Actor portrayal

Your voice matters.

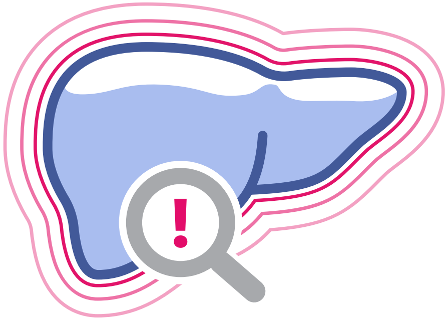
We understand that everyone has a unique PBC journey, and encourage you to share that experience with your PBC healthcare team to make sure your individual needs are being met and your voice is being heard.

Powered with Patients.

Real PBC talk

What is primary biliary cholangitis (PBC)?

PBC is a disease in which the body's immune system attacks healthy cells in your liver by mistake.



PBC CAN CAUSE...

Liver inflammation and buildup of toxins, which can lead to **liver damage** and **reduced liver function**.

KEY FACTORS FOR DIAGNOSING PBC

When diagnosing PBC, your doctor may perform blood tests to check for specific markers like elevated alkaline phosphatase (ALP) levels, which can indicate liver damage, or the presence of antinuclear antibodies (ANA).

Additionally, ongoing symptoms like those on the next page can be signs of PBC.

> *"PBC isn't my fault—this is just the way my liver works."*
>
> —*Kathy,*
> *living with PBC*

The impact of PBC

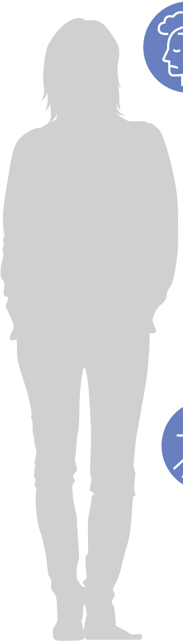
Living with PBC means dealing with ongoing symptoms, possibly including:

CHRONIC FATIGUE

Up to 78% of people living with PBC experience chronic fatigue.

PERSISTENT ITCHING

Up to 70% of people deal with intense itching, leading to loss of sleep and difficulty participating in daily activities.



BRAIN FOG

Memory issues and difficulty concentrating that can interfere with daily life for those with PBC.

BODY PAIN

Joint pain and stiffness occur in up to **35%** of those with PBC.

Your healthcare team will monitor your liver function tests and symptoms closely to look for signs of progression. **However, you may still experience symptoms even if your liver function tests show improvement.**

Your unique PBC journey

You may be at a higher risk of PBC disease progression if you:

Had very high ALP (alkaline phosphatase) levels at diagnosis.

Were diagnosed with PBC before the age of 45.

Experienced little to no improvement, based on liver lab tests, after 12 months of prescription treatment.

Your treatment response

Response to treatment for PBC can be different for everyone.

Treatment for people living with PBC is meant to help improve indicators of worsening disease, such as ALP and serum bilirubin, both of which can be measured with a blood test.

Although prescription treatment helps many people, **up to half** of those diagnosed with PBC do not respond well enough to the medicine they were first prescribed. This is called an **inadequate or incomplete response**.

Factors such as age and high ALP levels can increase your risk of an inadequate response to treatment.

While your treatment plan may not be reassessed until after 12 months, you may need to see your healthcare team more often to properly monitor your symptoms and your treatment response.

An inadequate response to treatment may lead to disease progression and poor outcomes.

You may worry about your risk of worsening disease. Your healthcare team is here for you. Regular and meaningful conversations about your needs, worries, and aspirations lay the foundation for a more effective and individualized care approach and may lead to better outcomes.

Starting the conversation

With your PBC healthcare team

Since disease progression, symptoms, and response to treatment vary greatly, it is important to explain your unique PBC experience to your doctor and other members of your PBC healthcare team, and work with them to create a treatment plan that meets your individual needs.

Talk to your PBC healthcare team about your condition:

> “What risk factors do I have that might impact my disease progression or my treatment plan?”

> “I’ve noticed some changes in my symptoms lately. Can we go over my current treatment plan and see if any adjustments need to be made?”

> “Can we schedule appointments more often so that we can monitor my symptoms and put my mind at ease regarding my liver lab tests?”

Starting the conversation

With your loved ones

You deserve patience, grace, and understanding—both from yourself and from your loved ones. Sharing your experience with your support system can help ensure you get the care and empathy you deserve, so your PBC journey doesn't feel like a solo venture.

Start the dialogue between you and your loved ones:

> "Due to my constant itching, I'm finding it more difficult to accomplish day-to-day tasks. If you could ________ that would be a huge help."

> "Fatigue due to PBC is more than just being tired. My fatigue makes me feel ____________."

With the community

Connecting with the PBC community allows you and other people living with PBC to share stories, learn from one another's experiences, and move forward with purpose in your journey with this rare disease.

Experiences that you could share to help the PBC community include:

- How you manage your PBC symptoms, including itch and fatigue.
- How you have shared your experiences with your loved ones and doctor.
- Tips on staying positive in the face of a PBC diagnosis.

Share your story

Many people may not understand what liver diseases like PBC are and may have preconceived notions about what causes PBC.

You're not burdening others by speaking up—your trusted friends, family, doctors, and community need to know what you're going through so that they can better help you in your PBC journey.

Fear of the possible negative opinions of others should not keep you from talking about your disease with those around you. By talking with people about your experience, you can help them understand and change their view of the disease.

Let's hear your voice.

Your voice and story have more value than you can imagine, especially to others living with PBC. Sharing your experience may help people understand PBC, de-stigmatize the disease, and encourage those living with PBC to find their own voice.

Visit **www.realPBCtalk.com** to learn more.

"I feel more armored when I go into a doctor appointment with my questions written down."

—Trudi,
living with PBC

"I look to peers with PBC on what to expect and what's to come."

—Leticia,
living with PBC

Ipsen—Committed to people living with PBC

For over 28 years, Ipsen has been listening to and working alongside people with rare diseases and their doctors to help develop new, innovative therapies that help address unmet needs.

Today, Ipsen is committed to supporting and collaborating with people living with PBC by building resources for people living with PBC and the people who care for them. Our goal is to ensure that the voices of people living with PBC are heard.

Through close collaboration and informed conversations with the PBC community, we are developing tools and resources to offer support and empowerment to help you face the unique challenges PBC presents.

Visit www.realPBCtalk.com to learn how to make an impact on your PBC.

IPSEN
Innovation for patient care