



### TELL YOUR STORY: Mary Powell

I knew I would get another cancer diagnosis (already had skin cancer). I just did not know that I would be diagnosed with cancer I have never heard of. My brother was diagnosed with leukemia in December 2012 and needed a stem cell transplant. I was a perfect match. In March of 2013, I went to MD Anderson to donate my stem cells. To complete my work up, I had a chest x-ray. Two days later, my brother's doctor called me and told me there was a spot on my lung and that I would need to do a lung biopsy. A week later she told me I had neuroendocrine carcinoid of the lung. Needless to say, we were both shocked.

The first thing I did was google NET and I was shocked. I started crying and freaking out, Literally! Then I found the group Loveable Lungnoids on Facebook, which was scary at times but helpful. The group had a lot of documents that were informative and the stories they shared were inspiring. I was able to get some knowledge before actually seeing a NET specialist. I felt that I knew enough to ask the right questions and make the right decision for me. Soon later, I had surgery in order to remove part of my lung.

I have been involved in Relay for Life for the American Cancer Society for a while now and I had never heard of NET cancer. Since, there are not that many specialists I assume that most cancers are lumped under a certain body part, i.e. instead of me having a NET, in the past, they would have said lung cancer with no mention of neuroendocrine carcinoid. I think NETs are talked about more because of the number of people being diagnosed. The education of NETs and Facebook groups like Lovable Lungnoids are spreading awareness of this type of cancer in order to help those that are uneducated about NET or misguided.

I currently get checked a yearly CT scan and blood work. There is a NET expert at Moffitt in Florida where I get my check- ups. Of course, like any other cancer patients every time I have a cold or a pain in my side, I freak out.

The scariest part of being diagnosed with NET is the lack of resources. Since my diagnosis, I have told people I have had cancer. I say that I have "neuroendocrine carcinoid of the lung" but sometimes I said I was diagnosed with "lung cancer." I put the latter on the patient information sheet and the doctor said: "I did not know you smoke". Well, I don't. So, I chose not to do that again. I will continue to say that I have neuroendocrine carcinoid of the lung so I can educate people about this cancer since we are our best advocates.