

Chelley's courage

Chelley Vukmanic is a lot like me. A graduate of Salisbury University's English program (where we met), who became a teacher, a wife, and a mom in rapid succession. She's a cheerleading coach, too, which, along with her Catholic faith, has brought her the optimism and hope she needs to face a serious medical illness. Here you will find her story. Here you will find a way to help Chelley and her family.

Fifteen Minutes

For the past five months, my favorite event of the day is my mid-afternoon shower. It's not because I need to wash away the sweat and grime of a hard day's work, though I wish it were. It's not because the warm shower is relaxing, and it's certainly not because I love our bathroom's old fashioned tiling. It's because for those 15 minutes each afternoon, I am standing and able to feel "normal."

My Painful Diagnosis

This journey - my journey - began the first weekend in August when I got out of bed and felt the worst headache I had ever experienced. It felt like my head was imploding, and I assure you that this is not a hyperbole. My neck was sore, and I also couldn't hear anything in my left ear. Once I began vomiting and could not even think straight, I went to the ER. I used trusty WebMD to diagnose myself with Meningitis, however, the ER doctor calmed me down and told me I was suffering from painful trigger point muscle knots in my neck and shoulders. He gave me pain medication, recommended physical therapy, and sent me home.

Being a high school English teacher and cheerleading coach, the end of August is usually exciting and fun. I get to help with Cheer tryouts, set up my classroom just how I want it for the new school year, and then plan out the first few weeks of lessons. Needless to say, this was an awful time of year to suffer from debilitating headaches. Instead of enjoying my reunion with colleagues on my first day back, I only survived the last 20 minutes of a department meeting with an ice pack held to the back of my head before needing to go home and lay down. Even though I was taking the maximum dosage of Ibuprofen and Tylenol each day, the only relief I felt came from lying flat on my back. The constant pain was keeping me so nauseous that my weight plummeted down to 82 pounds.

After weeks of physical therapy, three visits to my primary care physician, and a round of steroid medication, I was finally sent for an MRI of my brain just to "rule out anything serious." I was very nervous about the MRI because I live with a panic

disorder and being trapped in that small tube for any length of time will inevitably trigger an attack. My husband was able to stand in the room with his hand on my ankle for reassurance as I kept telling myself that the MRI would be over soon and the images would confirm that there was nothing seriously wrong with me. I repeated this like a mantra: "It's almost over. You'll find out that nothing's wrong. It's almost over. You'll find out that nothing's wrong."

My husband and I had only driven about 10 miles away from the imaging clinic when I got a call asking us to turn around and return for more scans. By then I had been upright for too long so my brain felt like it was being ripped apart. I couldn't handle it any longer, so as soon as the technician ushered us through the door, I pushed the patient chair out of my way and threw myself down on the floor of the neuroradiologist's office. My pain completely overshadowed any embarrassment I might have felt from being sprawled out on the floor of a medical professional's office as he was greeting us. When I apologized for having to lie down, the doctor's response was, "Oh no, I would do exactly the same thing if I were you." Then, he went into a detailed description of spontaneous intracranial hypotension caused by a cerebrospinal fluid (CSF) Leak.

In the most basic of terms, a small tear in my spinal dura is causing spinal fluid to leak out of my spinal canal. Without the proper volume of spinal fluid to support my brain, it sags. The sagging pulls on the meninges, which connect the brain to the skull. Hence, the horrible headaches whenever I am upright. The neuroradiologist added that I need to lay flat as much as possible because if the meninges stretch too much, they can tear and cause a hematoma. There are also potentially life-threatening risks involved, such as a stroke. He told me to stay on strict bed rest and see a neurologist for further instructions. He helped me off the floor just to put me back into the tiny, constricting MRI tube for an even longer period of time to scan my entire spine in search of the leak. I did not need my mantra though. I prayed instead. My entire focus was on asking God for help while tears flowed nonstop.



How Many Spinal Procedures Does It Take To Seal A Leak?

I have been blessed with a phenomenal neurologist, Dr. Price, who has been amazingly supportive through this entire ordeal. She graciously came into her office early to see me the morning after the neuroradiologist called her. Dr. Price informed me that my images did not display the exact location of the leak, so the protocol is to go through a spinal blood patch procedure. She made some calls to an interventional radiologist friend and was able to get me an appointment for a blood patch at the hospital that same day.

Looking back at how quickly events occurred over those two days, I recall thinking to myself, "I'll be back on my feet in no time!" Unfortunately, I was not one of the lucky people whose leak sealed with the first blood patch, or the second, or the third.

I can say with complete honesty, brimming on the edge of desperation, that I hope no one I know ever needs any of the spinal procedures I have received over these past five months. My panic disorder definitely makes most medical experiences more frightening and intense for me than the average person, but I cannot imagine them being enjoyable for anyone. I don't feel it's necessary to go into much detail for this blog, but the blood patch procedures consist of the Interventional Radiologist using a long needle to inject a collection of my own blood into my spinal canal with the hope of my blood coagulating over the tear in my spinal dura, which would seal the leak. My lower back is numbed for the procedures, but I am awake on the table and able to feel the manipulation of the needle, as well as sensations caused by the needle entering the spinal area. Sometimes I would feel intense pressure, while other times, I would feel an electric shock shoot down my leg or across my hip.

Following each blood patch procedure, I was told to do nothing but lay flat for twenty-four hours, and then slowly regain a normal routine with fingers crossed that the leak had sealed. It was emotionally draining to be filled with fear and anxiety leading up to and during the procedure, followed by physical pain for a week, and then a complete hopeful desire to make it through each day without a headache only to crash into a solid wall of disappointment when the symptoms returned. A few weeks after each blood patch when I would feel the headache and neck pain return, I would sink into despair, anger, and shame.

After three blood patches and one special spinal imaging procedure, my Neurologist and Interventional Radiologist referred me to a Neurosurgeon at John's Hopkins Medical Center. Dr. Price thought that Hopkins might have better luck identifying the exact location of the spinal fluid leak, which could possibly require surgery to seal. After a very frustrating month of commuting to and from Baltimore and two more MRI scans, we were no closer to a solution. My neurologist had heard of a CSF Leak Specialist who works at Duke University Hospital, so she referred me to him.

Ask, Believe, Receive

I cannot recall another time when I felt more hopeless and defeated. Since I am on unpaid medical leave and my husband had to resign from his job to take care of our six year-old daughter and me while I was on bed rest, we are approaching the edge of a cliff plummeting down into financial crisis. We are a young married couple who just purchased our first home and a new car now wishing that we had stayed in our little apartment and pushed our decrepit car around for at least one more year.

Hearing that my only hope of leaving behind this permanently horizontal life involved traveling to North Carolina to see a specialist seemed impossible. I prayed to God and asked the questions that I didn't know the answers to - How many months will I have to wait before the specialist could fit me into his schedule? How can I afford the trip? Who will look after my daughter? How will I handle more tests and procedures with my panic disorder? God answered each of my questions in his own unique way.

About a month after my diagnosis, I had a dream that I was at Salisbury University and failing Sociology because my professor didn't know that my reason for missing class was a CSF Leak. In the dream, my roommate was Marissa, a friend I hadn't spoken to much since we graduated from high school. Thinking it was a random humorous dream, I wrote about it on Facebook and tagged Marissa.

This sparked a conversation between us, which led to Marissa's Bible group being generously supportive of my family. At the time, I thought the dream was a way for God to bring this supportive soul back into my life.

Fast forward to the end of November when Marissa sent me a message just to see how I was doing, and I explained that my best chance is to try to get an appointment with the specialist at Duke. I told her that I was feeling hopeless about the situation, and Marissa's response was that she works there! I knew she was living in North Carolina, but since we had lost touch for so many years, I had no idea that she was working at Duke. Marissa offered to email the specialist for me and she even offered to host us while we are down there. Within two weeks of Marissa emailing the specialist, I had an appointment set up for early in January. I do not believe that it is a coincidence that I dreamt about a high school friend who I had not spoken to in over a decade and she just happens to work at the hospital where the only CSF Leak specialist on the east coast is located. I believe that Marissa is an answer to my prayers.

A few of my colleagues who had heard of our financial burden offered to begin an account for me at GoFundMe.com to help raise money for my trip to Duke and the unpaid bills quickly accumulating. I thanked them for the offer, but wasn't sure if I was comfortable with publicly requesting monetary donations. After much discussion with my family, my sister set up www.gofundme.com/vukmanic and began sharing the link on Facebook. I thought that if we were lucky, we could raise half of the money needed for gas, food, and a hotel room close to the hospital so we would not be an imposition to Marissa and her family. In less than 20 days, the account raised \$3,350! I cannot look at the webpage without crying tears of joy and gratitude. Family, friends, as well as current and former colleagues and students have been donating money. My heart swells even more when I see the names of kind strangers who are donating to help me and my family. I believe that everyone who made a

donation is an answer to my prayers.

My 6-year-old daughter has been such a trooper through all of this, even though she has been worried for me and a little frustrated that her mommy cannot get out of bed. The last thing I wanted was to scare her more by bringing her to Duke with us during my upcoming spinal procedures, but we will need to be there for almost a full week.

My mother-in-law just recently lost her job because the company had to make cuts for financial reasons. Upon hearing what we are going through, she immediately offered to stay at our home and take care of our daughter while we are away for the week. She can work on her resume and look for job opportunities while providing our daughter with the comfort of a normal routine during this difficult time. I believe that this is an answer to my prayers.

As I mentioned earlier, medical tests and procedures are extremely challenging for me because of my panic disorder. I have tried medications, meditations, and therapy, but the anxiety lives on until the panic attack rises. During one of my last MRIs, my anxiety was worse than normal so I kept moving. The technician told me that she needed to re-do the scans because they were blurry from my movements. When she pushed the button for me to slide back into the enclosure, I tried to focus on calming breathing exercises, but it wasn't working. Then, I began reciting the Rosary to myself. My focus transitioned from the loud clanking noises and the suffocating confined space to the Rosary. I was able to remain still and calm for the remainder of the scans. Even though my anxiety is a constant battle, I believe that turning my focus toward the Lord calms me much more than medication.

One Day At A Time

It is hard to live a life in a bed. I feel my muscles weakening, and I mourn the activities I can no longer do. I celebrated my daughter's first day of kindergarten, Halloween, my daughter's sixth birthday, Thanksgiving, Christmas, and the New Year while lying flat in bed. I wish I could say that I've been optimistic and positive through this entire journey, but that's simply not true. I have my bad days where I fear never returning to a life outside of my bed. But I'm trying to take it one day at a time. I'm learning lessons about humility, appreciation, family, friendship and faith. And as I await the upcoming spinal procedures at Duke that I pray will seal my leak, I'm really enjoying my daily 15 minute showers.