



Living Liver Donation: Medical Toolkit

CHAPTER • 10

Liver donation if you have a family history of primary biliary cholangitis (PBC)

What is primary biliary cholangitis (PBC)?

Primary biliary cholangitis (PBC) is a long-lasting disease that causes bile to build up and damage your liver. Bile is a fluid your liver makes that helps break down fats in food. PBC can cause cirrhosis (scarring in your liver) and lead to liver failure (your liver stops working). If your liver fails, you need a liver transplant to live.

If you and your potential recipient are related by blood and both have a family history of PBC, the main concern is that your recipient's liver disease is more likely to come back after you donate to them.

What causes PBC?

PBC is an autoimmune disease, which means that your body's immune system mistakenly attacks healthy cells in your body. In PBC, your immune system attacks and damages bile ducts in your liver, which causes bile to build up.

How will I know if I have PBC?

As part of the living liver donor evaluation:

1. Your doctor will ask about your family history of liver disease
2. If you have a family history, you will have a blood test to look for a certain antibody (a protein made by your immune system)
3. If you have this antibody, it means that you have PBC. Most people who have PBC have no symptoms at first
4. Your center may do a liver biopsy to know if you have liver damage. In a biopsy, a doctor takes a small sample of liver tissue to look at it in a lab

Can I donate if I have a family history of PBC?

If you have a family history of PBC and have PBC antibodies,

you may still be able to donate. Most centers will let you donate if you:

- Have low levels of PBC antibodies in your blood
- Are willing to donate to a different recipient who doesn't have an autoimmune disease, such as through a paired donation
- Have a normal liver biopsy that shows no damage

Talk with the doctor at your transplant center about if you can donate.

If I donate, will my recipient have a higher chance of their liver disease coming back?

Most recipients are biologically related to their living donors. Research has shown that donors with a family history of PBC can donate to their family members, but with some chance of their recipient's liver disease coming back.

REFERENCES

1. Akamatsu N and Sugawara Y. Primary biliary cirrhosis and liver transplantation. *Intractable & Rare Diseases Research*. 2012 May; 1(2): 66-80.
2. Kaneko J et al. Long-term outcome of living donor liver transplantation for primary biliary cirrhosis. *Transplant International*. 2012 Jan;25(1):7-12.
3. Trotter JF and Kam I. Living Donor Transplantation: Evaluation and Selection in Adults. *Transplantation of the Liver*. 3rd Edition. Ronald W Busuttil and Goran BG Klintmalm. Elsevier: Philadelphia, 2015.
4. Aravinthan AD et al. First-Degree Living-Related Donor Liver Transplantation in Autoimmune Liver Diseases. *American Journal of Transplantation*. 2016 Dec;16(12):3512-3521.

Note: This information is the opinion of the Living Donor Community of Practice (LDCOP) of the American Society of Transplantation. The LDCOP is a group of health care professionals and researchers who specialize in living donation. The LDCOP's recommendations are meant to offer you helpful information, but you may find opinions from other groups or organizations that are helpful to you, too.