And he could not
He would not
Do anything.

He was having
A seizure.

*continued*

His mind was not his
His body was not his
And now, in the mirror,
His face was not his.

"Can you imagine the pain?"

Minutes of your life,
You lose control,
Feels like you lose
Control of it all.

Why?
Why do the neurons fire?
Why?

"Why wasn't I left to die?"

Because
You still have to
Finish gardening.

Gardening.
Grow flowers, plant a tree
Start a life
Gardening.

I still remember
Melted skin
Like candle wax
Upon a face
Undeniably human
On a head looking up
With a soft smile.

We all need to
Do some
Gardening.
Grow flowers, plant a tree
Start a life
Gardening.

Erica Sanchez
age 34, son has epilepsy

My name is Erica Sanchez and my son, Jayce Sanchez, ad I have been living with Lennox-Gestalt Syndrome, a severe seizure disorder, since he was 17 months. Today he is 16 years old and still going strong, with the help, of course, of myself and my two younger children – Ciera, 10 and Jesiah, 7. I am a single mother, and we have all done quite well for ourselves and handling Jayce's illness…my babies deserve just as much credit in helping taking care of their brother as I do!!

## A Poem for My Son, Jayce
**by Erica Sanchez**

I want my son to know how much I care.
It hurts for me to see how life has treated him so unfair.
My tears run down my face
and my son is the one I embrace!
He looks up to me and says, "Mom it's okay."
It's so hard to know I cannot take his pain away.
Thank God for the smaller things in life my son has taught me!
But the life God has given him, I may not always agree!
His gentle touch and his innocent ways, in my heart is where he stays!
Everyone that knows him says, "He is a special boy,"
he brings such happiness and joy.
All the decisions I have to make,
I always wonder how much more he can take?
Jayce my beautiful son who I love with all my heart.
You have been special to me from the very start.
We are meant to share our lives together as mother and son.
I only wish this illness we could overcome!
Please son of mine know how precious you are to me,
it's to God that every night I make my plea!!!

Sarah Schmidt
age 56, person with epilepsy

**What is the inspiration for my written work?**

I finally have become comfortable with the fact that I have epilepsy. At first I was scared of "it". Then I tried to ignore "it". Then I tried simply to accept and manage "it". Then came the rough part. My medication controlled seizures well, but the side effects were disturbing. My life was in a downward spiral and was accelerating as it went. Change was not optional. Eventually, I pieced together a plan that worked. I became less intimidated by epilepsy. Confidence challenged the negatives. This poem was inspired by the need to share a positive attitude. Sometimes you just have to laugh. And now I can laugh at "it".

**How have seizures and epilepsy affected my life?**

Marriage, children, and grandchildren have opened my heart to impact the lives of those whom I love. Music, art, writing, inspirational speaking, and volunteer knitting for the Mayo Clinic Chemotherapy Unit 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.

**What is my seizure diagnosis?**

Seizure frequency is now gratefully controlled. I simply refuse to let epilepsy have a negative influence upon my life.

**Other information?**

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.

## In Heaven
**by Sarah Schmidt**

In heaven I will laugh at epilepsy.

I will have the strongest cup of coffee
with the most caffeine that can possibly be crammed
into any bean growing in Columbia.

I will stay up all night
and not think about the “strongest seizure trigger”
known as sleep deprivation.

I will have a glass of wine
and not worry about “lessening my
ability to drive or perform hazardous tasks.”

I will recall everything and not say,
“I don’t remember the word, but it has an “L” in it.”

I will not “suffer from clinical depression,
a serious but treatable mental illness
found in an estimated 30 percent of the 2.5 million
people currently living with the disorder.”

In heaven there will be no Lamictal.

Therefore, I will not
“take this medication exactly as prescribed
by my healthcare professional.”

I will “abruptly cease taking this medication
without consulting with my physician,”
unless he’s up there in heaven with me.

Mohamed Shivji
age 40, son has epilepsy

I have worked with the elderly in the health field for the past 17 years since 1992 as a CNA, TMA and LPN. It is my son who is now 9 years of age who is affected with seizures. To be honest, the first time it occurred it was a scary experience but having experience in the health field, I knew what to anticipate and how to act. However, when it hits home it is very different.

I'd like to let the world know that regardless of the disability one has, everyone was created special in his or her own way and needs to be treated equal. Let us not divide humankind as "normal and abnormal," for in the eyes of GOD everyone to HIM is normal. Thanks for giving me this opportunity to share my poem and thoughts with you all.

## The Plight of the Elderly
**by Mohamed J. Shivji**

Oh Elderly, aged but wise,
Give us the young all the advice,
We can learn a lot from you all,
For life isn't what it appears to be a ball.

No one may understand the thoughts in your mind,
And words for you may be hard to find,
However, whatever non-verbal expressions you make,
Should just be enough for us to take.

Some of you may have been left behind,
But you all never ceased to be kind,
However, all the experiences that you bring,
Is all, but enough to hold unto and cling.

Your physical appearance may not be what it was,
But only if you could put it to a pause,
For it is the soul that shall be with you the path ahead,
So let us not treat it as if it is dead.

This poem should be the only one coming to an end,
For we the young offer our hand,
You may have taken the steps ahead of us,
But we are all traveling on the same bus.

Krista Stotko
age 21, person with epilepsy

"The Internal Battle" was inspired out of myself. Along with my epilepsy I've battled depression, but have sought treatment, and am getting the help I need. This is just a piece of work I wrote during one of my struggles.

Epilepsy has had a huge affect on my life. I have grand mal seizures and I was having them almost daily, and now I have about one a month, sometime more or less depending upon the month. I lost a lot of my independence and that's really hard to deal with. It's teaching me to be grateful for what I have though, and I'm glad that I have many supporters by my side.

## The Internal Battle
**by Krista Stotko**

Hold me close and don't let go
I'm scared to be alone
I've been fighting and trying to stay strong
Now I want to lay my head on your shoulder and rest
And let you be strong for me
Can you handle the truth?
When I see myself in the mirror,
I can't see the joy I once felt
Nearly everyday I battle suicidal thoughts
You'd never know because I got to much pride to show it
I'm fighting this disease and taking it day by day
The dreadful word you don't even want to say "EPILEPSY"
You'd be surprised how many people it claims
It comes in unexpected
Leaving you broken and bruised
Medication change, after medication change
Finally you think you have it
When the sky turns grey with hate
And "BAM" you're on the floor
Leaving you incontinent, bloody, confused, and tired
Yet you have no control, the dreadful "E"
Just comes when it pleases
Another way to deal, another pill
If I just end it all, I'd finally be free
Sitting on my bed with a bottle of pills
Tears run down my face I start taking them 1,2,3,4...
Suddenly I think of those that I love
And I realize that I am strong and I am gonna
Get through this I get up and I leave
I glance back and I take one last look
A feeling of relief drifts over me

Karen Trudeau
age 49, son has epilepsy

This work is for my son, Dustin, now 20, who experienced seizures as the result of brain tumors. Sadly, the episodes began in Dustin's teenage years, a time of self-consciousness…Also a time when a young man wants to drive cars and achieve independence…Still, my son remains hopeful and is eager about his future.

## Starshine
### by Karen Trudeau

I believe that when stars
borrow the sparkle from your eyes
it is only for awhile. . .

And only when too many clouds
crowd the sky, does one hide
itself in you.

Your left hand probably trembles
when a bird has hurt her wing.

But I believe,
someday,
you will watch a sparrow fly
across a cloudless sky,
and the stars will shine
on their own.

Dolores Warburg
granddaughter has epilepsy

This poem is written in the voice of my granddaughter.

## WHY?

**by Dolores Warburg**

Why for some and not for others?
Why the young whose life it smothers?

Why does it have so much control
To stop our running to just a stroll?

Why do we wait so long for a cure?
This April will be my ninth year.

Why is the brain so complicated?
We don't understand it, we can only medicate it.

Why do I know I can fight this thing?
'Cause epilepsy can be controlled with meds, friends, family, and my "mom."

Stanford E. Ward
niece has epilepsy

My niece has epilepsy.

## Untitled
### by Stanford E. Ward

I have seen people that don’t understand them, when they go into seizure,
they don’t understand it.  No?

Epilepsy is something we don’t understand, but it’s something we can learn more about.
That’s a very different thing.

Don’t say you’re going through a time of difficulties, say you’re *coming* through it.
That’s a very different thing.

Coming through difficulties, coming through the worst, and yet believing in the best,
no matter what life does to you.
Always say you’re coming through it.
That’s a very different thing.

Coming through your troubles to brightness around the bend.
Coming through with banners flying stronger every day with hope to lead the way.
That’s a very different thing.

Natalie Washnieski
age 25, person with epilepsy

**What is the inspiration for my written work?**

I have always used writing as an outlet, whether it is writing in a journal or writing poetry and prose. It is a great therapy for my emotional and mental health, which is what my words are most likely about. In my early 20s when I was diagnosed with epilepsy, I was introduced to a whole new world of things to write about. Trying to capture how seizures make me feel, the emotions that go along with them, or ways this disorder has affected me is something new, something interesting, and a new inspiration for me to write about, which in a way is quite exciting.

**How have seizures and epilepsy affected my life?**

Seizures have affected my life in both negative and positive ways. I am now connected and a part of a huge group of people that I may not have given much attention to if I did not have a seizure disorder. I have also been reminded that the brain is a complex organ that we take for granted. However, I have also felt some very uncomfortable feelings, have had to make changes to my lifestyle, and have dealt with feelings of being an outsider. Despite the negativity I have experienced, I feel very lucky because many have it much worse than me.

**What is my seizure diagnosis?**

I was diagnosed with simple partial seizures in my left temporal lobe. My seizures can be better explained as "auras." I experienced these sparingly throughout childhood and never thought of them as anything serious. It was not until I was experiencing them frequently in early adulthood that I realized it was a problem. It has reminded me that life is full of surprises, whether they are good or bad.

## sick sense
**by Natalie Washnieski**

it's dull and cloudy
with a sick sense of movement and time,
like a creepy clown moving in a
slow, drugged up manner.
i try to look away.
but i become a part of its power.
i try to think of other things.
but it doesn't matter.
i become a part of its power.
i cannot escape it-
a terrifying thought.
not to disregard the feeling of my
stomach being pulled out of every
pore in my body.
slow and poisonous,
an effortless manipulation,
wanting me to feel ill in a way
only those who experience hell can understand.

## GONE
**by Natalie Washnieski**

Surroundings become SURREAL-
With a wave of PANIC-
Extreme FEAR-
Manic butterflies ATTACK-
My stomach.
My energy.
I feel SICK-
I get a sudden FLASH-
An absolute VIVID memory
With no connections to my physical BEING,
My earthly presence.
The SECOND it is over I try to bring it back.
But I cannot.
Lights out.
It is GONE.
Even though I just 'SAW' it.

# PROSE

Kathy Connor
age 51, person with epilepsy

Who is the inspiration for my written work?
My mother – she is one of the co-founders. She passed away. I want people to hear my life story.

Other information?
I have not had a seizure in over 25 years. My seizures are pretty much under control. I still have petit mals, but not as often. Because of long-time use and affects of Dilantin and other drugs, I developed Periodontal Disease. I have OCD, Dystonia, and Behavioral Problems which come from the brain. I take my meds so I am under control.

## My Life with Epilepsy

**by Kathy Connor**

Hi. My name is Kathy. I am 51 and I have epilepsy. I come from a very small family – just three of us kids. I was in the middle. We got epilepsy at a young age. My two brothers died of epilepsy. They were both young. My younger brother had a seizure and gurgitated on his saliva. He was in his teens. My older brother took his life due to epilepsy related issues. He was twenty-three.

When I was nine, I was in the bedroom. My mom was helping me get ready for school. All of a sudden I felt light headed, and I remember seeing my arm twist like a pretzel. After that I don't remember. This was the 70s – we did not know much. My mom and dad called the ambulance. They took me to the hospital. Back then, they did not know what happened. They released me and said to go see my family doctor. The doctor told my parents, "Every time she feels funny, give her a Dilantin."

I had a terrible time walking and seeing double. I could not keep up with the other kids at school or understand the school work. I was having seizures in class and my grades were way behind. So I only went to 11th grade and had to quit. I had no childhood or teen life, and I couldn't do kid things. I couldn't function from day to day. I was on every kind of drug there was to offer. Nothing worked. My self-esteem, well, there was none. It just seemed at the time I didn't care about anything. I felt like a guinea pig, trying different meds and tests.

Then I got in to see a neurologist. They put me on Depakote ER Time Release. That changed my life. And now I *have* a life. I am happy. I am married. I have interests, hobbies. I own my own house. I have not had a grand mal seizure in over 25 years.

In my early life, when I was having all those problems, people thought I would never be where I am now. They are so happy and proud of me that I am much, much better now.

Angela Halverson
age 36, son has epilepsy

My inspiration is my son, Evan, who will be 10 in January. Evan has Lennox Gastaut Syndrome. Seizures are a part of our every day life - as normal as breathing air or drinking water. In addition to the seizure disorder, Evan deals with many other health issues - but he is a trooper and never loses faith. He is an inspiration to everyone who knows him.

## Playing the Cards You're Dealt
### by Angela Halverson

Someone once told me, "You have to play the hand you're dealt." My response to that was, "That's easy to say when you got all the good cards and I got crap."

Well, nine years and a long, long roller coaster ride of a life later, I've changed the way I think about that statement made so long ago.

My son was born, fairly uneventfully, six weeks early. He was 5lbs, 14oz and although he had problems nursing at first and was a little jaundice, everything seemed to be going o.k. We were released from the hospital two days after he was born, and my husband and I excitedly, if a bit nervously, took our firstborn home.

On the exact date that Evan was originally due, he suffered a brain bleed and spent the next three weeks in the hospital, fighting for his life.

The pain of the next few months and years was crushing. We went from having a happy, healthy newborn to dealing with seizures, feeding tubes, enough medication and supplies to stock a small pharmacy, and learning all about what it means to raise a blind child. Instead of a tricycle, we purchased a wheelchair. Instead of vacations, we used our leave time for emergency trips to the ER and hospital stays. Instead of early childhood classes, we began the Birth To Three program for babies with special needs...

This was the "hand that I was dealt" and I was so horribly exhausted, depressed, and worried every day that I literally had to tell myself to put one foot in front of the other to keep from rolling up into a ball and dying. My husband and I adopted the "one day at a time" attitude and sometimes "one hour at a time" when things got really bad.

But as the years go by, life has a way of working itself out. Things get more familiar, issues get resolved, a routine is developed that becomes "normal," even if it is far from how other people live. I stopped feeling like I was just barely holding my head above water and began to live a little. Miraculously, by the grace of God, life went on.

And then slowly, I began to realize that there are lots of joys that come along with raising any child, typically developing or not. The hopes and dreams I had weren't lost forever, just modified a bit. We set goals and work toward them. We fail and we succeed. We learn as we go. But mostly we have a better appreciation for just being. Not being the best or the fastest or the smartest, but just being who we are and who God made us. And the unconditional love that comes with that is like heaven on earth.

The person that made the comment to me about playing the hand you're dealt was my brother. Since that time, his own teenage son was diagnosed with Schizophrenia. I realized then that his cards weren't as great as I once thought and that our cards will change as the game of life goes on.

I now believe we do have to play out whatever hand God deals us and, just maybe, realize over time that we really did get the good cards.

Barbara Hueston
age 42, person with epilepsy

I started having seizures when I was 4 years old and was put on two different medications as a child. My seizures had stopped by age 11 and I was taken off medication. It was not until I was in my 30s - and I did not even realize it - that I was again having seizures. When I was 39 I had a Grand Mal seizure in my sleep that lasted over 10 minutes and my husband dialed 9-1-1. I had a cat scan, EEG, MRI done and everything came back negative for seizure activity. I then was scheduled for a sleep-deprived EEG, which showed up seizure activity. I have been on medication ever since.

## Living with Epilepsy Is Not Easy

### by Barbara Hueston

Living with Epilepsy has not been an easy task. I found out my seizures are caused from lack of sleep and stress. These are two things that are hard to avoid when your career choice is working as a nurse. I have had a particularly bad time these past two years, because I have been fired by two jobs, I was in a car accident, I am still grieving over my father's death, and I was not able to finish college for RN. I started suffering from depression and anxiety and now I am on medication for that.

My dad died on October 18, 2008. He had been in the hospital for 10 days before his death. He was discharged to a nursing home for rehab, and our family was told he would be better in a week and able to go home. Instead he died four days later. My dad fell out of bed on his first night at the nursing home. He was not very well taken care of there and ended up dying of a ruptured bowel. It was the hardest thing I have ever had to go through was watching my own father die. I had asked them at the nursing home on the night that he died to call an ambulance, which took them over forty minutes to do so. He died six hours later in the hospital with nineteen people surrounding his bedside, and I was holding his hand and letting him know it was o.k. to die. I feel a lot of regret for letting him be discharged to that nursing home and wish he would have been allowed to die at home.

After my dad died I went through all the stages of grieving and sank into a deep depression, blaming myself for his death. I was put on Zoloft, and it still did not work like I wanted so my dosage was upped. I felt it still was not helping and I was switched to Effexor. This drug played havoc with me, and my mind was not clear taking this drug. I was enrolled in school for RN and was not able to study and retain what I should and started to have anxiety and more depression and suicidal thoughts. I did not finish school and looked for a job instead. I was working at a job but my hours kept on getting cut and my financial situation caused even more stress and depression. In the mist of switching antidepressant medications I was fired from my job supposedly because I was not concentrating like I should. I had another part-time job I was working and starting working more hours there. I was fired for turning someone in for medication errors – a conflict of interest, I was told. At the first job I was working at I was talking to a girl about my seizure disorder, and the next thing you know I was fired.

Living with Epilepsy causes a lot of different emotions that are hard to deal with, especially when taking medications that can alter one's emotions and sometimes personality. It seemed like when I do divulge my Epilepsy, I get treated differently by people. I have lost friends, jobs, and people's confidence in me. They think that I am diseased. I was asked by a fellow nursing student, “Do you have to wear a Helmet?” I have been told that people with Epilepsy are evil and have the devil in them. My response was, “I guess I am lucky I was born in this day and age so you would not burn me at the stake.”

I am not evil, a devil, stupid, retarded, a witch, spazz, or schizo, but a nurse, mother, sister, friend, daughter, and wife. I deeply care about people and do a good job when I am at work. I like being a mother and a wife. I volunteer in the community, attend church, and believe in God, and I am getting through all my horrible depression and anxiety. God has a plan for me, and that is to spread the word that Epilepsy is not the worst thing in the world and people can overcome the stigma of having a disorder that so many people know so little about. I will continue to hold my head high.

Ann Kempke
age 36, person with epilepsy

I am a technical services librarian in a medical library and a mother of one son. I've had epilepsy since I was twelve, and I've been seizure-free for almost ten years. My first seizure was a tonic-clonic seizure at home, but since then I've had simple partial seizures.

## Gaining Control
**by Ann Kempke**

In my job as a medical librarian, I am responsible for perusing a variety of medical journals in order to spot new books to order for the library. One afternoon I opened up a neurology journal and noticed a drug advertisement inside the front cover. A woman sat on a rock with a contented smile on her face while she embraced two children. "There's more to me than my epilepsy," the banner read. Underneath the photo was the caption: "Seizures aren't her only problem."

As a mother of a pre-school boy, I could relate to this photo and message. There's more to me than my epilepsy, too – namely, motherhood and its various joys and struggles, my marriage, my career, and my family and friends. Mostly it's the medication I take that's my problem – it leaves me tired from the moment I get out of bed in the morning until I sink back in at night – but it controls my seizures like a charm, so who am I to argue? I know it could be much, much worse.

As I scanned the full-page ad in search of the name of the drug that got this feel-good treatment, my eyes rested on nearly-microscopic lettering in the lower right-hand corner: "Individuals shown are not actual patients with epilepsy."

Individuals shown are not actual patients with epilepsy. "Hunh," I muttered as I felt my cheeks turning pink with irritation. I considered who that disclaimer was supposed to benefit. The drug company? The physicians and researchers glancing at the ad? The models in the photo? People with epilepsy – wake-up-exhausted, seizure-in-public, real epilepsy, not the photo-shoot kind?

I turned to a few other medical journals sitting on my desk. They contained ads for drugs aimed at relieving the symptoms of depression, herpes, and anxiety disorders. I searched each two-page spread for a disclaimer but never found one. These are highly stigmatized conditions, the types most people who have them wouldn't want their coworkers to find out about or to hear joked about in a social situation – a lot like epilepsy. I flipped through the pages of another neurology journal. While this one didn't carry the same ad the first one did, it did feature an editorial and a research article about the role that stigmatization plays in the lives of those who have epilepsy. Not surprisingly, the research showed that many people consider the stigma carried by epilepsy to be worse than the seizures themselves.

I remember being tuned in to the stigma of epilepsy back when I was diagnosed at age twelve. "This isn't epilepsy, is it?" my worried dad asked the pediatric neurologist. At that time, he probably had the same foggy, misguided impression of epilepsy that any member of the general public does; this has since changed. I learned pretty quickly to be grateful that I have simple partial seizures, so all I feel are twinges of time briefly warping while I have an uncomfortable pressure in my chest. I've had seizures in all sorts of public places: weddings, meetings at work, on a bus. Nobody around me had a clue that anything was amiss.  Unlike many people with epilepsy, I've never had to deal with the aftermath of having a seizure in public.  I've never been laughed at for it.  Because seizures are such a minor part of my life, it's easy for me to focus on the social side of having epilepsy.  I don't struggle just to make it through the day as some people with poorly- or uncontrolled seizures do.  I'm not running that race.

As a teen, I attended Camp Oz, the Epilepsy Foundation of Minnesota-affiliated summer camp. There are other people in the world who have this condition, I discovered with elation.  I wasn't alone.  The first time I witnessed a seizure was at Camp Oz.  After catching a glimpse of another camper in the dramatic throes of a tonic clonic seizure, I began to understand where some of those misguided fears about epilepsy come from.  The loss of control was scary.

In general, most people strive for control of their lives.  Women's magazines are full of articles about how to regain control of our over-booked lives.  Scientists and researchers search for more understanding of diseases and conditions, with the hope that with understanding will come cures or control of symptoms.  At work, many of us struggle for control over our workloads.  And I'll admit it: as a mother, on numerous occasions I've wished that I could control my son's actions.  If only he would put on his shoes or pick up his toys the first time I ask!

Control is a word that's used a lot when discussing epilepsy.  Are your seizures under control?  What medication controls your seizures?  If your seizures aren't under control, what will you try next?  This is important, because seizures are a complete loss of control.  Not only for the person having them, but for the people watching them.  Most bystanders don't know what to do; they simply know that something out of control is happening right in front of them.  That's uncomfortable.  It's scary.

For those of us who have epilepsy, we're forced to deal with being completely out of control sometimes, and on occasion very publicly.  And if that's not humiliating or frightening enough, we need to deal with losses of control that are forced upon us by others.  People with epilepsy lose their jobs after having a seizure at work.  Others get arrested after doing something during a seizure that is misunderstood by onlookers.  Many of us lose our drivers' licenses and, with them, our sense of independence.  And, on top of all of that, we're portrayed negatively or made fun of in the media.  It's still okay to make jokes about people with epilepsy.  Is it okay to make jokes about, say, kids with cancer?  Nope, not funny.

That's where I've decided to take control.  While I realize that, in the end, I can't make the general public feel a certain way about those of us with a seizure disorder, I can at least give them the tools to start understanding us.  When a tasteless joke is made within earshot, I take the opportunity to educate the teller.  When I hear snide comments, I don't ignore them.  I've made speeches, answered questions, written letters, and try to live my life in a way that is, if nothing else, an example to others that people with epilepsy can be just like anyone else: educated, productive, responsible, and friendly. As I meet new people, they form an opinion of me that's based upon the parts of my life that they view as "normal."  Once their opinion is formed, if I find a reason to reveal my condition to them, I will.  A round of questions usually follows, ending with, "Thanks for explaining that to me.  I didn't really know anything about epilepsy."  And here's the best part about the questions: most people want to learn!  My hope is that once they've learned what epilepsy is and isn't, they'll educate others if the opportunity arises.  Every contact like this contributes to a future of understanding and acceptance.

The other thing I can control is how I view my own situation.  I can either feel ashamed or embarrassed by my epilepsy, or I can feel empowered by educating others about it.  I can feel sorry for myself for having it, or I can tell myself that it's just one part of who I am.  I can live in fear of my next seizure, or I can make healthy choices that contribute to seizure control. If I do find myself getting down about epilepsy, I can search out the lessons it's taught me: don't stare at others who are different in some way, don't laugh at people who struggle in social settings, don't make jokes at other peoples' expense, and don't assume I know everything-let others educate me about their areas of expertise. Sometimes I wonder if I would have learned these lessons if not for my experience living with a stigmatized condition. It's true that the side effects of my medication and the interactions it has with other drugs sometimes frustrate me. I also realize, though, how lucky I am that one drug controls my seizures. When I read about those who struggle with many seizures a day, I can't stay frustrated for long.

It's easy to carry a negative view of epilepsy; after all, even a drug company makes it clear in their new, hip, feel-good seizure medication ad that there is still something shameful about having it. "Individuals shown are not actual patients with epilepsy" isn't my style, though. Like everyone with epilepsy, I search for control. For me, this means that I need to be willing to talk with people about my own seizures in a neutral or positive way; if I do, they will view epilepsy as just another medical condition. The drug ad is right about one thing, though: there definitely is more to me than my epilepsy. It's an important part of who I am, but it's just one part.

L.E. LaRue
age 34, person with epilepsy

**What is the inspiration for my written work?**

The inspiration of the written work is my life. I chose to write a sequel after reading what I wrote last year and knew writing about myself was easier than some other subjects because I know myself best. There was plenty that I had to leave out of the original for space reasons, so there was no problem finding material for what I wrote this year.

**How have seizures and epilepsy affected my life?**

Seizures and epilepsy has affected my life in some ways, but not all of them. The main thing is to try to avoid stress. I like to think more about what I still can do instead of what I can't. So I'm probably not allowed to drive a semi truck or fly a jet, big deal!

**What is my seizure diagnosis?**

I was diagnosed with epilepsy at age 4, and was on Dilantin until age 10. Since then my seizures have been rare, once a year or even less often. I feel fortunate to have lived a mostly normal life. I work full-time and it never prevented me from getting a driver license, so to most people that would be considered normal.

**Other information?**

My biggest interests are baseball and history, but I have others. I also enjoy traveling and I take pride in my writing skills - I've had plenty of letters to the editor published.

## My Life with Epilepsy, Part 2

**by L.E. LaRue**

As the title suggests, this is a 'sequel' of sorts. One year later, I can say that things could be better but also could be worse.

I had a list of goals created even before the movie "Bucket List" was released and I have felt good about accomplishing one of them - going to an open mic night at a comedy club. My friends had said for a while how I'm funny and should try it. It felt good being on stage, having the courage to be there is important, but I've done enough public speaking that I wasn't nervous about it.

Going to a comedy club did remind me of an important fact - sometimes comedy can be offensive. A few performers do jokes about neurological disorders, not just about epilepsy but also Tourette Syndrome. But when I got offended I knew it was best to keep it to myself. Besides, I was just as offended when I heard jokes about St. Paul, the city I live in. It reminds me of an observation I had made before: those who don't understand something well may make fun of it due to ignorance.

I am still reluctant to tell friends I've known for years - or colleagues from work - that I have battled epilepsy. I practice the 'need to know' policy - most people don't need to know about it. I'm afraid of what I will lose from it, not just friends but my job. I want to be judged on my job performance and

not my epilepsy, who wouldn't? I haven't dated much, but I've been trying harder in the past year with online dating. I will tell girlfriends about it when I'm ready and when the time is right.
I did tell one trusted friend from work, but I waited more than a year after we started working together. I wrote down the word when we were lunching one time and asked, "Do you know what that is?" "Yes, my cousin has it." It was a relief of sorts to hear this, knowing I had found somebody who understood. With some I knew early on that they wouldn't be. When I had a seizure in front of my then-landlord (I was living in suburban Chicago) I talked my way out of it after he asked if it was something medical so he wouldn't ask any more questions. I said I was cold, and have a family history of diabetes, that sounded more acceptable than epilepsy. I knew early on how closed-minded he was about gays, and figured he would be just as closed-minded about epilepsy.

Twice this year I could have told a college roommate about it but didn't. He is a Vikings fan, and I sent him some Vikings pictures I won at the silent auction during the [Epilepsy Foundation of Minnesota's] Light Up the Night event. All I said was that it was from a benefit event. The second was when I told him I had been diagnosed with syringomyelia, a spinal cord injury. The neurologist informed me it was due to a birth defect, and it seemed to explain better the causes of my epilepsy.

It has been well over a year since I was diagnosed with the spinal injury, and at times it has been rough living with it. At first I was wondering if my epilepsy was recurring, but it doesn't appear to be. I told the neurologist how my seizures were rare since age 10. Oddly enough, most of them happened in the bathroom. I guess that it must be colder in there - and thankfully no witnesses. But the EEG was normal, which made me feel good.

What also made it rough was the not knowing for sure what was wrong. I finally found out after having an MRI, a month after going to the ER complaining of numbness and tingling in my legs that wouldn't go away. The ER doctor said it was 'trench foot' (the wrong diagnosis, I later found out) and gave me a prescription for Neurontin and advised me to see my primary physician and get a neurologist referral. After a few months I dumped that neurologist and found another one as I had no rapport with him. He said it was no big deal, just monitor it, but I was constantly in pain and the meds made me feel worse. In spite of this he extended the prescription, until one day at work when I had to sit down for the final hour as my legs felt like jello. I was told to stop using it right away. He also wouldn't take the time to explain anything, and said there's no surgery available, nothing he could do. I thought one only said that to somebody that was dying! There were a few times when I thought I was, as the pain was becoming unbearable. I even wrote out a will and said if I died in my sleep that a friend from work is to get the rights to my poetry, as that friend was the inspiration for much of it.

Thankfully, most of my anxieties ended since switching neurologists, though at first I wasted time at appointments wanting to talk about how I was so annoyed with the first one. What made me angry after the fact was finding out how I had been lied to, related to surgery options. This one said surgery was available, but it's risky and may not work. After a while I knew I had to get over it. The switch has helped me because this neurologist has a better bedside manner. It started with doing a simple thing - writing down the name of the condition on a stickie so I could look it up myself online. She also would have me look at the MRI while pointing out where the spinal injury is, and would prescribe Lyrica, which has been way better for stopping the pain. I spoke with a pharmacist that suggested it after I spoke about the side effects with what I was using. When the first doctor wouldn't prescribe it, saying I was 'too sensitive' to meds it was the last straw. I was definitely dumping him as it isn't a one size fits all world. Right now I only need to make appointments twice a year. I may have to switch away from Lyrica since I've gained some weight in the past year. Living with this spinal injury is a 'day-to-day' thing, some days are better than others. I'm hopeful to keep my independence and mobility, as I know I could lose both. The possibility of becoming paralyzed does scare me, but I try not to think about it as I'm just fine at this point.

Recently I heard a bus driver speak about the importance of self-maintenance in his line of work. He often has to deal with difficult customers and can't take it personally with some of the comments directed at him. This resonated with me in more ways than one. I used to do call center work and it's important in that line of work as well. But it's also essential when living with epilepsy. There's a lot of truth to that old adage about looking out for number one, because no one else will. Even though I know how important it is, sometimes I forget. There were two occasions in the past year at work when I was frustrated and overreacted by continuing to whine about the subject and wouldn't let it go - all over a MINOR thing! Sometimes I think people know well enough to ignore my ranting. I think these tirades are less common now that I'm an adult, as I understand better how costly my actions can be. Working in corporate America has definitely taught me to be thick-skinned about most things as I have to look at the big picture more often. When you know that losing your job is a possibility it's easier to remember to keep your emotions in check.

I know I didn't do much of this self-maintenance when I was younger. I had huge self-esteem problems then. I grew up fast, and had to start fending for myself at age 14 since my parents had divorced and nobody was around to take care of me all too often. I had little or no emotional support even before then so I definitely felt orphaned. I know how true it is how those who have epilepsy battle depression a lot, I know I did. I knew what some people said about me at school, thinking I was suicidal. I knew full well I wasn't THAT messed up, but I was still an emotional train wreck and nobody was helping me. I tried speaking to a school psychologist but he didn't have any answers. Looking back at it I now realize that I became more emotionally healthy when I decided to stop torturing myself over missed opportunities. I also needed to refuse to get all frustrated and bent out of shape and sensitive about everything. It's called 'self-maintenance' for a reason. I had to do it for myself and by myself. Nobody could do it for me.

Much like what others wrote in last year's contest, it's helpful to find things you're good at and enjoy doing. I liked being equipment manager on my school's football team for 3 seasons. I took pride in a job well done and made a contribution to a successful team, as we made the state finals when I was a junior. I also discovered how much I liked history class, and eventually it became my college major. And I had a writing instructor pushing me, telling me I could do better, and she was right. Eventually I also turned to writing when needed, especially in college, pouring out my thoughts and emotions in a healthy manner. I felt great by finding my voice through writing. I don't even want to think about what it would have been like without finding these interests, it would have been way worse for me. Would I have been suicidal? I don't know, doesn't matter too much now. I did briefly consider suicide later on in life, after getting fired from a job because I hated feeling like a failure. But that feeling passed quickly, as I thought about how sad it would be to take my own life. I figured I would feel better once I found another job, and I was right.

My main regret was refusing to attend dances until I was a senior. I kept telling myself that I wasn't ready, wouldn't fit in, and wouldn't have a good time because I was too self-conscious. I do go to nightclubs, but not too often. When I go to social events now, I do my best to remember what my strengths are and stick with those strengths. I seem to do just fine, since I'm no longer self-conscious like before, and I've already achieved a victory just by showing up.

I am still thankful for all of the events sponsored by the Foundation, the most important one being the support groups held every month. Some things do work better than others of course. I didn't like the guest speaker one time - he wasn't treating the subject of epilepsy properly. It's a serious thing and should be treated as such. But what offended me most was when he wanted to make jokes about Iowa, my native state, just because he ran into intolerance there. Is that unique to Iowa? Absolutely not! I even spoke up right away and said how we have 2 people from Iowa here. It's wrong to battle intolerance by being just as intolerant. Thankfully this speaker hasn't been back since, and this is the only time when I've been offended so they do well at screening people.

If we do make jokes about epilepsy, I say keep it positive. The group's coordinator goes about it the right way, calling us the 'sparky neuron club.' It works because it's positive but not boastful. I see no need to brag about having epilepsy, acting like I'm better off than those who have it. Living with it isn't fun at all, and I would prefer not having to live with it at all. I'm for building character, but I prefer to have built it some other way.

I try to do every event sponsored by the Foundation, of course some of them I can't attend due to scheduling conflicts. As a baseball fan I definitely like attending the annual Twins game outing and the lunch that is held before it. I also liked the live music outing in late July, as I enjoy concerts as well. I really enjoyed meeting one of the artists at the Light Up the Night event, in fact it was the artist that created my two favorite pictures in the Brainstorms art collection. I was moved by both because it was unforgettable imagery. I like how both this event and the art collection have received media attention. I know this is due to Terri Gruca of WCCO-TV supporting the Foundation, because her husband has epilepsy.

As a history major the history of the disease does interest me. While there is still plenty of intolerance that exists, I think it's better than it was. It angered me when I read that when Adolf Hitler was running death camps in World War II how he also set out to exterminate epileptics, wanting to rid society of anyone who was a drain on it.

It still seems like something's missing in terms of a flag bearer for the disease to make it less of a disgrace. When you see what their strengths are - their brilliance and how they still can be high-functioning members of society - then it's more likely that the negative stigma attached to epilepsy will fade away. I did see the biographical movie "Control" about a musician named Ian Curtis, lead singer of the British band, Joy Division. But his life with epilepsy was a sad one, as he committed suicide at age 23.

While we still have a way to go, there is hope and pride in how far we've progressed. When I entered an art contest I had a simple message on the art: "Education defeats ignorance and apathy." It's our best tool available, so we have to use it.

Chris Poshek
age 37, person with epilepsy

My inspiration is my dealing with epilepsy and my daughter who deals with it on a daily basis. Also my wife, who has been with me every step of the way. She has never wavered in her love and support for Hannah and me as we have battled epilepsy. Seizures have changed the way Hannah does things, but they have just made me focus my life in a more positive direction. I control my epilepsy, it doesn't control me.

## Have I Always Been Normal?

**by Chris Poshek**

Purpose: To convey through my experience, how good and bad experiences can come from something that is life-changing and the effect it has on people. How hard it can be to come to terms with a major change in a person's life and show that taking away bad experiences is not necessarily good.

When people are often asked to think about their life, for some reason they always focus on the bad experiences. We tend to leave out all of the great times like watching Adrian Peterson rip off a 60-yard touchdown run or enjoying watching my daughter Hannah dance like a ballerina. I once looked at my life in a very negative way, but now I look at my life with the opposite view.

The thing I remember most about my first seizure is that I still considered myself normal. I still wanted to think that it was a freak thing. In the desperate hope that it was a one-time occurrence and that I didn't have epilepsy, everything was normal, and life was fine, the way it always was.

Then after my second seizure my world was turned upside down, when the suspected diagnosis of epilepsy was confirmed, the pain began to fill up inside me, as those words were said, as if I knew in my heart, but was desperate to be wrong. Why?

I couldn't talk; I felt no one would understand, even if I tried. I knew my wife was there for me; because we are a team, and always have been. But this was happening to me. How would I provide for her? Thoughts of maybe she deserved better than this kept going through me. I knew those thoughts were wrong. But I couldn't help thinking them.

Life can sometimes be heartbreaking. And for those who know me personally and know me really well, they know that before this happened I experienced enough pain already. Could I bear even more?

I know now that I could. I didn't then. You see when terrible unexpected things happen, you learn from them. Without these adversities life would be quite boring and people would never learn, become stronger or change. It has made me realize just how strong I am, it has made me more willing to accept, life isn't always what I want it to be.

After experiencing a few small seizures and watching Hannah go thru 50 to 100 seizures a day, I realized that I couldn’t hide from the truth. After talking to many people, who all go through the same battles as I do, I realized “whatever doesn’t kill you will make you stronger.” I realized I was not going to be able to deal with this overnight, it would take some time and it wasn’t going to be easy.

Life is always changing. We have to keep moving forward, regardless of what any doctor may say or any celebrity on some TV show may joke about even if they are misinformed.
Some people get angry when someone jokes about seizures or epilepsy or makes light of it in the movies or on television. While it would be easier to do that, I look at it as a chance to educate and inform.

For the most part, I have made my peace with epilepsy. It doesn’t control me. I control it. I am still normal. I just have to live a little differently now.

But that's epilepsy. It’s just something I live with and manage because there isn’t a choice. And when I tell people about my first seizure and about when I dislocated both of my shoulders, they always ask the same thing. Did it hurt?

Pain is a relative consideration, and my pain, which was really painful, could always get worse. Just when you think things can't get worse, they do.

I'm not sure where I am going with this other than to say that if you do have your health then value that. Then get outdoors in the sun and soak it up and just live your life. And if you have kids, cherish them. They grow up fast. Hannah is already four and she is already making me lose my hair.

Like I said earlier, I was normal before my epilepsy and I feel normal today. It is just now I am part of a much bigger family, my normal epilepsy family. But according to my wife I was never normal to begin with. (I love you honey.)

Thomas Raniere Jr.
age 32, sister had epilepsy

My inspiration for writing this is my younger sister, the youngest of five kids and diagnosed with Epilepsy at a very young age. She did not allow the seizures or disability to get in her way of achieving so much. Her life was cut short by seizures, but she was still successful in so many ways. She is my inspiration in many different ways, not just in writing this. She passed away from a seizure in August 2007.

## Acceptance

**by Thomas Raniere Jr.**

*written in loving memory of Amy Raniere, sister, daughter, granddaughter, aunt, and friend*

From the first time I entered your life, you embraced me. I know I was difficult at times and no one really understands me. You accepted me for what I was - a part of you. At first you might not have felt that way, but you were too young to know any better. As you grew, there were many attempts to keep me from coming back. The different medications just drove us closer together. You learned how to deal with me. More importantly, the family accepted you with me. You never let me bring you down; you never gave up on your dreams. You graduated from high school, you had a job, and you had a loving family that would do anything for you. I had a big impact in all that you achieved. I helped to bring your family closer together. I helped you overcome the water and win many medals and ribbons in swimming and basketball at the Special Olympics. I helped you meet many loving and caring people from many different organizations. I helped you bring a smile to the face of those passing by or less fortunate than you. I helped you become the ‘Sunshine’ to brighten up the darkest of days.

*I am a seizure.*
*You have told me to go away...“No more seizures!”*
*Now you can rest, I have finally gone away. The seizures are no more. The memories of who we were and what we achieved will live on. You made the best of our difficult connection.*

Maya Rose
age 53, person with epilepsy

The inspiration for this story is the connection anyone with a disability or limitation has. I think a lot of people can relate in some way to my memory of when seizures started and how confusing and traumatic it can be as it turns your whole life upside down and inside out.

## Meeting Myself Halfway

**by Maya Rose**

I found my soul sitting on a rock by a stream. As I crossed the water to her, a flood of emotions came surging up, almost drowning me in their intensity. I struggled to the other side dazed. “What was THAT all about? I feel like I've been hit by a truck!” My soul sat there calmly looking at me. “Welcome Home,” she replied, “I've been waiting for you to cross this river to find me.” I mistook it for a tiny stream until I stepped into it, then it overwhelmed me with its force! “Ah yes,” she sighed, “that happens when you begin to recover lost pieces of yourself. You encounter all sorts of fear and pain to wade through.”

We sat there together, my soul and I, feeling calm and refreshed, like a mountain meadow after a summer storm. Like blue sky shimmering around the yellow sun. I finally had to ask The Question:

“What separated us all these years?”

“Grief and trauma,” she said simply. Then, like a movie, I watched my young life unfold as my seizures introduced themselves, dousing all the passion and wonderment of childhood. Each seizure made my foothold on life more uncertain and I slid into a land of uncertainty and fear.
When would the next “episode” erupt? What was wrong with me? Am I going to die? Losing control...falling to the ground...crying out…coming to consciousness in the Emergency Room…seeing the faces of people I love gazing down at me with eyes full of concern.

Did "It" happen again?! No one explained "It" to me so I could understand, or maybe they did and my brain had just gone fuzzy.

I began to lose confidence in Life and mySelf because I couldn't understand why my body would do this to me, betray me so. I struggled with - even denied - my limitations for many years, way into my adult life.

As I reached the age of 50, I began to wake up, go searching, wade those deep emotional waters, find and accept Who I am. I've learned many things on my Journey. Each piece of mySelf recovered has a story to tell. I am lovingly putting the puzzle back together. My days are much richer because of my limitations, which have taught me compassion and a deep respect for this gift called Life. The Joy of Living is returning.

Never be afraid of new doors and never panic when old ones shut. It's OK, all is well, and you are never alone, even though in the dark you may feel alone. When the sun finally begins to shine, you will soon be amazed to see all the angels that have been surrounding you with protection and love.

It is never too late to live the life you were given.

Krista Stotko
age 21, person with epilepsy

A letter of thanks was inspired by my friends and family. Lynn, Diana, Milissa, and Stephanie were a huge inspiration to this story. They've helped me so much and have been so strong for me, I don't know how I could ever re-pay them. I wanted to express how much they, my friends, my family, and others mean to me.

Epilepsy has had a huge affect on my life. I have grand mal seizures and I was having them almost daily, and now I have about one a month, sometimes more or less, depending upon the month. I lost a lot of my independence and that's really hard to deal with. It's teaching me to be grateful for what I have though, and I'm glad I have many supporters by my side.

## A Letter of Thanks
### by Krista Stotko

It's funny to think about life and how fast it can change. It really makes you grateful for what you have, especially when you realize how fast you can lose it. August 2nd, 2007 is a day I will never forget. That day was a day of many tears, and at the same time, a little relief.

That day of August 2nd I was diagnosed with epilepsy. I was scared and crushed at the same time. I was told I couldn't drive until I was six months seizure-free and I lost my job. I worked in health care and was told I couldn't work there anymore because it endangered the residents. I immediately panicked. I had no job and no way of getting anywhere and I didn't know how I was going to pay my bills. Medical bills are outrageous!

Having seizures almost daily, stressed out, feeling helpless, I didn't know what to do. I started having bad memory problems and losing more of my independence. Throughout this battle, it was a relief to know that they knew what was wrong with me but they still left many questions. How can they not know what caused it? Why do I have it, or why me? Maybe there's a purpose, maybe I can help someone down the road. Why am I not better a year later? How can I go from being fine one minute to not fine the next? I just don't understand. I guess there may always be questions.

But enough about me, let's talk about you. To my friends at McDonalds and the nursing home. To the doctors and nurses, the medics and officers. To my sisters Nicole, Marissa, Aryn, and Alyssa. To my little brother Tj, my parents, and my grandparents. To my boyfriend Sam for loving and caring for me. For putting up with my moods and making me smile. To Theresa and her family, always by my side. To the Epilepsy Foundation. To strangers who may not have said anything to me but gave me their thoughts. To everyone at MSB, you were a family away from home. To my superhero Lynn, one of the smartest people I know. Someone that's strong, stubborn, and has the biggest heart. Someone that has touched my life in many ways, someone that I admire and have learned a lot from. A special thanks to Milissa and Diana for giving me hugs, and love all the time. My buddy Diana who's the cutest, sweetest little thing that can always make me smile. Milissa with her open loving arms, always by my side. I love you!

But especially to the strongest, kindest, most caring woman in the world, to my best friend Stephanie. For taking care of me through out all this, from driving, to being a nurse, to loving and supporting me, and just plain being there for me. To all of you I just want to say that I don't know that there are any words, or any jester that I can share with you other than just sharing a few words with you. I would just like to say from the bottom of my heart, THANK YOU!!! Thank you for giving me the strength to get through everything and to carry on living.

Shelly Venenga
age 35, son has epilepsy

**Who is the inspiration for my written work?**

My 4-year-old son Joshua and our journey with Epilepsy have inspired me.

**How have seizures and epilepsy affected my life?**

Seizures have affected my life in that I have learned so much over the past 2 years and met many amazing people. Epilepsy had also given me the opportunity to become a HOPE mentor and find a passion in educating people about the disorder.

**What is my son's seizure diagnosis?**

Joshua has TLE with secondary generalization, currently uncontrolled.

**Other information?**

We are truly blessed to have EFMN. So many people I have met have no local affiliate or group to reach out to. I cannot begin to say thank you enough for all that you do for us.

## Out of the Darkness and Into the Light

### by Shelly Venenga

*Out of the darkness come these thoughts…*

My job is to protect you. Protect you from all the crazy things in this world. How do I protect you from this? How do I keep you safe from something that comes from within you? The truth is that I can't. It breaks my heart to not only say this, but to know in my heart that there is nothing I can do to protect you from seizures.

I can't make them go away. I can't promise they won't happen at school or at the mall.
I can't tell you they won't come when you are swimming or riding your bike or hanging out with friends. I can't tell you that no one will treat you any differently because of seizures. I can't make them stop.

*Into the light come these…*

I can hold your hand when you need it. I can be your biggest advocate. I can be your strength when you have none. I can be your voice when you can't speak. I can be your comfort when you are scared. I can learn as much as I can to help you. I can help you to be your best. I can allow you to be a normal kid and not limit you with my fears. I can watch you smile and grow and prosper. I can help you understand. I can keep you safe in ways that I never knew existed. I can love you. I can be your mom.

Susan Welshinger
age 56, person with epilepsy

What is the inspiration for my written work?
My inspiration for my written work is my move to the cities and getting control of my own life.

How have seizures and epilepsy affected my life?
My seizures stopped me from living. I actually never had a life. Seizures and meds had control of my life.

What is my seizure diagnosis?
Petit Mal, but have improved over time with surgery.

Other information?
Things have developed after surgery that I am concentrating on more now.

## My Move to the Cities
### by Susan Welshinger

I moved here to the cities in 1990. I moved into the Search Program for a new start. As I learned in a program class I attended then, I have as much a say as the next person. How things were done for me when I lived close to family: my parents always did for me. Then came a time when I moved here away from family, and *I* started to do for me. I was in control of what I did. I made decisions and choices, and what a change that was. My self-esteem and confidence brought me to a higher level. I became more independent and was enjoying my new-found freedom and achievements and what I could do. I am *still* doing. All I can do and my accomplishments. That is what this move to the cities has done for me, and what the help and support of the Search Program and staff at the drop-in center have done. All I have learned and done along the way. Things I have tried. And the importance of you being who you are.

Toni Wilka
person with epilepsy

## Toni Wilka's Epilogue, 9/26/2008

To have Epilepsy is a battle. Unless you have the health condition, you will not understand what it is like to live in my existence.

There are so many feelings that go along with the word Epilepsy for me. I changed when I was 13, as this is when I was diagnosed with it. My grades dropped from A's and B's to D's and F's in school. I missed thirty days of school in the first two months of being diagnosed. I became sad and confused. Unfocused and distant. I tried six different medications and only one worked for me, which is Tegretol XR. I have been on this medication for 13 years, at 600 MG a day.

Do the neurologists really know how this is affecting my health, mind, body and soul? I believe that only the Creator knows.

Every feeling that I have is blown up ten times more that the average person would feel. Life is so much more difficult for me to handle. I feel alone at times. I feel the effects of having a chemical imbalance in my brain everyday.

I am an addict. I have been sober for three years and five months now. I do not regret many things in my life; however one is the lifestyle that I chose years ago. I damaged myself through using. I took a lot away from myself that I did not even have to begin with. I sometimes wonder if my life would be balanced without the self-destruction. I made the choice to use because I felt ALONE. I felt like no one understood what I was going through. I did not have the Epilepsy Foundation then. I also made the choice to become sober because of my Epilepsy. If I did not, I was going to die. So I thank the Creator for this even though it is an obstacle for me.

My mother was in labor with me for thirty hours before the doctors decided to perform a cesarean procedure. This caused severe scar tissue in my frontal lobe. This is why I have Epilepsy.

I feel for children and people of all ages that have Epilepsy who have a much more dramatic experience than I. I am SO THANKFUL that I have a medication that controls my health condition. I am very blessed.

I wonder if there is anyone else out there that feels the way that I do about life and how difficult it is. Is there anyone who shares the same trials?

**Pao Xiong**
**age 40, person with epilepsy**

**Who is the inspiration for my written work?**
My wife, "Bao Lee."

**How have seizures and epilepsy affected my life?**
They stop me from working and stuff that I love to do, and I'm shy to go to people's houses or school.

**What is my seizure diagnosis?**
3 times per month.

**Other information?**
I am a funny person, a helpful person, and I love to do stuff and work hard.

## The Life of Epilepsy
### by Pao Xiong

In my life before I had this bad disease to affect me, my life seemed like normal. We learned Laos language in grades 1 through 6. I just took 6 years. Some students take 7 or 8 years. I finished grade 6 in 1987. That was the year I started to have seizures, but I still went to school and learned about the sewing machine and how to fix sewing machines in the refugee camp in Thailand.

The seizures turned my life upside down. Many times, when I was still in class, some people named me "Mr. Funny." But one day, when I was in computer class at the Lao Family Program school, I had a seizure and pulled the cord out of the computer mouse. It broke off. My teacher said, "That's not a problem." But I felt very angry. I thought to myself, "Why can't I help others. I only just destroy the program and things that help me." That's why I stopped going to school about a year ago.

The earth is beautiful, but I think people who have seizures, like me, live just like we are in a jail cell or a dark place where nobody can help get you out. When I have a seizure, that means I apply to go to Heaven, but when I think about it, I am not qualified to go there yet. I think people who die while they are sleeping are lucky people.

I hope one of these days, if God agrees to heal me, then I will be free of seizures. I could then learn how to drive and go back to school again and find a better job, so I don't have to depend on government money every month like I do today. Then I will be a happy person again like other people who have a future to think about.