

# 

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



Dear Reader,

We are delighted to publish the eighth edition of Epilogues in 2014!

This book of written works was compiled by the Epilepsy Foundation of Minnesota (EFMN). The authors are living with epilepsy or have a relationship to a person with epilepsy.

The Epilogues collection is part of EFMN's Creative Arts program, showcasing the creativity and talents of people with seizures and raising epilepsy awareness in our community through visual, performing and written works.

The Foundation serves over 100,000 people with epilepsy annually through programs like Creative Arts.

The first portion of the book is authors who have epilepsy, and the second are writings by family, friends and caregivers of people with epilepsy. Short biographies follow each piece to share the writer's epilepsy story.

# EFMN congratulates each author for his/her contribution, and for rising above seizures!

- The Epilepsy Foundation of Minnesota & Creative Arts Committee

Decisions

by Sonny Chase

When we have epilepsy

All of us know How losing your dignity Will not always show

Early in my life, were difficult years Even at times, caused me tears My education was difficult, confusing at times But family and friends are a blessing of mine

In 2011, my decisions were made Stability in life would be a great trade I finally decided, to go on a limb God gave me a door, and let me in

I'm now on a mission to open your eyes So do not give up, you may be surprised!



Sonny Chase was born on November 13, 1967 and received an epilepsy diagnosis just a year later. While Chase says seizures limited him, he also believes they bring out a creative side in him to write stories. In 2012, Chase had his left Hippocampus removed in an effort to control his seizures and will celebrate being three years seizure-free in April of 2015. "After my surgery, life changed. Thoughts come to my mind differently." Chase, who lives in Detroit Lakes with his family, has shared his story at various EFMN events, including the Stroll for Epilepsy and in the Foundation's newsletter.

# In The Real World by Derrick Dawson

God and I are the real ones to have courage in, about me having confidence in my decisions I do make and go in life, "When going down the right path."

\*A Line for Courage

God and I are the real ones to show me in every which way how to continue to not be afraid, and don't have doubts, "About me surviving in this world."

God has and still will be the one to show he is the one that will always be truthful, honest, believable, trusted, "Most of all will be able to make me see it all."

\*Our Great Encourager

\*Building the Truth in Life 1. Honesty 2. Truthful 3. Courage 4. Belief 5. Believable and Trust

\*Wisdom

God has allowed me to have wisdom, "In those to be truthful, believable, honest and trustworthy."

# \*In Search of Wisdom

God has directed me to go down the right path, "To handle my situations." God has given me the strength to carry on day by day, "with wisdom."

## \*Truth Faith

God has shown me his true faith in me and the different steps I make, "As long as I continue to follow him."

# \*Courage

God gives me courage to do the things I need to do, "In order to achieve my own needs and wants to make it, "I can and have to make myself see the right path to go down."

God has shown me even more day by day, "How to look at what the future brings for me." "How I have not allowed my seizures stop me from moving forward or others."

\*I believe no one with epilepsy should allow our seizures and most of all others, stop us from living our own life, "The ways we want to enjoy our own wonderful life ahead."



Derrick Dawson is 44 years old. He has had epilepsy since he was seven months old, with complex partial seizures evolving to generalized seizures. He enjoys keeping track of his seizures monthly to try and make it to the next month seizure-free. "Trying to make a full year has been a big goal – so far six years," he said.

# Dear Epilepsy

## by Sarah DuCloux-Potter

## Dear Epilepsy,

It's time we had a chat. I know you thought you had me. For a while I almost gave in to you. I nearly surrendered in defeat. I started to walk away from everything that made me "me" as you stole bits and pieces of my personality, both directly through your misfires in my brain and indirectly through your need of medications that altered my state of self.

Not so fast, dear epilepsy. You don't get such an easy pass into my life. I demand some authority. You may rob me of control for blips of time, but you cannot strip me of my spirit. I am taking it back.

I sure fooled you, didn't I? You lost your hold on me, epilepsy! I have you in the crossfire now. You don't OWN ME. I am the master of my destiny. I have proof that I can conquer the likes of you. I reached for the stars and swung amongst them. I laughed in your face and felt no fear. I smiled a thousand smiles.

You told me I couldn't, but I did. You told me I would never, but I made it.

I ran 50 miles. I crossed the finish line. I conquered you. You will never own me.

Sincerely,

Independence



Sarah DuCloux-Potter said running 50 miles seemed like an impossible goal. "My training was continually interrupted by cramps due to dystonia or seizures. I second guessed the goal and was told by a lot of people that I would be unable to do it," she said. "Once I decided that quitting wasn't an option, the goal was to smile, have fun and overcome. How amazing to accomplish this goal and take back a bit of control." Sarah has partial complex seizures with secondary generalization. She said she sometimes gets frustrated or depressed, and doesn't like not being able to drive, but adds, "I try to remind myself of how lucky I am and not let seizures get in the way of my dreams and goals."

## My Life in a Nutshell by Pamela Engebretson

On or around December 26, 1965, my dad, mom and I were going to Brandt, South Dakota, to visit my grandparents when we got to Lake Lillian, Minnesota, our car was struck by another car. The glass cut my mom in the face, and I ended up under the dashboard. My dad didn't have that much damage done to him. The ambulance came and was going to treat my dad, but he said, "Don't worry about me. Take care of my daughter." He scooped me up off the floor of the car, and once we were out of the car, we were rushed to a hospital in Willmar, Minnesota. They treated my parents, but couldn't treat me. I was taken to the University of Minnesota in Minneapolis.

I had three blood transfusions and because I was so tiny, they poked me on my legs, ankles and elbows. My leg muscles had deflated.

Sometime in January of 1966, I went home and grew up into a world where I didn't play much as a child. I was teased and bullied during school from the time I was four years old. My teachers talked with my parents and said things like, "Your daughter is daydreaming." No – I was having seizures. I don't remember taking phenobarbital as a child.

I must have stopped having seizures because I never took medication in school. I didn't play any sports due to my traumatic brain injury. I needed a tutor in sixth grade for math and other subjects, so a girl from the junior high next door came to the elementary school to help me. A classmate was wondering why I was getting more time in math because she was studying hers during free time.

Then in junior high, I was in special education classes with other kids with learning disabilities as well as in regular classes.

On test day in Social Studies, the teacher would say to the class, "After you finish the test, you may leave." A lot of kids did their tests and left, but I was very distracted and lost my concentration. I got F's on the tests and a D in the class. Then I went to my special education teacher on test day. I walked out of class with the test and had my teacher read the test questions and choices to me. I got B's on the tests and B's on my report card the next quarter.

In senior high I asked the teachers if I could take the test with my special education teacher, and they let me. I had cooking classes and some other classes with special education teachers but not Social Studies. When I asked why not, they said it wouldn't be fair to the other kids because I wouldn't have to open the books. I was too smart for the special education classes and not smart enough for the mainstream classes, but there was nothing in the middle. I gave myself the nickname "an oreo cookie without the middle."

In 1980 I was working at jobs for \$3.35 an hour. I worked in the junior high office and at a clothing store. In my senior year, I worked at a department store and was released from that job because I didn't understand the cash register. So I had to go back to school, and I took Human Behaviors instead of history. I wasn't passing the class, so the teacher gave me books to read and then do book reports. I ended up with A's on the reports and a D in the class.

I then got back in the work force program and worked at an elementary school making a birthday board with the kid's picture on it, and did copying in the office and putting books back on the shelves in the library. I was doing well at the job and got an A on my report card.

In 1984 I went to vocational school where I took office classes as a receptionist. I was again distracted during test time. I was then given three choices: stay in class and flunk, change majors or go home. I chose to change majors. I graduated with an electronics assembly/installing degree. I had to put kits together and make a light dimmer, a light plug-in and an A.M. radio. When I was done with the kits, I asked, "Are there any more kits?" The teacher replied, "Those kits are supposed to take days, and you're finishing them in hours. There's nothing left, so go up to the roof with the other students and work on the cable TV."

My job was to listen to the guys on the ground and relay what they said to the guys moving the antenna for a clear picture.

I got my first job through a temp agency and worked at an assembly plant, making parts for tape cassette players.

On March 1985, my hand cramped up, so I put my soldering iron back in the holder, flexed my fingers and returned to work. The next thing I remember was waking up in the ambulance with oxygen on my mouth. I was scared and screamed. I was told that I had a seizure.

After the doctors did an EEG, I was told by a neurologist that I had grand mal seizures. I cried. I was given medication for epilepsy. I then returned to work, and soon I was given another job in the company. Then after hearing that I wasn't fast enough, I was laid off.

I next worked at another job, checking the work done on an item before the customer got it back. I was taking time off, and the boss wanted to know why I was having so many doctor appointments. When I told him that I had epilepsy, he fired me.

Later that year, my medication wasn't working, so my doctor put me on Depakote. When I got up to five pills a day and they weren't working, I took the bottle and slammed it on his desk and said, "Take me off this medication, or I'm taking myself off because it's not working." I was then given Mysoline, which also wasn't working, but he added Lamictol and those worked.

I couldn't find a job in electronics due to the seizures, so I went back to school for photography. I was taking black and white when, before class one day, I had a seizure. When I woke up, I asked the teacher if I was in trouble. He said, "No."

I then took the color photography course and was told I wasn't getting the colors right. Later I found out that I was color blind, so I dropped out and went to Office Occupations. I graduated with a clerk typist degree.

In August of 1987, I went to the store and came home to curl my hair for an appointment with a job counselor. While I was curling my hair, I started having another seizure. I had enough time to shut the curling iron off and put it on the dresser. When I awoke, I was in my bed and dad was sitting with me. He picked me up, gave me a hug and cried with me. He had heard me hitting the floor and came up to find out what was wrong and found me having the seizure.

I had interviewed for a job at an insurance company, and I got the job. During work, I had another seizure. I rubbed my face into the carpet, gave myself a black eye, and I awoke in a bed at the work site. I had had two at that job. I later quit because I was bullied and I couldn't take it anymore. In 1996, I went to the electric company to work with microfilm. I was later fired from that job.

I next went to work at a medical facility in the medical records department. In September of 1996, I had a seizure in my bathroom while brushing my teeth. When I woke up, I went to my bed and tried to remember the phone number of where I worked. When I finally remembered it, I called my boss and told her that I had woken up from a seizure. She said to take some time off, but I came to work the next day and she was surprised. I told her that I didn't need the extra days and that I wanted to work. Later that year, I was fired from that job because I wasn't filing the records correctly.

In October of 1997, I was taking a library test. I had given the test back to the instructor and told them that I didn't feel good when I had a seizure. My dad was in the parking lot because I couldn't drive due to previous seizures. When he heard a noise outside the school where I was taking the test, he got out of the car, went inside and told the medics who had arrived to leave; they did. My dad took me to my condo, and I packed up some clothes and went to stay with my parents.

During the next few years, I had had a total of nine grand mal seizures and ten petit mal seizures. I had one of the petite mals in my bathtub. I tried to get out, so I wouldn't have it in the tub and drown. I didn't take baths for a few years because I was scared of drowning. Later on, I got enough courage back to take baths.

Between 1980 and 2014, I've had a lot of jobs. I have filled out applications and have had job interviews, but no one has hired me until today. I wasn't sure if it was my lack of education or being too old. All they told me was, "We found someone else who is more qualified." They wouldn't even give me a chance. Now that I have found one, I hope that I can do the job and keep it. This is my last chance.

Pamela Engebretson is the inspiration for her own work. She has had grand mal and petit mal seizures since 1985. She said that her traumatic brain injury limited her from physical activities when she was younger, and in adulthood, epilepsy has kept her from working at certain jobs.

## By the Pond by Angie Freshwater

Freddy Frog and Susie Snail were sauntering along the lake path one fine day when they happened upon Tommy Turtle. Tommy was just coming out of his shell after a long, leisurely, afternoon nap, when the two friends passed by his hiding place under the cedar tree.

Tommy Turtle, who was old and slow, but very friendly, stuck out his front leg in greeting. As he did so, he nearly knocked over Freddy, who had stopped just under the entrance to Tommy's hiding place.

Freddy, who was quite a bit younger and a lot more agile, hopped back. "Pardon me," Tommy said in his slow, languid way. "I'm just an old turtle whose body doesn't move the way it used to. If I'm in the way, I'm sorry."

"Don't worry about it," Freddy Frog said. "We understand you don't move that fast. We won't judge you for it. You're safe with us."

By the pond, it was a nice summer day. The sun was shining. The sky was blue. The temperature was perfect. Birds were flying around, or in their nests, singing. Frogs hopped alongside the pond or among the lily pads. The water lilies were in bloom. There was a light breeze.

The wind picked up. Clouds blew in. Raindrops fell. The frogs disappeared. Birds huddled in their nests, scared and shaking. Thunder boomed. Lightning flashed. All the baby animals cried. The world was gray and scary, and not so nice.



Angie Freshwater has been writing stories of various types since she was 15. She finds inspiration for her written work everywhere: her personal life, world events, history, her imagination and more. She is 37 and has grand mal seizures. She was first diagnosed with a seizure disorder when she was eight months old. She says, "I live on my own, and try to work on my writing as much as I can. I have lived for 8 ½ years in an apartment in Sibley Tower in downtown St. Paul."

## A New Style of Life

## by Steve Ireland

In the past few weeks I have had a new style of life. Besides, just enjoying my epilepsy life of 64 years, I've also learned to except a medication life as well. I've not been able to cross the street anymore without a cane or help or both. I cannot take liquid drink from one area to another as I shake too much.

I enjoy each day with some shaking involved; how much I will never know. Yet I may try to stay relaxed and I shall not shake as much for that day.

Due to the fact that I was experiencing double vision, I sat down on bench and almost asked for security to help me out of the Mall of America, but I left there under my own steam, never, probably, to shop there again.

Besides experiencing double vision, I've also experienced a lightheaded feeling, and sometimes I also enjoy a hearing situation as well.

I may appreciate that I will take medication to either stop or relieve my epilepsy day-to-day life. But what I nor anyone should have to put up with is the day-to-day life full of problems - problems that came with the epilepsy medication.

I would rather experience an epileptic life with medication for the epilepsy as "normal" as possible.



Over the past 20 years, Steve Ireland has been involved in a variety of activities at the Epilepsy Foundation of Minnesota, including volunteering at the State Fair. What inspires him to contribute to the "Epilogues" writing collection are others who cannot for various reasons. He lives in Minneapolis and enjoys model cars and planes, music, movies and walking in addition to expressing himself through writing. No More by Tayler Johnson

# Tick tock, Tick tock.

The sound begins to fade.

1,825 days. 60 months. 5 years.

No longer does the clock mock me.

Its mocking has finally faded.

Tick tock, tick tock.

One day the clock will remain silent.

Mocking me no more.

Tick tock, tick tock.

Tayler Johnson was diagnosed with periventricular binodular hetertopia at 12 years old. She is five years free of tonic-clonic seizures, but still has absence seizures daily. She says, "The clock is a large symbol in some of my pieces. It symbolizes that after having a seizure, my body has to reset to how it was before a seizure, and that now, it's time to start the process all over again. The ticking of the clock is just a reminder that time is against us in some way. For myself, it's a reminder that it does not matter when the seizure happens; it'll happen when it happens." Tayler says her diagnosis has altered her life with a variety of lifestyle changes and precautions. She says that she has met some wonderful people and in the end, she wouldn't change it. "It has opened many doors and brought forth many opportunities."

#### Shaken Up

#### by Jacob Knapp

#### Editor's Note: "Epilogues" is publishing this piece posthumously, unchanged from its original form.

For years, I have been prescribed some level of anti-anxiety medication. Lorazepam, diazepam, alporazam also, lexapro and over the past 6 years I have eaten them all. What they didn't tell me when I was being written scripts for these pills, was that these were drugs in the truest sense of word. These aren't medications that you can easily quit, and even if I wanted to, it would likely have to be under supervision of a doctor. Little did I know the kind of backlash I would end up receiving, from scripts written by my family doctor back in MN.

The aura of a seizure seems similar to that feeling you get right before a big concert you've been waiting for. Like ping-pong sized ball of concentrated nervousness is slowly running down your throat but never quite reaches your stomach. A kind of unexplained excitement, this welcomed anxiety fills my body with a kind of mania. I can't sit still, and I quickly get bored with any task I try to set my mind to completing. This feeling is foreign, but oddly welcome, like a young kid bored with recess. I walk confused around the apartment, acting not completely out of the ordinary and trying to get a hold on what I think is a light anxiety attack. I have Not taken my medication for close to a week. I was sure this uncomfortable feeling would pass, maybe I just needed a good night's sleep.

#### Confusion:

I open my eyes to the lights on, my girlfriend gasping in the corner, my roommate by my side and I am on the floor. When did all this happen? It's impossible to focus on anything, and my mouth tastes like I had been chewing my lips for days. The air I'm breathing feels like it came from a machine, everything is not as it should be. I am so confused that I'm sure the fault of my odd situations should be blamed on the two people trying to assist me.

With my confusion, I scream out angry words and kick these people away from me. As my legs extend I realize that my entire body is suffering from an intense soreness. The pain from my shoulders shootslike fire- down my spinal column. Now I was nervous, the most primitive kind of fear was running through me. Who was I, and what happened to me? As my brain continued to struggle for answers my roommate chimes in on cue...You were having a seizure, just sit still and take it easy a bit. His words played to me like a cruel joke, I couldn't have possibly had a seizure, I thought I had just fallen asleep.

He began asking me easy questions, such as, "do you know where you are?" I couldn't possibly imagine answering anything but... "My Bed".

As I sat there trying to put all the pieces of my night together, the paramedics came through the door. Immediately, I was grilled with questions..."have you take any drugs tonight, Jake?" the paramedic asked already with a thick tone of doubt in his voice. I shook my head no, even though I honestly had no clue what I was doing before I woke with people buzzing around. "Do you know what year it is?" This question I was determined to answer. I answer 1982, as it came out I knew I was wrong and I knew I should know the answer. So, I took another stab at it, "No, wait, 1902?

They had turned to my friend and told them that I needed to go to the hospital. I was a child to them now, not even worthy of being told about my own situation. Quickly I grew angry and unsettled; there was no need to take an emergency vehicle to the hospital. I may have been medically slow, but that much common sense was still intact. I plead with everyone that I can go on my own account. They thought I was still muttering nonsense until I uttered the magic words. "I don't think I can afford an ambulance ride"

Soon I was back in the care of St. Elizabeth hospital. I found myself again trying to defend myself from the doctor who was sticking needles in my throbbing arm. "No, I have NOT taken any drugs tonight; I was doing the opposite, so please stop asking if I'm "absolutely sure".

Are you on any medications? Yes, I was, but I didn't think I needed them anymore. I was on the road to being a self-reliant man, without any need for the trivial anti-anxiety and antiOdepressants I had been taking. She says, "You can't just stop taking those" as she marks my chart and walks out.

I felt trapped by what the doctor had just told me. Did that mean I was going to be confined to this little room, with these machines, surrounded by these people, indefinitely? As more and more saline and tranquillizers coursed through my body I began to feel calmer and finally after a few hours of observation I was allowed to go home. We drove home, and I was filled by everyone else's relief. The tone became casual, and although I was terrified for what will happen when I come down off the tranquilizer solution, I couldn't help but feel comfortable with my friends sympathy.

## Jacob Ronald Knapp 8/5/86 – 3/2/09



Jacob was finishing his final semester at Columbia College in Chicago when SUDEP took his life. He majored in Cultural Studies. We found this paper that he had written for a class. He wrote how he felt about his seizure in June 2008. We miss him so much. He was the funniest guy, so quick-witted and such and old soul. Quick to hug, he always said, "I love you," and he quick to make a stranger feel welcome. We pray that no other family has to go through losing someone they love to SUDEP.

#### Am I Boxed In?

#### by L.E. LaRue

During the past year, I went to see four plays at the Minnesota Fringe Festival. One of them, called "Boxed," was about a young woman living with epilepsy. I saw it as the Epilepsy Foundation gave us a "heads up" message before the festival began, which told us about the play. I liked it because it was relatable. I understand the feeling of wanting to be, and feel, normal. I even wanted to write about it on my blog, but I didn't, as I haven't told most of my friends about my history of epilepsy. I am still afraid I might lose friends because of it. I still feel this way even though one of my fellow comedians was willing to talk about having this disorder onstage. So I have to ask myself, "Am I boxed in?"

I liked reading through all of my previous writing for the "Epilogues" program – seven in all – as it has shown my progression over the years. I had mentioned some of the artwork I had submitted before, but I haven't submitted visual art in a while. I saw one of them again for the first time in a while at an event in downtown St. Paul recently at the Amsterdam. It was called "Finally Over The Top." I knew which one it was when I was told in advance that it would be on display; it was the pole vaulter. But aside from this, I didn't recall the detail of the art. It sure was an eye opener, and I was reminded of how I did the art before I started in stand-up comedy. We are all our own worst critics, but I still think it looks crudely drawn. I think this was why I later switched to doing art that was just words, as I did have words on the borders of this one of the pole vaulter. I also liked seeing some photography as part of this exhibit. I enjoy photography as well, so I will have to figure out what to submit when this program is available again. I am hardly ever without my camera now, as there are so many things I want pictures of. I know why I enjoy writing and photography – I like being able to document what I see and what has happened. Originally I think this interest stemmed from wanting to remember it all a little better. Seeing a documentary about street photographer Vivian Maier in April really helped with my picture-taking. She was a Chicago nanny who had briefly worked for talk-show host Phil Donahue. When I saw how she was taking pictures of nearly everything, I said I had found a kindred spirit. The nice thing about the digital cameras I have now is being able to take more pictures, not being limited by having to keep buying film. So much like other interests I have, finding something I enjoy and am good at is a good coping mechanism for any struggles I have in life, epilepsy related or otherwise.

I am still fairly active in the local stand-up comedy circuit, and I like trying new ventures as it helps me with my blog writing and comedy material. It helps me understand how comedy is a business, same as anything else, when I see what happens behind the scenes. This includes helping with the 10,000 Laughs Comedy Festival in October. I promoted the weeklong event by hanging signs around town, and then was on duty as "house manager" – basically an usher – at one of the shows. And then there was being a volunteer actor at a haunted house. I figured since I had done some acting in comedy sketches – one last year and another in August of this year – then I would do fine here. I was put in full costume and makeup, and tried to scare anyone sent my way. I think I did my job well, as I scared half of the people. Not bad for a rookie. There was also doing karaoke at a recurring comedy show. I was told I did it well,

better than most. I chose relatable songs that I could sing passionately. This included "Lose Yourself" by Eminem, "Muzzle" by Smashing Pumpkins, and "Basket Case" by Green Day. I couldn't ignore the Green Day song, as the lyrics ask, "Do you have the time to listen to me whine about nothing and everything all at once?" When the video takes place in a mental hospital, this added to the relatability, as I sometimes wondered if I was mentally ill, likely the by-product of having epilepsy. But I found out the company I keep made a world of difference, and my attitude improved over the course of my life when I started to surround myself with more positive people. It meant making the tough decision of having to part ways with some, but I really had no choice because it is my life, and my happiness is more important. This is why I take pride in doing comedy; I do it for *ME* and nobody else. I like being able to turn my pain into laughter. I have asked myself why I still struggled with some things, then told myself I shouldn't since I can tell a joke about it.

I still struggle with Internet dating; nothing has made it past three dates since my long-term relationship ended last year. At first I wondered if seeking professional help would make a difference, but it didn't. I quit after two sessions with this therapist. I told myself I wanted somebody to help me, not lecture me. Comedy has been a better therapy, and cheaper too. I am willing to try in-person singles events now, and tell myself there is no need to blame myself for those failures when I am putting my best foot forward nearly every time now. I have seen my ex twice, both at St. Paul Saints baseball games, in May and August. It went just fine talking with her, but I am also happier now than I was before. As long as I have comedy, I have something that makes me happy enough that it doesn't bother me much to be single. Comedy has fulfilled me more than dating ever has by far. If I meet somebody that is a good match, then of course, I will welcome it. But it has to be somebody who understands I do comedy and will *NOT* give it up for them or anyone else. As Bob Newhart said in his book, "It is a narcotic I need," and of course, performers understand the need to perform.

I did see a friend from the support groups again this year, as part of my annual visit to St. Louis. She was in the hospital to have surgery for her epilepsy, which I knew was worse than mine. It was tough to see and hear about it, but I know even the tough stories need to be told. I support my friends, and I think my moral support helped her through this time. I liked attending the conference this fall; there is usually something to be learned. In my case, I liked hearing about the way epilepsy is treated in foreign countries, although I know that those countries often do not hold the same values as America does. For example, we believe in human rights. I wanted to attend the lobbyist day at the Capitol in March, but I was ill. I threw up just before we were to leave and was told I should go home. I didn't want to, but it was for the best. I had the time to recuperate and still went to the comedy club that night, although I had to tell people to avoid touching me as I was ill. I have a hard time giving up a night at the comedy club. I am hopeful I can make it back next year. I felt good about losing weight after seeing a documentary called "Fed Up," blaming the problems of obesity and diabetes on too much sugar in food and drink. I found out I could make some changes in my diet that could make a difference. I am hopeful I can keep the weight off; I had lost weight five years ago but then gained it all back.

and drink. I found out I could make some changes in my diet that could make a difference. I am hopeful I can keep the weight off; I had lost weight five years ago but then gained it all back.

Once again, I think I will be able to handle whatever comes my way. I have the tools that I didn't have before.



L.E. LaRue's inspiration for his written work is his own life. He says, "Seizures and epilepsy have had more of an emotional effect on my life, as I lead a fairly normal life." He earned a degree in history from the University of Iowa, where he once received treatment for the disorder. He is pleased that the disease didn't prevent him from getting a driver's license. L.E. says, "I find that writing about myself is easier than other subjects as I know myself well. I was diagnosed with epilepsy at age four and was on Dilantin until age ten. Seizures are rare now, less than once a year. If epilepsy has affected my creative abilities, it taught me not to take things for granted. I like how I am free to be myself, explore who I am, through my art. I would like to let my writings speak for themselves."

#### EFMN Scholarship Essay

#### by Libby McGraw

"I told you to take the trash out. You never listen to me," my mom scolded. "You were looking right at me; I know you heard me." But I wasn't just a selfishly preoccupied five-year-old who failed to pay attention to her mother. Sometimes I really never heard her when she spoke. Since I can remember, I've suffered from partial-complex seizures. My neurologist, Dr. Armantina Espinosa, speculates it was triggered when the parietal lobe of my brain was damaged in our horrible car accident 13 years ago. The Emergency Medical Technicians said we were lucky to be alive, but we didn't ride away in the ambulance unscathed. The biggest injury was mine, and it was invisible to the average eye. I would "zone out" sporadically and try to piece together what I'd missed of conservations or instructions. Eventually, my mom realized something wasn't right. She took me in to see Dr. Espinosa, and I was diagnosed with my seizure disorder. My parents decided they didn't want to medicate me for my seizures until the episodes started impacting my life.

In middle school, the seizures grew more frequent. I would have zeros in the grade book for not handing in assignments when I swore I'd turned them in. But then I'd find them in my folder, completed and ready for turn-in, but I had never heard the teacher say to put them in the box. My mom met with my teachers, and they agreed to keep an eye on me to see if they ever observed me "spacing out." Two of them noticed on multiple occasions that I wouldn't be all there, but that it was different from your typical middle-school daydreamer. The summer after eighth grade, I was playing with my club volleyball team in Orlando, Florida, in the U.S. Junior Olympic tournament. The game was tight; the pressure was on. I was playing outside hitter. The ball was set to me, and I just stood there. My episodes were brief, so I "came to" quickly, and my coach noticed how disoriented I was. I reacquainted myself with the location and the people around me and continued playing. Later in the game, I "zoned out" once more when I rotated to the front row, so I thought I was still playing back row. I got set again, but I thought it was for my friend Sam, the other outside hitter, and was calling for her to hit it. Her face was taut with confusion as she screamed at me to hit the ball. Another point lost. The match was still close, but we lost. I felt responsible. I felt helpless. I felt my team couldn't trust me being on the court because no one understood what was happening to me, and it was obvious to all of us that it was out of my control.

Shortly after my return to Minnesota, my parents, with the help of Dr. Espinosa, thought it best to get me medicated long before driving age to ensure the medication was effective before I was ever behind the wheel of a car. Ever since, I've been taking three pills of Keppra every morning. I've had my blood drawn every few months to check the levels and effectiveness of the dosages. I feel safe doing every-day activities. I feel safe driving myself and others around. I'm blessed to be able to feel safe. I no longer fear having an episode; nothing is more awful than being helpless in your own body. I know there are others with epilepsy, some my age and some much younger than I. There's no pill for them. There's no easy fix, and it is heartbreaking. I cannot cease their suffering, but I can gradually lessen the societal stigma of epilepsy. I speak of my disorder with confidence and nonchalance to make others learn that I am a normal kid who has epilepsy, but that I am not an epileptic.

I have never and will never be ashamed of my seizures. They are a part of who I am. They do not define who I am.



Libby McGraw attends the University of Minnesota Twin Cities campus and plans to major in Fisheries and Wildlife and minor in Spanish. Next summer, she hopes to work as an intern with the Nature Conservancy, conducting research studies to gain experience in that field. "I aim to work hard in school and receive my Ph.D. in Conservation Biology," Libby says. "I want to work with a non-profit organization like the World Wildlife Fund to preserve habitat, end poaching and save endangered species. I will travel to the most remote places on the planet to save the beautiful animals who have suffered terribly from the selfish and ignorant actions of mankind."

# Rising Above Seizures – A College Student's Perspective by William McMillan

It has been almost three-and-a-half years since my last seizure. My initial seizure was in September of 2010, a month after I started college. I had had occasional headaches and days when I did not feel very well ever since suffering a concussion in a January 2009 car accident, but nothing like this. I woke up in a hospital bed the next morning with doctors and nurses telling me I was epileptic. Not knowing what was happening to me, I was extremely scared. I had never heard this word and had no idea what it meant. I soon learned a lot about epilepsy, what caused me to be epileptic and how to treat and handle my epilepsy. Education is the biggest part of epilepsy, and I have worked hard to learn more about it for myself as well as to teach others about epilepsy.

Through learning what causes my brain to misfire and monitoring my health and the environment around me, I feel more informed and am able to go about my daily life. I know stress plays a big part in how often and severe my headaches become, so I keep a constant watch on things that affect me. Keeping my course load at 12 credits a semester has helped me do better in my classes and feel less pressured. Although this has meant taking Winterim and summer courses to stay on track to graduate in four years, the extra work and expense has been well worth it.

I am fortunate to have a great Disability Services office on campus that works with students and professors. By receiving distraction-free rooms and extended time to take my exams, there is less stress for me when working on the tests. I also do not work on my computer or watch television for excessive amounts of time. The slight flickering and fast movements on the screens affect me as badly as fluorescent lights and projectors during class lectures. Most people do not even notice the minute movements of light or images like I do, so I have had to educate them on how these day-to-day activities and situations affect me. By explaining the things that have triggered my seizures in the past, I have helped others appreciate the many issues involved with epilepsy.

By being open about my "disease," I have helped many people understand epilepsy. I do not hide the fact that I have epilepsy. It is not a contagious disease, and the more people know about it, the better they understand and can help spread the word about it. Recent articles about Coach Jerry Kill have brought epilepsy to the forefront. My dad had the great honor of working with Coach Kill and the Gopher football team at the University of Minnesota. He saw firsthand the interactions that Coach Kill had with his coaching staff, the students and players, and my dad's IT staff. I have also had the pleasure to meet and talk with Coach Kill. He is a wonderful man and huge spokesperson for epilepsy. I have followed his lead in being upfront about epilepsy, letting people know it is an illness that can be controlled and is one that often does not receive the proper attention and research funds to help find a

cure. Through continuing education and openness about epilepsy, I can do my part to share what

epilepsy means to me and to rise above seizures.

Author's note: Hours after I finished writing this, I had a seizure while home for spring break. Even more now than before, I am diligent about my stress levels, taking my medications at 12-hour intervals and watching my overall health.



William McMillan is 22 years old. He graduated in May of 2014 with a Business Administration and Marketing degree from the University of Wisconsin-Stevens Point. He began having seizures in September of 2010 following a severe car accident in January of 2009 in which he suffered a concussion. William enjoys downhill skiing, cars, video games and spending time with friends and family.

### The Picnic

## by Sylvia Nelson

I went to a picnic to meet new friends. Yummy food and cool beverages teased my palate – I enjoyed this tasty blend!

My friends are amazing people. They live with epilepsy. As I listened to each one, they shared their personal story.

One gal was getting acquainted with a seizure service dog, Another gal liked music, she had a new home and job.

One gentleman introduced himself, his nametag spoke to his pride, Another friend opened up to say how she felt inside.

These words are but a glimpse into the lives of EFMN friends, I enjoyed their company and hope to see them again.

## A Bright Mind

## by Sylvia Nelson

I have epilepsy.

- My amazing brain has **a bright mind** that is an asset in the American classroom.
- It collects information to grow itself into a book to read.

The book is published. and is a bestseller.

This book teaches people in the American classroom that it is o.k. to have epilepsy.



Sylvia Nelson has tonic clonic and complex partial seizures, and says they taught her how to be resourceful during "bumpy road" events. She has been seizure-free for five years, and she says the authors who write in "Epilogues" are the inspiration for her own work. "I wrote this piece after having attended the Creative Arts program early in November. That program energized my brain!" She also feels that seizures have had an effect on her creative abilities, adding, "I was unaware that I could write. Being connected to EFMN resources was a huge encouragement!"

#### Strength

by Tessa Palmer

In life I go through lots of struggles

It might be good

It might be having to do surgery

I never looked at how unfortunate I am

I always leaped in knowing everything will be all right

It never stopped me from doing what I want to do

I can do almost anything others can do

I can even do some things others can't do

So I might fall then God lifts me up to try again

Through God I have strength to face anything that comes my way even with seizures

It strengthens my heart and soul and mind

So I might have seizures my whole life but it will never slow me down too much



Tessa Palmer is a 19-year-old who says she "likes to be out and about." In her free time, she enjoys writing stories and poems. She is in a transition program through her school where she's learning to live more independently. "Through my years, I have done two 5K races and a triathlon. I also have gone on four missions trips and traveled with my friend. I never let having seizures slow me to a halt because life is too precious," Tessa said.

# Extreme Photography by Kevin Reed



I enjoy photography because it opens up a whole new world for me. I have explored the Twin Cities using my camera. From Como Park to the State Fair, I have captured many images of our great city. The most extreme photograph I took is titled "Arctic Falls," which was taken at Minnehaha Falls. It was an extremely cold day, perfect conditions for my next Creative Arts image. I found the ideal spot to take the picture. It was bitter cold, but this had to be done. I took my gloves off and took the photo freezing cold, but at the end of the day, it would be worth the cold exposure I experienced to capture an excellent shot of Minnehaha Falls, frozen in its natural wonder.

I took a chance of frostbite, but I'm glad I took the risk to show Minnesota's best natural wonder.

#### I Want to Do More than Rise

#### by Sarah Schmidt

I really don't want to be a hot-air balloon to rise above seizures. I would rather keep my feet on the ground and be a package of yeast. Why a package of yeast? Follow me...

Currently, Rise Above Seizures is the celebratory theme of the Epilepsy Foundation's Diamond Anniversary. Today I reap the benefits of 60 years of focused energy.

In the 1950s, a "rising above obstacles" was happening because of advancements in many areas of medicine. The first kidney transplant was a reality. An effective polio vaccine was on the verge of mass distribution. Even though 45% of American adults smoked, the connection between cigarettes and cancer was becoming undeniable. The word "epileptics" was being replaced with the phrase "people with epilepsy." A new light was beginning to shine on their care and treatment.

Today in 2014 America, smoking levels have plummeted. Polio has been eradicated. Great strides have been made in the field of seizure research and treatment.

Yet epilepsy is still stubbornly with us. There is still the call to Rise Above Seizures.

But rise to where? How will I know when I've gotten "there?" What am I supposed to do when I get "there?" Answering these three questions explains my desire to be a package of yeast. Yeast does more than rise. Yeast causes change.

Perhaps my rising to "there" will cause changes in my own life. My changes may come in the form of resolutions to get adequate sleep, to take meds regularly, or to place value on physical exercise as part of managing my disease. Keeping those resolutions requires internal commitment. Externally, others will see a healthier me living well with epilepsy.

In bread making, yeast causes a change in other elements around it. Perhaps my rising to "there" will cause a change in other elements around me. Perhaps my rising to "there" will address educational outreach, fundraising or participation in various walks and events. "There" may also address lobbying to be an audible voice for epilepsy.

Kept resolutions are stepping-stones of success. My kept resolutions bring about successful changes in the lives of people affected by epilepsy.

I want to be part of those changes. I want to be a package of yeast.

I want to <u>Resolve</u> Internally – <u>Succeed</u> Externally.

There will always be a call to R.I.S.E. Above Seizures.

Sarah Schmidt's work was inspired by the Epilepsy Foundation of Minnesota. "To celebrate success seemed only natural. What an amazing history!" she said. Through her submission, she said she also wanted to thank the organization for the examples of progress in an area with great promise. "I wanted them to know how their programs and support have influenced my life with epilepsy." Sarah lives in Gaylord with her family.

#### The Monster

#### by Sekai K. Ward

"Am I dying?" My voice sounds strange, as if I am submerged beneath a thin layer of water. "No!" my mother yells. "You're not dying! You're going to be okay. You're not dying!" Her words bring me comfort in this darkness that I am careening through and like Alice falling down the rabbit hole, I wonder if this will ever end or if I will fall right through the earth. The Monster – the name I have bestowed upon the Tonic-clonic seizure – latches on tight, dragging me down, down, down. This invisible and powerful entity pulls my muscles taut, like a rubber band that is about to snap. I try calling for help, but the words don't come. Suddenly I am paralyzed. An intense sense of dread and panic take hold. A feeling of disconnection quickly follows. It is as if I am no longer a participant in this world but merely an observer, standing with my face pressed up against the glass looking in. My mother stares down from far above, and the farther I fall, the smaller she becomes. Before I know it, she is gone, leaving me alone to battle The Monster and I am freefalling down the rabbit hole until everything fades to black.

When I awake, I am lying on the hard linoleum floor of our kitchen. Pillows and blankets surround me like a cocoon. My mother is lying next to me. I try to remember what has happened and how I ended up here, but my mind is blank. I know the memory is there, but I am unable to access it. I try adjusting my body into an upright position, but the throbbing in my head and the aching in my muscles force me back down. The movement wakes my mother. She gently brushes her fingertips against my arm, pushes my hair out of my eyes and tells me that I had a seizure but that everything is going to be all right. I hear her words, but I don't understand them. Am I dreaming? I start to cry. I struggle to keep my eyelids open, but sleep is calling, and I am so very, very tired.

I am 13 years old when the neurologists diagnose me with Juvenile Myoclonic Epilepsy (JME). They tell me that before the Tonic-clonic struck, I had probably been having absence seizures for months without knowing it. I, like the majority of those with epilepsy, will never know the root cause of their diagnosis but for me this is of little consequence. The sense of relief is overwhelming. Finally, something to explain all of the unaccounted for moments that I should have remembered but couldn't. No longer will I be on the receiving end of humiliating tongue lashings spewed out by angry teachers accusing me of daydreaming in class. My frustrated parents will no longer scold me for losing coats and other sundry articles of clothing. Unacceptable behaviors will now be attributed to absence seizures instead of mere apathy on my part. As the years go by I am also diagnosed with depression. The neurologists tell me this mood disorder is commonly linked with epilepsy. Again, my reaction is one of relief. The ominous, dark grey cloud that has always hung overhead is finally identified and treated and although the cloud doesn't disappear entirely, the antidepressants help it to fade to a significantly paler shade of grey. The Monster still visits me occasionally, sometimes marking me with scars like a cattleman branding a member of his herd to denote ownership. There was a time when I was ashamed of these scars, but not anymore. I've learned that every scar tells a story, so I wear each one proudly. These scars bookmark a

specific chapter in my life, proving that I survived. Sometimes when I'm getting dressed, I'll catch a glimpse of the pear-shaped scar that sits low on my left thigh, and I am back in Memphis, Tenn. where I traveled via Greyhound bus as a broke undergraduate student to visit the Lorraine Motel where Dr. King was assassinated. My firsthand knowledge of this vast country was fairly limited in those days, and I was eager to see as much of it as possible while I had no real obligations to anyone other than myself. I knew this type of freedom was fleeting and would become rarer as I grew older, so I'd save money from my part-time job at a convenience store and, whenever I'd get a break from classes, travel to various parts of the country. On this particular trip, I didn't sleep much on the Greyhound and I'd missed a dose of my medication. These missteps made me vulnerable to another visit from The Monster. It came for me my first morning in Memphis while I was in the bathroom of my hotel room, primping and preening before setting out to tour the city. When my body began to seize, I fell on top of my hot curling iron which is how I got that pear-shaped scar on the back of my leg.

Each morning before going to work I look in the mirror to put on my makeup, and the tiny scar that sits atop my upper right lip transports me back to my mid-20s when I lived on the Caribbean island of St. Thomas. I rented a small cottage on a hill overlooking the blue-green waters of Magens Bay. My days were spent writing about crime for the local newspaper and my nights were spent barhopping until the early hours of the morning with the other mostly young, single reporters who, like me, had moved to the islands looking for adventure, excitement and a more diverse lifestyle than the mainland could offer. When I was first diagnosed with epilepsy my neurologist warned me that sleep deprivation and drinking alcohol to excess would lower my seizure threshold, so I was aware of the dangers but I was young, living in the moment and feeling immortal. The scar on my lip is a constant reminder of the night The Monster came for me after I had one too many Cruzan Rum and cokes and not enough sleep. I awoke on the terracotta floor of my living room with blood oozing from my mouth, half a front tooth missing and a black eye.

I would be lying if I said that the seizures and their aftermath are not traumatic because they are and in some cases – such as the Tonic-clonic I experienced while shopping in a crowded Rochester, New York, grocery store the day before Thanksgiving – humiliating by virtue of their very publicness. Every seizure has left me shrouded in a cloak of shame, guilt and depression that plunges me into the depths of despair, out of which I can only be lifted with the help of a good therapist and an appropriate dose of antidepressants. There is a sense of anxiety that I think will always linger, a subconscious fear that at any moment The Monster will pay me an unexpected visit even though I know this is unlikely if I continue to tread with caution. I take much better care of myself these days, not only because I have grown older and wiser, but because my husband and our nine-year-old son need me to be well; I

minimize my alcohol intake, maximize my sleep, use healthy coping mechanisms to manage my stress and always take my medication. I am not naïve enough to think I won't ever fall down that rabbit hole again, but I've managed to stave off a visit from The Monster for the last six years, so I know I'm doing something right.



Sekai K. Ward was born in Nigeria and raised in between Madison, Wisconsin and Harare, Zimbabwe. She worked as a reporter for a variety of newspapers, magazines and wire services in Southern Africa, the Caribbean and the United States before switching careers. She is now a licensed clinical social worker on an Assertive Community Treatment team tasked with helping those with a chronic mental illness remain happy, healthy and productive members of the community. Sekai also facilitates a weekly therapeutic writing group for her clients. She holds a BA from the University of Wisconsin-Madison, an MFA in creative writing from Antioch-Los Angeles and an MSW from the University of Michigan-Ann Arbor. Sekai lives in Ann Arbor with her husband Stephen and their son Che.

## The Shards of Glass

# by Bill Atwell

Eyes flew wide as the bomb exploded through the cell phone And the sun beat down on the tin roofs Stephanie ... gone Reality shattered And after the new reality was fully realized Shattered pieces of it were ground into our bodies Leaving a shard of razor-thin glass in each of our hearts

We limp on autopilot Doing things that have to be done To bring the closure that can never be Supported by people that try so hard To discover the healing words That do not exist

Time goes by And a new life routine evolves That is emptier, less robust and less joyous Than the one when she was here And the shards of glass in our hearts remain They pierce our memories at random times Making a good day bad Making a bad day worse.

Optimism is harder But often bolstered by the thought That she would have despised the shards For the effects they have on us And we throw ourselves into the comfort of being busy We make some progress We live

No matter how much time evolves The shards of glass remain Although they hurt We are glad they remain We carry on And do the things we do But the shards of glass remain The shards of glass always...remain Brain clicking too fast Memory lapses Extreme muscle pain Medication- a daily routine Loneliness, Isolation, Anxiety DEPRESSION!

This has become my daughter Julie's new life. Last May, she had just graduated from college with a degree in Medical Coding. She was excited to start her new career, a future full of promises. *BANG!* A seizure. She ignores it, doesn't tell anyone, hoping it didn't really happen. Then *BANG* another one three days later. This one happens while we are shopping in St. Cloud. An ambulance ride and five hours of testing give no results. What do we do now?

This was a year ago. We still have no answers, and the seizures continue. We were blessed and had six months free from seizures, but changes in medications took that away from her. I say "we" because epilepsy not only affects the afflicted person, but the whole family. We have researched information that may help reduce her symptoms and give us answers on how to get the seizures under control. Julie has tried two different stays at the hospital for a four-to-five day EEG, but has not been able to hold it together over two days. To watch my adult daughter have an anxiety attack because she cannot deal with the situation (normally this would have been only a nuisance for her) breaks my heart. The seizures and all the drugs she takes have stolen our daughter from us. She no longer laughs and finds joy in small things.

Julie has had some other major diagnoses during this past year and a half. She had trouble seeing out of one eye and found out she has Macular Retinal Dystrophy. Eventually she will go blind in that eye. The other eye has some tears, but is not progressing as fast. She was also having trouble with joint pain and found out she has severe rheumatoid arthritis. I have become a researcher of these diagnoses and a strong advocate for my daughter's well being. I keep complete records, hoping to find some pattern or trigger. So far, nothing.

The Epilepsy Foundation support group has been a godsend for both of us. Julie needed to hear others' personal stories and realize she is not alone. She has developed strong relationships with people going through similar situations and is learning how they cope with the unknowingness of each day. She has also received information on choosing a doctor, medication options and homeopathic oils to relieve pain.

Is this an uplifting story of success? Not completely, but God is with us. He alone knows what his plan is for Julie. Through patience and prayers, his purpose will be revealed. I have no doubt Julie will conquer her fears, find her new path in life and help others she meets by spreading the knowledge about epilepsy and endurance. Pray for her.

Penny Borash's adult daughter, Julie, is the inspiration for this story. "As a mother and full-time teacher, I recognized that changes had to be made in our daily living because of Julie's health," Penny says. "My husband and I have adjusted our work schedules to get her to all her doctor appointments and just be there when she needs comfort. This may be a difficult time in her journey, but it has brought us closer as a family. We realize how important our health is and the importance of being grateful for each seizure-free day."

# A Walk on the Beach... by Linda Gute

I found an agate today.

A crystal white center

with four layers rippling around it in contour.

A time washed, pitted exterior shell.

My collection is filled with stones within stones.

smooth within rough

beauty within the ordinary

tenderness within a battered shell.

The center is what is important.

It appeared first and the layers built around it-

hugging its walls at every turn.

A layer for betrayal

A layer for loss

A layer for guilt

A layer to contain our anger

Those events which happen beyond our control

scar us with their presence but add to that gem within.

Though we hide it well with the last covering of common

ugliness, this is the easiest to remove.

Yet, we choose to keep our mystery to ourselves until

maybe the day will come when someone takes the time to stop

and look around, maybe even bend down

to turn a few rocks over -

And by chance our sparkle catches their eye.

But, time is hurried

Glances are quick

The shell is ordinary

The moments pass.

I found an agate today.

Its underbelly was exposed to the sun

And its sparkle caught my eye.

A new moment has passed -

Linda Gute has a close friend with epilepsy and worked in a service field helping others with disabilities, including epilepsy. She says, "Writing is really just an occasional outlet for me as sometimes I just feel the need to. My inspiration has mostly been from Nature herself and the 'conversations' we've had."

#### Ahhhh RELIEF

#### by Jerry Hartlaub

First an unwanted head trip, Sometimes wrestling with multiple drugs. Eventually reverted to the old reliable, And a quieted brain, Ahhhhh, relief.

Then an angry crazy peripheral nerve, Aggravated by tons of jogging, Well, actually speedy running. Attacked with a vengeance.

Sitting brought intense pain, Excruciating, unrelenting. A glacier scrapping the mountainside. Fingernails scratching a blackboard.

Only standing was tolerable, When not sleeping. Only sleep time, Gave full relief.

Over a year slowly crawled by, Trialing every known and reasoned strategy. When medics could only speculatively help, Self therapy and patience came to the rescue.

Now carefully managing each day's activities, The peripheral nerve nearly at peace. Only a low level threat of a rattled brain, Many lessons learned. Ahhhhh relief!



Jerry Hartlaub says this poem characterizes his son's recent challenges with misbehaving nerves in his body. "It is only my arm's-length perception of his trials. He might describe things a bit differently," he said. After many months of discomfort, thorough research, doctor visits and careful trials, most symptoms and pain associated with his son's peripheral and central nervous systems have greatly subsided. Jerry says, "This is a testament to my son's wonderful problem-solving skills. And his good luck. I pray that his relief is long lasting."

#### The Veteran

#### by Lisa Riley

The sun was shining, the morning clear. He awoke from sleep knowing battle was near.

His comrades beside him, they call him brother. They set out in Humvees to defend all others.

As they proceed to war, an explosion is heard. An IED from the enemy abroad.

The Doctors said he would not be the same, His brain is injured, he is sent home again.

The seizures begin with a vengeance and roar, They changed his life, right down to his core.

Another battle is fought, the storm is inside. He stands up to seizures, his brain they reside.

His mother she wept as they told her he died, Her heart is broke as she remembers his life. Never a father, never a wife.

He is buried and honored with a six-gun salute, A flag drapes his coffin as he's put in the ground. The flags and the flowers and tributes abound.

His family and friends will never forget, the life that he gave So we all might be free. To be honored and cherished as they remember this day.

Written to honor the veterans that have returned to our soil with traumatic brain injury. There are over 169,000 veterans expected to develop epilepsy. This is to honor those veterans.



Lisa Riley is the mother of a young man who had left temporal lobe epilepsy and tonic-clonic seizures, and who died from SUDEP in 2012. Her son is the inspiration for her written work. He lived with epilepsy for just three years, and his death has been devastating for her and her family. She says, "Losing someone and not knowing we could lose him from a seizure was a shock to our family. We're still reeling from the loss." She explains that her son's seizures "began as nocturnal, but he died when they broke through his medication."



1600 University Avenue West, Suite 300 St. Paul, MN 55104 800.779.0777 | efmn.org