



TELL YOUR STORY: Annie Suiter

I had limited knowledge of this disease when diagnosed as well as before my diagnosis of metastasis. I learned so much more following this and mostly because I went in search of it. It was not explained to me by any medical professional that I saw or worked with as being something that I will have to battle for the rest of my life. I was referred to a "gold standard facility" for an opinion from a "specialist" who did not share any knowledge with me but simply told me to go home and live my life as fully and as healthy as possible. I sought out information from the internet, support groups that I found through social media, and attended the national conference for patients. It is because of my research ONLY that I have a plan to see a true specialist in the area of NETS.

In 2012, I started having abdominal pain; especially after eating. I also had been "flushing" for several years but thought it was due to hormonal changes following a total hysterectomy. I finally went to an after-hours facility because I could no longer handle the pain, I had a CT which showed a blockage and it was believed to be an infection. I was given 5 days of IV antibiotics and sent home with a referral to a GI for a colonoscopy to follow up. The colonoscopy/EGD with biopsy was completed a week later and then I received "the phone call".

I am an oncology nurse, working primarily in infusion. At one time I was a clinic nurse for a prominent oncologist. I consulted with him on my pathology report because this was a diagnosis I had no experience in, and because at that time the only knowledge in that area was "surgery and Sandostatin", that was the advice he gave to me. I had the partial colectomy and lost the majority of my colon as well as a large portion of my small intestine. I had positive lymph nodes as well. But because the surgeon was confident that he "got it all" I felt that I was lucky to have found it before it got out of hand because even though I had positive nodes, scans, and blood work for 4 years showed no evidence of disease. I continued Sandostatin shots monthly and was followed by an oncologist in my area. I had severe abdominal pain and was found to have an enlarged and inflamed gallbladder. I consulted with a surgeon who was reported to me as having experience in Neuroendocrine cancer and had it removed as well as exploratory surgery. I was told by the surgeon that he took biopsies of a couple of places on my liver but that he wasn't worried about them, which came back positive for neuroendocrine cells. I have had several tests and scans and blood tests which have all been either "inconclusive" or "negative" AFTER the positive biopsy. Treatment for me is still the same according to the oncologist, and have been given a "watchful waiting" prescription. But I don't do that well.

I am now on Lanreotide because I have had several nodules that were found on CT and have had "knots" after the injection of Sandostatin related to incorrectly administered injections. With Lanreotide being given subcutaneous instead of in the muscle, I have not had any further issues.

I battle diarrhea and severe fatigue daily, sometimes flushing, however, it decreased since taking Lanreotide. I have aches and pains in my joints and muscles. I don't like to take medicine for it because I don't like the sedative effect that they have on me and have to be able to function as a medical professional. I still work a minimum of 36-40 hours per week, I am a single mom with no choice but to keep working and providing for my daughter. I continue to take monthly Lanreotide and have a plan to see a specialist to receive the best advice, care, and monitoring that I can get.

I know that not all NETS patients are the same. We all have similarities and understanding of what the other is going through. But I truly believe that the only way to have peace about what we are living through is to have confidence in your care provider and the knowledge that you are doing all that you can do to keep living the best life you can live. Normal has a new meaning. Every day is a gift. With gifts, you enjoy some more than most. But they are still gifts!