

# PBC Doctor Discussion Guide

## What is a PBC risk factor?

**PBC is a progressive disease, which means it can get worse over time if it isn't treated.** Certain things about you and your PBC experience may put you at a higher risk of faster or more severe disease progression; these are risk factors for disease progression.

**Once on treatment, there is a chance your PBC therapy won't slow disease progression enough, or at all.** This is considered an inadequate response to treatment, and there are risk factors that may signal you are at a higher risk of experiencing an inadequate response to treatment.

## Instructions

Fill out this 2-page form and take it to your next doctor's appointment to help you discuss your unique PBC experience.

### PBC risk assessment checklist

Understanding your risk of disease progression is important and should be discussed with your doctor. You may be at a higher risk of disease progression if:

**You were younger than 45 when you were diagnosed with PBC.**

Yes       No

**You had more severe disease, including cirrhosis, when you were diagnosed with PBC.**

Yes       No

**You had very high ALP levels at diagnosis.**

Yes       No

**Your ALP and bilirubin levels did not improve sufficiently after 12 months of treatment.**

Yes       No       N/A

**Having one or more of the risk factors listed above does not necessarily mean you are at risk for progression. Only a trained healthcare professional can determine your risk.**

ALP=alkaline phosphatase; N/A=not applicable; PBC=primary biliary cholangitis.

## Tracking your PBC

Living with PBC means dealing with ongoing symptoms, which may persist even if your liver function tests show improvement.

### Symptoms

Rate your symptoms on a scale of 0 to 10, with 0 being no symptom impact and 10 being unbearable symptom impact.

Date				
Fatigue				
Brain fog				
Itch (pruritus)				
Body pain				
Other symptom*				

\*Symptoms listed above are not the only possible PBC symptoms.

### ALP and bilirubin levels

Record your most recent liver lab levels.

ALP				
Bilirubin				

## Try using these discussion starters when talking about your disease with your PBC healthcare team.

- What risk factors do I have that might impact my disease progression or my treatment plan?
- Can we talk about these changes I've noticed in my symptoms?
- Can you explain my current treatment plan to me?
- How can we work together to frequently monitor my symptoms and put my mind at ease regarding my liver lab tests?
- Are there any adjustments to my treatment plan that may address my PBC experience in a more holistic fashion?