ABOUT US

The Canadian PBC Society was founded in 2003. For more than 20 years, ours has been the only organization in Canada that is dedicated exclusively to supporting those affected by primary biliary cholangitis (PBC). Our mission is to provide support, information and education, and to raise funds for PBC research.
We produce a newsletter, maintain a website and welcome participation and communication from everyone. We also maintain continuous interaction with a network of hepatologists and gastroenterologists who participate in regular patient education and networking events.
We are a non-profit organization, run by volunteers with strong regional and local support representatives across Canada.

Please write, phone or email us at:

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***FOLLOW US*:**
twitter: PBC_Canada
facebook: CanadianPBCSociety

DONATING

If you would like to contribute, there are multiple ways to donate:

- By mail
- By phone
- On our website

All donations contribute to PBC education, support, advocacy and research.

VOLUNTEERING

If you have time, we will be able to put your talents to good use!

We have a number of areas where individuals can offer support to PBC members, in either official language.

CCR No 88162 3904 ROOOI

June 2023

Canadian PBC Society

Here for you

DEDICATED TO SUPPORTING THOSE AFFECTED BY PRIMARY BILIARY CHOLANGITIS (PBC)

What is Primary Biliary Cholangitis (PBC)?

PBC is a chronic auto-immune condition that affects the liver. When a person has PBC, the immune system attacks the liver causing slow, progressive damage to the bile ducts. These bile ducts are designed to allow the flow of bile from the liver, so damage of these ducts leads to poor drainage of bile acids, known as cholestasis. The bile acids then leak from the bile ducts, damaging surrounding liver cells, which then causes further inflammation and scarring in the liver, which may, after many years, become extensive and lead to cirrhosis.

Who is affected by PBC?

PBC generally affects women between the ages of 40-60, but it is sometimes seen among younger women and some men as well. It's estimated that one in 1,000 women over the age of 40 will have PBC.

What causes PBC?

At present, the cause is unknown. PBC is thought to have an autoimmune component, likely triggered by an environmental factor in people who have a subtle genetic predisposition. It is not caused by alcohol consumption, but smoking appears to be a risk factor.

Researchers have identified genes that are associated with the development of PBC. These genes are also implicated in related autoimmune diseases that are often seen in patients and their families, such as celiac disease, rheumatoid arthritis and scleroderma. Studies are underway to assess the relevance of genes associated with PBC, but it will take some time to understand the role of individual gene candidates. Other studies are being performed to look at the possibility of environmental triggers such as bacteria, viruses and chemicals. No environmental agents have been confirmed to date.

What are the symptoms of PBC?

Individuals with PBC may experience mild or no symptoms; however, symptoms most commonly associated with PBC are:

- **Fatigue, independent of lack of sleep**
- **Itching (called pruritus by doctors)**

Other symptoms may include:

- **Dry eyes and dry mouth**
- **Vaginal dryness**
- **Dental issues**
- **Non-specific abdominal discomfort**
- **Restless legs**
- **Xanthomata, small white bumps under the skin, especially around the eyes**
- **Jaundice, a yellow discolouration of the skin and eyes (though this is now very rare)**

How is PBC diagnosed?

Diagnosis is made through blood tests, ultrasound and, less frequently, liver biopsy.

Blood test findings include:

- **AMA - antimitochondrial antibodies are found in approximately 90% of patients.**
- **Increased ALP - alkaline phosphatase, a common early finding.**
- **Increased GGT - gamma glutamyl-transpeptidase, another enzyme.**
- **Increased cholesterol levels.**
- **Serum bilirubin is often normal in the early stages. It is one of the most significant markers of progression.**

Liver biopsy may be performed, but the diagnosis can normally be made by blood tests alone.

How is PBC treated?

There are good treatments for the majority of people. A bile salt, ursodeoxycholic acid, (UDCA or Urso) has been shown to significantly slow progression of the disease. There does not appear to be any significant difference between generic Urso and the original Urso. For patients with insufficient response to UDCA, there are second-line treatments, including obeticholic acid (OCA or Ocaliva), which is licensed and reimbursed in Canada, and off-label use of bezafibrate.

Clinical trials are ongoing around the world with promising drug therapies used alone or in combination with Urso.

What is the prognosis of PBC?

For the most part, prognosis is very good. For a small proportion of patients that progress to cirrhosis and subsequently develop liver failure, a liver transplant may be needed. However, the need for transplants is becoming less frequent due to early use of UDCA and increasing use of second-line drugs such as obeticholic acid and bezafibrate.

What lifestyle changes may be helpful with PBC?

People with PBC are encouraged to live a healthy lifestyle. Fatigue can be a troublesome symptom, but pacing daily activities can help to maintain stamina and energy.

Your doctor may recommend that you exercise (walking, running, swimming etc.) and avoid being overweight. Other simple advice includes taking Calcium and Vitamin D supplements, proper skin care, regular dental examinations and artificial tears for dry eyes.

Alcohol can usually be consumed in moderation, if you do not have cirrhosis. Smoking is very bad for the liver and people with PBC who smoke may experience more scarring.

It is wise to consult with your doctor before taking any medication, including painkillers, over-the- counter drugs and herbal supplements. The liver is the body's most important drug metabolizing organ, so drugs must be taken with caution.

What questions should I ask my doctor about PBC?

It may be advisable to have a family member or friend accompany you, to take notes and remind you of what to ask. We suggest that you keep a running list of questions to ask your doctor at your next visit. Here are some potential questions to keep in mind.

- **What treatment do you recommend? Will this slow the progression of my disease?**
- **Have I responded to the treatment? Do I need any additional treatment?**
- **Do I have liver damage? If so, is their evidence of disease progression?**
- **Should I change my diet?**
- **Are there any supplements you would suggest that I take or avoid?**
- **What can be done to relieve my symptoms?**
- **Should I have my bone density checked?**