

# PBC Patient's Bill of Rights

**People who have been diagnosed with primary biliary cholangitis (PBC) have certain rights.**

Every journey with PBC is different. If your concerns and care related to PBC – or those of someone you care for – are not being addressed by your medical team, it may be time to talk with your healthcare provider about how to better meet your needs.



## AS SOMEONE WITH PBC, YOU HAVE THE RIGHT TO...

- 1 Receive the best care and treatment possible** for you at all points in your PBC journey, with the goal of keeping your liver healthy for longer.
- 2 Access PBC disease information** to help you take an active role in decisions about your care and understand your treatment options and the meaning of your test results.
- 3 Know your alkaline phosphatase (ALP) liver levels**, because ALP is one of several markers of liver health and an early indicator of disease progression.
- 4 Partner with your healthcare team** to develop strategies to follow your treatment plan, monitor for disease progression and manage your symptoms.
- 5 Ask for enough time with your healthcare team** to discuss your questions and concerns, and schedule follow-up appointments as needed.
- 6 Understand how your PBC treatment works**, including what it is intended to do and its potential side effects.
- 7 Know your healthcare coverage options**, and follow-up in the event your insurance plan denies coverage of a treatment or procedure.
- 8 Engage with others for emotional support**, both one-on-one and in active patient communities.
- 9 Advocate for yourself and the entire PBC community** by sharing your story and bringing attention to PBC as an autoimmune liver disease.

### FOR MORE INFORMATION ON PBC, VISIT:

**American Liver Foundation**

[liverfoundation.org](http://liverfoundation.org)

**PBCers Organization**

[pbcers.org](http://pbcers.org)

**Living with PBC**

[livingwithpbc.com](http://livingwithpbc.com)

**Healthy Women Liver Health Center**

[healthywomen.org/  
category/tags/liver-health](http://healthywomen.org/category/tags/liver-health)