

Pamela

My story of severe facial pain that started in 2012. I woke up one morning with a feeling that I had a needle in my eye, the worst sinus infection ever and my teeth hurt and I had an electric shock in my mouth. I had no idea what this was. I went to my primary doctor; he sent me to the eye doctor and the eye doctor said it was a sinus infection and sent me back. I was treated with antibiotics. As you know, that did not touch this severe pain I had in my face.

I went to an Ear Nose and Throat doctor and he offered to do a balloon sinuplasty but he said he had never done that on anyone that did not have infection, I said no thanks. I went to a neurologist and he said I have a migraine, I knew it was not a migraine, this was different.

I then went to a neuropathologist and she knew exactly what I had, Trigeminal Neuralgia. I tried to deal with it for 4 years with antiseizure medication but it still was not cutting it. I had this all day long. I had it when I woke up and until I went to bed. It did not give me a break. I cried a lot. I decided to try sphenocath blocks, and they would try to numb both of my nostrils and shoot a solution up my nose and I had to hold my head back for 10 minutes to try and numb something. It was like you were drowning but you stayed that way for 10 minutes. I did this for months but it still did not work very much but I was desperate.

I then heard about a doctor that did microvascular decompression, we drove to Wyoming, I live in Kansas but I heard this doctor was really good. I had the procedure and my face felt good but the back of my head felt like I was hit in the back of my head, it would not stop. I was also having electric shocks in the back of my head that were so excruciating it would make you stop in your tracks. They did occipital prolotherapy on me 2 times and it hurt so bad but it stopped the electric shocks but I still had the pain in the back of my head. I now know I have occipital neuralgia, constantly. Occipital blocks were done about 7 times by 3 different doctors with little success.

After 2 years the trigeminal neuralgia came back with a vengeance and now, I have a feeling of a needle poking my nose and a nails in my teeth, needle in my eye, severe burning by my eye and my cheek feels like a curling iron is on my face and electric shock in my mouth. I had a radiofrequency to try to stop the facial pain, the first time was not enough, I did not feel anything so the doctor did it again and the right side of my face was so numb, I could touch my eyeball and not feel it. The doctor said I would have to put eye drops in for the rest of my life because of the dry eye. So not only did it effect my eye but it effected my nose, it was like I could not breath out the right nasal passage very well, my smile now drooped a little and my mouth is numb on the right side, so I have to remember to wipe my mouth after I eat because I can't feel if food is on my face. I tried acupuncture and people told me my smile did not droop as much. It brought my smile back a little but the right side of my face is still numb and I still have facial pain. So, I now have Anesthesia Delarosa. I asked the doctor if this has happened before, my right side of my face is numb but I still have facial pain, he said it happens in 20% of the patients. My favorite thing to do is read and my glasses hurt to put on my face and touch my nose.

I went to another neurosurgeon; he was closer and my other one in Wyoming retired but this one wanted to do a deep brain stimulator but insurance said it was experimental. He then wanted to try spinal cord stimulator and it was denied like 5 times with insurance. I had tried chiropractor and physical therapy the physical therapy made the trigeminal neuralgia worse. The neurosurgeon then decided he would like to do a pain pump after me bugging him so much to do something. I was willing to try this. I was the first one he did this on. He put the pain pump on my front and the catheter goes to my back side and up my spinal cord up to the tip where the brain stem is. I have two medications in the pump. The catheter did sever once and he had to go in and repair it and I know I drove them crazy because of calling too much until we got to the right pain dose. I am still on a lot of medication and that was the goal to get me off of oral medications but that did not happen. I was at a point I thought I would have to get on disability and there was a month I did not go to work, I just cried day and night but if it was not for my faith and people praying for me, I probably would still be on my couch crying. I still have the terrible flare up but they only last 4 or 5 days then thankfully it calms down for a while until it storms or weather change or it just wants to. I am back to work full time. I am so thankful my boss was so patient with me. I did see a chronic pain psychologist and he helped me a lot not let this terrible disease control my life. I do have to stay home when it does flare up. I also have a neurologist that I like who is helping me with my medications. He is local, I am thankful for that. I am also thankful for my husband because he did alot for me during this time and still does.

I hope this is not too long but it has been a very hard and long 10 years but I am doing so much better but it is sad that I am on so much medication just to function. I still have electric shocks in my mouth all the time but I have gotten used to them. I have been through a lot of doctors and traveled so many miles to them but when your face hurts that bad you do what you have to. It has been an expensive journey. I am excited to say I can wear glasses again, they are really lite and I can read again. God is good.