

Our Research Study:

Are there specific genetic predispositions and environmental factors that contribute to the higher rate of PBC in Pacific Coastal First Nations people?



If you or a close relative have a diagnosis of PBC and are of First Nations descent, we invite you and your family to participate in our ongoing research study.

- ✚ We currently have over 30 families participating.
- ✚ This is a participatory research study. We stay in regular contact with our participants and provide families with updates of our progress and ask for feedback.

Funded by:



[The Canadian Liver Foundation](#)

Please contact us for more information on participation:

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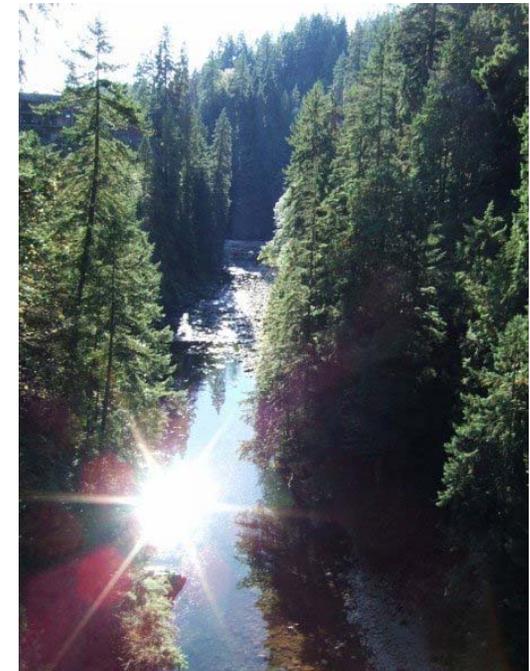
Additional information regarding PBC:

- ✚ [PBCer's organization: www.pbcers.org](http://www.pbcers.org)
- ✚ [Canadian Liver Foundation: www.liver.ca](http://www.liver.ca)
- ✚ [The PBC Patient Support Network: www.pbcpatup.net](http://www.pbcpatup.net)

PRIMARY BILIARY CIRRHOSIS (PBC)

Although PBC is a rare liver disease in most places, it is not rare in BC Coastal First Nations people. It is estimated that the original people of the Pacific West Coast have one of the highest rates of PBC in the world.

We are carrying out research to understand why.

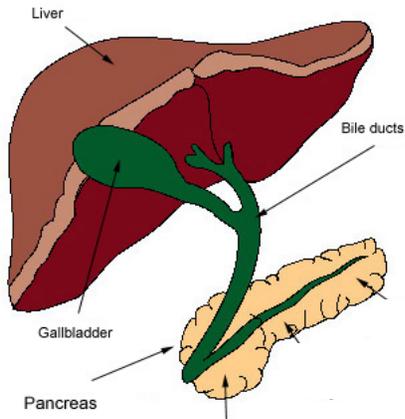


What is PBC?

✚ PBC is an autoimmune disease where the immune system attacks the bile ducts of the liver.

✚ Over time, bile and other substances are no longer able to leave the liver. Waste and toxins build up, eventually causing damage to the liver (cirrhosis).

✚ Cirrhosis means scarring of the liver. While cirrhosis can be caused by alcohol abuse, it is NOT the cause in PBC.



✚ PBC is thought to be caused by a gene/environment interaction, the details of which are being researched.

Who is affected by PBC?

✚ Although PBC is rare in many populations, BC Coastal First Nations and Southeast Alaska Native people have an increased rate of this disease.

✚ The disease occurs more often in women than in men. Most cases are diagnosed between age 40-60 years.

✚ As with other autoimmune diseases, if you have a close relative with PBC, you may be at higher risk of developing it than people who do not have a close relative with PBC.

What are the symptoms of PBC?

✚ PBC can have non-specific symptoms like fatigue and itchiness of the skin.

✚ Other possible symptoms include jaundice (yellowing of skin and eyes), swelling of the ankles or abdomen, and easy bruising and bleeding.

✚ Patients with PBC are also more likely to have other autoimmune conditions like arthritis, thyroid disease and lupus.

How is someone diagnosed?

A blood test is performed to diagnose PBC. A liver biopsy is sometimes done to confirm the diagnosis.

What is the prognosis for patients?

The outcome of PBC varies greatly from one person to another:

✚ PBC usually progresses slowly. Many patients lead active and productive lives and have few symptoms for 10-20 years after their diagnosis.

✚ However, in some patients, the condition progresses more rapidly and liver failure may occur in a few years.

Is there a cure?

✚ Although research is being done, there is currently no cure for PBC,

BUT:

✚ If PBC is discovered in the early stages, there is medicine available that can prevent it from getting worse.

✚ Liver transplantation is a common treatment option for people with advanced PBC.