

CONQUER

the patient voice™



Interview with the **Advocates**™

EMPOWERMENT THROUGH KNOWLEDGE

THE CHOLANGIOCARCINOMA FOUNDATION:

An Invaluable Resource to Patients and Professionals



Stacie C. Lindsey
President & Founder
Cholangiocarcinoma Foundation



Melinda Bachini
Advocacy Coordinator
Cholangiocarcinoma Foundation



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CONQUER™

the patient voice™

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Each Issue of CONQUER™ Contains
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to patients who are battling cancer as well as their

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AONN 10 YEAR ANNIVERSARY
Academy of Oncology
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CONQUER™ is the official patient magazine of the
Academy of Oncology Nurse & Patient Navigators

The Cholangiocarcinoma Foundation: An Invaluable Resource to Patients and Professionals

An Interview with Stacie Lindsey, President, and Melinda Bachini, Advocacy Coordinator, Cholangiocarcinoma Foundation



Stacie Lindsey



Melinda Bachini

Cholangiocarcinoma (CCA) is cancer of the bile duct, a thin tube that connects the liver and gallbladder to the small intestine. The major function of the bile duct is to move bile from the liver and gallbladder to the small intestine, where it helps digest the fats in food. About 8,000 people in the United States are diagnosed with CCA each year, but the actual number may be higher, because these cancers can be hard to diagnose and may be misclassified as another type of cancer.

Treatments for CCA are available, and research into new therapies is ongoing. The treatment of CCA depends on the size and location of the tumor, whether the cancer has spread, and the person's overall health. In many cases, a team of doctors will work with the patient to determine the best treatment plan.

Thus, it is important that patients with CCA, and the healthcare teams that treat them, fully understand the disease and its treatment options, are aware of available clinical studies, and receive the

support they need to navigate this disease. The Cholangiocarcinoma Foundation has been providing education and support for patients with CCA and healthcare providers alike since 2006, with the goal of being a resource for all stakeholders involved in this type of cancer, and ultimately to find a cure.

Recently, *CONQUER: the patient voice* met with Stacie Lindsey, President and Founder of Cholangiocarcinoma Foundation, and Melinda Bachini, Cholangiocarcinoma Foundation Advocacy Coordinator, to talk about how the foundation came into being and the many activities the foundation is involved in to improve the lives of patients with CCA.

CONQUER: Stacie, can you provide the history of the Cholangiocarcinoma Foundation, how it was formed, and the goals you've set for the organization?

Stacie: In the beginning, the foundation was not a foundation, it was just a discussion board. My older brother Mark was diagnosed with CCA in the fall of 2005. I went online, searched Google, and found a few scientific articles; however, I noticed the researchers' names at the bottom of those articles and began to reach out and contact these people. We got together as a family and decided that there wasn't enough information on CCA for us to help Mark; we needed to contact other families who were struggling with CCA, gather information, and find out where the best places were to receive treatment. This is how it started.

In 2005, we set up a discussion board, and within the first week, 18 people were participating, and they were all young. We started having monthly phone calls to share the different protocols and institutional direction we were all getting. We were gathering the information and organizing it, and as time went on, more people were consistently coming on the discussion board from all over the world. At that time, if you were Googling "cholangiocarcinoma," you were

going to find a few scientific articles, and us.

Three months before Mark passed away, we were driving home from chemo and he said, "Stacie, what are you going to do when I pass away? What's going to happen to all the information we've gathered, to all these relationships you developed? We need to start a foundation, because there are going to be people who don't have families like ours, who don't have the help they need. How will they make these connections, and how will they get this information? We have to do something to help them."

The next week, we went into Mark's law firm and they helped us set up the foundation. When they asked us, "What do you want to call the foundation," we had not even thought about it. I asked Mark, "Should we name it after you?" He said, "No. I'm going to pass away. This foundation isn't for me; it is for everyone that comes after me. We need to name it so people can find it," so we named it "Cholangiocarcinoma Foundation." It was born out of love for people my brother would never know, but he felt strongly that there would be a great need.

CONQUER: How would you define the mission of the Cholangiocarcinoma Foundation?

Stacie: The Cholangiocarcinoma Foundation was founded in 2006, and its mission is to find a cure and improve the quality of life for those affected by CCA.

CONQUER: Melinda, how did you become the Advocacy Director of the foundation?

Melinda: I was diagnosed with CCA in 2009. I Googled "cholangiocarcinoma," and happened to stumble upon the Cholangiocarcinoma Foundation. I remember getting on the discussion board right away, reading and gathering information.

I was a paramedic before my diagnosis, so I had some medical knowledge. I knew that being diagnosed with this disease wasn't good. I reached out and started posting on the discussion board, I began volunteering with the foundation, and started interacting with patients and caregivers on the discussion board, helping them to navigate the disease and providing people whatever information I could.

Two years ago, I joined the foundation as the full-time Advocacy Coordinator. My role is to talk to patients and caregivers and help them navigate the disease. We provide the specialist maps so that they can get second opinions that are critical in this disease. I help them look for clinical trials. The biggest questions when I get contacted are, "Where do we go? Who do we see? Who are the experts in this disease?" and "How do I find a clinical trial?"

CONQUER: Let's review the Cholangiocarcinoma Foundation website (<https://cholangiocarcinoma.org>). The foundation's website is an incredible tool for patients. Can you discuss the elements of the site, and how you develop content?

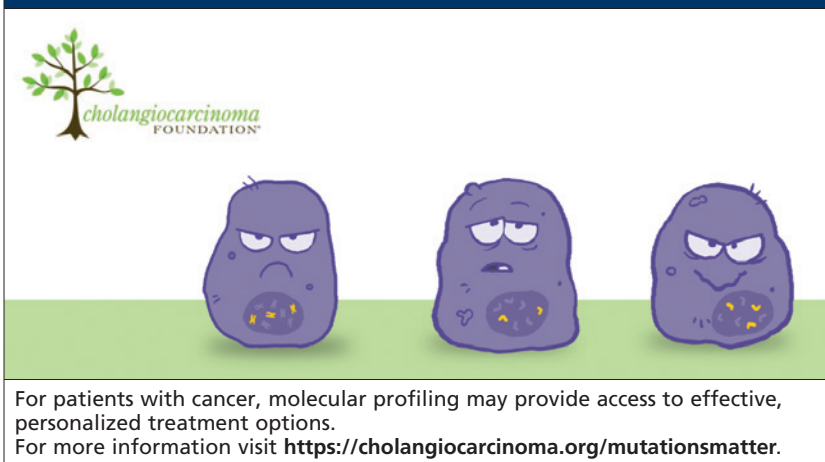
Stacie: The content for the website comes from our Science and Medical Advisory Board, as well as from the publications we

read and the conferences we attend. We're taking in all this information and trying to make it understandable for patients. We try to give all patients who are looking for help the answers for any questions they may have. The website also provides information for healthcare professionals. Often, scientists, doctors, and nursing professionals are looking for information to help their patients. We provide them with current information, including professional, up-to-date, scientific, peer-reviewed publications.

For example, "Mutations Matter" is a section of our website in which we help educate patients and community oncology providers on genomic profiling. We wanted to help community providers understand why it is so important that their patients with CCA undergo molecular biomarker testing.

Mutations Matter has 3 prongs. The first is to educate patients with CCA about the importance of genomic testing. Second is to educate community oncologists who see these patients. The third prong is a version that covers all cancers in which genomic testing is important and for which a genomic mutation in the tumor is a criterion to be eligible to join a clinical trial. We did 3 videos about molecular mutations, each covering one of these prongs, and the version that covers all cancers was sent to all the nonprofit organizations we had contact with. We told them that this was a gift, and that we wanted them to share it widely within their

FIGURE. Mutations Matter



communities, so that it would help educate their patients (see **Figure**).

Melinda: Our website also includes a section called “CholangioConnect,” which stemmed from a caregiver who lost his wife to CCA. When he reached out to me in the beginning, he had tried desperately to make connections with people and find information. When his wife passed away, he was a single father of a young boy, and he felt strongly that he needed to connect with someone who was in the same situation. He proposed the CholangioConnect mentorship program, which matches mentors to mentees when they are requested. It’s not about giving medical advice, it’s about providing support and the network that a patient may need, especially when being first diagnosed. The mentors help facilitate direction and are there to listen. This has been very successful for patients and for their caregivers.

CONQUER: Please tell us

about the Cholangiocarcinoma Foundation Annual Conference, which draws hundreds of health-care professionals as well as patients and their caregivers.

Stacie: We are planning the annual conference from the minute the previous conference concludes. We are diligently monitoring the most recent news from relevant clinical trials, published articles, and meetings with industry partners and other conferences. We’re watching for the “next big thing” for our community, in terms of what clinicians and patients need to know. As far as the speakers, we take information, suggestions, and ideas from the chairs, our Science and Medical Advisory Board, and other seasoned professionals.

For the 2020 Annual Conference, Rachna Shroff, MD, is a co-chair, and she was an obvious choice. She is the principal investigator in an important ongoing clinical trial for patients with CCA, among several other things. The other co-chair for 2020 is Jesús Banales, MD, from

Spain, who is running a couple of impressive scientific groups in Europe—the Europeans are doing a lot of CCA research right now. The US researchers and the European researchers have not been very well-connected, yet this is a global disease, so one of our goals is to bring these researchers together at our annual conference. We want this meeting to be global in its reach and its impact. I want the meetings to be innovative, and I want the chairs to feel that it is their meeting. We work closely with them, but we give them creative license to incorporate fresh ideas into the conference—that is part of the magic of the meeting.

Melinda: The first year, about 40 patients and caregivers showed up, and the next year we had more than 100. Last year, we had more than 200 patients and caregivers at the conference. They absolutely love it. I always describe it to people as a kind of a family reunion with people you’ve never met. It’s an indescribable feeling for patients and caregivers to be able to connect with other people who are in the same situation. Every year at the conference, we do a program called EPIC, which stands for Engaging Patients in Cholangiocarcinoma. In the EPIC meeting, patients sit at the table with researchers, physicians, and industry representatives, and they discuss topics such as understanding clinical trials or their molecular biomarker testing results. Including patients in the foundation’s annual conference is a highlight of the meeting.

Stacie: About 3 years ago, one of the researchers from Asia approached me at the conference and said, "I've never met a patient with CCA before." He put his hand over his heart and said, "You've put CCA in my heart." This is what the conference is all about—creating the opportunity for all the stakeholders to be in one room, learning together and making this personal. These interactions add a level of depth and meaning to everyone's work.

For patients who attend the meeting, the truly hopeful and motivating thing is watching and listening to expert scientists and clinicians from around the world interact. These are professionals whom the patients have only heard about, and who are at the forefront of CCA research. It gives patients hope to watch them make a presentation, and then watch experts from distinguished institutions all across the globe asking questions, sharing ideas, and collaborating on future projects. One of the core values of the Cholangiocarcinoma Foundation is collaboration, so the last couple of minutes of every presentation is about collaborative opportunities regarding what was just presented.

CONQUER: The Cholangiocarcinoma Foundation also funds research and clinical investigations. According to the foundation's website, almost \$2 million in research and educational grants has been awarded to

date. Can you describe these activities?

Stacie: We fund Research Fellowship Awards for young investigators, and these awards are for clinical and basic science investigators. We funded 4 basic science fellowships and 3 clinical fellowships this year. We provided \$365,000 in funding this year, and we want to increase that every year. We need the brightest, most innovative talent in this field, and we need to keep them working on new, innovative treatments for CCA. For example, we fund the Mayo Clinic Biorepository, which houses all the information for our International Cholangiocarcinoma Research Network (ICRN). All CCA information that's housed at the Mayo Clinic Biorepository can be accessed by any of the institutions or clinicians who are involved in the ICRN.

CONQUER: You also fund educational activities?

Stacie: Yes, we fund many patient programs. We host regional symposia; in fact, we have just completed a symposium at the Cleveland Clinic. We've hosted them across the country, including Washington University, the University of California at San Francisco, and the University of Chicago. The regional symposia are mini-conferences in which local community clinicians can get updates on what's going on in surgery, clinical trials, and radiation therapy from cancer experts. There is

also time for patients to ask questions, and we try to facilitate a gathering for the patients with CCA within that geographic area to meet together.

Melinda: We want every person diagnosed with CCA to have the correct information about this cancer, to understand the treatment options, and to have as much support as they need. If they reach out to the foundation, we can help them every step of the way. It is very important for people to know that they are not alone. This made all the difference in the world to me when I was first diagnosed with CCA. If I could wave a magic wand, I would want every patient to connect with us as soon as possible.

CONQUER: Thank you both for your time today, and for all the great work that the Cholangiocarcinoma Foundation is doing. ♦

PATIENT RESOURCES

Cholangiocarcinoma Foundation
<https://cholangiocarcinoma.org>

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The Cholangiocarcinoma Specialist Map

<https://cholangiocarcinoma.org/misc2/specialist-map>

The 2020 Cholangiocarcinoma Annual Conference

April 1-3, 2020; Salt Lake City, Utah

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