

PRIMARY BILIARY CHOLANGITIS (PBC) PATIENT BILL OF RIGHTS

Your disease does not define you. You are not alone.

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 living 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. **Educate others about rare liver disease to reduce misinformation and stigma** that can be associated with it. Share your story with elected officials who can influence health care policy and research funding.

For more information about PBC, including resources you may find helpful when having a discussion with your healthcare team visit:

- American Liver Foundation liverfoundation.org
- PBCers Organization pbcers.org
- Living with PBC livingwithpbc.com
- Healthy Women Liver Health Center healthywomen.org/category/tags/liver-health

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