



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

Thank you for the opportunity to provide proponent testimony in favor of House Bill 537, sponsored by Rep. Cindy Abrams, that recognizes February 12th as Cholangiocarcinoma Awareness Day. My name is Stacie Lindsey, and I am the Founder and CEO of the Cholangiocarcinoma Foundation, a 501(c)(3) nonprofit established in 2006. My testimony is respectfully offered on behalf of tens of thousands of members of the Foundation community, who are patients, caregivers, volunteers, research advocates, scientists, clinicians, industry partners, and providers.

The Foundation is part of a global alliance and partners with institutions in the United Kingdom, Thailand, Italy, Denmark, Japan, and other countries. We are devoted to patients and work tirelessly to find a cure for cholangiocarcinoma - bile duct cancer. We support basic and translational research and raise awareness and funding through advocacy, education, collaboration, and research.

OVERVIEW OF CHOLANGIOCARCINOMA

Cholangiocarcinoma, pronounced (koh-LAN-jee-oh-KAR-sih-NOH-muh), is a deadly bile duct cancer of the liver with a poor prognosis. With approximately 10,000 new cases of cholangiocarcinoma being diagnosed in the United States each year, bile duct cancer is the second most common primary liver cancer in the world. It is most often diagnosed at advanced stages when treatment is minimally effective, emphasizing the urgent need for novel therapies.

I understand this disease hits close to home in Ohio with your colleague, Lt. Stephen Wilger, currently receiving treatment. The Foundation has many volunteers from Ohio who support patients like Wilger, and who actively campaign to raise awareness about the disease. Unfortunately, you may not see them today as most of them are patients themselves. One in particular, (Lisa Craine) is having life-saving surgery as you read this testimony. I understand the toll bile duct cancer takes and the lives it impacts personally. I lost my 38-year-old brother, Mark Clements, to cholangiocarcinoma 16 years ago.

Mark and his wife, Marianne, were expecting their fourth child when they told us that he had been diagnosed with inoperable, incurable cancer. Stunned silence was immediately followed by confused tears.

When my husband and I got home that night, I immediately got on the computer and began what would become 15 months of intense research, networking, and soul-searching. Our family made a plan. Mark would look after his well-being; Marianne would take care of their newborn son, Lucas, and their other three children: Patrick, Chase, and Tessa. My mother, father, two sisters, and I would divide and conquer everything else.

Those first weeks and months of research were heart-wrenching as I realized there wasn't much information to be found. Some of the information was buried in PubMed, but I realized if I wanted to understand what was there, I would have to learn a new language, so I learned it.

Bit by bit, information was cobbled together from the dozens and dozens of conversations I had with physicians across the country willing to hear our story and review Mark's medical records. Pieces of



information and additional research from other patients were assessed and integrated where applicable. False hope and miracle cures abounded, but we were willing to consider everything, without restriction.

We worked long hours trying to provide hope for Mark, his family, and ourselves. In the end, my family did not receive what it had hoped and worked for, but we did receive comfort in answer to prayer, clear direction from above, and abundant love from the many patients and friends we had connected within the process.

As heart-wrenching as this journey was for us, we were determined that no one else should have to invest the time and effort we did to gather information and surround themselves with an empathetic community. Somehow, we would find a way to endow others with hope and support. Out of this desire came the Cholangiocarcinoma Foundation.

CONCLUSION

Every hour that has gone into cholangiocarcinoma awareness has been volunteered. However, the efforts made need legislation like House Bill 537 to emphasize its importance with urgency because the incidence of cholangiocarcinoma is growing at an alarming rate. A recent study ([JAMA Network Open](#)) estimates that by 2040, liver and bile duct cancer will be the third deadliest cancer in the United States.

To amplify advocacy and promote education about the disease, I urge the Ohio House Health Committee to join in the vision of the Foundation that a cure will be found for cholangiocarcinoma. In the meantime, the bill passage will stand as a symbol of support for patients and caregivers not only in Ohio but around the country.

Mr. Chairman, thank you for allowing me to provide my written statement. I would be happy to answer any questions you have.

Testimony submitted by:

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