



PBC Care Partner Story

Thomas, a resilient gentleman living with Multiple Sclerosis, has become a steady source of support for his wife, Catarina, who manages the challenges of Primary Biliary Cholangitis (PBC). Their daily lives reflect a deep commitment to one another and Thomas remains by her side, helping her navigate the physical and emotional toll of PBC, just as she supports him through his own condition.

Recognizing Symptoms:

Catarina's journey with PBC, an autoimmune disorder that causes the weakening and decay of the bile ducts in the liver, first began when she first developed severe itching and profound fatigue that quickly disrupted her daily life. The itching came on fast and intensified to the point that she often couldn't leave her bed or tolerate wearing fitted clothing. She couldn't stand to be hugged and this was the first time she and Thomas couldn't touch each other. Catarina talked about how she felt contagious, like there were bugs under her skin and she had chicken pox at the same time. Thomas insisted she make a doctor's appointment. He knew she was not contagious and that no one else in the house had any symptoms.

Healthcare Experience:

When they decided to meet with a doctor to figure out what Catarina's condition was, they first went to a local primary care doctor. This was the first of many visits. Thomas was determined to join her for as many visits as his health would allow. The first practitioner listened to them both as they described how her symptoms were affecting them both. She could not stop scratching. It was causing them both to lose sleep and worry all the time. Her practitioner listened carefully to them and did a full "work up": blood tests, questions, and a full examination. Thomas and Catarina asked a ton of questions and were given a chance to talk about how it made them feel-worried, frustrated, and scared. They left and waited in the labs to return.

The itching was so intense that sleep was not an option. She quit hugging her children, as their body heat made her too hot. As her labs got worse, and her itching got more unbearable, Bradley, her family care provider, knew that they needed a specialist and fast. On the last visit, he made Catarina compare her eyes to Thomas's. Thomas's eyes were white and Catarinas were yellow! They had not even noticed that and saw each other every day. With only two hepatologists in Mississippi, and only one taking new patients, the wait was too long. They need to act fast. Bradley got them an appointment with a local gastrointestinal doctor an hour away. Surely a specialist could help!

They arrived at the specialist, full of hope and ready for answers but felt disappointed when the doctor talked at them and not to them. The doctor never asked Thomas about his observations about Catarina. He only asked her about her diet and her digestion and took blood samples. When the bloodwork came back, he told her she had PBC, but did not explain it in any detail. He gave her a pill and sent her home, but the itching continued and actually worsened. Lying in the bed with a fan on her was the only way she was not miserable. Thomas insisted they go back and talk to the doctor again.

At this visit, it was clear the doctor was tired of hearing about the itching and recommended a dermatologist, who then referred her to another specialist. Thomas initially took multiple visits as a good sign but after many referrals, he had enough. Although the specialists didn't acknowledge him, he demanded that they see a liver specialist. During this time, Catarina's itching was still unbearable. She was actually getting worse and they were both losing hope.

They found a hepatologist that specializes in PBC in Colorado, a three day drive away, that was willing to see them. Even though it was expensive and a long way, they needed to have answers and were willing to do whatever they needed. For the first time in this journey, and in their marriage, Thomas had to let his wife go alone to a doctor in another state. This doctor changed their lives! Catarina called Thomas after the appointment crying happy tears. Like her primary care doctor, he listened to her, explored all of her symptoms, and told her they could treat them. He explained PBC in terms that she understood and could explain to her family. He also discussed treatment options and told her that there was more than one pill that was sometimes needed to help. Up until now, they assumed there was only one treatment and that they didn't have any other options. If she did not feel better, there were always more options. Now Catarina only itches occasionally and they can hug again. They see the doctor yearly in Colorado and her local practitioner as they need.

Thomas is continuing to support Catarra unwaveringly, offering steady support as she fights through the pain. He recognized that her symptoms demanded constant care and continued presence. With quiet determination, Thomas committed himself to being there for her through every challenge PBC brought into their home.

Currently, Thomas and Catarra are now still caring for each other each day. Catarra still itches when she is stressed or overheated, but she now can work and has even started her own business. Thomas's wish is that they are both able to be as healthy as possible.

What would Thomas tell another PBC care partner:

1 Speak up!!!

1. Sometimes a care partner sees things the person affected does not
2. Sometimes doctors dismiss you. Dismiss them and find someone that does listen
3. Don't be afraid to have a conversation

2 Track YOUR symptoms as a care partner

1. How much sleep are you losing?
2. How much is their itching affecting your daily life?
3. Keep logs of the symptoms

What Thomas wishes:

- 1 That we had more primary care practitioners that knew the signs of PBC
- 2 That the care they receive in some parts of the country would be available everywhere
- 3 To help others learn to be advocates for themselves



PBC Patient Story: When the Itching Wouldn't Stop

Sometimes the body's first warning signs aren't easy to explain. For Catarra, it started with a relentless itching that no one could seem to have an answer for. After multiple doctor visits, one simple blood test uncovered the answer: primary biliary cholangitis (PBC). PBC is a rare autoimmune liver disease that slowly damages the bile ducts in the liver. The bile ducts normally carry bile, a digestive fluid, out of the liver. As these ducts become damaged, bile builds up in the liver and blood stream. This buildup can trigger intense itching, one of the most common and frustrating symptoms of PBC. Today, she's sharing her story in hopes that others don't stop searching until they are seen, heard, and answered.

Meet Catarra:

Catarra is a wife, mother, and an advocate who knows the importance of listening to her body. She was balancing life between family and work and then without warning, everything changed. It all began with an itch. Not an ordinary itch, but one that no amount of scratching could relieve. Before she had a name for what she was experiencing, she was simply trying to understand why an intense, persistent itch wouldn't go away. This would lead to a year long search for answers.

Symptoms:

"It wasn't just an occasional itch," Catarra recalls, "it kept me up at night. It changed my relationship with my husband. 'It changed my entire life.'" She made an appointment with her local healthcare provider and was feeling unsure and nervous. The itching was relentless, making it feel as though something was crawling beneath her skin. It reminded her of having chickenpox as a child. Her healthcare provider, Bradley, asked detailed questions about her overall health, not just her symptoms, including the persistent itching. He ordered a full panel of blood work, including liver function tests, after hearing his wife, a liver advocate, on a Zoom call with a hepatologist. Catarra was shocked that liver function tests were being ordered. "What does my liver have to do with this?" she wondered. "I don't drink. Why are you checking my liver?" When the test results came back it revealed that her liver enzymes were significantly elevated.

Over the next several weeks, despite changes to her diet, her liver enzymes continued to climb while the itching only became more intense. At her third visit, Bradley noticed something she hadn't: her eyes were beginning to turn yellow. She was developing jaundice. Concerned by her worsening condition, he referred her to the nearest gastroenterologist, nearly an hour from home. With only two hepatologists accepting patients in Mississippi and wait times approaching nine months, seeing a liver specialist wasn't a realistic option.

Experience with specialists:

A month later, Catarra met with the gastroenterologist, hoping for answers. Instead, she left feeling invisible. Throughout the appointment, the physician typed on his computer without looking up, asking only about her eating habits and rather than how she was feeling. Her husband noticed it too. Afterwards he urged Catarra to find a different doctor because he didn't believe her symptoms were being taken seriously. Before leaving the room, the physician briefly mentioned he thought she might have PBC but offered no explanation before walking away. Confused, Catarra went home and researched the disease herself. She learned that PBC is most commonly diagnosed in older white women. As a younger Black woman, she couldn't help but wonder whether she had been dismissed because she didn't fit the typical patient profile.

The gastroenterologist scheduled a liver biopsy, but even after the procedure, Catarra was left waiting for answers. She never received a phone call with her results and had to check her patient portal and follow up herself. When she finally returned to the office, she was prescribed the standard medication for PBC, but no one explained what the diagnosis meant, why her liver disease was causing the relentless itching, or what improvement should actually look like. The medication didn't ease her symptoms, and life at home became increasingly difficult. The warmth of a hug from her family made the itching worse and spent hours alone in her bedroom under a fan, desperate for a moment of relief.

When Catarra returned to her gastroenterologist, she was still itching despite taking the medication she was prescribed. By then, she was also experiencing overwhelming fatigue. Instead of looking deeper into her liver disease, he referred her to a dermatologist. Looking back, she learned this was not a typical step for someone with PBC. The dermatologist performed a painful skin biopsy but found nothing. Her itching continued to worsen, leaving her feeling hopeless. That's when she realized she had to advocate for herself.

Knowing she needed a hepatologist, Catarra made the difficult decision to travel to Colorado for specialized care, although it meant leaving her husband, Thomas, and taking on the cost of travel. She knew it was necessary. From the moment she met her hepatologist, she could tell things were different. He listened to her story, explained that her itching was caused by her liver disease, and developed a treatment plan focused on both her symptoms and her quality of life. He prescribed an additional medication for the itching, and while it wasn't a cure, it finally brought relief.

Today, Catarra still experiences occasional itching, especially when she's stressed or overheated, but it no longer controls her life. She measures success by being able to hug her children, spend time with her husband, attend church, go to work, and live without constant suffering. She even started her own business.

What did she learn from this?

Find a care team that cares!

From the primary care provider to the specialist, caring about what matters to you is the most important element in getting the whole person treated

- Make sure your provider takes the time to listen to what you are experiencing, not just what the labs are saying
- Find a healthcare provider that doesn't type the whole time-find someone that listens to you

Hug your loved ones

When you are hot and itching, you cannot hug your family. She has spent the past few years hugging my family and friends to death

Be your OWN advocate

- Bring someone that can also advocate for you to each appointment, if you can
- Listen to your body
- If you feel like someone does not care about you and your health, don't be afraid to go somewhere else
- Ask what can be done closest to home when you have to travel to a specialist

Describe your itch!!!!

- Don't be afraid to bring it up. It made her nervous to bring up the itch. When you itch, it makes you feel like you have a contagious disease. As it turns out, most itching is NOT due to a contagious disease
- Compare it to what you know; like chicken pox
- Don't back down with what you feel and how it affects you
- Describe what it is doing to your life - itching too much to sleep
- When you describe your symptoms, it helps to also tell your provider a number or a value. For example, "I lost 10 hours of sleep over the last week due to itching"

What Catarra wishes:

- That she didn't have to travel so far for a PBC specialist
- That more family practitioners knew how to identify and treat PBC
- More of her care could be done "at home"