

*Determined to be*  
**MORE THAN**  **PBC**

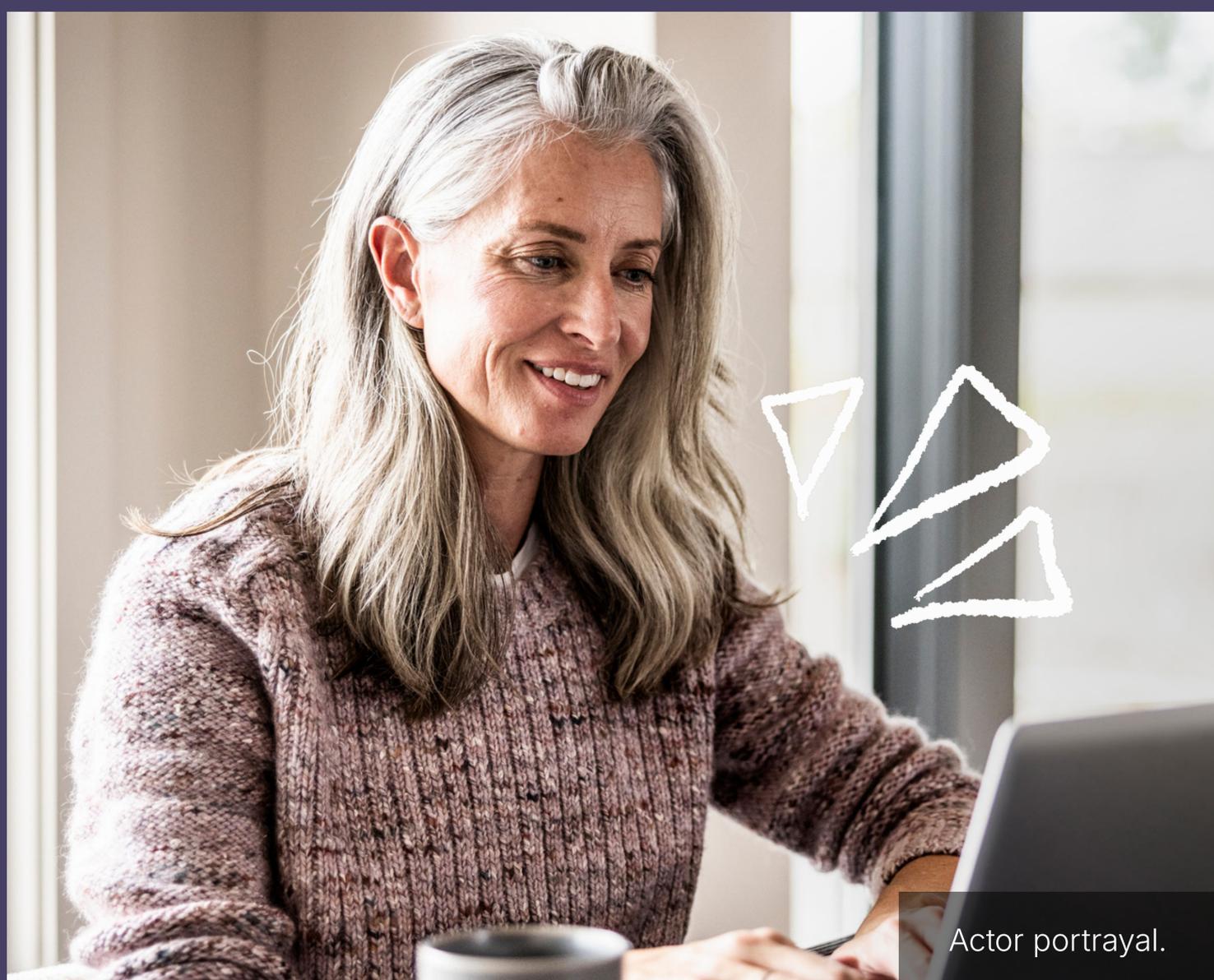


# **Your guide to understanding and discussing **primary biliary cholangitis (PBC)****

**Learn all about PBC and build your skills to confidently discuss PBC and its treatment with your doctor.**

## What's inside:

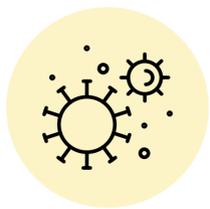
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Actor portrayal.

# Overview of PBC

## PBC QUICK FACTS



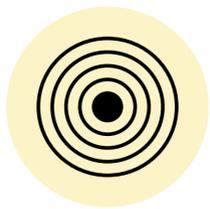
PBC is a **lifelong autoimmune disease** that occurs when the immune system attacks bile ducts in the liver.

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A PBC diagnosis is confirmed when 2 of these 3 signs are present: **elevated alkaline phosphatase (ALP), antimitochondrial antibodies (AMA), or liver biopsy showing damage to bile ducts.**

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Damaged bile ducts cause a buildup of bile in the liver, **leading to inflammation and scarring.**

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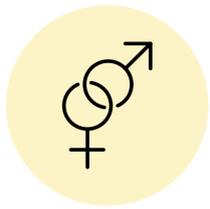
About **130,000 people** in the US are living with PBC.

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PBC is most likely to occur in people aged **40 to 60 years.**

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**90% of people with PBC are women**, but men can also be affected.

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PBC can affect people from **all ethnic and racial groups.**

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Researchers believe there may be certain factors such as a person's **environment and their genes that can lead to PBC**, and it is not related to alcohol use.

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You may have PBC because of the **genes handed down to you** by your family.

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When not treated or managed, PBC can lead to the **permanent destruction of bile ducts and, eventually, liver failure.**

# Most common PBC symptoms

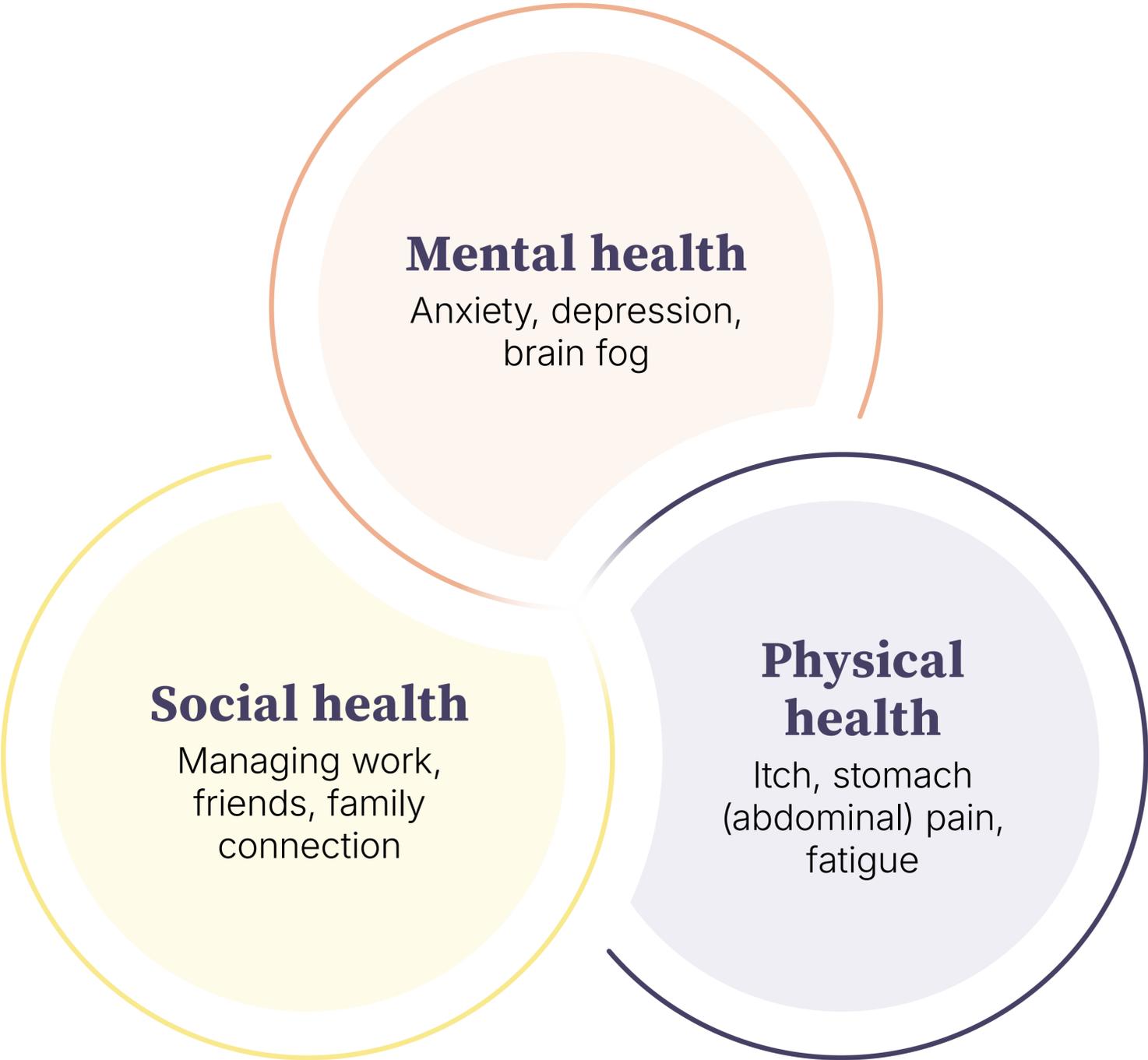
PBC has many symptoms, and each person’s experience is unique. But 2 of the most common symptoms are itch (or pruritus) and fatigue. Itch can make it difficult to sleep, contributing to fatigue.

## HOW CAN PBC SYMPTOMS BE RELATED TO EACH OTHER?

Physical symptoms can affect your mental and social health. That’s why it’s important that your doctor has an overall picture of your symptoms and how they impact your well-being.

**For example: Staying up at night scratching can disrupt sleep and lead to fatigue, while repeated scratching can cause scars that may lead to social anxiety and other symptoms.**

You may not have all of the symptoms listed below, but you may experience some of them to different degrees. They may be related to your experience with PBC.



**Which of these symptoms do you feel most often, and how do they impact daily life?**



Actor portrayal.

## WHAT CAUSES PBC ITCH?

Symptoms such as **PBC itch** are primarily caused by the **impact the disease has on the bile ducts**. In PBC, the immune system attacks the bile ducts in the liver. Bile acids leak from the bile ducts into nearby liver tissue, causing symptoms.

### PEOPLE SAY ITCH FEELS LIKE:



Deep itch inside the body or under the skin



Bugs crawling under the skin



A burning sensation

### WHEN YOU TALK TO YOUR DOCTOR ABOUT ITCH, MAKE SURE YOU TALK ABOUT:

#### → SENSATION

What it feels like

#### → IMPACT

How deeply and how often it affects daily life

#### → SEVERITY

How bad it is on a scale from 0 to 10

# WHAT CAN I DO TO HELP MANAGE SYMPTOMS LIKE ITCH AND FATIGUE?

One thing you can do is talk to your doctor about all of your symptoms so they can help find a treatment plan that is right for you.

**If you are taking ursodiol and still experience abnormal labs or symptoms with no improvement, it may be time to ask your doctor if adding an additional PBC treatment option may be right for you.**

## OUTSIDE OF TREATMENT, SOME PEOPLE FIND THESE STRATEGIES HELPFUL:



### NUTRITION

Add vitamin-rich, anti-inflammatory foods to your diet



### MOVEMENT

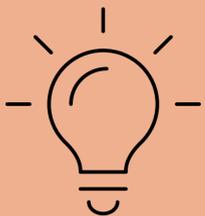
Try short walks or gentle yoga to improve fatigue



### COMMUNITY

Connect with others to boost mental health

If itch keeps you up at night, it makes sense that fatigue will follow. However, researchers have discovered there may be a scientific link between PBC itch and chronic fatigue.



**People with PBC itch are about 2x more likely to also experience fatigue.**

# Tips for daily life with PBC

There are things you can do to help with PBC itch and fatigue and things to avoid that could make them worse. Consider these tips to help you manage day to day. It can also help to ask your doctor for their recommendations.

	GOOD ✓	BAD ✗
<b>Shower, bathing, and personal care</b>	<ul style="list-style-type: none"><li>• Mild, non-alkaline soaps and oils</li><li>• Baths or showers with lukewarm water</li><li>• Showers or baths lasting 20 minutes or less</li></ul>	<ul style="list-style-type: none"><li>• Hot water</li><li>• Rubbing your skin after showering/bathing</li></ul>
<b>Clothing</b>	<ul style="list-style-type: none"><li>• Soft clothing made from natural materials like cotton</li></ul>	<ul style="list-style-type: none"><li>• Tight clothes</li><li>• Wool sweaters</li><li>• Scented detergents</li></ul>
<b>Skincare</b>	<ul style="list-style-type: none"><li>• Mild moisturizers with synthetic urea to help hold water and soften skin</li><li>• Creams, salves, or lotions with cooling or anesthetic qualities and ingredients like menthol</li><li>• Ultraviolet (UV) phototherapy</li></ul>	<ul style="list-style-type: none"><li>• Irritating herbs like chamomile or tea tree oil</li></ul>
<b>Lifestyle</b>	<ul style="list-style-type: none"><li>• Consistent sleep habits</li><li>• Balanced meals</li><li>• Reduce stress as much as possible</li><li>• Break large tasks into small steps</li></ul>	<ul style="list-style-type: none"><li>• Large amounts of hot or spicy food, hot drinks, or alcohol</li><li>• “Pushing through” when feeling tired</li></ul>



Actor portrayal.

# Importance of ALP

When treating your PBC, it is important to aim to improve your liver lab results, including alkaline phosphatase (ALP). **Getting your ALP to a normal level has been shown to reduce the risk of PBC getting worse over time.**

## ALP NORMALIZATION



*The main goal of PBC treatment is normalization of ALP.*

Marina Roytman, MD, FACP, FAASLD  
Clinical Professor and Liver Program Director, UCSF-Fresno

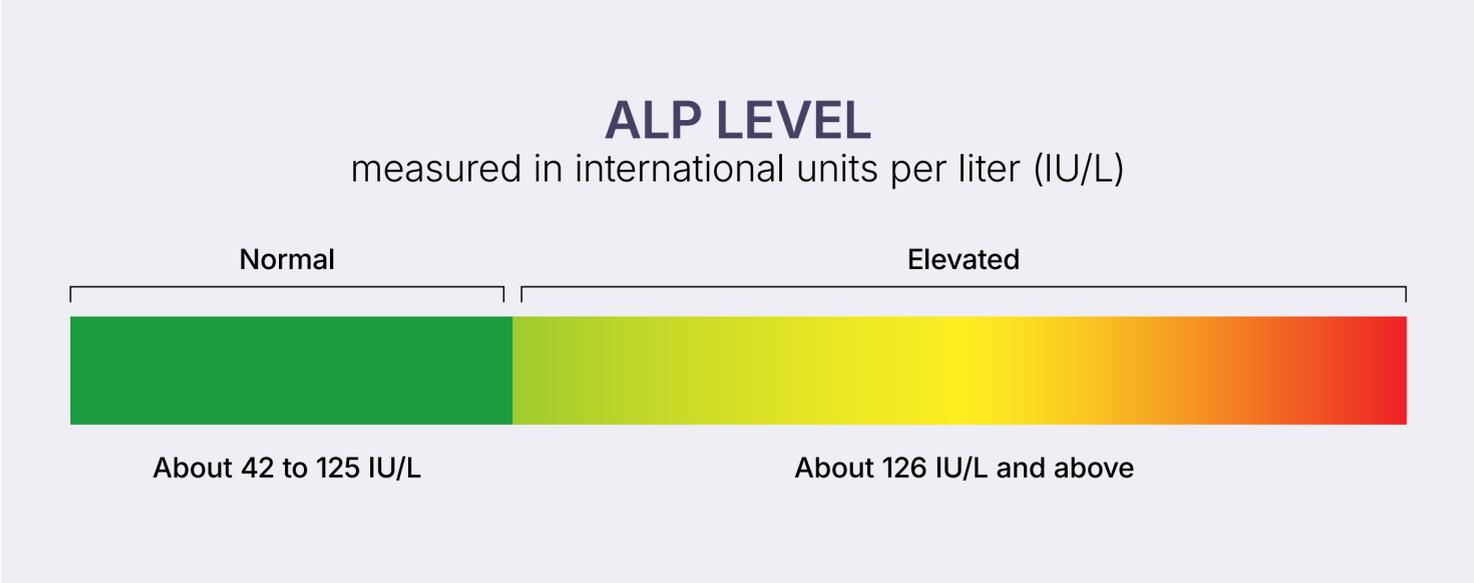


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## NORMAL VS ELEVATED ALP: WHY DOES IT MATTER?

Growing evidence suggests that **any ALP number above the “normal” range may impact the risk of disease progression.**

The normal range that’s listed in ALP lab results changes from lab to lab, but a common range is about 42 to 125 IU/L.

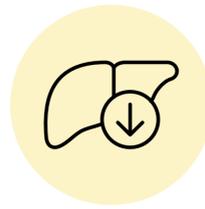


# WHY IS HAVING AN ALP WITHIN YOUR NORMAL RANGE IMPORTANT?

## ALP NORMALIZATION WAS ASSOCIATED WITH:



**Reduced risk**  
of disease  
progression



**Reduced risk**  
of liver  
transplant

## 15-YEAR DATA ANALYSIS REPORTING THE PERCENT OF PEOPLE WITH PBC WHO LIVED OR AVOIDED LIVER TRANSPLANT

### People with elevated ALP levels

(ALP above 1.67 x ULN)

74%

### People with partial ALP elevation

(ALP between 1 x and 1.67 x ULN)

76%

### People with normal ALP levels

(ALP equal to or less than 1 x ULN)

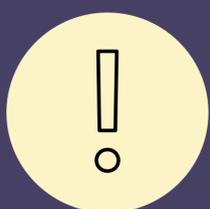
84%

**8-10%**

more people were predicted to live or avoid liver transplant when ALP was within the normal range

Researchers predicted PBC survival rates based on normal total bilirubin and ALP levels using data collected over 15 years. Survival estimates were calculated using the number of people who died after liver transplant or for any other reason—this was the main measurement of the study.

Medical charts were collected from 17 centers across Europe and North America, and researchers studied follow-up data from 3059 people to estimate how long a person may live with PBC based on normal total bilirubin and ALP level. The study included people treated with ursodiol and people who were untreated. Survival estimates included 2005 people who were treated with ursodiol and reached a normal total bilirubin level at 1 year.



## STABLE DOESN'T ALWAYS EQUAL NORMAL

Even if your ALP decreased and is stable (not going up) with first-line (1L) treatment, you could still be above your normal ALP range. This could put you at risk for liver damage or worse outcomes. **That's why it's so important to advocate for yourself to hit normal levels.**

# Navigating PBC treatment

Depending on the stage your PBC is in, your liver lab results, and the severity of your symptoms, you and your doctor will work together to select the treatment plan that may be right for you.

## PBC TREATMENT TYPES



**PBC treatment begins with first-line (1L) therapy (ursodiol) taken by itself.**

Many people positively respond to ursodiol treatment, but up to 40% of people with PBC will need to add an additional treatment to their PBC management plan.



Second-line (2L) therapy can be **added to ursodiol—or taken by itself**, depending on your needs.

**It is important to review liver labs with your doctor regularly** to keep an eye on the disease. If your doctor notices your current treatment is not working well enough, it may lead to PBC progression, which can include liver damage.



### **Get details on a 2L PBC treatment option.**

In one PBC study, around 50% of people were left untreated though they were eligible for 2L therapy.

**LEARN MORE** →

## HOW OFTEN IS IT RECOMMENDED TO ASSESS MY LABS AND TREATMENT PLAN?

Within the first **3 to 6 months of 1L PBC treatment**, ask your doctor if it is time to check your labs to see how you are responding to treatment. Here is a schedule your doctor may follow:



### EVERY 3 TO 6 MONTHS

Check lab work, including liver-related labs.



### EVERY 6 TO 12 MONTHS

Check labs again and evaluate to see if you have:

- Reached ALP normalization
- Reduced symptoms such as itch
- Experienced negative side effects



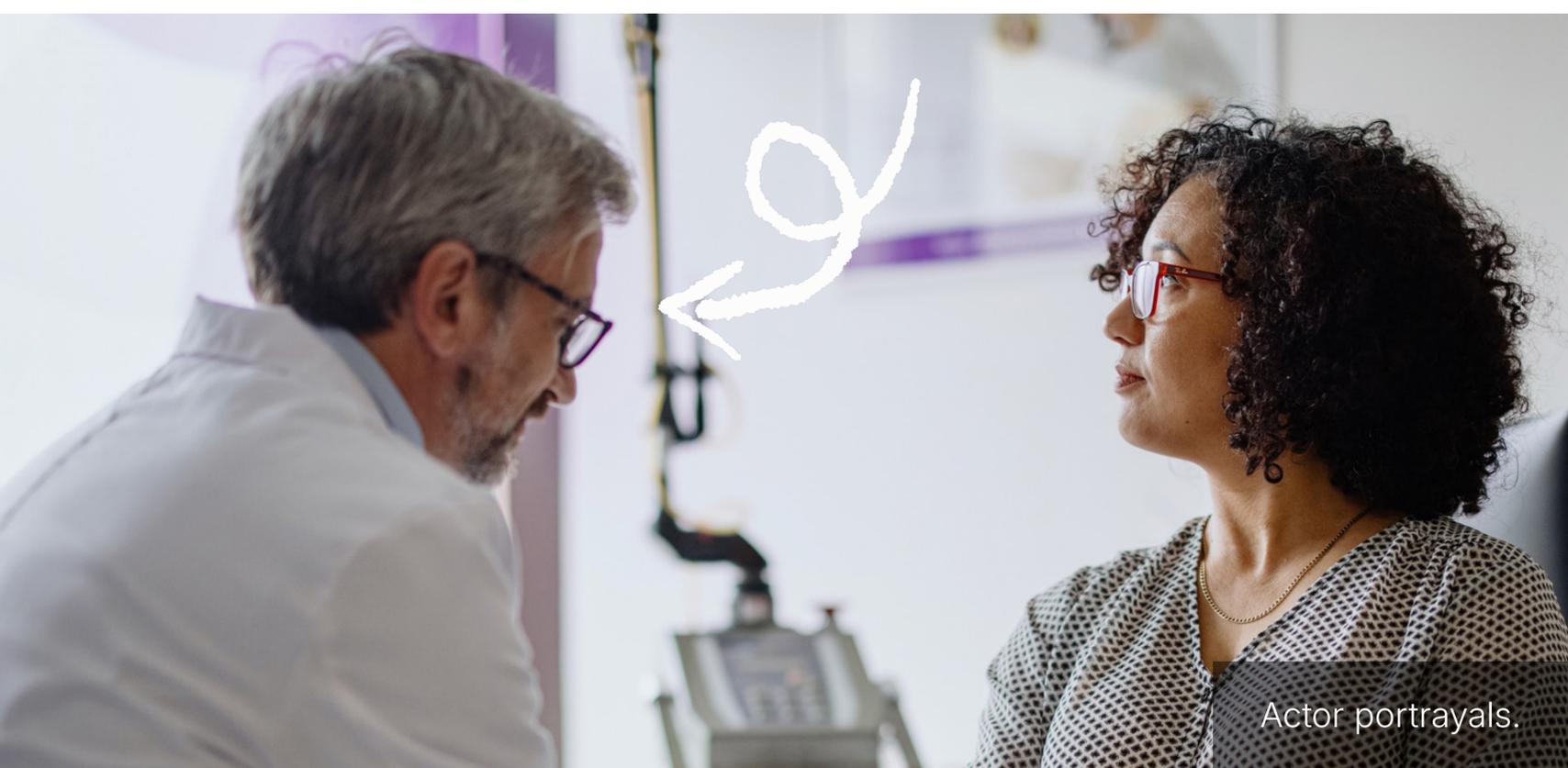
### ASSESS WHERE YOU ARE EVERY YEAR

**Regular assessments help your doctor** understand the stage of your disease and how well your treatment is working.

- FibroScans and other imaging tools may be used as well to check for liver cirrhosis or fibrosis and determine if any treatment changes are needed



**If you have PBC and are not currently taking a PBC treatment, talk to your doctor or ask for a referral to a liver specialist.**



# Treatment FAQs

**Q** WILL MY LIVER LABS AND SYMPTOMS IMPROVE ON URSODIOL?

**A** Ursodiol helps many people with PBC, but if you're not meeting your PBC lab goals, it may be time to ask your doctor about a 2L treatment.

**Q** IF I NEED A 2L TREATMENT, IS MY PBC GETTING WORSE?

**A** Adding a 2L treatment **might not be due to worsening disease**. There can be other reasons your doctor adds a 2L treatment—for example, to help lower your ALP to normal, which may help lower the risk of disease progression.

**Q** WHAT TREATMENT OPTIONS ARE AVAILABLE AFTER URSODIOL?

**A** [Click to learn about types of PBC treatments](#) and what your doctor might decide is right for you.

**Q** WHAT IF I'M TAKING MEDICATIONS FOR OTHER CHRONIC CONDITIONS AS WELL?

**A** Certain medicines might affect how your PBC medicine works, so be sure to **talk with your doctor about all the medicines you take** before modifying your treatment plan.

**Q** WHAT IF I HAVEN'T BEEN ON TREATMENT FOR PBC IN A WHILE?

**A** Talk with your doctor or a liver specialist right away to **help determine the treatment plan that is right for you**.

**Q** HOW LONG DO I HAVE TO BE ON PBC TREATMENT?

**A** Because PBC is a chronic condition, you will have to **continuously treat it for as long as your doctor advises**.



Actor portrayals.

## Talking with your doctor about PBC

When creating a PBC treatment plan with your doctor, there are several considerations to discuss. Each person's goals and expectations for treatment may be different. Think of this list as a guide to help you remember the important points you'd like to talk about.

### WHAT MATTERS TO YOU?

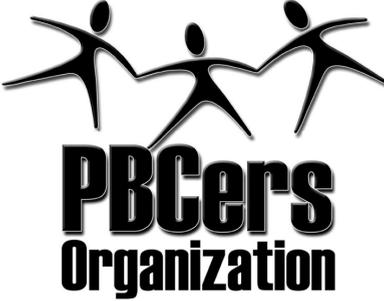
This list doesn't cover everything you and your doctor need to talk about, but it's a good place to start. You can use it to get the conversation going so you can ask about whatever is on your mind about PBC treatment.

### PBC TREATMENT TOPICS

- |   |  |
|---|--|
| <input type="checkbox"/> Lowering the risk of disease progression   | <input type="checkbox"/> Other treatment concerns that impact daily life |
| <input type="checkbox"/> Lowering the risk of a liver transplant  | <input type="checkbox"/> Other: _____                                    |
| <input type="checkbox"/> Reducing itch  | _____  |
| <input type="checkbox"/> Reducing PBC symptoms, like itch, that impact sleep, ability to work, or socialize | _____  |

# PBC community

Visit these foundation websites to enhance your understanding of PBC and help you find connections and support.



# MORE THAN PBC



*I've educated myself on PBC, and joined a few groups to hear other people's stories, and I've learned that I have PBC, PBC does not have me.*

Suzanne Anderson  
Real PBC patient & advocate



Person featured was compensated by Gilead.

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