YOUR VOICE SHAPES PBC CARE

National PBC Patient Survey — help the Community Liver Alliance understand the experiences, needs, and priorities of people living with PBC.

The Community Liver Alliance is conducting this survey to better understand the experiences, needs, and priorities of people living with Primary Biliary Cholangitis (PBC). Responses will help inform future patient education, support resources, and advocacy priorities.

Name _____ **Date** _____

Community Liver Alliance

This survey takes approximately 10–12 minutes. Check the boxes that apply and write your answers on the lines. You may skip any question, including the Women's Health section if it does not apply to you. This survey is educational and does not replace individualized medical advice.

HOW TO COMPLETE THIS SURVEY

Check ☐ the answer that fits best unless a question says "Select all that apply." Write your answers on the lines. Skip any question you prefer not to answer.

Section 1 — About You

1. What is your age range?

☐ Under 30 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ 60-69 ☐ 70+ ☐ Prefer not to answer

2. How do you describe your gender?

☐ Woman ☐ Man ☐ Nonbinary / another identity ☐ Prefer to self-describe ☐ Prefer not to answer

3. In what state or U.S. territory do you live?

_____

4. How would you describe where you live?

☐ Urban ☐ Suburban ☐ Rural ☐ Unsure ☐ Prefer not to answer

5. Approximately how long have you been living with PBC?

☐ Less than 1 year ☐ 1-2 years ☐ 3-5 years ☐ 6-10 years ☐ More than 10 years ☐ Unsure

6. Approximately how long did it take to receive your PBC diagnosis after you first sought care for symptoms or abnormal testing?

☐ Less than 6 months ☐ 6-12 months ☐ 1-2 years ☐ More than 2 years ☐ I was diagnosed before symptoms ☐ Unsure

7. Who currently manages your PBC?

☐ Hepatologist ☐ Gastroenterologist ☐ Primary care clinician ☐ Advanced practice provider ☐ Other ☐ Unsure

_____

8. How far do you typically travel for PBC specialty care?

☐ Less than 15 miles ☐ 15-49 miles ☐ 50-99 miles ☐ 100+ miles ☐ Telehealth primarily ☐ Unsure

Section 2 — Diagnosis Experience

9. Before your diagnosis, had you heard of PBC?

☐ Yes ☐ No ☐ Unsure

10. How well was your diagnosis explained to you?

☐ Not at all well ☐ Slightly ☐ Moderately ☐ Very well ☐ Extremely well

11. At diagnosis, did you receive educational information you could understand and use?

☐ Yes ☐ No ☐ Somewhat ☐ I do not remember

12. What information do you wish you had received earlier?

_____

_____

_____

Section 3 — Symptoms & Quality of Life

13. Which symptoms or issues have you experienced? Select all that apply.

☐ Fatigue ☐ Itching/pruritus ☐ Sleep disruption ☐ Cognitive difficulties ☐ Emotional/mental-health effects
☐ Pain/discomfort ☐ Social impact ☐ Work impact ☐ Sexual-health/intimacy impact ☐ Other

_____

14. Which THREE have the greatest effect on your daily life? Select up to three from Question 13.

_____

15. Do you feel your healthcare team understands how PBC affects your quality of life?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Very much ☐ Completely

16. Have PBC symptoms caused you to miss or reduce any of the following? Select all that apply.

☐ Work/school ☐ Family responsibilities ☐ Social activities ☐ Exercise/movement ☐ Travel ☐ Other
☐ None

_____

Section 4 — Treatment Experience

17. Are you currently receiving treatment specifically for PBC?

☐ Yes ☐ No ☐ Unsure ☐ Prefer not to answer

18. How well do you understand the goals of your PBC treatment?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Very well ☐ Extremely well

19. Has your healthcare team explained how they determine whether your treatment is working?

☐ Yes ☐ No ☐ Somewhat ☐ Unsure

20. How comfortable are you asking about other treatment options?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Very ☐ Extremely

21. Have you experienced barriers obtaining recommended PBC treatment? Select all that apply.

☐ No ☐ Yes — insurance ☐ Prior authorization ☐ Cost ☐ Pharmacy/access ☐ Specialist access
☐ Transportation ☐ Other

_____

Section 5 — Communication & Shared Decision-Making

22. How comfortable are you raising symptoms that affect your quality of life?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Very ☐ Extremely

23. How involved do you feel in decisions about your PBC care?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Very ☐ Extremely

24. What would help you have better conversations with your healthcare team? Select all that apply.

☐ Appointment checklist ☐ Symptom tracker ☐ Test-result guide ☐ Treatment-question guide ☐ Caregiver guide
☐ Peer support ☐ Other

_____

Section 6 — Women's Health (skip if not relevant)

25. Have perimenopause or menopause affected your experience living with PBC?

☐ Yes ☐ No ☐ Unsure ☐ Not applicable ☐ Prefer not to answer

26. Have you found it difficult to know whether symptoms are related to PBC, perimenopause/menopause, another condition, or a combination?

☐ Yes ☐ No ☐ Unsure ☐ Not applicable

27. Have your liver and women's-health clinicians communicated about your care?

☐ Yes ☐ No ☐ Unsure ☐ Not applicable

28. Which topics would you like more information about? Select all that apply.

☐ Fatigue ☐ Sleep ☐ Bone health ☐ Mood/emotional wellness ☐ Sexual health
☐ Medication/treatment conversations ☐ Coordinating hepatology and women's healthcare ☐ Other

_____

Section 7 — Information & Support

29. Where do you currently obtain PBC information? Select all that apply.

☐ Healthcare team ☐ CLA ☐ Other patient organizations ☐ Online search ☐ Social media ☐ Peer groups
☐ Family/friends ☐ Other

_____

30. Which sources do you trust most? List up to three.

_____

31. What type of resource would you be most likely to use?

☐ Printable guide ☐ Downloadable PDF ☐ Short video ☐ Webinar ☐ Peer discussion ☐ Symptom tracker
☐ Appointment tool ☐ Website ☐ Other

_____

32. Have you connected with another person living with PBC?

☐ Yes ☐ No ☐ Prefer not to answer

33. **Would greater access to peer support be valuable to you?**

☐ Yes ☐ No ☐ Maybe ☐ Unsure

Section 8 — What CLA Needs to Hear

34. **What is the hardest part of living with PBC that healthcare professionals may not fully understand?**

35. **If you could change one thing about PBC care or support, what would it be?**

36. **What is one thing you wish you had known when you were first diagnosed?**

Thank you for sharing your experience.

Your responses help the Community Liver Alliance shape future PBC education, support resources, and advocacy priorities.

Acknowledgment

This toolkit was made possible through an educational sponsorship from Ipsen. The Community Liver Alliance gratefully acknowledges their support in empowering patients and caregivers affected by Primary Biliary Cholangitis (PBC).