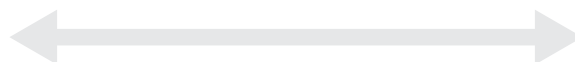


CONVERSATIONS IN PBC

A Guide for Patients and Clinicians



QUESTIONS FOR PATIENTS TO ASK CLINICIANS

What are the goals of my treatment plan?

Can we talk about changes I've noticed in my symptoms?
Are they related to the disease or to my treatment?

Should I keep a log of my symptoms – and when they are generally worse or better?

Besides medication, what else should I do (diet, exercise, OTC meds, vitamins)?

Why do I have “brain fog”?

What medicine(s) can help stop my itching?

Can you explain what ALP and bilirubin are and why they are important in PBC?

QUESTIONS FOR CLINICIANS TO ASK PATIENTS

Do you understand that while we can't cure PBC, we can slow down the progression of the disease? Let's talk about goals of treatment.

How are you feeling compared to the last time we met? Do you have new symptoms that occurred after we started the new medicine?

Are you willing to track your symptoms over time? This will be very helpful for us to assess how your therapies (both prescription and lifestyle) are working

Are you able to exercise? Do you take any OTC meds for symptoms, or take vitamins?

Do you ever have brain fog? When during the day does this occur? How often does it last?

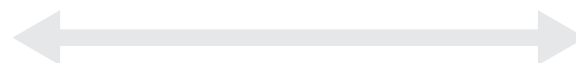
How are you doing with itch? Does your scratching – especially in your sleep – result in breaking the skin? What have you tried to reduce symptoms?

Two very important tests are ALP and bilirubin. Can I tell you more about these?



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QUESTIONS FOR PATIENTS TO ASK CLINICIANS	QUESTIONS FOR CLINICIANS TO ASK PATIENTS
Why am I so tired all the time? What can be done?	Do you generally feel tired and fatigued? On a scale of 1 - 10, how bad is the fatigue?
Can anything be done for my dry eyes and mouth?	Have you noticed dry eyes and mouth (often referred to as sicca symptoms)?
How often should we reassess my PBC? Can I change treatments if things aren't working as well as they could?	I would like to reassess your PBC. Are you ok with me taking blood at this appointment? Can I tell you about newer treatment options that may be an option for you?
Do I need liver imaging or elastography?	I would like to assess your liver for signs of fibrosis/stiffening. Are you ok with a few non-invasive imaging and vibration tests?
What is portal hypertension? Should this be of concern to me?	I would like to see if you have portal hypertension – or high blood pressure in the portal vein that runs through your liver. We can do this with non-invasive elastography, ok?
What are complications related to cirrhosis?	Do you drink alcohol? Have you, your partner, or your friends, noticed a progressive yellowing in your eyes or skin? Have you had any swelling in your abdomen?
Can you recommend a support group?	Are you currently part of a PBC patient support group? These can be very helpful.