

Breaking Barriers

everybody belongs • everybody serves

Summer 2016 (Living with seizures)

We Don't Know, but God Knows

by Rachel Daining

Calvary CRC, Pella IA

What if she has a seizure in the middle of the night and dies? That question began to worry me about a month before Natalie had her first known seizure. Some 90 percent of people with polymicrogyria have seizures. I am not completely sure why this question did not worry me the first four and a half years of her life. Perhaps we were too busy trying to survive the rest of her medical conditions; plus, I had hoped we were in the “elite” 10 percent.

I wrestled with God in my worry. I wondered if there were precautions we should take or more tests we should run. I feared Natalie dying and feeling like there was something we could have or should have done. The crazy thing was, up to that point I had no reason to be worried, except for the statistics. After these worries tormented me for a couple weeks, I wrote this prayer in my journal:

Father, if you choose to take Natalie from us, I will trust it was in your timing. I long for heaven for all of us, and if she makes it there before us, I pray you will let me see it as your grace, and not as my fault or anyone else's. Help me to trust you.

Just 11 days later Natalie had a tonic-clonic, or grand mal, seizure. That night in the hospital I wondered if I would be able to sleep, or if I would stay awake all night staring at her, wondering if she would have another seizure. Then I thought back to my journal. I thought, "God prepared me for this." I could sleep knowing God had prepared me not just for what happened that day, but for the worst case scenario.

Natalie already has a lot of developmental challenges, so adding seizures to the list felt very heavy, and we grieved. Thankfully we think her tonic-clonic seizures are under control with medication. However, last December we found out Natalie also has a rare seizure disorder called ESES (electrical status epilepticus of sleep), which occurs while she is sleeping. This additional diagnosis once again brought that heavy feeling, especially since the ESES hasn't been treated successfully.

Though our journey with Natalie is often overwhelming, we are comforted by our Savior in many ways. Psalm 139 says, "All the days ordained for me were written in your book before one of them came to be." God knows what

each day of Natalie's life will hold, and how many days she has. He loves her so much that he sent Jesus to die for her, so I can rest in knowing her life is in his hands, not mine.

Themes

Summer 2016—Living with seizures. About 2 percent of adults have a seizure in their lifetime, and one-third of them experience more than one. The stories here (with more online) are written by individuals or their loved ones who have experienced seizures.

Fall 2016—Disability and employment. The unemployment rate of people with disabilities is about double that of people without disabilities. We would love to hear three kinds of stories: churches that are assisting people with disabilities in finding employment; employers that are seeking out people with disabilities for employment; or, people with disabilities with an employment or unemployment story to tell. Please send us a note (not to exceed 400 words) by **August 26**.

Winter 2017—Disability and spiritual practice. As someone who belongs—body and soul, in life and in death—to Jesus Christ, how has living with a disability shaped your own spiritual practice? Where do disability and your devotional life intersect? Please send us a note reflecting on your experience by **November 1**.

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Support, Surgery a 'Saving Grace'

by Ginny and Charlie Haas

Reformed Church in Kinnelon NJ

When Dawne was born in 1966, our beautiful baby girl had red marks on either side of her forehead because forceps were used during delivery. Eventually the marks faded, but as a toddler we noticed she would stand in a frozen state and stare straight ahead. Testing when she was four came back positive for epilepsy and she was put on phenobarbital. Things went along well until she started becoming a woman and hormones played havoc with her medication, so Dilantin was added. As seizures became severe tremors, she would stare and feel like she was spiraling, which she actually was. She was hospitalized numerous times through high school and medications were changed constantly.

"I did not have an aura or any knowledge a seizure was coming on," Dawne recalls today. "I was lucky to have friends in high school and church who were aware of the problem and always came to help me."

Eventually Dawne married and had a baby, which she carried to term without ever having a seizure. Five days after delivery the seizures started again, only this time they were more pronounced.

“After I married and had our daughter, the church came to our aid by helping take care of her as I attended doctor appointments, which were many,” Dawne says.

Eventually an epileptologist diagnosed Dawne as having two types of seizure, one controlled by the frontal lobe and the other by the temporal lobe. (Finally we had an answer to the red marks on her forehead at birth—damage to the temporal lobe, causing spiral seizures.)

At 28 she became a candidate for brain surgery. The surgeon had performed this operation on only seven prior patients, so we and our church family were in prayer continually. During surgery portions of the frontal and temporal lobes were removed and other sections of the brain were scored—and Dawne has not had a seizure since 1995.

“The church has always been there for my family and for my parents and my brothers,” Dawne says. “Not much was known about epilepsy in my early life, but as I got older doctors became epileptologists and that was my saving grace. When the church started a youth group for people with disabilities, we became involved because of the support we had during my years of seizures and also because our daughter has mental challenges herself.”

Angie Knows the Love of Jesus

by Bob and Jean DeJong

First United Reformed Church, Chino CA

Our precious daughter, Angela, started having seizures at 18 months of age—30 or more seizures nightly. After many hospital stays, she was diagnosed with a very rare, uncontrollable seizure disorder called Lennox-Gastaut syndrome.

She had brain surgery at the age of 8, has tried multiple anticonvulsants, and now takes maximum levels of four different seizure medications. A vagus nerve stimulator inserted in her chest transmits an electrical impulse to the brain every 1.3 seconds. With all of this treatment, she is currently experiencing only one or two seizures per week, praise God!

Now 37 years old, Angela is nonverbal with limited mobility skills. She lives in our home and goes everywhere with us. She is totally dependent on us for her care—eating, hygiene, toileting, and dressing.

Throughout her life she has known the love of her family, and even more important, the love of her Savior, Jesus Christ. She used to be able to sing her version of “Jesus Loves Me” using the words “Jesus Bible.” She would also point to a picture above her bed of Jesus and some little

children when asked if she knew how much Jesus loved her!

God is in control. As her parents we feel blessed, privileged, and honored that God chose us to care for this beautiful child of God who has taught us so much!

Recovery, Discovery, and Grace

by Anita Brinkman

Bethel CRC, Waterdown ON

What is it like to have a seizure?" Sometimes people have asked me this, hesitantly, because they're not sure if it's polite to ask. I have to answer honestly, "I don't know." I don't remember ever experiencing one. I know what it's like to recover from a seizure, though.

About ten years ago, I developed nocturnal epilepsy, so every four or five months I have a seizure shortly after I have fallen asleep.

The pattern has become frustratingly familiar. I wake up in the night with a severe headache and my tongue bruised, even cut, from the full force of my teeth. My mind is foggy, detached, grasping at consciousness, but somehow missing. When I'm alert enough just to realize I've had a seizure, I sigh and drop back to sleep.

The next two days are recovery time. I can function. Most people don't notice any difference, but those who know me well can see that I lack focus. I'm easily confused, move stiffly, and eat carefully, trying to bite around my swollen tongue.

The mental recovery takes longer. Slowly, connections come more naturally. I don't have to search as long for the word I'm looking for, and I can open a new tab on my Internet browser without pausing to remember what I was going to look for. I'll have a few months of living at this level—a level so many take for granted—and then I'll have another seizure and the pattern will start again. (I've learned to keep things very organized to make allowances for myself.)

We are told to give thanks in all circumstances (1Thessalonians 5:18), and I am grateful:

- My seizures only happen in sleep, so I can keep my driver's license.
- I feel fine most of the time, and my brain has time to recover well between seizures.
- I am growing in humility. If I have a seizure while I'm staying with friends or family, I feel odd knowing they have seen me like that, even taken care of me. I have accepted this and gained a deeper understanding of the struggles and grace of others.

Saved from Death to New Life

by Jon Rink

South Olive CRC, Holland MI

I was born one month after my scheduled due date. After birth, I had 36 hours of continual seizures and almost died. My birth doctor never signed my birth certificate.

Between my birth in 1957 and my eighth birthday, I had hospitalizations due to grand mal seizures, the flu, bronchitis, and a fever. When I was three and a half my parents took me to the hospital because I had a double seizure. It was even suggested that I go to live at Pine Rest Children's Retreat, but my parents declined and said that they could take care of me at home.

Although I took medications every day and needed a neurologist, my parents enrolled me in "regular" school like my brothers, and I participated in swimming, Little League baseball, Rocket football, and received varsity letters in cross country and track.

I graduated from high school with my class, attended Central Michigan University, and participated in InterVarsity Christian Fellowship, where I met my future wife. After graduation in 1979, I attended the Urbana student missions conference.

My wife Noel found out that my medications caused various mood swings. The medications all have side effects, which have impacted our children because the drugs caused a lack of communication on my part and reduced my ability to understand what was going on.

At least our children understand how different drugs affect me physically and mentally. As my health has improved with better medications, we are thankful that I live more normally and participate in home and church life.

Parenting and the Body of Christ

by Pastor Ryan and Sophie Landt

Aberdeen Reformed Church, Grand Rapids MI

Our son Levi had his first seizure shortly after his second birthday and was diagnosed with epilepsy two months later. We wondered anxiously what this diagnosis would mean for him and our family. With each subsequent seizure, his medication would be increased or changed, bringing us again into the unknown of potential side effects. Again and again we felt frustrated that there were no clear answers to some of our most pressing questions. An even bigger challenge and source of anxiety presented itself every evening at bedtime, because he has most of his seizures while falling asleep. We never know when the next seizure will be.

Living with a child diagnosed with epilepsy has been, for us, an extended exercise in learning to trust God. From the beginning, we prayed that God would take this scary, difficult situation and bring good from it for God's glory. Almost three years in, it is a joy to see how God has answered that prayer in granting us peace and increasing our trust in God's faithfulness to walk with us through any difficulty. This path has not been linear. Although there are times of increased fretting, we see how God is transforming this experience from burden to blessing. He is equipping us as a family to embrace others even though we don't know where that will lead.

Remarkably, we've found that it's not just our family, but our whole church has a child with epilepsy. From the afternoon Levi had his first seizure, he has been covered in prayer by members of our congregation and many other people. They have brought us food and gifts, sent cards, babysat our daughter during emergency room visits and doctor's appointments, and joined us at the hospital. They genuinely want to know how Levi and the rest of the family are doing. Living with the reality of this diagnosis can be frightening, and we wonder what the future holds. Still, through Levi's struggles we see our congregation live out what it means to be the body of Christ, and we see God at work in our lives.

Editor's Note

Well Done, Advocates and Friends!

As editors, we're grateful for so many across the RCA and CRC who—sometimes without much advance notice—submit or solicit articles related to our published themes. We may squirm occasionally when the copy deadline is upon us and we have not received a sufficient number of articles, but one way or another we get what we need.

Thankfully, we did not find ourselves in that situation this time. We received many more articles about living with seizures than we could squeeze into the printed version of *Breaking Barriers*. Please visit one of our websites (www.rca.org/disability or www.crcna.org/disability) to read the other stories we received from Reinder Bouwma, Al Hoekstra, Yvonne Hoekstra, Crystal Laney, Jeannie Murphy, Bonnie Roda, and Linda Roorda.

A testament to the quality of articles is the honor recently awarded to *Breaking Barriers* by the Associated Church Press (ACP)—namely, the 2015 Award of Excellence (first place!) in the newsletter category. The ACP's criteria assess the overall quality of the publication and appropriateness for its audience, including content and coverage; writing and editing; and typography, format, and design.

The ACP judge said *Breaking Barriers* “does a wonderful job of sharing meaningful and touching stories...[that allow] the reader to connect with the subjects of the story in a very real and human way, uniting them in the ministry of God...[and] provides excellent messages of inclusion in ministry!”

Breaking Barriers also received an honorable mention for Cathleen Bast’s Winter 2015 article, “A View of Prayer Transformed,” in the feature article category for newsletters and newspapers.



Our disability blog: To read and engage weekly blog posts by CRC and RCA members related to disability and ministry, check out Disability Concerns on the Network (network.crcna.org/disability-concerns). The Network, which includes a searchable disability resources section, can also be accessed through the RCA and CRC disability webpages.

—Terry A. DeYoung

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