



TELL YOUR STORY: Marjorie Freedman

I was originally diagnosed with invasive ductal carcinoma of the breast. Having a family history of breast cancer and a very thorough breast surgeon, I was required to have a chest x-ray and MRI prior to surgery. A spot on my lung showed up on both the x-ray and MRI. Biopsy confirmed a neuroendocrine tumor in my right lower lobe.

My oncologist told me that I had a slow growing carcinoid tumor. I immediately looked up everything I could online about carcinoids and NETs. I am well versed in accessing scientific articles so used PUBMED to download the most recent published papers. I created a binder of these published papers and gave them to my oncologist. I also accessed FB pages relating to this disease, list serves, and information available on the Internet. I attended the NET conference held at UCSF in January 2015.

There is a lot of information online and in books, but sometimes it's hard to get the most recent published papers if one does not subscribe to the journal or the library does not have a copy. More doctors need to become educated about this disease. I have heard horror stories!

Be proactive. Ask questions. Don't assume others, including all of your doctors, know about NETs. There is a lot of misinformation. Don't believe everything you read online. Be diligent. Realize that cancer is sneaky, and may lie dormant for a while before rearing its ugly head. I think that many erroneously believe that if have had their primary tumor excised and sampled lymph nodes are negative they are cancer free. In the lung, for example, only a few lymph nodes are typically removed. There's a 50/50 chance that the node removed will test positive. Other nodes that are NOT removed may be positive, even though a removed node is negative. Be diligent and be your own advocate. Participate in clinical trials. Appreciate every day and work to improve awareness and treatment options.