

## Testimony for HB 345

I have been to the Ohio House of Representatives twice before today, both times to witness a proclamation declaring either November as Pancreatic Cancer Awareness Month or a specified date in November recognizing World Pancreatic Cancer Day. Both times I was brought to floor by Representative LaTourette in honor of her father Congressman Steve LaTourette. That is the story of pancreatic cancer. Someone must die in order to bring attention to the disease and yet, it is the deadliest major cancer and has the lowest five-year survival rate of only 9%, of the top 5 deadliest cancers.

One of the chemotherapy drugs I took, Gemcitabine, was approved by the FDA in 1997. In 2005 the drug Erlotinib, "was found to increase survival rate modestly" so it was approved by the FDA to be used in conjunction with Gemcitabine. In 2013, two new therapies were introduced; Folfirinox (a combination of 4 drugs), and nab-paclitaxel a.k.a. Abraxine were approved by FDA. These were found to only increase survival by "a few months". Prior to this, it had been over thirty years for any breakthroughs in fighting this disease. Most of the drugs found were already being used to fight other cancers.

I bring this timeline up because in February, 2013 is when I was diagnosed with stage 2B pancreatic cancer. I underwent 3 rounds of chemotherapy, a combination of Gemcitabine and Abraxine with a heavy dose of steroids and anti-nausea medicines. Unknown to me was Abraxine had JUST been approved by the FDA. I then had radiation therapy with an oral chemo called Xeloda for 5 weeks. All of this allowed me to have what is known as the Whipple procedure (surgery) in August, 2013.

When I was diagnosed, the survival rate for the first year was about 25% and the survival rate for 5 years was 6%. Five years later I am still here and the survival rate for 5 years is now 9%. I go for CT Scans every six months now. I have seen people with, as we say in the cancer world, "NED", No Evidence of Disease, for 10, 11 years, then bingo, it rears its ugly head in the liver or a lung. Some people are taking Xeloda for the rest of their lives. Xeloda, I found, is not covered like IV chemo under major medical, even though it is a chemotherapy drug, but as a prescription that costs well over a \$1000 for a 30 day supply in 2013. I can't imagine what it costs now. You don't think the makers of Xeloda are making a huge fortune? Just like Tamoxifen for breast cancer survivors. Most survivors of breast cancer are put on an oral chemo of Tamoxifen for up to 5 years after treatment and surgery. This is a daily treatment! I don't know what the cost is for that drug.

Speaking of breast cancer... I was diagnosed with stage 1 breast cancer in 1980. It was the year Susan Komen died of breast cancer. Her sister Nancy Brinker made a promise to her sister on her death bed she would fight to find a cure for her disease. Here we are 38 years later. No cure. Yes, we have over a 90% survival rate after 5 years. Breast cancer is THE most heavily funded disease in the country, probably in the world. Billions upon Billions of dollars have been poured into "research". Still no cure! Why? Is it the makers of all these drugs who would lose billions of dollars if a "cure" was found? I think so! Plus, look at everyone who makes money off the Pink Ribbon! It has become more commercialized than Christmas. If you find a cure for breast cancer, what happens to the economy? For all the companies who slap a pink ribbon on something. Where people actually believe "oh if I buy this money will go to breast cancer". I have asked some of these companies where the money goes? A portion of

the proceeds will go to breast cancer research. Really which organization? They cannot tell me because it doesn't happen, or maybe a portion so small I could write the check myself for the same amount.

Obviously, the way we do things today is not working. I think this bill will turn the industry on its collective heels. All we need to do is find one CURE for one disease and let ball roll from there.

When Representative Butler told me and a friend of mine about this bill, we thought it was an amazing idea. After reading about it more in depth, I think it is exactly what we need. None of us get paid for trying at our job, we get paid for doing our job. This is the same thing. Let's reward and incentivize a job completed, not attempted.

Thank you.

Catherine Schwandt