

Lisa Craine
Patient Advocate, Research Advocate and Mentor

Craine's Cholangiocarcinoma Crew
Founder, Research Advocate and Patient Mentor
Cholangiocarcinoma Foundation
Research Advocate and Patient Mentor

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Lisa was diagnosed with Stage IV Cholangiocarcinoma in 2010 and given six months to live. Lisa secured a second opinion at The Cleveland Clinic Foundation and was given hope from Dr. John Fung, Dr. Kevin Stephan and Dr. Bassam Estfan. Lisa's Medical journey has included five recurrences with eight tumors. Her treatments have included four different chemotherapy regimens, two liver resections and SBRT multiple times.

The decision to educate and arm herself with the tools and medical team to establish a successful and aggressive treatment protocol came early. Navigating a rare cancer made Lisa realize the difficulty of doing this while not feeling 100%. Another observation was the lack of awareness and research for Cholangiocarcinoma. Lisa wanted to make a difference and Craine's Cholangiocarcinoma Crew was established in 2012. Craine's Crew is a 501c3 fund granting 100% of the money raised to Cholangiocarcinoma Research. The mission is "Providing hope to cholangiocarcinoma patients by raising and investing in breakthrough research to prevent and cure cholangiocarcinoma, and providing support as they navigate their journey through mentoring, advocacy, love and prayer."

Lisa explains that all the treatments, recurrences, complications, and long term side effects have molded her into a good Mentor because she can understand the physical and emotional suffering of patients. Lisa has mentored over 1200 patients, helping them navigate second opinions and treatment plans. You can find Lisa spending hours a day on calls from patients all over the world, sitting with patients during chemo, researching treatments and clinical trials for patients, spreading awareness and constantly learning. She has a true love of people.

Sharing her story is her way of giving hope to others who have been given a poor prognosis. Her favorite advice is to never let anyone take your hope away. Lisa and her family open their home to cancer patients monthly for a gathering to share a meal and their stories. Lisa has said she never wants anyone to feel alone while dealing with cancer.

Lisa has completed Advocacy training with The Research Advocacy Network, The Global Liver Institute, AAADV, ASCO, AACR and The Cholangiocarcinoma Foundation. Her mentoring training was completed through The Scott Hamilton Cares Initiative. She is a board member of The Voice of the Patient Advocacy Council for the Cleveland Clinic Taussig Cancer Center, The Cleveland Clinic Digestive Disease Institute, The Mike Shane Memorial Foundation, Summa Health Cooper Cancer Center and Genomic Focus. She is involved with the Cleveland Clinic Survivorship program as well as an active volunteer. Lisa is a Peer Reviewer for the US Department of Defense Congressionally Directed Medical Research Program and is serving a 2 year term with the FDA Patient Engagement Collaborative.

Lisa has advocated for Liver cancer on Capital Hill with The LIVER Act of 2019, H.R. 3016.

Lisa is a George H.W. Bush Points of Light Award Recipient. She has also received recognition from the White House for her volunteer work in cancer advocacy. Lisa and her husband, David were the 2020 Stewart's Caring Place Spirit Award recipients for their service to local cancer patients and the Cholangiocarcinoma Foundation 2021 Mark. R. Clements award recipient.

Lisa has a passion to spread awareness and hope, move research forward and to help patients get the best possible care available. She continues to advance her advocacy knowledge by attending conferences and training programs. She is an active Research Advocate, Patient Advocate, Mentor and volunteer for Cholangiocarcinoma Foundation.

Lisa is wife to David and Mother to Jacob and Noah. She is thankful for the dedication of doctors, researchers, industry and advocacy organizations in the pursuit of a cure.

Organization Affiliations

The Cholangiocarcinoma Foundation

Research Advocate

Patient Advocate

Mentor

CARE Team(Cholangiocarcinoma Advocacy Research and Education)

Education and Awareness to doctors/hospitals/medical communities

U.S. Department of Defense (DOD) Congressionally Directed Medical Research Program (CDMRP)

Peer Reviewer

U.S. Food and Drug Administration - Clinical Trials Transformation Initiative

Patient Engagement Collaborative Representative

ASCO

Member

Patient Advocate

The Research Advocacy Network

Focus on Research Scholar Program graduate

SWOG

GI Research Advocate

CPRIT Cancer Prevention and Research Institute of Texas

Advocate Reviewer

The Global Liver Institute

Advanced Advocacy Academy graduate

Capital Hill Advocate for The LIVER Act of 2019, H.R. 3016

AACR(American Association of Cancer Research)

Scientist - Survivor Program graduate and Poster presenter

AAADV

Accelerating Anticancer Agent Development and Validation Training graduate

The Mike Shane Memorial Foundation

Board of Directors

Craine's Cholangiocarcinoma Crew

501(c)3 non-profit

Co-Founder

Research Advocate and patient mentor

Rare Disease Advisor

Cholangiocarcinoma writer/contributor

Cleveland Clinic Foundation Taussig Cancer Center

Voice of the Patient Advocacy Council Board Member

Scott Hamilton CARES Foundation

4th Angel Patient Mentor

GRASP CANCER

GUIDING RESEARCHERS & ADVOCATES TO SCIENTIFIC PARTNERSHIPS

INCYTE

Advocacy Ambassador

Servier

Advocacy Ambassador