



### TELL YOUR STORY: Mary Koch

In April of 2013, I was diagnosed with a non-functional pancreatic neuroendocrine tumor. In the weeks leading up to my diagnosis, I wasn't feeling very well. After consulting with my primary care physician, he ordered some bloodwork which indicated elevated liver enzymes. The test was repeated 2 days later, which indicated the liver enzyme levels were on the rise. I had an abdominal ultrasound, followed by an abdominal CT scan and was told that I likely had a blocked bile duct and would need an ERCP to diagnose things properly. Less than a week after my initial doctor visit. The ERCP test confirmed I had a pancreatic tumor blocking my bile duct, which was most likely neuroendocrine. I spent the next several days in the hospital recovering from severe pancreatitis caused by the ERCP. The day I left the hospital to go home, the biopsy results confirmed that it was a neuroendocrine tumor.

For several years prior to my diagnosis, I had abdominal pain and vague stomach upset on a regular basis. Although I sought out advice from my doctor, nothing definitive was found, and I was told I had irritable bowel syndrome. I am convinced that this was the tumor wreaking havoc and I wish there would have been some way to detect and diagnose this earlier on.

I had very few resources available to me. Doctors gave limited information and I had to find more on the internet. I would have liked more information on various treatment options early on. However, I have had wonderful, successful treatment (cap/tem chemo, Whipple & liver resection treatment, more chemo and monthly octreotide injections) in retrospect. I wish I would have known about all the tools in the toolbox earlier on in the process. I also think it is important for patients to know all their options for treatment before

choosing the best option. I am fortunate to live in Milwaukee and have access to the physicians at Froedtert Hospital, who really know their stuff. I realize that not everyone is that fortunate.

With all this being said, there is always hope and there are always alternatives. Take your time, seek a NET expert's opinion, find a health care team you feel comfortable with, and choose a treatment plan that helps you achieve YOUR goals.