

NFCM Video Transcript

Ángela:

Hi, my name is Ángela. I'm from Puerto Rico. This is my husband, Pedro. We met back in college, and we've been together ever since.

Pedro:

Back in 2020, my general overall health condition started to worsen. They found a very small cholangiocarcinoma inside my bowel ducts. We start treatment, and everything was looking good.

Slate: Cholangiocarcinoma (CCA) is a rare cancer that forms in bile ducts – thin tubes that connect the liver, gallbladder and small intestine. (Source: What is bile Duct Cancer? American Cancer Society <https://www.cancer.org/cancer/types/bile-duct-cancer/about/what-is-bile-duct-cancer.html>)

Slate: CCA is difficult to diagnose due to its non-specific symptoms and is often diagnosed late, when the prognosis is poor. (Source: Banales JM, et al. Nat Rev Gastroenterol Hepatol. 2016; 12:261-280. Uhlig J, et. Al. Ann Surg Oncol. 2019; 26: 1993 – 2000)

Ángela:

When it came back in 2022, it was the worst news that I received in my life, and having to tell our kids, it was even worse. And that's when I decided, okay, we need more information, we need to get more educated.

Slate: Early biomarker testing is key

Pedro:

When we received our second diagnosis in 2022, my local oncologist again ordered new biomarkers, and they spot right away, like five or six markers that were targetable. That changed completely the whole picture.

Ángela:

We felt hopeful. We felt like we had options. When we meet other patients with cholangiocarcinoma, the first thing we ask them, "Have you done biomarker testing?" because we know a difference that can make in the treatment plan.

Slate: Caregivers are VITAL in the CCA journey

Ángela:

As a caregiver for Pedro, I provide physical support, emotional support. When we go to appointments, the emotional load, or the emotional toll that he's going through,

sometimes it can be a little too much. So, it's my role to be present, to gather as much information as we can, and go back home and research.

Pedro:

She's my hero, and she's the hero of the whole family. She's the one that did the research. She's the one that educate herself and educate me when I was ready to give up.

Slate: Advice for the CCA community

Ángela:

Learning to ask for help, that's very hard, because you don't want to be a burden to others. But I've learned that people really do want to help, and just surrounding ourselves with people going through this experience.

Pedro:

That also makes the whole difference to know that you are not alone, that there are patients like you that are facing this condition.

Ángela: [TestMyCholangio and CCF logos appear at each bottom corner of screen]

Making resources available, being TestMyCholangio, or being the Cholangiocarcinoma Foundation, really plays a huge role.

Pedro:

With this kind of condition, things changes at a very fast pace, and you have to concentrate in what comes immediately next. What is the next step that you have to take in order to bring you to a better place from where you are right now.

Closing Slate: [TestMyCholangio Logo] Get tools and resources to support your cholangiocarcinoma journey at TestMyCholangio.com

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