The ChOLLECTIVE World Cholangiocarcinoma Awareness Month Transcript

Introductory Slate: The ChOLLECTIVE Logo, tagline underneath: "Uniting Stories, Inspiring

Hope, Empowering the Cholangiocarcinoma (CCA) Community"

Lower Thirds: Karla, Living with Cholangiocarcinoma

Karla: I found out I had cholangiocarcinoma when I went to the ER, and I was

diagnosed immediately. You just go into a fog. You just kind of

disconnect.

Lower Thirds: Kathy, Living with Cholangiocarcinoma

Kathy: I learned I had cholangiocarcinoma very unexpectedly. I had been feeling

terrific, but some strange blood work results led the doctor to refer me to get a CT scan. I was very much focused on processing what this diagnosis would mean, accepting the fact that I had a rare and very

aggressive cancer.

Slate: Cholangiocarcinoma (CCA) forms in the bile ducts and accounts for only

3% of all gastrointestinal cancers. (Source: Banales JM, et al. Nat Rev

Gastroenterol Hepatol. 2016; 12:261 280)

Slate: Most people with CCA do not have any symptoms until the disease

reaches an advanced stage, making it difficult to diagnose early on. (Source: Banales JM, et al. Nat Rev Gastroenterol Hepatol. 2016; 12:261

280)

Slate: Prioritizing Early Biomarker Testing

Kathy: Right from the get-go, my oncologist ordered biomarker testing. I didn't

know what it was, but he said ,"This is what we're going to do". If your doctor does not suggest it, go ahead and push for it. It's just provides

such important information.

Lower Thirds: Alie, Legacy CCA Caregiver

Alie: Biomarker testing being done early is so important. It is the number one

thing that I would recommend to anyone who has been faced with a cholangiocarcinoma diagnosis because, as we've learned in the last ten years, if you have a biomarker that is treatable, then you are opened up

to a whole world of different options.

Lower Thirds: Learn more about biomarker testing at TestMyCholangio.com

Lower Thirds: Katie, Legacy CCA Caregiver

Katie: My dad did have biomarker testing. He was diagnosed back in 2016, so it

was fairly a new concept. And we were lucky to be at a major cancer institute, and they did offer biomarker testing right away. But after working with many other patients and caregivers, I know that that's not always the

case.

Slate: With Knowledge Comes Hope

Kathy: Surround yourself with a knowledgeable and empathetic medical team.

That's so important. You want to seek a second, and maybe third or

fourth, opinion. Go for it.

Katie: When I work with other patients and caregivers, I point them to a lot of

different resources. Mainly, I point them to the Cholangiocarcinoma Foundation's website. They have the most up-to-date research, and they

have great resources for all of us.

Lower Third: cholangiocarcinoma.org [CCF Logo]

Karla: I've learned to be positive and to lean on my own joy, and also to remind

myself life is to be lived. Even with this diagnosis, I still keep moving forward, one foot in front of the other. And to remember that life is a journey. You can't stop. You have to keep pushing forward every day.

Closing Slate: [The ChOLLECTIVE logo] The ChOLLECTIVE is a storytelling initiative

that aims to bring to life the reality of living with cholangiocarcinoma by

highlighting unique journeys, perspectives and learnings of the

community.

Visit TestMyCholangio.com to access tools and resources to support

your cholangiocarcinoma journey.

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