Epilogues 2009

a writing collection displaying the talents
of people affected by seizures

EPILEPSY
FOUNDATION®
MINNESOTA

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.

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Introduction

Dear Epilogues Collection 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 Collection 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 Collection Committee of EFM received the works in this book during September and October of 2009. 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, a Letter of Appreciation, a copy of this book and possible public readings or further publication of works on behalf of EFM.

New this year, the Committee organized the writings into two sections in the book: *Sustaining Ourselves - writings by people with epilepsy*; and *Movements of Love - writings by family, friends and caregivers of people with epilepsy*. Poems and prose pieces are interspersed, as the voices, emotions and themes flow one to another.

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

Epilogues Collection Committee

Sustaining Ourselves

writings by people with epilepsy

Minden J. Anderson

In the Blizzard

Heavy-burdened,
I am walking,
Perspiring tension finding gain.
Becoming misty,
Fading, sickened.
Until the blackened sky churns dull,
My head is emptying.

I sink into my weak joints,
Melt loose knees into the ground.
Head is bowed now,
Seeking consciousness,
Eyes are closing in to fully concentrate.

In a moment I am standing,
Feet plow swiftly through the snow.
I am joyous,
Near courageous.
Celebratory in the movement,
Toward serenity of home.

My hands no longer chilly,
I extend them to the door,
Grasp the handle,
Draw a breath in,
Anticipate explosion of the safely warmed.

Yet I cannot force it open,
Feel sudden pressure crush my cheek.
Heavy eyelids,
Cursed ringing,
With my body lying motionless,
An aching indescribable.

An island in a naive, snowy sea,
Painfully gazing toward the stars.
Wandering thoughts of better outcomes,
Have served a dreamed distraction,
In this reality of the moment.

Minden is 27 & has epilepsy…

I have had epilepsy for 15 years. My seizures are grand mal, and I would have roughly 3 per year, but am lucky to have welcomed much success with medication. This poem was inspired by a rather terrifying seizure experience I had while walking home alone during a snow storm.

Jean Manrique

brain betrayal

hey, brain,
i thought we were in this together
you were me
i was you
the same entity

i treated you well
gave you good stuff
you did what i asked
did my thinking for me
told my body what to do when

i was proud of you
you were well-trained
good to me

what’s up now?
are you rebelling?
just decide to go off on your own
do your own thing
shoot off whatever neurons
whenever, wherever
think really strange thoughts
that seem genius at the time
take my body
hold it hostage
not letting go until you’re good and ready
then demand hours of sleep
guard words when i need them
not letting me think when i need to

can’t we just get along?

in the coffee shop

is it music repeating
or my brain
something’s stuck
or nothing
repeated syllables
repeated tones
unintelligible
neurons start firing
repeated rhythms
or not

is it the music?

maybe the neurons
aren’t connecting at all
i’m inside somewhere
removed
staring
frozen
apart

music muted
voices loud
senseless
snippets of words
of conversation
focus
click the start button
tap the keys
write something

bowed head
look up
at something
at someone
move your eyes
hello?
am i here?

close my eyes
give in
let the music wash over me
let the world go
no control
stop fighting
breathe
relax
it will pass
let go

sparks trying to connect
to nowhere
lying on a wet dark
back alley
firing
sputtering
dying

music changes
heavy dark beats
become happy
light

trumpets dancing
but i’m still stuck
sitting
staring
waiting
for repair
movement
life

changing meds

i’ve lost control
i’m always in bed
punctuated by an hour or two
at the coffee shop
or a meal

otherwise i’m in bed
hearing the crickets
Ian come and go
sounds of others living life

all the things that used
to make up my life
are on the shore
getting farther and farther away
until i barely recognize them anymore

waves splash in my eyes
and obscure those things
until i vaguely see them
i’m drowning
and beginning not to care

slugs have eaten my hostas
the flowers in my pots are wilted and brown
the epazote has grown rampant
and the basil has gone to seed

i haven’t photographed
any flowers this year
the deep purple morning glory
climbing the deck stair
is stunning

but i’m drowning in bed

Jean is 53 & has epilepsy…

I was diagnosed with epilepsy a year ago. Since then my life has totally changed. I am unable to continue my work, for now, as a junior high Spanish teacher, unable to drive, and trying to find that right combination of meds to stop my frequent simple and complex partial seizures. I have always enjoyed writing and have found writing helps me through the difficulties of life. And since this has been a difficult time, I've been doing lots of writing!

Joseph Hager

Lightning in My Brain

The road stretches ahead straight and narrow as we zip along under the sweltering July sun. This place is called Big Sky Country for a reason – the Montana horizon disappears in the summer distance under an aluminum blue sky that stretches on, its immense scale measured only by a few wisps of white clouds scattered like shredded sheets of cotton. I'm bored of counting grain elevators in the rear view mirror and the orderly fields of corn whiz by like a patchwork quilt made of different shades of the same material, over and over.

Sunlight floods the windshield of our Toyota minivan, the glass flecked with a mounting number of insect carcasses. I'm hunched in the front passenger seat – Dad is in the driver's seat, hands on the wheel 10-and-2, popping peanuts and drinking Gatorade, with his face half covered by a large pair of driving shades he bought at the Holiday station when we left. Pulled over his forehead and blocking the sunlight is a Minnesota Twins baseball hat.

Later, we arrive under the cover of darkness to our cabin in the mountains, perched perilously over a cold, rushing stream. We barely see it in the dark as we climb out of the van but I can hear the racing water. We wipe our eyes and stretch our muscles to unclench ourselves after the daylong drive. My brother Bill, an adventurer five years my junior, is the first one to the stream. Patrick, the youngest, and I stumble down the ledge, sending gravel skipping down the slope and tripping over knobby, stubborn pine roots that break the ground like arthritic fingers. The water is cold but it still feels good to dip a hand in.

As we unload the van and struggle with the green Coleman cooler, I hear the first hint of a deep, unhurried rumble in the distance. It's thunder. Despite my brothers' requests, my dad assures us the thunder is far off enough that we can continue unpacking. Once the backpacks, pillows, sleeping bags, toothbrushes, and rations are all put away we take a stroll around the camp. After the tour my brother leads the way back down to our cabin as the first few drops of cold mountain rain fall from the overcast night sky. In the dim, obscured moonlight the shapes of clouds the color of lead migrate quickly across the night's canvas. The cold rain swells into a pattering shower and cuts through my cotton t-shirt. Raindrops stream down my back and forearms like tiny, cold diamonds. I begin to shiver but I like the rain, so I stay outside while the others head in.

Beyond the silhouette of the lodge, closed and squatting in the darkness like a sleeping turtle, the first few arteries of lightning snap overhead. They come in random, chaotic spurts; lightning trails across the sky, indecisive protons fly blindly through the atmosphere at light speed. A few minutes later, I retreat inside to watch the storm through a window greased with dead bugs. The bowling alley crashes of thunder approach our camp and soon the old, warped pine boards and pillars that make up our tiny hut are shuddering and creaking in the wind as the thunderstorm picks up and the rain rages against the roof. My dad initiates a game of poker and as we gather around to gamble the night away, tragedy strikes: the fuse box snaps and the lights flicker out, pitching us into complete darkness. A mad exchange of lightning bolts above bathe our cabin in a bony luminescence that lasts for a split second.

What is Wrong With Me?

My doctor, a neurologist named Betty Ong, stands less than five feet tall. She hides behind an enormous pair of glasses impossibly suspended on the bridge of her thin nose. Her tiny voice reminds me of a bird. She always calls me "Joseph." Dr. Ong told me when I was diagnosed with epilepsy that seizures are like lightning storms in my brain. She explained that the human brain relies on an exceptionally complex network of electrical nerves that carry impulses back and forth—messages connecting the different parts of the brain so that it can function properly.

Sometimes one of these millions of nerve pathways will get stuck in a redundant cycle, sending the same electrical impulse over and over, the same message again and again. Many times this electrical anomaly will work itself out as the brain overrides the problem. But sometimes, surrounding nerves can get “sparked” into falling into the same cycle. These impulses, repeated over and over, can catch fire and set the brain alight in a storm.

I still remember the first time, earlier that year, while I was visiting Grandma and Grandpa in Ohio. Their house on Mull Avenue in Akron was the first place I experienced a grand mal seizure.

Grandma prepares the house like a hotel for our yearly stays—fresh soap and towels in the bathrooms, the pink cotton sheets on the beds in the guest room pulled tight and orderly, glasses of water arranged neatly on the folded hand towels set on each nightstand, and a stack of books and magazines piled on the dresser top. There is a dry mustiness to the place, a smell that evokes years of memories in an instant—a scent cultivated over the forty years my grandparents have lived here, a smell brewed with the messes and clomping feet and spilled food of my mom as a child and her five brothers and sisters—all of whom grew up in the house on Mull Avenue. There is also the smell of babies, toddlers, and children; grandkids and cousins and nieces and nephews, who all still spend the young years of their lives seated in front of Grandpa’s chair, raptly listening to his terrible puns and nonsense jokes, sucking on pastel dinner mints pilfered from the ceramic dish in the foyer, catching whiffs of Grandpa’s pipe tobacco, wrapped and stashed inside a blue and orange tin.

Surrounding Grandpa is an assortment of wind-up toys and noisemakers—little oddities which dance, play music or do at least *something* loud and obnoxious. Pushing my grandmother to the limit seems sometimes to be one of my Grandpa’s more unconstructive hobbies. His toys include holiday specialties which are produced from the stale shelves of the basement each year in December. Among these is a particularly vexing Santa Claus doll that sings and dances in the country-western style. My grandpa savors the psychological effect of repeat performances of his dancing Santa. It’s become his cantankerous form of *schadenfreude,* the delight some experience in witnessing another’s misery.

I wake up in an unfamiliar dark. The few thin streams of light slicing the black space of the room beam from odd angles. I soon realize that I am in Ohio, thirteen hours from home, sleeping in the guest room and listening to the uneven snoring of my little brother Bill. Something feels weird inside. I want to turn on the light and stand and leave but I find that I cannot move very well. I throw an arm out into the shadows, pushing my hand toward where I imagine the lamp might be. My hand fumbles in the dark, brushing against several objects and knocking a book to the floor. *I want that light on, I don’t know what’s happening and I just want that light on* – for some reason, an unexplained panic builds inside me. I find out later that this stage of a seizure is known as an “aura”—the strange feeling that comes over me in the ten second period of time preceding an epileptic fit.

Suddenly something else changes. A feeling blooms inside me; I get a weird, sticky taste in my mouth and my arm feels weighted and clumsy. With the light still off and the shadows of the unfamiliar bedroom swallowing me, my chest jolts forward and I draw a gasping breath of air and my ragged breathing is suddenly accompanied by an involuntary, uncontrollable moan. The seizure has begun. My body begins to rock back and forth on the mattress, drenching it with sweat that pours off my clenched body. Oxygen seems a precious resource but oddly I know I am not choking as the air keeps pulling in long, ragged surges. The muscles in my diaphragm and torso are locked stiff across my chest—the tendons at my knees and elbows pull and convulse from skin like cords of fiber.

My brain sits in the pitch black of my skull, a slab of jelly strung together by strands of nerves, more than 100 billion neurons firing furiously in all the wrong directions. I glance around wildly, unable to focus in the shadowed darkness, worried for some reason about waking my brother sleeping nearby. My teeth grind, catching the sides of my slack, unmoving tongue. I chew my tongue like a piece of meat but I can’t feel any real pain. Just a dark, uncontrolled panic. My body flails on and I only think about turning on the light.

A second later it flickers on. My mother, clutching a blue robe around herself, hurries into the room squinting. Her voice calls out to my dad. I can hear that it’s stronger than usual and I know she’s worried. *I must look like I’m dying right now,* I think. I want to call out, to console her, to tell her I think I’m all right. But I can’t; the seizure has taken everything. My dad, his eyebrows arched madly in worry and his eyes pulled wide, rushes in and bends over me, grabbing firm hold of my body with strong, panicked arms. He runs his hand through my damp hair as my own panic begins to subside. The worst of the seizure is over, lasting around four minutes. The breakneck pace of the convulsions begins to slow and I continue to groan, still unable to speak.

Power is Out

The lightning starts in and splits the sky loudly and often. I'm lying in bed, at home in Minnesota, hiding from a growing storm outside. The thunder follows immediately, a sign that the powerful center is nearby. Thunder ruptures the night sky and sends the bookshelf near my head shaking. My baseball trophies wobble back and forth and coins sing as they fall to the floor.

The power has not come on.

My watch says it's a little past 1:30 am. The sliver between my curtain and the window pane now lights up constantly with the electric flash of lightning. The thunder continues its deep, moaning crash and it feels like the foundation of the house is going to uproot and tip all of us like a capsized ship in the middle of a record nor'easter. The sky behind the lightning is endless black. Not even the outlines of the trees show except during the brief bursts of lightning, which illuminate everything in sight. These moments of brilliance are fast and fleeting.

Putting my head to the pillow I try to sleep through nature's ruckus. But a moment later a deafening crash rings in my ears as something strikes the house. My bed is situated in the corner of my bedroom and when lying down my head rests in the very outer corner of the house. Something big and heavy hits the corner a mere foot or two from my restless head. A great whining, screeching sound pierces the bedroom. The sound of tearing, crumpling metal—the house's aluminum siding peeling off like birch bark—sends me scrambling for the door. I fling it open to run downstairs, as far downstairs as possible, to hide in the deepest, darkest, safest corner of the basement.

My dad is there with a flashlight, outside my bedroom. His mouth is drawn. He is here to rescue me. I let him lead me through the dark hall and we stumble down the stairs together. The flashlight beam bobs in the shadows, backed by the flickering rhythm of lightning. We pass the front door and see the brambled claws of a fallen tree pressed against the window pane. Each flash of lightning illuminates the silhouette of this scraggly tree as it scratches the glass, trying to get in, trying to hide from the storm that has killed it.

Morning comes and we shield our eyes as we approach the surface. The storm has passed and in its wake the sun is trying to burn through the last layers of gray, lifeless cloud cover. My stomach drops when I realize that the treeline of our backyard has *changed.* Something, or perhaps several somethings, have gone missing.

Our silver minivan is parked in the driveway and three feet to its left lays one of our giant birch trees, on its side. The fallen tree had barely missed the van and indeed one of its heftier branches has marked the side door with a deep scratch. We investigate further. The noisy crashing in the night is explained—trees lay on their sides everywhere we look. Mighty oaks felled by wind and lightning criss-cross our yard like Lincoln logs thrown across the floor of a playpen.

I walk around back to look up at my bedroom. I mutter silent thanks: outside my window the sky-blue siding has been stripped off like a Pull-and-Peel Twizzler. Twisted metal lies in scraps in the grass. There are also soggy ribbons of torn screen strewn about. The siding is scarred and dented from the impact of one of our largest black cherry trees, which has fallen onto the corner of the house, the crash that sent me scrambling for the lower levels. The colossal size of the tree gives me shivers—I could have died had the tree fallen three feet to the right and crashed through my window.

"You Have Epilepsy"

The grand-mal seizure ends and I am left in a body shivering from the cold dampness of the bed. My face is covered in saliva and tears and my throat, still working and contracting furiously, refuses to swallow even a sip of water. It takes awhile to speak. A few minutes later I am able to force air through my throat to produce rough noises, and shortly after that I am talking again albeit with an embarrassing slur. My speech continues to slur for another fifteen minutes. My tongue feels like a limp sock in my mouth.

In the days following, my parents—fearful and confused—tried a variety of solutions as my seizures kept happening, each night. One day I just started having seizures and they began to happen nightly. Every evening I dreaded putting my head to the pillow, knowing that another one of these episodes might happen. My mother, convinced that it may be a respiratory problem and sure that it was caused by my sleeping on my back, sewed six tennis balls to the back of a t-shirt in the hopes that it would prevent me from having any more of these mysterious fits.

The t-shirt didn't work and when chest x-rays revealed no problems and the doctors we visited in Ohio were stumped by my symptoms, we finally arrived back in Minnesota and visited a hospital there and consulted a doctor. After a recommendation to a neurologist, I visited my four-foot savior Dr. Betty Ong and after seeing a videotape of one of my seizures, she said "Joseph, you have epilepsy."

Joseph is 25 & has epilepsy…

I was diagnosed when I was 16 while on vacation in Ohio visiting relatives. That was also when I had my first seizure.

Seizures have affected my life tremendously – and not all for the worse. Having and dealing with epilepsy has opened my mind to a new perspective on life, one that persuades me to view each day as an opportunity for joyful experiences. Having epilepsy has made parts of my life difficult, but steering my attitude in an optimistic direction has helped me over the years.

This non-fiction essay titled "Lightning in My Brain" is about my epilepsy and my first seizure. I tried to capture the fear and the uncertainty that accompanied the experience of having a seizure. Enjoy.

Lisa Renee Ragsdale

Off the Track

“What’s that you have?”
“A spike.”
“A spike like they use on a railroad track? What would that be doing
in my head?”
“No it’s not that kind of spike. This is more like a bolt of lightning.
In other words, if we could take a picture of it and enlarge that picture
you would be able to see that spike’s resemblance to a bolt of lightning.”
“Is it possible to get that spike out of my head?”
“Well that is what we would like to do. But the best we can do is to control it.
And all we can do is give you some pills to control them.”
“You mean all we can do is control these spikes that I get during the night?”
“Yes. All we can do is try to control the spikes from happening and
waking you in the middle of the night. We have to try giving you a pill
or two in the hopes that these spikes will not happen. We would really
like to see that they never happen again. That is what we are trying to do.”

Lisa is 59 & has epilepsy…

I am a Musician, Composer, Writer (obviously), and Photographer. Life has been very difficult since “acquiring” epilepsy in 2005, as I have not worked a day since that time. I try to not let it get to me, but being out of work as long as I have, plus being denied disability 2 or 3 times, has been ----------.

Liz Holzemer

3 yellow pills

a Walgreens vial stares at me from across the room
its contents await patiently as the appointed hour looms
against the white kitchen counter yellow pills stare up at me
pleading and begging to swallow all three

their chalky taste makes a promise again
of electric pulses not to send
i put my faith in them, i have no choice, i must
but the misfirings begin another broken trust

neurons gather like armies of ants
agitated and angry, on and on they rant
colors become brighter, emotions out of control
my sense of being, no longer whole

please quell the fires you said you'd stop inside my head
the thought of more of you, i absolutely dread
liar, liar, liar, you make me ill
3 nasty, chalky, little yellow pills

Liz is 42 & has epilepsy…

I am a writer and mother of two. This poem was inspired after my Meningioma and epilepsy diagnosis. I'd been experiencing déjà vu sensations prior to my diagnosis, not realizing I was in fact having simple partial seizures caused by my brain tumor. I had to experiment with several AEDs before I found one I could tolerate. I still battle fatigue on a daily basis, but have learned not to feel guilty for taking naps and saying no when I need to! Epilepsy has given me a voice to educate and empower others about this disease.

Sarah DuCloux-Potter

Medication Merry-Go-Round

Medication merry-go-round
Trying each blend
Til the magic one's
Found.
Want to get off this
Dizzying ride –
Seems though
My request has been
Denied.

This one blue
Oval and small.
That one white
Round like a ball
Then a capsule
With a gel,
Together making
A repulsive smell.
Red and orange,
Purple and pink,
I'm not even sure what
I'm supposed to
Think.

My eyes go crossed,
My hair falls out,
My words are jumbled,
My mouth a drought.

In my head I fight
Each day
Not to jump out,
I know things will
Get better –
No doubt.
If I stay on this ride
Hold on,
Head high
To hit my stride.
My combo's out there
Minus the
Crossed eyes.
The bonus of
No misfires
The true prize.

Seizures and Art

A word on a piece of paper
Scribbled down,
With a pen,
Can’t describe
How you make me feel.
A note in the air
Hanging loud,
Floating there,
Can’t describe
How you run the show.
A picture drawn on a board
Shaded in,
Penciled on,
Can’t describe
How you affect me.
Write it down,
Sing it loud,
Sketch it off,
Get it out.
Feel better –
Without
Perfection.

Driving

Strong,
My fingers flex
The rubber grooves.
Music
Floods my ears.
A strand
Of hair breaks
Loose.
Free,
Like me.
The world runs
By in colors.
Power
Runs through
My feet
Increasing the speed,
Then bringing
It to a
Stop –
Where *I* want
To be.

Someday
It won’t be
A dream.

Sarah is 30 & has epilepsy…

Epilepsy doesn’t really affect me anymore (isn’t that great to hear?). When I was diagnosed (partial complex with rare generalization, mainly nocturnal), I thought it was the end of my world. It turns out that while a seizure takes away my control every once in a while, for the majority of time, I’m in control. The only part that still sucks is this medication, which makes me more tired than I think I should be, and I can’t drive!

I work full time in a demanding position. I’m married to a handsome preschool teacher and have the coolest 6th grade daughter. Having epilepsy doesn’t mean that a person’s life will come to a halt. Things just need to be adjusted until you get a new groove. Then, hopefully, the epilepsy will be a small blip on the radar while the rest of life will go on. What’s frustrating is the stigma that the word epilepsy carries with it.

I’m constantly inspired to write. I write about silly things, sad things, things that make me angry or frustrated, and things that make me laugh so hard I cry. It’s only natural that I’d write about epilepsy, especially when I’m feeling upset about it. Writing tends to ease that – or at least put it into perspective. After I write something I can let it go.

Leah Osborne

A Epileptic's Fairy Tale: Exorcising the Demons of Disease

I wake up one morning to find my life irreversibly altered. The paramedics scrambling around my room inform me that disease, under a veil of darkness, has invaded my room and my existence. My life, previously bridled and checked, now careens wildly unrestrained. By morning light, I discover I became deficient overnight, the rug of my old life pulled out from under me. I am instructed to put on proper clothes. I resist. Somehow, if I deny any abnormality, if I don't walk through those sliding hospital doors, I can continue my life uninterrupted. In my chaotic last moments as a "normal" child, I apprehend my imminent removal from ordinariness. I delude myself into believing that I can remain undetected in my defectiveness, an impostor of commonality. But my seizures inadvertently reveal my secret. I had already left my understood reality behind. Now I am forced, against my will and at the tender age of twelve, to leave behind the normal assumption of a child to trust that her body will not revolt or betray her.

Once in the hospital, I disrobe: my brain's mutinous misfiring leaves me physically exposed, the hospital gown failing to cover whatever remains of my preteen dignity. The olfactory output of hospitals provides a visceral reaction; the stench of urine and sickness combine with ineffective odor-covering cleansers to produce a uniquely potent perfume. I wish I could escape this powerful stink that accompanies the endless parade of blood-drawing nurses and droning, faceless doctors. But I do not want pity. I mindlessly play Nintendo, simply wishing to live in blissful ignorance of my condition.

Initially, I felt that the qualifier "diseased" was imposed upon me by the outside world but with time, I realized that I self-imposed that label. I never revealed my condition to anyone but my closest friends and even then I would never discuss my hospitalizations or the effects of my medication. To the world at large, I kept my condition a covert operation.

Ignoring or hiding my illness proved a hopeless effort in 2003. During this year, epilepsy literally takes the wheel and ultimately usurps control of my life. Driving to a skating competition on a Saturday morning, my memory goes blank. According to the police record and statements taken from various witnesses, I have a seizure, hit a freeway guard rail and total my car. I possess halting memories of the ambulance ride to the hospital. Miraculously, I escape the crash without a bruise or a scratch and injure no one but my life changes from that day forward. I no longer able to control my destiny with my driver's license suspended. I immediately quit my job and scramble to devise a new life plan in a matter of days. Since I no longer have the freedom of independent movement in a vehicle, I decided to bike or bus it back to college, a road long-abandoned and now my only option. I hesitate in reapplying to school, unable to escape my previously weak academic track record. The first time around, I left a lot of dirty Tom Collins glasses in my wake, college offering a directionless girl no reprieve, as reflected in my cumulative GPA. Yet unable to imagine any alternatives, I begrudgingly stumble back down the academic road again.

The short-lived excitement of returning to academia quickly gives way to inner turmoil when I have a seizure in class. In the fall out of my desk, I dislocate my shoulder which later causes me to shudder in horror at the expletives I may have uttered through the searing pain. An ambulance comes; class dismissed. I feel I can never return, I cannot conquer the hot shame I feel bubbling up and over my capacity to endure another public humiliation. I had exposed my well-hidden secret to complete strangers who would have otherwise nodded off to the droning of our gentle, dull Shakespeare professor.

I thought I had been safe in my disguise – I wore the camouflage of a regular student – messenger bag, notebook, and a pack of cigarettes. Armed with my Teflon vest of apparent ease and ordinariness, I thought I was protected from scrutiny. But I can never be safe from myself. I quietly visit my professors' office hours, tip-toeing through the halls in an attempt to avoid detection, ready to notify them of my intention of dropping out until my health improved. I break down in tears each time I speak, unable to contain my emotions. And just then, when I reached rock bottom having no further to fall, I come back. I attend class the following week like nothing ever happened. Returning proves my second most embarrassing moment, entering the room I left on a stretcher the previous week. With my eyes on the floor, I carefully take my seat without a word. I suppose I could have handled myself better, try to make a joke or play it off, but I am afraid of losing control if I speak. So I don't. I just wait silently for class to begin. And it does. Entering that classroom exemplifies my greatest moment of personal fortitude.

Academic life proves difficult, occasionally hampered by epileptic obstruction of progress but I persevere. Breakthrough seizures provide hurdles through grad school. Still, I find validation in my work and my efforts are rewarded when my professor tells my family that I was the hardest working Masters student he had ever advised. Ultimately, I discover a hidden life unperceived until shoved from the path I had laid for myself brick by brick. I know that the best laid plans of mice and men often go awry ("The best laid schemes o' Mice an' Men / Gang aft agley" Burns *To a Mouse*). Through this, I find that, strangely, my seizures present opportunities for growth. By defying disease to move forward, not only did I disprove my personal belief that I could not or would not become a successful student, I demonstrate to myself that I can thrive despite heightened physical, emotional and mental hardships. Dressed in the disguise of disease, my return to school reveals a blessing. Although I still struggle with epilepsy, I cannot deny that my disease produces an inner strength previously unknown which consequently strengthens my abilities as a researcher, an academic, and a writer with my own tale to tell.

Leah is 30 & has epilepsy…

I was born and raised in Roseville, and was diagnosed with generalized tonic clonic seizures at the age of 12. I was a competitive figure skater throughout childhood and turned professional at 18. A seizure behind the wheel halted my skating career in 2003 – and being unable to drive to various area rinks, I returned to school and graduated from the U of M in 2005 with a BA in English Lit and a minor in History. I immediately entered the graduate program in English at St. Thomas and got my masters degree in 2007. My husband and I just returned from a year living in Hawaii and I have returned to my activities in Montessori education and figure skating!

Any person who suffers from epilepsy and feels/has felt a sense of shame, embarrassment surrounding their disease, or has experienced a desire to conceal their disease from others provides inspiration for me. I have struggled with (and continue to wrestle with) these feelings from the diagnosis of my epilepsy onward. However, I must remind myself that the disease is a fundamental part of my identity and has had as much a hand in my personal formation as any other influential part of my life.

My seizures continually throw up roadblocks that I have to maneuver around or break through. I discovered that I cannot plan or control my future for tomorrow is uncertain. I must be willing to be flexible with my plans, for they are bound to change in ways that I may not be prepared for but must be willing to accept. I must live and work in ways that I find personally satisfying and hope for the best.

Tayler Jean Johnson

Roles Reversed

For the past three years now, I've looked at the same wall that I see each time I am in the ER. I see the same face each time – my brother's. He's the same one who would say nothing and then pull out a joke to make me laugh as I was being poked with needles. Only to be told he would be poked with needles too if he didn't stop. The little brother, who grew up way too fast, having to watch out for his older sister. Our roles reversed.

My brother is the boy who sat, his iPod in, as my relatives would ask if he wanted a caffeinated drink to keep him awake but would turn it down saying, *If Tay can't have it, then I won't drink it.* Those words forever etched in my mind as I'd look at him, fast asleep, sitting against the wall. Wishing I could go cover him up with the blanket that covered me. Wasn't it my job to watch out for him?

My brother has been the one who has ridden in the ambulance with me, holding my hand and telling me over and over again that everything would be okay. His voice is the one that calmed me and his hands wiped away my tears. Our roles reversed. Wasn't it my job to wipe away the tears if our parents weren't there to do so?

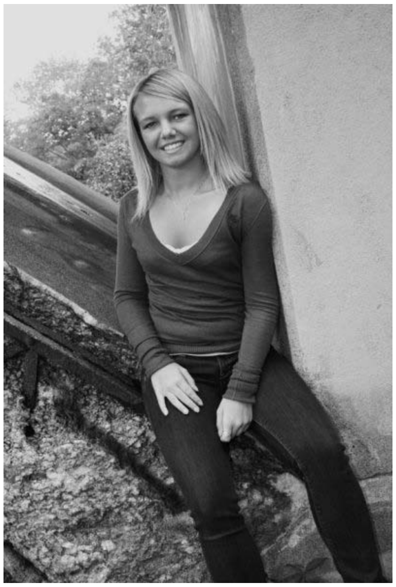
So many times I've said, *I'm sorry.* So many times I've heard, *It's gonna be ok Tay, don't worry.* Isn't it my job to say those words, those words of comfort?

All I know is that during the past three years, our roles have reversed. He's the Silent Hero, the boy who grew up too quick. The little brother who has forever promised everything will be ok. I'm holding onto that promise. The things my brother has done for me, I'll never forget.

Restart

Tick Tock, Tick Tock.
Months of being worry free;
one moment changes it all.
Blacking out, waking up in a daze.
Tears begin to fall,
the clock has been restarted.
Tick Tock, Tick Tock -
That's all that I hear.
The clock's becoming my enemy again.
Wishing I wouldn't have made that mistake.
A mistake -
I couldn't afford to make.
Now in the ER I wait -
I wait to leave.
I wait for the phone calls.
Tick Tock, Tick Tock.
The clock is mocking me.
Telling me of my mistake.

It’s all I seem to hear now -
Tick Tock, Tick Tock
Tick Tock, Tick Tock…



Tayler is 15 & has epilepsy…

I was diagnosed with grand mal and absence seizures in December of 2006, and I just had my fifth seizure earlier this month. I'm 15, and I’m on the Anoka Twisters Dance Team. The inspiration for “Roles Reversed” is my younger brother, who’s had to grow up quicker than most kids his age. The inspiration for “Restart” was my last seizure that was on October 14th, 2009, and how I think of “restarting” being seizure-free – since I made it 18 months, it's just like a clock is mocking me.

Molly Cooney

configurations of grief

somewhere the images drop
thud of a head held under
shatter : gather
the tinny pitch of spit back teeth

we fall : we watch each other fall
husked by the hollow
        it breaks me like the light between the trees

from the river i gather the delicate shavings of our wooden backs
and lay them side-by-side like pieces in a mosaic,
the tesserae of our tenacity

trust that water holds hands when it lands on concrete, ceramic, on ice
that hydrogen elbows oxygen when it drips
        that the bathtub takes the shape of you when i sink

Writing Memory

If you asked me how my brain works, I might say, "Not very well, thank you." Or I might talk of sclerosis, temporal horns, and the hippocampus. Or I might not remember those fancier words because the first answer is the truth.

It wasn't always that way. I used to have a solid mind that justified the space the gray matter occupied. I could recite poetry I'd memorized years earlier and cook without putting the frying pan in the refrigerator, the milk in the cupboard. All that changed when my brain misfired during the night and my body seized, my brain struggling to reroute electrical impulses, to start my breathing again.

My brain had actually started to seize several months before that night, small lapses, barely perceptible, eroding my memory pebble by pebble. I joked about it at first, thinking I was just getting lazy, letting my brain relax too much. My friends called me *amnesia girl.* Then I had a grand mal seizure. The jokes stopped. Hundreds of smaller seizures followed, interrupting the electrical flow through my brain, tangling my thoughts and poking holes in my memory. Then the gaps began to fill with childhood moments.

My 6th grade teacher shifted into my college classroom and the family dog I never knew bit me instead of biting my older sister. I was convinced that a friend had a kidney transplant rather than a tonsillectomy. Or was it her friend that had the surgery? To me the images and stories were accurate, the timelines precise. My memories were visceral. I could map it all out, the way my mind held memories, the way my memories moved. I believed, and often still believe, that what I remember is true, despite collective family stories and pictures telling me otherwise.

"What's wrong with me?" I asked from the dusty blue office chair.

"You have epilepsy, left temporal lobe epilepsy," the doctor said. "You need medication to control the seizures."

I left without pills but a promise to call if the seizures continued. I was sure they wouldn't. That they'd leave as suddenly as they arrived.

I read furiously: Seizures-199 Answers, Diagnosing Seizure Disorders, Living with Seizures. I took copious notes, filling journals and folders. Countless articles from Neurology and other medical journals explained how messages travel between neurons through synapses, which are gaps between nerve cells that pass electrical impulses around the brain, commanding the body to squeeze its fingers, swallow food, multiply six by two. A disruption in the flow of energy reroutes the electricity and causes a flaw in the message, like a blip on a meteorologist's radar screen—a seizure.

Each time an electrical current flows through a neural pathway it reinforces the connection between the nerves, deepening the groove between them like water wearing through rock, slowly creating canyon walls. My brain gets stuck in a rut. Each time a seizure occurs the path it follows strengthens, inducing more activity. My brain was teaching itself to have more seizures.

My brain connections became erratic, spontaneous. I'd be teaching and a sudden heat would rush up my legs and hollow my stomach, then my mind would yank me back to five years old when I was waiting at Groveland playground for my mom to pick me up from gymnastics. My purple leotard stretched over my belly and white tights reached for the cement as I leaned against the railing at the top of the stairs. As an adult in my twenties, I fully relived that five-year-old moment. Then I'd be teaching again.

My brain dragged me back to that same scene over and over. The seizures knocked me down, my mind swimming with a gush of memories as I lay on the floor like a fish in the bottom of a boat.

This happened everyday. Several times a day. Six times in two hours. I called my doctor.

"Déjà vu seizures," he said.

"What caused them?"

Pause.

"When will they go away?"

Slight shrug.

"I don't know. We may never know."

I started medication. Pills that would suppress my central nervous system, exhaust me and steal my sharpness. I'd forget things. Lose coordination and be struck by dizzy spells. My metabolism would slow and my food preferences change. I'd gain weight and bloat from retained water. Eventually my teeth would soften, my gums recede and my facial hair darken. I wondered if the medication would change my personality. But the pills were my hope of stopping the seizures, so I'd swallowed them and cried.

I didn't know then just how deeply those daily drugs would give me my life back, slowly and over time. That I'd drive again. Swim laps. Run a marathon. Summit 14,000-foot peaks and lead 45-day whitewater canoe expeditions in the Arctic. Witness the polar bear migration down to Hudson Bay and the calving glaciers of the Alaskan waters. Go to graduate school. Write a book. Fall in love. Watch from my mountain bike night after night as the hills pull the sun below the saguaro and sandstone, deepening the sky, sliding pink down dry draws to the waterless riverbeds.

The seizure-induced memory never goes any further than me just standing there, it's static, never shifting details or changing length, and I can't remember any context for it. The memory doesn't feel especially dramatic, just a scrappy pony-tailed girl by herself on the cloudy concrete steps waiting for her mom. The scene lingers, suspended like the hang of poured water. Sometimes I'm actually seeing through my kid eyes, but most of the time I'm just watching the girl that is me hang out in her own little world: a whistle, twirl of hair, slight shift of her weight to hook a foot on the lower railing. Or maybe nothing moves. I can't remember. I have no idea why my brain sticks on that precise moment of my childhood, but there it is again and again. Again.

My déjà vu seizures are not simply witnessing that memory and reliving it cognitively, nor are they full immersion into that time. It is a truly visceral experience of the past while still staying mired in the present. I sink into my self and hover outside myself all at once in a strange gap that somehow, despite the fear, deepens my sense of myself. It's the absolute weirdest sensation I've ever experienced, and not wholly unpleasant if I don't think about what they really are.

The seizures are interesting, curious, even to my own brain that bears them like a lead bullet. The heat begins low and rushes up my legs, washing through my chest and arms, gushing into my brain and sloshing memories around until I re-live that memory from thirty years ago. Then like a near-drowning victim pulled from the water, I lie gathering my surroundings into consciousness, reorganizing my purged brain. These are amazing moments to live through, these déjà vu seizures, and almost, though I hesitate to say it, fun. It is the minutes that follow, as the numbness ripples through the gray matter, receding, settling my brain again, that are full of fear. I imagine the electricity zapping my brain, ripping tiny pieces of tissue, reattaching them haphazardly, until it bulges like an overly exercised muscle.

If I am alone when I have a seizure I lay quietly afterward, thinking that if I stay still long enough the brain matter might settle back where it had been before the seizing began, curing me. I know it isn't possible, but I hope anyway. If I am with someone when a seizure strikes and it is brief, just a flash, I can hide it, but if the jolt ripples out like lightning across water, I disconnect with the world, staring glassy eyed with my jaw set tight. Ten seconds, thirty, one minute.

"Molly, are you okay?"

"Don't tell anyone this happened," I say.

For years that what I said, automatically, reliably. *Don't tell. Don't tell. Don't tell.* But somehow, somewhere, in the past few years, my belief changed, and I began to talk about the fear, the relief, the fear again, the relief that for now my seizures simmer under my skin without breaking through. I began to tell my story.

But in the photo album of my mind, the captions wander. My melting memory slouches the truth to the left, and sometimes to the right, making it seem impossible for stories of my past to accurately sidle up to the present moment. So I carry paper to write down everything as it comes to mind, as it's told to me. A phrase I want to keep or a detail I need later that day, a description I want to remember tomorrow. If a friend starts a story and my face stays blank, she keeps talking until it registers and my shoulders relax. Then I make a note in my striped book. My memories stay memories only if I write them down.

I don't know exactly why my seizures started or why they have stopped. I don't even really know if they are gone because each tiny heat on my legs or tingle in my feet, each feeling that *I've been here before* hollows my stomach and scrapes through my chest, leaving me raw, scoured by the anxiety that the seizures might be back. I don't know if they'll return. No one does. So I stumble through the tangle of approximated prognosis and into images of how I pass my days.

The pull of my paddle through rapids, scratch of my pencil on paper, slip of my arms when I swim and slap of my shoes when I run. The tug of my dog's leash. The melt of dark chocolate and zing of red pepper. The snuggle of fur. The gentle hold of my partner's hands when we hug.

Molly is 35 & has epilepsy…

I putzed around with writing even as a little kid, but it took being diagnosed with epilepsy at 24-years-old for me to take writing seriously. Seizures made me take everything more seriously, from brushing my teeth to hiking in the jungle. But serious didn't mean slowing down, it meant cultivating a fiercely stubborn hope that I could do anything, however ridiculous. I found supportive doctors and pills that work. I am fortunate. I am grateful.

Tara Moen

Out of the Shadows

Like a thief in the night
Lurking in the shadows.
First the aura,
Then I fall down,
My body loses control.
My mind is screaming,
Yet no one can hear.
Time seems to spin out of control,
Endlessly,
Wandering into the dark.
Shadows are everywhere.
I am helpless.
My body is numb.
The evil has robbed me of
My power, my strength, my soul.
I struggle to come back.
I hold my breath, suffer,
And wait until
The shadows reappear.
Only to take me back.

Tara is 37 & has epilepsy…

The inspiration for my written work is trying to portray to the reader both the physical and emotional feelings that come with having epilepsy. I was diagnosed with having right temporal lobe epilepsy when I was 16. Seizures have affected my life in many ways. Most importantly, I have learned that everyday is a gift and another opportunity to live my life with intention and love – and that time waits for no one. My life is now and it is up to me to make my own happiness. Even though I have epilepsy, I am not defined by it. I have chosen to embrace who I am rather than try to live in the shadows of this disease.

Gregg Schreiner

To the One You Trust

Hear it coming on try to hold it down
Look for the door anyone around
To help if this one pushes through the drugs

Life goes on you hear you hear so much
Put the past behind
Took off can you see the dust
Movin so fast then you wake up

Watch their lips nod you feel you must
Agree or disagree matters only to the one you trust

When that one arrives please tell me
One hell of a surprise

Feel it coming on try to hold it down
Looking for the door anyone around
To see if this one pushes through the drugs

Life goes on you hear you hear so much
Put the past behind
Took off can you see the dust
Movin so fast then you wake up

Watch their lips nod you feel you must
Agree or disagree matters only to the one you trust

The Road to Reason

I met him on the road to reason
He said 20 years and it was time to move on
He was on the road to endless freedom
I said how would it be if I came along
I met him on the road to nowhere
He said nowhere was better than living a lie
How can you find the answer
When the bottle is your only friend

And he said with cocaine eyes and a little death surprise
Lie de die
de die
Lie de die

He said anger and depression
Were the only true emotions and I believed

He said that he was a prophet
And who the hell am I to disagree
I met him on the road to reason
He said 20 years and it was time to move on
I said god damn it give me the answer
He said god was just another reason to move on

And this is what he said with a shotgun pointed at his head
Lie de die
de die
Lie de die

Life comes life will go
Nothing happens after the show
Who you slept with who you seen
Never know where they been
See a girl start a fling
People die with a wedding ring
Love is just a fantasy
For people like you people like me

He said that he had the answer
Full tank of gas and the balls to leave
Now he is running ever faster
From a troubled past and misery

This is what he said with cocaine eyes runny nose death surprise
Lie de die
de die
Lie de die

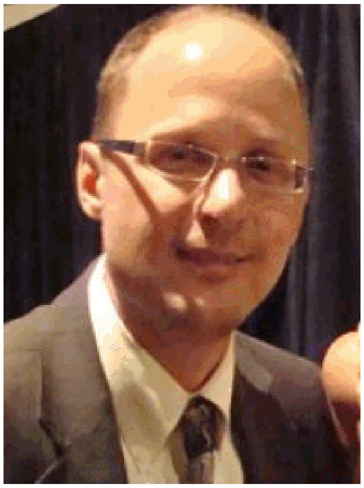
Dr. Seuss

Here comes the taste and the smell it’s the Aura again!
I look up to the sky and plead for it to be just a tiny little stone
not a boulder that bends my head around again and again.

Thoughts and words of the wonderful people that are
walking and talking all about the town.
Just keep moving in my mind around and around.

The right side of my body is numb and feels like it has
left me on this bench forever in the playground.
For a moment I’ve hit the center of a hurricane.
It’s so quiet no feelings in my body so strange and so eerie.
Still I wish it would never leave me.
Because the other force I know is coming to take over
and whip me to the ground.

So slowly the weather gets better clearer and less wetter.
When it hits the ground I tell myself again and again
that I can't let these seizures take my Life under ground.



Gregg is 40 & has epilepsy…

I was a manager at a brokerage firm, going to MBA school at night. I was married in 2002. But that year I got into an accident and they needed to do an MRI. The MRI found a tumor called Oligodendroglioma. During surgery they found out that part of my tumor cannot be fully removed. I was divorced one year after the accident. I kept working until the tumor showed growth this year. I had to get radiation through the month of May and the first week of June. I had to leave work in April because of the growth and the need for radiation. I had worked there for ten years, and now I can never go back. My short-term disability turned to long-term disability in October, and I must apply for Social Security. I'm sending in that paper work now.

If my family wasn't helping me I would not be able to get through this mountain of forms. I used to be married, a manager, and an MBA student. Now I don't get enough money to pay my mortgage. I need to take thirty pills a day and I still have daily seizures, which eliminates my ability to drive. I also have a VNS implanted in my chest. On Tuesdays I walk over to a church that gives away two bags of food twice a month. All of this has created a whole new viewpoint on life, both good and bad. What's turned my viewpoint around on the good side has been my involvement in fundraisers. The last two years I've worked on fundraisers for epilepsy and brain tumors. My view point on the other side gets typed into this computer.

Jessica Stein

Confessions of an Epileptic

If you were to look at me you would probably smile, everyone does. You might smile at my affable laugh or my happy-go-lucky attitude, but you wouldn't smile at my disorder, mostly because if you looked at me, you wouldn't be able to tell I had a disorder, and for a long time that's the way I liked it.

The doctors say I've probably had epilepsy since I was four but I wasn't diagnosed for another seven years. Thirteen. What an age. Entering the teenage world filled with all the pros and cons that comes with it, what an age to be diagnosed with epilepsy. My self-esteem was crushed. I had become a sick puppy in a crowd of hungry hyenas. Hiding my new identity was my only shot at survival. So I strategized. Taking my medication only when I was alone became a routine, my identification necklace was placed in the bottom of my jewelry box instead of around my neck, and the only reason for my teachers taking me aside was for nothing other than to say hello. My plan was perfect, and it worked until that one fateful morning in the band room.

As always, I hadn't taken my medication, and as always, I thought nothing of it. I sat down to put my clarinet together, tuned it, and blinked in front of fifty of my classmates. I opened my eyes to a whole new world, the smell of medication and sanitized counters, a bed with a paper sheet laid across the cot, and a nurse hovering over me. Lifting my head slightly, I looked around, then immediately brought myself back down to the paper-covered pillow. I was exhausted, woozy, my pants were wet, and it was hard to concentrate. My secret had been revealed. After what my classmates had witnessed, it was over.

An hour had passed; the nurse asked me if I was ready to return to class. "No, it's over. I can't go out there!" I said to myself. "Yeah, I should be fine," I said aloud. Suffering through a quiet and lonesome walk, I made it back to my classroom. Everyone eyed me, everyone whispered. After I took my seat, a few of the kids asked me if I was ok, I smiled. Throughout the day, a few kids turned into half the kids and all of the teachers. No one made fun of me, all they did was ask what had happened and if I was going to be ok. I was safe and accepted.

Epilepsy has been apart of my life for almost five years now, and with it I have accomplished many great things, including winning a 2008-2009 Epilepsy Foundation scholarship. I will always struggle with this part of my life but never again will I doubt myself in how "normal" I have to be to be accepted.

Jessica is 18 & has epilepsy…

I was diagnosed with epilepsy a little bit before my 13th birthday. Since then, I have had a total of seven grand mal seizures due to my lack of remembering my medication. But I am currently five months seizure free and intend to stay that way. I have a job at a local Applebee's as a hostess, and I am currently attending Century College of White Bear Lake, going for my AA degree and then planning to transfer to the University of Wisconsin in River Falls where I will major in secondary education.

Mike Mielenhausen

Conquering Epilepsy and Staying Involved

When I was 4 years old I had my first seizure. I am now 16 and have been seizure-free for 3 years and seizure-free off medication for over 10 months. In July I went to my neurologist for an EEG. After the EEG, I had an appointment with my neurologist, who had looked it over. In the 12 years that I have had epilepsy, I never thought I would hear a neurologist tell me that I didn't need to see him anymore.

That night, to celebrate, I went to a "Fountains of Wayne" concert with my neighbor, Paul. I got home at about 10:30 that night. I found this to be a very ironic way to celebrate the good news I had received earlier that day, because sometimes sleep deprivation can cause seizures. As it turned out though, I was fine.

I remember, when I was 11 years old, feeling really isolated because I felt like I was the only one who had seizures. I later found out that the exact opposite was true: lots of other people had seizures, especially kids my age. I worked with Vicki Kopplin from the Epilepsy Foundation of Minnesota to get kids with epilepsy together through various events. Vicki and I planned a bowling event, which tons of kids showed up to because they wanted to connect with other kids who had epilepsy as well.

This is how the Shining Stars program was born. When we first planned the bowling event, there were a large number of people who showed up. Since 2003, when the program was founded, there have been more than 270 kids who have joined the program. For me, the biggest challenge I faced with epilepsy was feeling isolated. Through the Shining Stars program, I was able to connect with other kids with epilepsy, which was important for me, and also important to all the other Shining Stars.

In 2004, I was named the Epilepsy Foundation of Minnesota's "Winning Kid." For a whole year, I spoke on behalf of the Epilepsy Foundation. I got to go to Washington D.C. to talk with Senator Norm Coleman and Senator Mark Dayton (he told me to call him Mark), throw out the first pitch at the Twins game, speak at various functions for EFM, including the 50th Anniversary dinner, and many other fantastic things. I also was on the very first Youth Advisory Council for EFM. This was a very fun experience, because I not only got to meet other kids with epilepsy, but also to tell them that they can do anything they set their minds to and that their epilepsy does not have to and should not ever slow them down. This was one of my favorite parts of being on the Council, which I will be a part of again this year.

I have been seizure-free for 3 years now. This does not mean, however, that I will quit being involved with EFM. When I was first diagnosed with epilepsy, I was very scared that no one else had epilepsy besides me. The workers at EFM helped me get over that feeling of isolation by allowing me to connect with other kids who have epilepsy, who may be feeling isolated like I did. Originally, I thought that having epilepsy was somewhat of a curse. After I got connected with the Foundation, however, I realized that having epilepsy could be a blessing in disguise, because I have had so many opportunities that I wouldn't have gotten otherwise.

When I began to feel isolated, the Foundation really came through, because they realized that no one should have to go through that. When I had my first seizure, my parents had absolutely no clue what was going on (neither did I, for that matter, because I had almost all of my seizures when I was sleeping). After my parents figured out that I had a seizure, they were scared, but always very supportive. My best friend since kindergarten has always been very supportive of me and was very glad to hear the good report from my doctor last summer. After I was diagnosed with epilepsy, aside from medication, as it turned out, all I needed was support, acceptance, and someone to lean on.

I have always wanted to be a rock star and play shows all over the world for fans who are cheering for me the whole time. The Epilepsy Foundation of Minnesota, my family, and my friends have been cheering me on since the time when I was first diagnosed with epilepsy. I may not be playing sold-out shows, but I have to say that I've got a pretty sweet gig right now. I know I could not have gotten through having epilepsy without the help of EFM, so for that I thank them very much. I would also like to thank my family and friends because they have always been there for me. I'd also like to thank the academy because I have always wanted to.

I now realize that epilepsy is kind of like Brett Favre. It's been around forever, but we all hope that it will go away eventually. I know I will stay involved with the Foundation in big ways and small for the rest of my life, and I thank them for doing so much for me. They have showed me that you can do anything you set your mind to, even if you have epilepsy. I know I can be proof of this important message for future generations.

Mike is 16 & has epilepsy…

I serve on the Youth Advisory Council for the Epilepsy Foundation of Minnesota.

Kelsie Johnson

Why?

It’s back, this feeling
of frustration.
I just want to scream,
and let it be known to the nation!

Why do I hunger
For this world’s pleasures?
Why can’t I understand
That God’s love is the greatest treasure?

I’m on my wits end!
Why can’t I move on??
This feeling of remorse
Is always so strong!

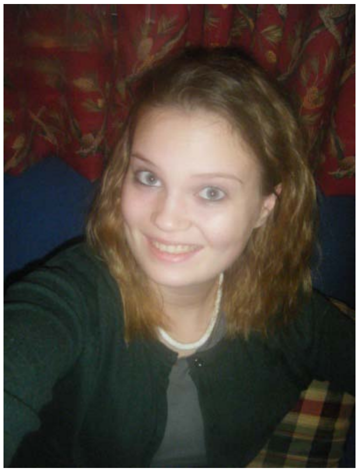
It makes me feel so lowly.
It makes me feel so empty.
This weight on my chest
Is getting too hefty.

It’s like a foul taste
That I can’t get rid of.
I need some sort of mouth wash.
It is most definitely God’s love.

It’s not that He’s not loving me.
I’m the one not liking what I see.
I need to have trust that God has a plan.
And it can’t be disturbed by any kind of man.

Where to turn next?
God’s word is my best guess.
The answers to this world’s questions.
The healing of these nasty feelings.

It’s just another bump in the road.
An obnoxious, slimy toad.
God will provide what I need most.
He is our Maker, the Holy Ghost.



Kelsie is18 & has epilepsy…

I was diagnosed with left temporal lobe epilepsy when I was 17. It took me over so much that it feels like I lost 2 years of my life. On top of that, school was very difficult. Somehow I was able to proudly get my diploma and graduate with fellow classmates. My grandma also had epilepsy. She passed away 4 months before I was diagnosed.

The inspiration I had to write this poem was the feeling of confusion and hopelessness that epilepsy was giving me. I felt the only way to get rid of these feelings was to put them on paper and give them to God. I am hoping to attend college for creative writing and to be a motivational speaker.

Bill Aleshire

You Are Not Alone

For most of my life
I thought I was alone!
And because of that I had a lot of pain and strife!
But as I grow I realize that I'm not alone!

People may take advantage of me
because they don`t understand.
But I'm happy to be me!
For I pray that god is at hand!

I remember when I went to the Inner Voice, Inner Strength event.
I looked at the list of amazing people who
also have epilepsy.
Seeing that made me happier than before.
So if you feel alone! -
remember that you're not
because you have your parents, friends, and of course god.
You know that's what they're all for.
Because you are not alone!

Bill is 35 & has epilepsy…

I've had epilepsy for most of my life. It became noticeable when I was 4. I have focal seizures. They have made me a stronger man. As I've gotten older, I've found I can still do a lot of things I never thought I could do, because people were afraid that I would embarrass myself or get hurt!

There are so many inspirations in my life now. Of course, my family, friends, other people who have seizures, and God. Like my poem says, "You are not alone," and also, "Don't give up." If you want to try something new, go for it! You'll be glad you did!!!

Sylvia Carol Nelson

The Support Group

Guys and gals gather together to talk, to listen.
Each has a unique storm in their brain.

To share with each other, and listen as well,
each one has a Talent to give,
so support in the group becomes strong,
can grow and can live.

For whatever the puzzles that each person has,
Talent plus Talent combine to conquer those storms.

GROUP becomes a gift to each person.
The storm is over.

Sylvia is 69 & has epilepsy…

If medications were perfect, seizures would be non-existent. This world is not perfect, therefore I still seize now and then. My diagnosis is grand mal and complex partial seizures. I take meds along with people who have arthritis, high blood pressure, diabetes, etc. God created me for a reason and still has use for me. For that I thank Him. My inspiration is the EFM Twin Cities Adult Support Group, a multi-talented group of individuals – intelligent, creative, and friendly.

L.E. LaRue

Turning a Corner

I read a poem in high school by Langston Hughes called "Mother to Son." It spoke of life being like a staircase, and I could relate to it well. Because life hasn't been a "crystal stair" for me either, due to battling epilepsy. Despite this, I've still been turning corners, especially this past year.

I knew I had turned a big corner in March, when I went to Washington, DC and participated in the National Walk for Epilepsy. It was my fourth visit to the nation's capital in my lifetime, but probably will always be the most memorable to me. I have plenty of souvenirs from the event, such as the shirt and the "participant bib" - I was number 2673. It was a wet Saturday morning on the National Mall, but I don't think it dampened the spirits of anyone there, including me. I took plenty of pictures of the event, seventeen in all, including one of an ad for the event I saw on a Metro train. For those unfamiliar with the National Mall, we began and ended the walk near Capitol Hill and walked over to the Washington Monument. So I see these two buildings in many of my pictures.

The walk began with some famous people talking on stage about their experiences with epilepsy - either personally or with a relative who has it. This led to me getting a postcard and button for an online organization called "Talk About It," which is dedicated to defeating the myths about epilepsy and seizure disorders. I met somebody on the walk that reminded me of why I don't tell people at work about my history of epilepsy. It was a New Yorker who wore a shirt, telling her story about losing her job because of it. It said "forced medical leave or threatened with suspension." It went on to say how she wasn't allowed to be an RN (registered nurse) because of her epilepsy. Near the end of the walk there was an opportunity to share your story, and I did after a short wait in line. I spoke of how I liked meeting people from all over the country at the walk, and how I was thankful to have found the Epilepsy Foundation as it has led to me feeling more empowered. I know it has been medically tougher for others, but the emotional side of having epilepsy was hard to handle. I no longer wanted to be stuck with my mother's attitude about it - she wouldn't even call it epilepsy - insisted on calling it "seizures" - and couldn't say anything positive about it. This is the best evidence of me turning a big corner - having the courage to share my story on camera. I liked how the event didn't end there, as I went to the Empowerment Exhibit and did some finger painting on the Canvas of Hope.

The good thing about the walk being in the morning is it allowed me to see plenty of sights later in the day, as I ended up taking even more pictures after the walk, forty-two in all, before the weekend was over. I walked over to the Jefferson Memorial, where the Cherry Blossom Festival was being held. On the grounds of the Washington Monument there was a girl holding up a "Free Hugs" sign, so I gladly hugged her. Then I found my way over to the Daughters of the American Revolution (DAR) building and toured it before the Gladys Knight concert in the evening. The concert was sponsored by the Epilepsy Foundation and was held at the DAR Constitution Hall. I have only one picture of me from the event, taken at one of the tents. I am wearing a Minnesota Twins hat and a purple button. Buttons for "Purple Day" were given out - it was an event held three days earlier, also supporting epilepsy.

I turned another corner in June, though it wasn't as much fun as what I just described. But it was still very necessary. I went to Iowa for a visit with family and decided I needed to confront my mother - again. I had confronted her the previous August, asking her to quit bad-mouthing my dad (my parents divorced when I was a teenager). I realized it wasn't enough, as I had always felt frustrated and upset after visits with my mom. She refuses to treat me like an adult, so I had to speak up. Before anyone rushes to judge me, one needs to understand the history. I had wanted to confront her for years, but I kept getting shouted down and heckled. After reading a book I found at a secondhand store called "Toxic Parents" by Dr. Susan Forward, I knew I needed to work up the courage to confront her. The book covers different types of abusive parents. While mine weren't physically or sexually abusive, Mom sure was verbally abusive. I told her how I didn't like how she was always so belittling when I was younger and then would often say "just teasing." The one I never forgot was when she threatened to shut me up with furnace (duct) tape.

I told her how much it also hurt when she could never say anything positive about my having epilepsy and would only call it seizures. She claims it's what the doctors called it. She always treated it like an annoyance, but this attitude did me no good at all. It may have just been ignorance on her part, but I really don't care for why she had such a lousy attitude about it. Suffice it to say, it got ugly. We went back years, and she was unfair with me all over again, wanting to rehash the divorce. I told her I didn't want to hear about it anymore as it's been 20 years (and she's been remarried for all but a year and a half of it). I could have made it even uglier but I didn't. I could have used two words in particular: hypocrite (which she is) and orphan (always felt like one due to my brutal upbringing). It was the first time I had told her about the Epilepsy Foundation and how her lousy attitude about the disorder drove me to join a support group. I haven't talked with Mom since then, though I recently sent a follow-up letter telling her I have no plans whatsoever of wavering from my two demands. They are: quit talking about the divorce (and bad-mouthing my dad), and treat me like an adult (and talk to me like I'm an adult) when I visit.

Do I feel better since I confronted my mom? Absolutely. My friends from work and from the comedy clubs have seen a difference in me. I conduct myself with a lot less pent-up anger than before. They knew my family was a touchy subject and didn't say anything about it. I had a separate talk with my dad on this same weekend and asked for the same from him. He did admit to not knowing at first how to respond, but he has met my demands. I have talked with him often since then, and he even came to the Twin Cities to visit me in August. But I pretty much expected this much, as I've known for a while how my parents were two very different people. I have more in common with my dad and this helps of course. My college major was history, and my earliest influence in this area was him, as he enjoys that subject immensely. There were things that Dad did when I was a kid that were hurtful - he could be belittling just like Mom - but I have forgiven him. Why? Because he has admitted his mistakes, and I have more respect for people who are willing to admit mistakes. I would like to have a good relationship with both parents, but if it's not possible, then I can be content with knowing I get along well with one of them - my dad. And if I continue to be estranged from my mom, then at least much of the poison is now gone from my life.

There have been other ways I've turned a corner this year, but those two stand out the most. I've continued going to open mic nights at several of the area comedy clubs. I still may not be on stage often, but each time I am it feels good because I've found another skill I'm pretty decent at. I like how I get plenty of laughs, even if it's often self-deprecating humor. After one show I had somebody in the crowd spot me and say to me how much they liked my jokes. Of course this feels good, and I even referenced a quote by Bertrand Russell about it, how "anything you're good at contributes to happiness." What I like is how I no longer need much validation from others as I've built up enough confidence due to my successes. To me it's therapeutic to go on stage and tell jokes, including how online dating isn't going well.

Yes, I've also continued dating, even if it hasn't been very satisfying yet as most of my matches I never meet or end after one date. I did take one courageous step, telling one girlfriend about my epilepsy. But I feel like I may have told her too soon - we had met less than a month earlier. I told her during a St. Paul Saints baseball game, in response to something she had said - I think it was knowing somebody who had epilepsy. But her attitude wasn't too good about it. When I said it was never serious enough to prevent me from getting a driver license she said, "It's a good thing because then neither of us would be able to drive." (She lost her driver license due to an eye problem.) I eventually decided to end it because we had too little in common, among other things.

I haven't said anything about having epilepsy to my latest lady friend, as I wanted to wait for when the time was right. And I don't feel the need to tell her when it feels like the relationship won't last much longer. I had a good feeling about her at first - had a good time with her at a heavy metal concert as I let loose with the "I don't care" attitude for once. Even spoke of having her do my first-ever tattoo. But I've been finding out I likely have too little in common with "tattoo girl" as well - like how she drinks a lot more than I do. But live and learn. I'm still trying, and I continue to have hope that the right woman is out there.

I still get plenty out of the events sponsored by the Epilepsy Foundation, including their October conference. Most relevant to me was the speech by Dr. Penovich about life matters - took plenty of notes. One slide said social competence skills begin in childhood. I wrote down how odd it was when Mom spoke of nurses not picking me up in the hospital when I was a baby, as she didn't hug me often when I was a kid. Then I wondered if she saw me as damaged goods when I was diagnosed with epilepsy, since her brother had it too. (Dad told me this, she never mentioned it to me.) I know Mom said he had spinal meningitis, which may have caused it. The main thing I know is he died in a tractor accident at age 23, and Mom's family doesn't talk much about it. But I wondered if he was mentally ill at all, due to epilepsy, and just wanted to commit suicide. On the slide about the social functioning continuum, I wrote how I liked the "Free Hugs" picture, as it reminded me of being at the national walk in Washington, DC.

I also liked seeing some of my art on display there - and at an event a week later at Open Book in Minneapolis. I used a simple message of "I will not let epilepsy beat me," and I liked hearing how the framer compared me to a famous artist, but didn't hear which one. While I do like hearing this about the art, I see my writing as being a much stronger skill. The caption spoke of how I continue to feel about the disorder. I don't tell most people about having epilepsy as I'm afraid of losing jobs and friends because of it. To date, only one co-worker has ever heard about it from me - not even my boss has heard about it. At times I am still overly grateful to this friend from work and show it in an odd way. One time I said I feel as though they deserved the biggest apology because I once considered suicide, even though it was years before I even knew this friend. I should ask how they felt about hearing this. But it's nice to know somebody so positive and encouraging and who "has my back."

In other issues, things are just fine for me and it's all I can ask. Living with the spinal cord injury hasn't slowed me down yet, it's stable and I only need to see my neurologist twice a year. The Lyrica I take for it is working fine, and I'm hopeful to continue to be able to walk - I no longer take it for granted. I'm trying not to think too much about the possibility of paralysis, just taking it one day at a time. I had wondered if the meds were causing the weight gain - they weren't. I proved this by entering my company's weight-loss program and lost 12 pounds during the 3-month run just by changing my eating habits and making some healthier choices at each meal.

It's hard to say what the future holds for me, but after this year of turning a corner in more ways than one I truly believe my best days are still ahead for me. My successes have taught me how anything is possible.

L.E. is 35 & has epilepsy…

I was diagnosed with epilepsy at age 4 and was on Dilantin until age 10. My seizures have been rare since then – once a year or even less often. I feel fortunate to have lived a mostly normal life – I work full time and was never prevented from getting a driver's license.

Seizures and epilepsy have affected my life from more of an emotional standpoint than a physical one. Besides trying to avoid stress, I eventually learned how attitude makes the difference. Since my epilepsy hasn't limited me much physically, I know there's plenty I can do in life. I enjoy traveling a lot, I've seen quite a bit of America. Much of my travels involve seeing historic sites. Baseball and history are my two biggest interests. I also like attending live theater.

My writings have been published in various papers as letters to the editor. The inspiration for my written works is my life. I know that writing about myself is easier than some other subjects, since I know myself best.

Mosmi Malhotra

My Power

busy mind
let it relax
seizure will come
then it will pass

where is the focus
feel the mind run
confusion sets in
clarity is gone

I won’t let it defeat me
It’s not part of my plan
I’m on the mend
It’s my power in the end

Mosmi is 29 & has epilepsy…

This poem is inspired by the power of epilepsy in my life. Although I experience the before and after of the seizure, I know in the end it is in my power. As my positive thoughts increase, the power of my seizures decreases. I am diagnosed with complex and simple partial seizures after infected with viral encephalitis in 2001.

“When I dare to be powerful - to use my strength in the service of my vision, then it becomes less and less important whether I am afraid.” – Audre Lorde

Francine Coyan

No Longer Ache

Let her no longer ache
No matter what the tides wash in

That she may find the need for solitude is fundamental
The space for time apart as essential to success

To be selfless in lifestyle,
Caring in spirit,
Wise enough to sense true intentions,
Triumphing in style, method and strategy

Forgetting the cruelties wrought against her
Finally having her chance to soar
For it is one chance for change or despair will cling forevermore

Francine is 56 & has epilepsy…

Epilepsy has been a battle that has affected employment, transportation, and lifestyle. First seizure happened when I was 28 years old. Apparently, a birth defect did not make its appearance until growing into adulthood. Now that CRT and MRI machines are available, it was correctly diagnosed. I have been seizure free since 2003 and can stay that way with rest, watching out for stress and looking for telltale signs when necessary.

Kay Irving Kramer

Mom

As I look back through the many years of my life,
I remember so well, your always having been near;
You helped me in every way that you knew how,
By providing me with answers and comfort with my disability,
Taught by you, that my health condition was a temporary part of life,
That enabled me to eliminate an excessive amount of strife;
You always emphasized the constant need to maintain faith and hope,
Which I fortunately did and was able within my life to better cope,
Miracles can happen and our prayers can be answered bringing cheers,
I experienced this through The Lord's guidance over the years;
Another asset I obtained mostly from you, I refer to as perseverance,
For as you said "if you can't do something like others do, if it's
Significant – do it your own way to achieve it, too;"
My life has thus brought me many things, from growth, employment,
marriage, a family, and reasonable health;
So I now do say "I'll never forget The Lord's guidance, or your
nearness to me;"
Until such time as I meet you both in Heaven you see.

Our Seasons

We call them seasons and they're with us throughout the entire year,
They begin in the month of January, as we both see and hear;
Snowflakes come, as well as go, and the temperatures tend to get very low,
The wind often howls in its own way, blowing snow everywhere, I do say;
Then the month of March enters the horizon, slowly bringing us the Spring,
During these months we come to see the "true beauty of nature;"
When our lawns turn green and our many flower colors are often seen,
We thus come to enjoy these things bring to our heart;
For we know, all too well, that the Summer is close behind – with its start,
During its time, the temperatures are warming and helping our
lawns and flowers to flourish;
We seek to enjoy the times we have under the sun, as well as many activities that
we come to enjoy,
For we know, all too well, that the Fall months lie just ahead of us;
When the trees come to shed their leaves and our flowers begin to wither and die,
all in preparation for the Winter months,
We continually go through this cycle during our life's many years and
know that they may bring sorrow, but their seasonal beauty brings us cheers.

2009

This forthcoming year of 2009, I thus foresee,

Great happenings and challenges for the world and our country;
In setting this world's stage for this properly,
We can and should put forth a greater friendship with our fellow man
to gain peace, happiness, and prosperity;
We've seen and learned things through the many acts of war,
That many problems from which they were fought became even more;
Thus, within our great country, we've always sought to set an example for the world to see,
It wasn't easy to always attain these goals, but it showed others
what could be had through democracy;
We should begin here at home by renewing the elements and practices of faith, hope, peace, and family unity,
Many of these things have seemed to fall apart from what was
previously shown as respect, responsibility, to bring cheers;
The pace of living one's life today, seems to have simply runaway,
So many people are busy trying to make their ends meet, when
They've often been at fault, I do say;
If people would take the time out of their daily lives to re-learn and practice the fundamentals our previous generations had,
Everyone would be far better off in 2009, rather than facing items
that can become quite sad;
Hence, mankind should have and show more respect and peace to each other,
just as if they were a sister or brother.

Kay is 70 & has epilepsy…

I have had epilepsy since birth. I attended college, raised a family, and held a job for over 31 years at Honeywell. I served with the Council of Honeywell Employees with Disabilities; Honeywell Corporate Representative to the President's Committee on Employment of People with Disabilities (teaching businesses how to adapt to the Americans with Disabilities Act); Epilepsy Foundation of MN; and League of MN Human Rights Commissions, among others.

I now have another confrontation in the form of cancer – but I've achieved the impossible in the diagnosis from renowned doctors, and I won't stop now. My collection of poetic verses is entitled, "The Rhyme and Reason Works of Kay I. Kramer." My verses were written to be inspirational in respect to the items they refer too – family, life, and nature, etc. – and with the purpose of helping people realize more fully the many attributes that life affords us all.

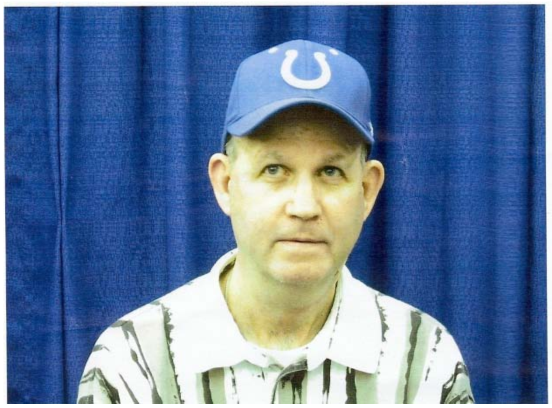
Steve Ireland

My Life

I've had epilepsy all my life, or since the day I was born – I had a seizure this day and every day since. Like all people, my medical history has become one of interest. I have many memories of my medical history.

I've enjoyed and appreciated my family and friends, which have been there with me or for me all my life. I've also been able to participate in and enjoy various activities all my life. I've enjoyed not only being employed, but I've enjoyed the various jobs I had as well.

My life is like a rollercoaster ride. The rollercoaster cars are filled with seizures, medical doctors, hospitals, schools, various tests and medications, various activities, realities, my resume, volunteer work, church and church activities, dreams, and the times I've had and haven't had a seizure.

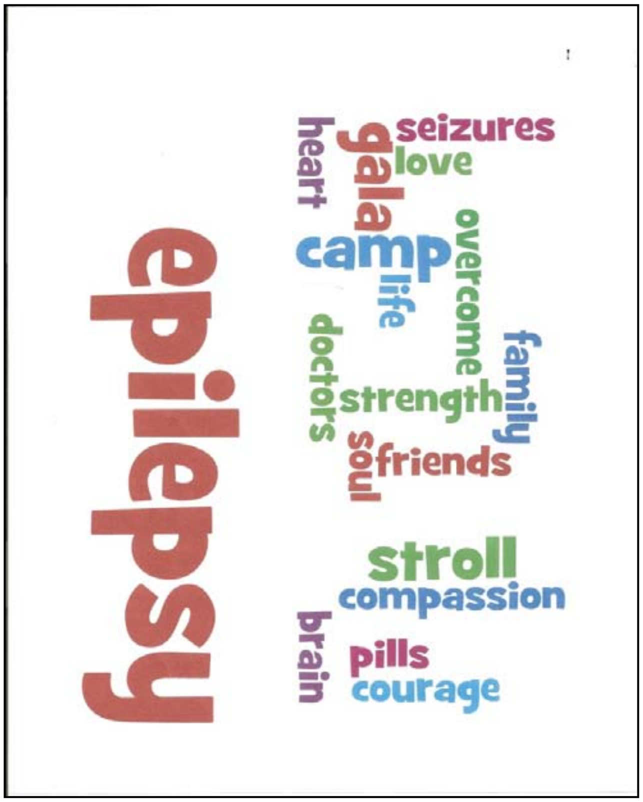


Steve is 59 & has epilepsy…

During my life I've seen various doctors, nurses, and hospitals. I've had EEGs, EKGs, long term hospital care, as well as various medications. I will be on medication all my life as I'm not capable of having an operation. Seizures have affected how I live my life. For 1 year, 11 months, and 6 days I've gone without a seizure. I still know that I have epilepsy, and I live and do things that are affected. I live within the realm of my life. I've had various jobs – good jobs. Now I'm volunteering at the Epilepsy Foundation of MN. I am inspired by various EFMN staff.

Travis Boyum

Travis' Epilogue



Some of my hobbies are fishing with my dad and going to the cabin with my family – I also enjoy drawing, writing, catching frogs, and playing basketball, lacrosse, and football. These are some everyday things I enjoy.

I have two special talents. First, I like talking to others. One thing I'm good at talking about is epilepsy and my life with epilepsy. Another talent is including others and being kind to others even if they have a disease like me.

Some honors of mine are to have epilepsy. Epilepsy is not a bad thing, it does not slow me down. Another honor I have is to have raised all the money I have for the Epilepsy Foundation of Minnesota, which is close to $15,000 dollars in four years. A couple more honors are to be a school patrol captain, to be student of the month, and to go to Camp OZ, a special place.

I do not struggle very much. But for all you who do, don't worry about the outside, only worry about your heart and soul because if you follow your heart and soul you can be and do whatever you want!

Travis is 12 & has epilepsy…

Travis is the 2009/2010 "Winning Kid" for EFMN. His parents say: Travis was first diagnosed with Epilepsy at the age of 4. He has Absence Seizures, which have been controlled for the past 18 months with Zarontin. We have never sheltered Travis from his condition. As a result, Travis does not try to hide the fact that he has epilepsy. He openly tells his friends, his teachers, his coaches, and others. Travis writes about his experience with seizures and, most importantly, with EFMN in his school journal and has also done school projects on epilepsy.

Travis has learned through his participation in the Stroll, Camp Oz, and most recently the Gala that he is very fortunate in that his condition is currently manageable. This is not to say that Travis does not have moments of frustration with taking meds daily and some of the side effects. However, he is amazingly quick to realize there are many that are less fortunate, and he has frequently voiced the wish to help more. Epilepsy is part of who Travis is, but it has not defined who he is, which he clearly shows in his Epilogue.

Stephanie Gensmer Chappell

The Federal Precedent of a State Law

Here I sit. Waiting. I'm waiting for a judge to change a decision that affects 3 million people. I'm waiting for a judge to decide that I do have the right to a trial based on employment discrimination. I'm waiting for my next loan payment, the loan I took out to cover legal fees to prove to a judge that I have been discriminated against. I'm waiting for my credit card statement to see how much food and gas was last month since I no longer can afford to pay cash. I'm waiting for my next seizure. I never thought this situation would happen.

The Federal Discrimination Case

Four years ago, an employer asked me to resign after I made a request for reasonable accommodation. I have chronic, physical, invisible medical conditions including seizures. The first request I made was simple: I'd like to notify other employees of my seizure disorder. It makes sense that if you feel there is an environment that may trigger a seizure – the people in that environment should know and know how to respond. The employer requested the usual doctor's note to prove I had a disability. After that request was made, more appeared. The employer demanded to know what medications I took, the dosages of each and how long I'd taken them.

Also, the supervisor made it a point to enter my work area and disrupt the environment either through harassing a customer or me. The environment became increasingly difficult and hostile. The employer changed policy and demanded only I follow it. The policy interfered with my ability to treat my seizure disorder and created another obstacle in my employment. Finally, a drill was called while I was without remedy for my request that made the situation one of immense frustration for myself. When the drill is called, no one can leave or enter the building while supervisors sweep the area. All of these changes created a lot of unrest over one request.

Due to the changes, demands, and treatment after requesting an accommodation, I notified the employer's Human Rights Officer, aka my supervisor. Within hours, the Supervisor had discussed my disability with numerous staff and community members. There was an attempt to trigger a seizure with a code drill. Also, interruptions to my work area escalated.

At a meeting, the employer asked me to resign due to allegations I made. I refused and instead of suspending the person I accused of harassing me, the employer suspended me so they could investigate.

Before any investigation began, the employer demanded my resignation and stated it would notify the State for revocation of my certification if I didn't resign. My union was now involved and caused more confusion. The threat was real and the union was really useless. This employer was so misinformed of seizures that persons there felt a seizure disorder was grounds to revoke my professional certifications/licenses.

I reluctantly tried to resign with a single sentence letter of resignation. THAT WAS REFUSED! The employer decided I now had to sign a release to any claims within the deadline. I understood that if I wanted to keep my professional certifications and get my salary since the last pay period, I had to sign.

By the time the employer finally produced the document, I had less than 15 minutes to find an attorney. It didn't happen. A union attorney scanned it after it was faxed to the union office. The union attorney gave me this ultimatum, "Is your professional license more important than your claim of discrimination?" Great legal advice, huh?

I wanted to rescind. I didn't understand the form – I don't think many people could with the time demands and that threat of revocation and that ultimatum. I didn't even understand the number of days I had to rescind the paper. I only knew I needed my paycheck to survive.

If you're wondering what I got for my signature, I *gave* the employer about $300. The employer conveniently used an old pay schedule and kept all benefits – the $300 is only the difference between the old pay scale and the current union pay scale I was hired under. I was so scared that I signed the form written by the employer's attorney. I was afraid of the employer.

My State Rights

So, that's the Federal discrimination case in short. But, the reason I'm sitting here, waiting, is because I chose to answer that ultimatum by filing a discrimination lawsuit. Years after I did that, I lost my rights under Minnesota Law according to a Federal Court judge. No, it shouldn't be. Federal courts rule over Federal laws like the Freedom of Information Act. State courts rule over State laws like the Minnesota Government Data Practices Act. Both Acts give citizens access to government documents. One Act is in the State courts and the other is in the Federal court. Since the employer was in a public sector (county, city owned hospital, public school, state department are some examples), I had a right to view documents in that employer's possession under both acts. I chose Minnesota's law, Chapter 13 (MGDPA). I didn't opt to utilize the Federal law because it wasn't necessary. Everything I wanted to look at was accessible by the State's law.

Over the years, I researched the employer and found complaints with various "institutions." For example, I found complaints regarding the employer's nonexistent ADA policies. The employer replied to one investigation with a "we are in the review stage" type answer to the initial inquiry. To date, there was a "compliance agreement" between the employer and one Department. The employer missed nearly all of the deadlines in the agreement. I haven't been able to check on further compliance. That's what brings me to this dilemma and why I wait.

This isn't part of those neat court TV shows. My former employer's attorney thinks my MGDPA request falls within the Federal Court's Rules of Procedure (rules that set limits on trial preparation). My time limit had nearly expired when I decided to dig further into what the employer had and had not done regarding other laws. This time limit for my Federal case had nothing to do with my quest for information of wrongdoing about other issues.

Using the State's Government Data Practices act, I tried for months to see papers from the employer to follow up on the above mentioned investigation and other issues of disabled employee/customer rights, security, background experience of the professionally certified/licensed staff, safety and staff credentials. These areas had red flags in my research. Under the MGDPA, I needed only to request the information according to the public entity's published methods and the answers would appear. There was no need to exercise my rights under Federal court for a few reasons: the information I sought was unrelated to my Federal case (litigation), the State Act provided the avenue necessary to view the documents, and it wasn't a National issue – this was a State public entity. I met a gigantic roadblock.

First the employer's attorney sent a letter to my Federal discrimination case's attorney demanding I stop requesting information. In response, my attorney explained that my request had nothing to do with my Federal litigation and was within my rights under Minnesota's Chapter 13. They stated the employer would comply with any and all Chapter 13 requests. Great, right? Wrong!

Since the employer's attorney seemed to understand, I rewrote my request to make it easier to understand for my former employer. In the request(s), I identified what I wanted to review, the time I wanted to review, and some calendar dates to review it. For two months, the employer made excuses. Finally, I just gave a time and appeared with witness in tow. Before a witness, the employer refused to allow me to review any record or document including my own personnel file even though their attorney promised the opposite.

Now, the employer's attorney filed a legal motion in my Federal discrimination case to prevent me from getting any information from the employer. As a show of defiance, their attorney ignored the State court and abused the Federal court system. The defense attorney filed a motion in Federal court to cancel my rights under State law.

That's the clincher. Federal courts do not have jurisdiction over State laws. If I had acted under the Federal Act, the court would have to make a decision since the defense could easily argue that I was trying to work outside of the rules of the Federal court. However, because I was seeking information under the State act, the Federal court had no jurisdiction over State laws. It didn't matter that I wasn't seeking information about my discrimination that occurred four years ago. The judge overlooked the fact that Federal court has no jurisdiction over State law and granted the motion. By doing that, a new precedent was set.

The Precedent

What does this mean for me? I have to hang up my personal rights to plead my discrimination case because the judge said so. I have no right as a Minnesota citizen to investigate anything about this employer. It means I may never know what safety issues were or weren't followed because I am a litigant in a discrimination lawsuit against the employer.

Even though there is a complaint and compliance issue with a U.S. Department that governs the employer, I can't see what this employer has and has not done to correct its policies for staff or customers. No one is checking on these issues.

I could just drop the whole Federal discrimination lawsuit. I could take my legal fees and costs and turn it into a bigger loan than the one I took out to pay for some of the big items I've spent to get this far in the case (lawsuits aren't free).

If I quit, that means the judge's decision will stand. The precedent will continue for my lifetime. U.S. defense attorneys will use this decision to support defendants across the nation. It will be a roadblock for disabled in the nation for years to come! Any defense attorney can block a disabled litigant from making any requests for documents from any public entity. There are too many ANYs in that sentence.

In other words, the decision this judge made will be cited by attorneys to keep others from exercising their State rights under the MGDPA (most states have similar laws to MN's). Litigants in a lawsuit against a public entity, like county governments or public schools and hospitals, will not be allowed to investigate other issues the employer may be doing wrong, illegally, or not at all.

It means that this one decision, a small issue of whether or not a person can exercise the freedoms of checks and balances on a public entity, has the potential to affect the rights of more than 3 million people, the current estimate of people with a seizure disorder. I can't imagine how many other disabled people will be affected!

The Future of 3 Million People

I sit and wait. I'm waiting for two decisions: a decision on the appeal I filed (the discovery motion about my State right to view files) and a summary judgment (whole other thing) motion. My attorney filed the appeal about the State law vs. Federal jurisdiction. One decision should be made in Federal court while the other cannot.

I've been down other avenues to find information about the employer. Various State departments and authorities helped a little in finding a document that questions the honesty of the employer's hiring practices; the employer's records will help clarify this for me. A few websites have given me information about the employer and some shocking comparisons that no one else finds odd, yet. Even a few trips to the areas that benefit from the employer have given me more hypotheses that need to be tested against the employer's files.

I have questions that need answers and the Minnesota Government Data Practices Act gives me the right to those answers, but the judge has to realize that. I never thought I could lose those rights just by suffering employment discrimination. Better yet, the judge has to decide that I have those rights and those rights have no "right" being brought up in Federal court. Right? (Right!)

It's been four years since I worked for that employer and the employer continues to discriminate against me. The employer refused my MGDPA (State law) requests in writing and in person. The employer took my classification as disabled and used it again to keep me out of the building. It seems things haven't changed.

It's been four years since I used my professional license. Yes, I still have it. Getting a job again in that field may prove impossible with the new decision. I can't see what my previous employer states about my disability in my file. I have no knowledge of what statements were made or what statements the employer would make to another. It's apparent this employer likely isn't familiar with what can and can't be included in a personnel file. I'd like to be back in that environment and excel as I did before this employer changed one thing, my schedule. The only reason I made a request for accommodation was because my schedule was changed after I was hired. Otherwise, I could have kept my disability to myself.

I face a new ultimatum: Fight against a precedent in Federal court, or fight against a Minnesota public entity's wrongdoing in State court. If I don't fight the battle in either case, the precedent stands for any future case involving a disabled person in the United States Federal Court system and possibly each State's court system. It's a lot of stress when you realize you're the only person who can change the future of 3 million.

Here I sit. Waiting. Waiting for the next seizure…Waiting for the next credit card bill…Waiting on my future… and 3 million other futures. Which one will come next? The credit card bill.

Stephanie is 40 & has epilepsy…

I am diagnosed with complex partial, tonic clonic seizures. The complex ones don't occur without the big daddies! It's been nearly two years since my last seizure. Still, my freedoms are threatened daily with seizures. For example, if I have a seizure, my driving license will most likely be suspended for a 3-month minimum. Losing that one freedom will start a domino effect – no car, no way to get to work (no bus lines), no way to get to a doctor, no job, no socialization. Complete isolation as well as lack of medical care is inevitable.

Seizure ignorance isn't limited by educational level, training, or employment arenas. A person with a master's degree (and nearing the doctorate level) identified shock and fear as just some of the reactions she had when learning that I had a seizure disorder. This same person started a rumor that was right out of the Middle Ages, and the witch hunt was on!

This is a brief summary of part of the struggle involved in employment discrimination. Currently, a case of employment discrimination is working its way through the Federal Civil Court system. Before there can be a trial, there are several steps that need to be taken. Pre-trial motions and actions are just one step. This story focuses on that one step of the journey – one big step.

Heather M. Gilmore

Untitled 1

O Love’s heart, sing, sing!
That ageless melody-
That angel’s song-
My soul doth long to hear ‘t!

His voice amid the mid-night stirs-
What once was fell, and fallen
Behold! ‘t is risen, doubtless fair!
My Love did such, for lowly me.

Love begets love, and love
Shies away from me now, hiding-
Leaving me cold and bereft-
        -like night without stars-
O that my Love would’st return to me!

In the Night

Darkness falls on the sleeping earth;
Soft winds caress my heart
Whispers of an innocence lost
Surround my troubled soul,
Icy fingers reaching, touching
Gripping me tightly as the darkness slowly envelops me.

I close my eyes as the daylight fades
Warmth seeping from my brittle bones
Songs of sadness drip from my lips
Tears I thought long gone
Return from distant places
As my heart cries to the moon, the stars.

Dreams I lost, heart's peace ne’er found
Subtle reminders of a long-ago life
Fill my days with shadows of a hope-less past
Memories creeping forward
Slipping through the cracks
In the walls I built to keep them out.

As I lie here beside you in bed
My mind turns to days long-buried
Something softly calling to me
An urgent siren song, resounding in the depths of my soul-
I dare not follow, for my heart might break
At revelations the night might bring to me.

Could ever peace be found
Could solace ever be mine?
The night breezes sigh with my heart;
A familiar yet aged melody-
And as the moon keeps silent watch over the earth
Sweet sleep comes to claim me once more.

Untitled 2

His voice falls sweet upon my ear
As he bends his breath around my name-
Unaware he’s set my soul to trembling.
His eyes a blend of slate and ice
Twinkling as he looks my way-
His gaze meets mine, setting my heart afire
And I fear in my eyes he may see
All that I feel, for none but he.
He laughs, and all is right in my world-
He hurts, and I hurt with him.
Every beat of my heart cries his name-
The slightest brush of his skin against mine
Leaves my knees weak, and I long for more.
I ache for just one sweet, lingering kiss-
To feel the strength of his arms around me
His heart, pressed so near to mine.
Love is fine, although fickle-
I want, need, love this single, beautiful man
Yet to keep him near, I dare not reveal
The truth behind my words.
I lie awake with thoughts of love
Asleep, I dream once more of he
Who holds my heart in aching thrall
Though he remains unaware of all
The power, the hold he has o’er me.
O fool heart, how can a lowly woman such as I
In loving a beautiful soul, a man such as he
Ever hope for more than this-
To win his heart
And gain his love...

Heather is 24 & has epilepsy…

I was born with epilepsy, though I was not diagnosed until I was seven years old. Life with epilepsy is somewhat difficult, but I've learned that it doesn't define who or what I am. It's just a part of my life, something to be dealt with. There's so much more of life to be enjoyed, and despite the limitations caused by seizures, I am determined to make every day better than the last. Poetry is my outlet, my way of channeling my emotions and thoughts into something beautiful and worthy.

Maddi McGillivray

Lost Words

My lips move, there is no sound.
Lost for words,
They cannot be found.
Shunned, pushed aside
Crying for help,
Heart aches inside.
I have so much to say,
Yet something's in the way.
I feel like a circus act,
Performing for show,
Just put on a mask,
They'll never know.
Head is screaming,
I need to speak.
They shut my mouth
There is no doubt,
These words are for me to keep.
Now you're gone,
It's too late
To show how much I appreciate.
I'm invisible to those who don't care,
Though hurt, you'll always be there.
Protection and Blessings
Are the words I describe you.
My mouth is mute,
But my eyes speak.
I love you always
Those words are yours to keep.

Maddi is 18 & has epilepsy…

My inspiration? I've just had a great interest in writing. I'm not the greatest writer in the world, but if the words can't come out of my mouth, then all I can do is write them down. My seizures have made me think that I have complex epilepsy for a reason. Maybe to keep me humble for something. I'll never know the reason for why I have epilepsy. But I do know that my life is in God's hands and He has even bigger plans for me than I had for myself.

Sarah Schmidt

Give Me Your Hand

My dear friend,

A true friend says what needs to be said. Tonight I take that risk.

I cannot change your diagnosis. I cannot calm your anxiety. I cannot make you accept your epilepsy.

Up until now, you found strength by being in control. Dependency was a sign of weakness. Up until now, your world has been very black and white.

Well, girlfriend, epilepsy doesn't come in black and white. Epilepsy comes in gray. Gray is the color of strength and dependency existing side by side.

Gray is a new concept for you, isn't it?

You were having a fantastic day when that seizure pulled the rug out from under you. Happiness turned into one big headache and a lot of tears. Fear rolled over you like an insurmountable wave. It was OK to feel doubt and anger. But, even in your anger, I saw a spark of determination and courage.

You know that I speak from experience. We have been close for so many years. Now, unbelievably, we share this bond. I don't think that either one of us signed up to have seizures. Now we take the same meds and visit the same epileptologist.

Some things haven't changed and never will. We have husbands who love us. We can pick up a conversation right where we left off – no matter how long it has been since we've seen each other. We love being called "Mom." We like Gorgonzola cheese on our pizza. We love long walks and living in the country. We have a heavenly Father Who for some reason thinks that epilepsy is a blessing. (Remind me to talk to Him about that!)

It's weird, but right now I have a smile on my face. Finally, you really truly do understand what I have said for years,

"Epilepsy takes a lot out of you. It's hard to hold your head up high when you're lying on the ground."

Come on. Give me your hand. It's time to get up and love yourself again.

Always,
Sarah

Sarah is 57 & has epilepsy…
Never once did I hear the words, "You can't do that because you might have a seizure!" Never once! This little city girl grew up, fell in love, got married, and left that city to start farming. My seizure frequency has been gratefully controlled. What follows a seizure is an unusual comment. The best thing that has come into my life is the generic form of Lamictal – seizure control remains the same, but the negative side effects (of the brand name) were gone within days. The insomnia and mood swings were no longer an issue. Once, my husband tenderly took me in his arms, looked deeply into my eyes, and said, "I

like this Sarah." The warmest thing I overheard my husband say to one of our daughters was, "Your mom is more of what she used to be."

How have seizures affected my life and creativity? Flip the question: How has my life and my creativity affected my seizures? There! Feel the difference? Now the emphasis is on life and creativity. I don't think about epilepsy on a daily or even a weekly basis. It is a part of me and has been for many years. How I live and what I do express who I truly am. I want to express love, trust, gratefulness, hope, confidence, and appreciation. Music, art, and writing allow an even deeper expression. Music – vocal or instrumental – is not only able to alleviate stress, but is also able to inspire.

What inspired this written work? Empathy. Pure empathy. My epilepsy story began 40 years ago. Now my dear friend writes her own story of living with a seizure disorder. This "letter" is real. She and I speak face to face. This "letter" speaks to every person affected by epilepsy. I write it with love and compassion.

Brett Boyum

In Retrospect

It was easy to be brave
When it was my four-year-old I was telling it would be ok
That you can be anything you want to be
This won't get in your way
You don't have to be afraid or angry
It doesn't have to define you
Just let it be a part of you
Make this your olive branch
To reach others with your strength, attitude, and faith

He has proven he can do anything
Basketball, football, lacrosse
Leader, scholar, and yet be a playful kid
Loving brother, faithful son, and caring friend
He lives with no bounds

Now, I am looking out the dark window as buildings pass by
Looking at the tubes running up my arm
Illusions of strangers taking me away from the comfort of home
The determined stare in my wife's eyes
With me along for the ride, thankfully

I am in the hospital with all the wires leading from my head
Thoughts of the tests my son goes through
Move from drama and the unknown
To the fearful realization
The words cut like a knife through silk
You have had a seizure…

Where is my bravery now?
Questions cowardly fly through
Why me, why now, how can I, will I….
Yet no comforting answers come like they do when counseling my son

It has only been a few weeks since they said the word Epilepsy to me
And though we have prayed and lived the word for 8 years
It somehow now has different meaning – right or wrong

In retrospect though
I know one day I will find my bravery through the eyes of my son
Who has been graced by God with the will to prove
Life with Epilepsy is defined by you, not by the word

Brett is 41 & has epilepsy; his son has epilepsy…

Our son, Travis, was diagnosed with Absence Seizures at the age of 4. For the past 8 years we have been active with EFMN and helping to spread awareness of seizures through school programs, the

Stroll, and other programs. This year Travis was chosen as the "Winning Kid." We have not sheltered Travis from his diagnosis, rather we have encouraged him to use it as his opportunity to change other people's lives and perceptions.

Approximately one year ago, I had a grand mal seizure. I had no history of seizures or brain injuries. Thank goodness for our friends at EFMN and the education they have provided with Travis, or the experience could have been a lot more frightening. While scary, life moved on and it appeared it was an isolated incident. I received my driver's license privilege back, no medications required, and no more doctor appointments. Until recently, when I had a second seizure. Now things are not so certain.

Emotionally, for a Type A personality who wants answers to everything, this has been a trying time. If not for the will of Travis, the love my wife, daughter Claire, and second son Ty, and many wonderful friends who are reaching out, this experience could be more than devastating. I know there is a reason and a plan, it just is not clear yet.

Movements of Love

writings by family, friends and caregivers
of people with epilepsy

Angela Halverson

Grieving

the stress is worn
like a dark cloak
so heavy at times
it's hard to breath

my shoulders are heavy and tired
as i bear the burden
of this thing
doing my best to live
a life without color

i am left numb
exhausted
my spirit broken
my soul searing
i feel so lost

i am angry at God
and can only beg for mercy
driven to my knees
grieving for what might have been

my prayers are full of
broken dreams and damaged hearts
an ache so great it spills out of me
like a river undammed

i cry for you, my love
for all you go through with me in tow
my bed pillows forever wet
with tears

The Storm

i watch as you struggle
and am powerless to help
you are fighting your way through it
in and out, here then not
desperately trying to break free

this one is hard
violent and threatening and angry
an electrical storm raging inside you
instinctively i start to time
how long has it been

a minute, then two
i beg God for the millionth time
to intervene

almost 3 minutes now
i ready the potent drug
the one thing I can do
but would rather not
administering it is invasive and aggressive
and will mean I have to accept
the monster is evolving again

the narcotic effect is quick
the storm begins to ebb and flow
a little less vehemently
and a little less
and a little less
until your eyes flutter
then shut
mercifully, peace descends
the storm recedes
for now

Angela is 37; her son has epilepsy…

My inspiration, as always, is my 10-year-old son, Evan. His diagnosis is Lennox Gastaut Syndrome. He has about 5 seizures a day right now, and that is an improvement compared to a year ago. Epilepsy can, at times, be a dark cloud hanging over our lives. The trick is to see the sun shining behind those clouds. Some days it is easier than others.

My 2 poems reflect very different times in our lives. Things aren't always so bleak, but when they are, it helps for me to write. Evan has lots of medical issues, and we also have a very active 3-year-old, Ellie. People often say to me, "You have your hands full!" And to that I reply, "If you think my hands are full, you should see my heart."

Ethan Wilke

Jake

J-ust him all the time, and never will try to be
someone he's not, or try to "fit in" in some way.

A-lways would make people laugh in some way,
and always would have a smile on his face.

K-ind and gentle soul, and never would hurt or
make fun of anybody in any way.

E-ternal life up in heaven, and never will be
forgotten.

For Jake

If it's not funny, I don't want
Anything to do with it, sums Jake up
And his courage to meet new people
By simply saying, *'Sup?*
He would usually think of the good side of things
Instead of the bad,
And would make people happy
Instead of them sad,
Making people laugh is the way he would be,
But the one thing I want is Jake
Here with me.

Ethan is 12; his cousin had epilepsy…

Ethan is in the 7th grade. He loves baseball, basketball, and lacrosse, and he lives in Woodbury with his sister, mom, and dad. He did not know about seizures until his cousin, Jake Knapp, had one –

and his whole family received the same "crash course" in seizures. Ethan was very sad when his cousin died from SUDEP (sudden unexpected death from epilepsy). He wrote these poems for Jake.

Lachelle Venenga

What Do You See?

What do you see when you leave my side? When you go away for a few fleeting moments each day, what do you see? Is it a distorted view of what is actually there or some beautiful Eden far away? You look so calm and peaceful. I think it must be beautiful, though you never say.

What do you feel? Are you safe and warm or scared and alone? Are you running or dancing? Sometimes you smile when you are away, sometimes you scream. Sometimes you laugh the biggest laughs. I think you must have amazing friends there, though you never say.

What do you hear? Can you hear my words calling you to come back? Can you hear me telling you that everything will be ok? When you turn your face to me, I know that I am not where you are. Can you hear me say I love you? I think that you do, though you never say.

Lachelle is 35; her son has epilepsy…

My son Joshua, age 5, inspired this work. He was diagnosed at age 2 with partial complex seizures. He doesn`t verbalize about his seizures and I find myself curious as to what goes on in that little mind of his when he is away.

Roxanne Olson

Strength of the Heart

My son is now eleven and seizure free.
Life has been great for us to see.
Twenty six months and twenty seven days,
No seizures here, just total sun rays.

Medications stopped for one whole year,
Gives us relief and wipes away our fear.
From swimming unsupervised with loads of fun,
To playing with his brother with his squirt gun.

Days were normal as normal can be.
Home school mornings with afternoons free.
Just an average eleven year old young man,
Playing hard as hard as he can.

Day twenty-eight from two years came.
Something’s not right, something’s not the same.
He came running straight at me with that look.
I could read him just like a book.

His face trembling like I saw once before.
He fell into my arms and dropped to the floor.
Shaking and jerking and eyes rolled back.
My heart jumped out of my chest with this attack.

This seizure was not normal for me to see.
He was diagnosed with only partial epilepsy.
The sounds he made when he was down,
Had me in tears as my heart would pound.

I held him, soothed him and prayed for him to awake.
This seizure was unexpected, it must be a mistake.
As this passed and he started to wake,
He knew nothing more than he had a stomach ache.

As frightened as this had made me,
To the doctor we went to see.
As they checked him over, there was nothing new.
Just watch over him, there’s nothing to do.

I wish I understood all of this.
What went wrong, what did I miss?
From epilepsy on the left side before,
To full body jerking with such a roar.

Why so long after his last one?
Why so different than before?

So many questions left unanswered for me,
What now? Is he not seizure free?

Feelings rush through our heads and heart.
Will we have to do this from a restart?
All we know now is what we knew then,
We live day by day and won't know when.

A seizure may happen and we must prepare,
That no matter what, we will be there.
For our son is our world then and now,
He is our heart and soul, he is our POW WOW!!

Roxanne is 33; her son has epilepsy…

My inspiration for my written work is my 11-year-old son, who was diagnosed with partial epilepsy. This affected his left side of his body when he seized. These seizures have only brought us closer together. Last year we started home school, and we spend a lot more time together and learn so much more about school and seizures. My son is the biggest blessing I could ever have. He makes life worth living, and living it to its fullest.

Mary Kay and Mike Cooney

Our Molly

Eleven years ago our Molly had a seizure in her sleep. How could this be? She's a grown woman, a Spanish teacher in Colorado. Molly has always been physically active and an avid canoeist, planning to lead a white water canoe trip in the Arctic Circle. Life changed for Molly that day.

As her parents we searched for possible signs we missed when she was growing up. No head trauma that we could recall, but she did grind her teeth while sleeping. Was this significant to what was happening now?

Molly met this "head-on" like other challenges she has faced. Multiple neurologists, different diagnosis, side effects, and ineffective medications have often been a struggle and a frustration, but Molly is determined to live life to the fullest.

Her current medication is effective. She's been canoeing in the Arctic Circle three times, is a published author, and has shared her love of outdoor activities with children at Camp Candlelight in Arizona. She stays informed about the latest research and leads a healthy, happy, productive life.

It is easy to forget that Molly has epilepsy because she is doing so well. Molly doesn't forget. She takes her medication, embraces a healthy lifestyle, and keeps a positive attitude. She has met this challenge and has not let this disease define who she is. We are so proud of Molly and pray she continues to be healthy and seizure-free!

Mary Kay & Mike are 64; their daughter has epilepsy…
We are the parents of Molly Cooney.

Anne Iverson

no more sitting on the couch

In the beginning I worried sometimes. At the bowling alley with strobe lights. When she didn't get enough sleep. I read all I could on the internet. What to do if. What to do when. I kept a seizure response card in my nightstand and memorized her medication. I thought there would be challenges, being with someone with seizures. Turns out, the real challenges were ones I never anticipated, the crazy things she brought me to do: crossing a chin-deep river in the jungle, venturing into the ocean in a kayak for a week, hanging from a trapeze...

Anne is 34; her partner has epilepsy…

The inspiration for my work is my partner, Molly. She rocks.

TC Tolbert

If Precipitant. Then Reason Says Rest.

Because that the cranium makes contact with the pillow. Because that the teeth string an unlikely music in the mouth. Implicate agent or agency. Retract. (retractretractretractretreact.) And I did not think *toothbrush sincerely in washing machine*. I did not think *keys*. I thought *keys*. *Come on boy*. I did not think *purple leotard, I will need you in Colorado*. I did not think *I like that hike so much, we should absolutely do it again*.

TC is 34; friend has epilepsy…

My best friend, Molly Cooney, is the inspiration for my work. Molly has left temporal lobe epilepsy. She experiences complex partial seizures. This poem attempts to embody the struggle for rest, clarity, and resolution as she has described it to me. Knowing Molly and learning more about epilepsy has made me acutely aware of how little I do know. I am thankful that Epilogues exists. This important work is critical in helping the public be more aware.

I am a genderqueer feminist, photographer, thinker, and poet committed to social justice. My poems can be found, or are forthcoming, in The Drunken Boat, The Pinch, Volt, A Trunk of Delirium, and jubilat. You can find more of my work at www.tigercakes74.blogspot.com.

Margery Weichers

Epilepsy (a mother's view)

It's been thirty years
since the seizures began.
Now looking back
we all deserve a hand.
Sitting on the table
when you were only three.
Who would have thought
what a challenge this would be.
One little jerk and then many more
we didn't even think of what was in store.
Off to the doctor as quick as could be
to find out the outlook for Dad and for me.
Our beautiful little boy so happy and alert
would be facing a life of medication and hurt.
One thing we knew is our life had changed
nothing in our life would ever be the same.
Looking back I wonder how we ever survived
a marriage, a family, a man still alive.
Take my advice from a mother who knows
Love, Patience, Humor, Education, and Persistence
will guide your existence.

Margery's son has epilepsy…

My son, David Andrew, is my inspiration. Over the years he has had many kinds of seizures – generalized tonic clonic, myoclonic when he was a little boy, and now atonic seizures. Thank God and the St. Paul Epilepsy Clinic they are pretty much controlled. Epilepsy has been my life for the past 30 years. Keeping David safe, making a living, providing health insurance, getting him educated, trying to keep a marriage together, and raising his sister are just part of the impacts that raising a child with epilepsy puts on a family. Epilepsy makes you tough and teaches you that life isn't easy and by taking one day at a time you can come out on top.

Jerry Hartlaub

Can’t Promise You Bliss

I was cruisin’ you see,
Pal Dilantin and me.
He rarely let me down,
Never a class clown.

Much to my chagrin,
My bones began to thin.
Time to part company.
Dilantin and me.

My Doc said, “Try this!
Can’t promise you bliss.”
So joining my old friend
Was Lamictal to the end.

Oh gosh! Turning my head!
Nearly fell back on my bed!
Each day this way,
When I moved, I would sway!

Can everybody see,
Me weaving like a tree?
Embarrassed am I,
Oh darn, I could cry.

None said it’d be this way,
Off balance each day.
This is terrible, a disaster,
I need to work, I need to purr.

Back to the Doc,
“This is a crock!”
Explain he could not,
But I don’t want to rot.

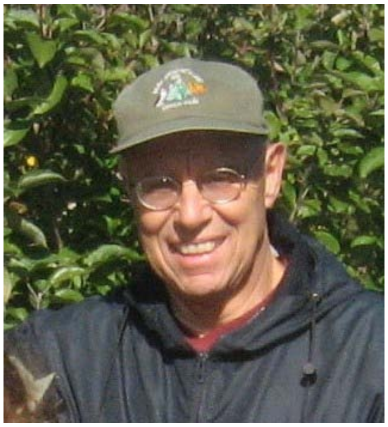
Many tests to find out,
I hated to pout.
Time to return my grin,
With buddy Dilantin.

Oh each day when I twirl,
My head’s a small swirl.
But less than before,
Don’t nearly fall to the floor.

I wish to return,
To the path that I burned.

Time's my new pal,
Each day's almost swell.

Am over this episode,
Back in the happy fold.
Workin' to keep my attitude,
And my deep gratitude.



Jerry is 69; his son has epilepsy…

A few years ago my adult son, at his neurologist's suggestion, migrated from Dilantin to Lamictal drugs for controlling his seizure disorder. He had been under excellent control for decades with Dilantin, but had some undesirable side effects. While in the middle of the migration (taking both drugs simultaneously), he experienced major balance issues and significant general discomfort. After weighing his choices, the decision was made to discontinue Lamictal and revert to Dilantin. Unfortunately, after returning to Dilantin, his significant balance issues persisted and were very unpleasant.

After many months of doctor visits and many tests at various specialty clinics, there were no confident explanations for his symptoms and the balance symptoms persisted. All they could prescribe is balance self therapy.

It's been several years since this episode and the good news is the symptoms have continued to diminish. My son is very thoughtful and courageous. I am impressed with his super resilience. I wrote the poem to capture the situation. It can't do justice to my son's journey as I am only an observer. But as a parent, I felt his pain every step of the way.

Lorna Knight

Epilepsy is…

unpredictable, scary, misunderstood,
frustrating, challenging, bothersome,
uncertain, apprehensive, fearful and random.

But it makes you stronger, smarter,
forgiving, accepting, caring,
grateful, hopeful, courageous,
determined, independent and understanding.

Lorna is 39; her daughter has epilepsy…

My daughter has had epilepsy for 9 years. She's finally feeling better and can do activities she wasn't able to do before.

Joy R. Borchardt

My Son Has…

A Good Nature
A Great Sense of Humour
A Wonderful Smile

Curiosity
Courage
Inner Strength

My Love and Respect
Caring Family Members
Many Fine Friends

College Classes
Internet Skills
Favorite Songs

Two Dedicated Chihuahuas
A Garden Patch
Plans for the Future

A Twinkle in His Eyes
A Zest for Life
His Own Style

He Also Has…
Epilepsy
Which Doesn't Change
These Other Things

Joy is 51; her son has epilepsy…

My son, Iner A. Borchardt Jeppesen, is my inspiration for this poem. He was diagnosed with epilepsy about 5 years ago. He has tonic clonic, absence, and “unclassified” seizures. He is now a sophomore in college.

Epilepsy has changed our lives first with the tumultuous and unexpected entrance resulting in the spiraling chaos of ambulances, emergency rooms, many neurologists, CAT scans, EEGs, MRIs, medications, medications, medications; more seizures; no answers, no answers, no answers. Life has been permanently changed by the understanding that at any moment, at any time, beyond our will, beyond anything we can try to do to prevent it, he can be taken over by an electric storm in his brain that wrenches his body uncontrollably; or maybe just lets him stare into space and get left behind from the conversation, only to always be trying to catch up.

One time, after Iner had a rather violent tonic clonic seizure, while he was post ictal, I was next to him and I cried, only for him to come to ask me what was wrong... So I try, try, try to be brave for him; but I’m his Mom and sometimes it just tears me up inside. But when I see what a good, caring person he is and how he has accepted this life challenge with such good grace, I get my strength from him.

Sandy Tollefson

Uncertainty of Epilepsy

The sun comes up
She wakes up
Smiling and full of life
We're talking and laughing
Suddenly there is no response back
Just a blank stare
A sigh, a yawn, a rest
She's back
Will this happen again
today, tomorrow, next week, next month?

Uncertain

The sun goes down
Today is a good day
We are grateful
What will tomorrow bring?

Uncertain

Sandy is 40; her daughter has epilepsy…

I am inspired to submit writing for the Epilogues Collection by our daughter Emma, who was diagnosed with epilepsy after a probable central nervous system infection in April of 2008. The biggest thing that seizures have taken away from our daily lives is the carefree feeling. There is always an "on guard" sense of urgency in our minds. Emma's diagnosis is complex partial seizures with a history of secondary generalization.