Amplify your voice in your PBC journey

You are the expert on your body and your experience of primary biliary cholangitis (PBC). Talking openly with your loved ones and doctor can help you get the care and support you deserve. Learn more about symptoms, treatment response, and signs of disease progression to help you start the conversation. **Visit RealPBCTalk.com for helpful tools and resources.**

Watch Chris' story

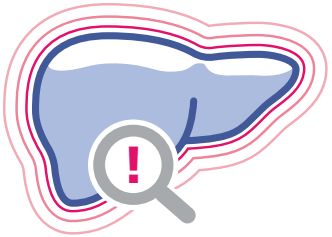
People featured were compensated by Ipsen for their time.

What is primary biliary cholangitis (PBC)?

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

People with PBC experience liver inflammation and buildup of bile acids, causing liver damage and reduced liver function.

If left untreated, PBC can lead to liver complications, resulting in the need for a liver transplant or in death. Understanding PBC and talking to your doctor about your treatment plan can help with managing the disease.



WHAT CAUSES PBC?

Genetics and environmental triggers can increase the risk of developing PBC, but ultimately the cause is unknown. **It's important for you to know that your diagnosis was not caused by anything you did.**

"PBC isn't my fault—this is just the way my liver works."

Kathy

LIVING WITH PBC

PBC symptoms can be debilitating

People with PBC can experience a physical and mental burden that impacts their daily life. It's important to talk to your doctor about symptoms so they can assess if your current treatment plan is right for you.

SYMPTOMS VARY FROM PERSON TO PERSON, BUT COMMON SYMPTOMS INCLUDE:

Fatigue

Up to 78% of people living with PBC experience chronic fatigue. And PBC-related fatigue can be more intense than general fatigue. It can feel like whole-body exhaustion, brain fog, or needing longer recovery time from daily activities.

Severe itching

Up to 70% of people with PBC deal with intense itching that can lead to loss of sleep and difficulty participating in daily activities.

Other symptoms can include:

Body pain

Brain fog

Did you know?

Up to 60% of people with PBC do not have symptoms at diagnosis, but symptoms may develop over time and do not show how severe your disease may be. This is why regularly monitoring both your lab results and symptom experience is important.

Learn more about symptoms

Fatigue is the most common symptom of PBC

If you're feeling forgetful, hazy, or unable to focus, it may be related to your PBC.

PBC fatigue can be mistaken for other things. You may just think you're sleep deprived or overworked. But if you find yourself in a constant state of brain fog or if sleep doesn't help, it could be something deeper.

Fatigue is more than just being tired.

People with PBC fatigue might describe it in many different ways:

In the body...

- A physical heaviness
- Hitting a wall

In the mind...

- Brain fog
- A lack of ambition

In both...

- Feeling drained and tired
- Being slowed down
- Struggling to do all you need to do

PBC-related fatigue is a separate symptom from itch.

While itch can contribute to fatigue, people can experience PBC-related fatigue even without any itch. That's why you should work with your healthcare team to examine and manage both of these symptoms separately.

"One of the hardest parts of fatigue is that people can't see it. You look 'fine,' but inside you feel completely depleted. It's invisible—and sometimes that makes it even harder to explain to others."

Jackie

LIVING WITH PBC

What should you consider when assessing your fatigue?

Tracking fatigue

It's hard to note every time you feel tired. Instead, it can be helpful to track each time you skip an event, stay home from work, or delay a chore. We designed the Real PBC Talk Fatigue Assessment Tool to help you do just this. Fill it out and bring it to your next appointment to help your doctor understand your experience.

You deserve to be heard

Symptoms like fatigue are a significant part of your PBC experience. Your doctor is there to listen and offer solutions to help manage them. Be sure to have an open and honest conversation about symptoms.

Download the Fatigue Assessment Tool to help share your experience with your doctor

Monitoring PBC progression

PBC is a progressive disease, which means it can get worse over time. **Slowing progression as early as possible is key to management.** By monitoring your lab results and assessing symptoms like fatigue over time, you and your doctor can identify signs of progression early and adjust your treatment plan.

Some people may be more likely to experience disease progression or poor treatment response

Certain factors could put some people with PBC at a higher risk of disease progression, including:

- People diagnosed with PBC before the age of 45
- Men with PBC
- People of color with PBC
- People with high alkaline phosphatase (ALP) levels at diagnosis
- People with additional autoimmune diseases

Inadequate response to treatment

An inadequate response means you are not responding to treatment as well as you could be.

This may mean that the treatment is:

Not lowering ALP levels enough

Not lowering ALP levels quickly

Worsening or not addressing symptoms

Did You Know?

50%
of people with PBC

Up to half of people with PBC do not respond well enough to ursodiol (ursodeoxycholic acid, also known as UDCA) and **may require additional treatment.** For this reason, it's important to frequently monitor your treatment response.

Additional treatment options are available. Ask your doctor about your unique treatment goals.

Understanding your liver lab test results

Liver function is measured with a series of laboratory (blood) tests. These tests show levels of substances like **ALP** and **bilirubin**, which can give you and your doctor a clearer view of if and how your PBC is progressing.

PBC GUIDELINES RECOMMEND

Lab tests every 3-6 months

Treatment evaluation every 6-12 months

Did you know?

Even if lab levels are well managed, PBC fatigue or itch can still affect you.

Ask your doctor about getting ALP levels to normal range

Sometimes treatment controls ALP levels but doesn't lower them to normal range. **Normalizing ALP is key to reducing the risk of disease progression.**

Learn more about PBC treatment options

Starting the conversation

Be open and honest with your healthcare team

Disease progression, symptoms, and response to treatment can vary greatly. It is important to explain your unique PBC experience to your healthcare team. This allows them to work with you to create a treatment plan that meets your individual needs.

Talk to your PBC healthcare team about your condition:

> How should we be monitoring my PBC over time?

> What can I do to manage my symptoms?

> What are my treatment goals and how frequently do we need to reassess them?

Download the Doctor Discussion Guide to help start the conversation with your doctor at your next appointment

"I realized life with PBC can get easier and I don't need to relegate myself to accepting that nobody will ever fully understand my experience."

Amber

LIVING WITH PBC

Reaching out for support

Bring your loved ones into the loop

Many people with PBC don't feel comfortable talking about their symptoms. But you deserve support and understanding. Try to find a loved one who can listen to your experience and help you advocate for yourself.

Start the dialogue between you and your loved ones:

> PBC-related fatigue is more than just being tired. My fatigue makes me feel *exhausted*.

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

Connect with the community

Getting involved with the PBC community allows you and other people living with PBC to share stories and learn from each other's experiences.

Shared experiences that could help you and the wider PBC community include:

- Ways to manage your PBC symptoms, including fatigue and itch
- Ways to share your experiences with your loved ones and doctor
- Tips on staying positive throughout your PBC journey

At Real PBC Talk, we're meeting you where you are in your journey

Here are a few points to remember as you consider the impact and management of your PBC:

PBC is a rare autoimmune disease.

People with PBC experience liver inflammation and buildup of bile acids, causing liver damage and reduced liver function.

Monitoring your symptoms and lab results is key.

Use lab results as well as your symptom experience to track your disease and any signs of progression.

PBC-related fatigue impacts daily life.

Symptoms vary from person to person, but fatigue is the most common and is experienced by up to 78% of people with PBC.

Openly communicate with your doctor.

Being clear about your PBC experience helps your doctor understand the severity of your disease and find a treatment plan that works for you.

Sign up to join the Real PBC Talk community and hear about events, resources, and more

Ipsen—committed to people living with PBC

Ipsen is developing tools and resources to offer support and empowerment to help you face the unique challenges PBC presents.