



HOUSE HEALTH COMMITTEE

Chairman Scott Lipps

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Members of the House Health Committee

Tuesday, March 8, 2022

11:00 a.m., Ohio State House, Room 121

STRONG SUPPORT OF HOUSE BILL 537 – CHOLANGIOCARCINOMA AWARENESS DAY

My name is Melinda Bachini, and I am a 12-year survivor of cholangiocarcinoma – bile duct cancer. I'm grateful for the opportunity to offer my proponent testimony for House Bill 537, which recognizes February 12th as Cholangiocarcinoma Awareness Day. The official recognition of this day is a beacon of hope for tens of thousands of people with bile duct cancer. Its passage tells them that they matter, and that the cancer impacting their lives, and the lives of their families, is as noteworthy as other cancers that have received more mainstream exposure, such as breast cancer and colon cancer.

Unlike those diseases, bile duct cancer does not have preventative, early detection procedures such as mammogram or colonoscopy. Bile duct cancer is often misdiagnosed or not detected until it has advanced to Stage 4, also referred to as **metastatic cancer**, which often means the cancer has spread from its origin to distant parts of the body. This is likely due to the symptoms of the disease mimicking other medical conditions, such as itchy skin, fatigue, weight loss without trying, night sweats, yellowing of the skin, and abdominal pain on the right side, just below the ribs.

It is not fully understood what causes cholangiocarcinoma, other than consumption of raw or under-cooked fish that have parasites. Once eaten, the liver flukes grow to adulthood inside the human biliary duct system. The irritation and scarring caused by liver fluke infection can lead to bile duct cancer that arise from the epithelial cells of intrahepatic and extrahepatic bile ducts. Generally, a person who is diagnosed with bile duct cancer has a very poor prognosis. Many studies report a dismal median survival of approximately six months.

That is why raising awareness about the deadly disease is so important. Awareness helps families not feel so isolated and strengthens efforts made to advocate for more research. With more research comes more knowledge that is desperately needed by the public – as well as healthcare providers – so people may be diagnosed earlier and given life-saving treatment. When states like Ohio support cholangiocarcinoma awareness, money can be raised for research to develop treatments that may enhance and prolong the lives of people with bile duct cancer. People like me.

MY CHOLANGIOCARCINOMA STORY

In 2009, at age 41, I was diagnosed with cholangiocarcinoma. I had very vague symptoms and I thought my job as a paramedic explained all complaints – an irritable stomach from eating at odd times, fatigue from working 24-hour shifts, right shoulder pain from carrying medical equipment. I was surprised to find out my symptoms were the result of a grapefruit-sized tumor in my liver. I was able to have surgery, which is the only option for a potential cure. I had two-thirds of my liver removed.

Unfortunately, three months later cancer returned to my lungs. I was now at Stage 4 – a terminal cancer patient. I knew if I wanted to beat this disease, I was going to have to find something new for treatment because the standard-of-care treatment was not curative. I wanted to join a clinical trial, but my health insurance would not cover the standard of care costs that went into participating in a clinical trial. In order to not put my family in financial distress, I chose to forgo the clinical trial and settle on the standard-of-care palliative chemotherapy treatment.



Two years into my diagnosis, I had received three different chemotherapy regimens with no success in controlling the cancer and a lot of toxicity. It was at that point I made the difficult decision to stop treatment and choose the quality of life over the quantity.

Miraculously, a few weeks after that decision, I found a clinical trial at NIH/NCI that involves the immune system. The trial was federally funded and involved surgery and adoptive cell therapy. I enrolled in the trial in March of 2012. Before the trial, I had so many tumors in my lungs that I couldn't walk without coughing. But after receiving my first t-cell infusion, I started feeling so much better. Incredibly, I was the first person in the trial to have a positive response. It was an incredible improvement for me, as after the first initial infusion of the cells, there is no further treatment needed. You do have to have surgery to harvest the TIL (tumor-infiltrating lymphocytes) and spend 3-4 weeks in the hospital to receive this treatment. I have had two treatments of adoptive cell therapy using TIL eighteen months apart, a total of five surgeries, and a follow-up of another immunotherapy drug.

But I can say that for more than 10 years, it has been my immune system fighting my cancer and it has now been more than five years since I have had any treatment whatsoever. We monitor for recurrence closely. I very much credit my survival to the grace of God and clinical research.

CONCLUSION

A few years ago, I was asked to go to the state capitol in Montana with a group of patients to tell my story and why it was so important to have a law to mandate that insurance companies cover the standard-of-care costs for cancer patients in clinical trials. The law was passed, and that was my first taste of patient advocacy.

From that experience, I became involved with the Cholangiocarcinoma Foundation as a volunteer. In 2017, I served part-time for the Foundation as an advocacy coordinator and two years later became the director of advocacy. What I've learned from sharing my story is that it CAN make a difference. I'm hoping my story makes a difference today and House Bill 537 passes for the sake of patients and caregivers in Ohio and throughout the United States. They all deserve your support.

Mr. Chairman, I am grateful for your time and the time of the House Health Committee for considering my testimony. I truly believe what you decide today can be a positive step forward for the much-needed awareness of cholangiocarcinoma.

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