ABOUT US

The Canadian PBC Society was founded in 2003. Our mission is to provide support, information and education, and to raise funds for research iÛo primary biliary cholangitis.

We produce a newsletter, maiÛain a website and welcome participation and communication from everyone. We also maiÛain coÛinuous iÛeraction with a network of hepatologists and gastroeÛerologists.

We are a totally voluÛeer, non-profit organization. All of the money we collect goes toward information and communication, and financial support of research.

DONATING

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

- By mail
- By phone
- On our website

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.

Please write, phone or email us at:

CANADIAN PBC SOCIETY
4936 Yonge Street, Suite 221
ToroÛo, OÛario M2N 6S3

Phone: 416.440.0917
Toll-free: 1.866 441.3643
Email: info@pbc-society.ca

PBC-SOCIETY.CA

REGIONAL GROUPS

ATLANTIC CANADA
atlaÛic@pbc-society.ca

BRITISH COLUMBIA
bc@pbc-society.ca

MANITOBA
manitoba@pbc-society.ca

NORTHERN ALBERTA
albertaN@pbc-society.ca

ONTARIO & ALL OTHER AREAS
info@pbc-society.ca

QUEBEC
QuebecRep@pbc-society.ca

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Canadian PBC Society

Reaching for the Cure

A SUPPORT GROUP FOR PEOPLE WITH PRIMARY BILIARY CHOLANGITIS

What is Primary Biliary Cholangitis (PBC)?

PBC is a chronic and slowly progressing disease which results from inflammation of the small bile ducts in the liver. For some individuals, the inflammation leads to scarring 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 is seen in some younger women. Men can also have the disease. The ratio is 9 women to one man. A good estimate of its frequency is that 1 in 1000 women over the age of 40 have PBC.

What causes PBC?

At present the cause is unknown. PBC is thought to have an autoimmune basis, probably triggered by an environmental factor in a person with a subtle genetic predisposition. It is not caused by alcohol consumption. 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, often seen in patients and their families, e.g. celiac disease, rheumatoid arthritis, scleroderma. *Studies are being performed to assess the relevance of genes associated with PBC. However, 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 of PBC, such as bacteria, viruses and chemicals. No environmental agents have been confirmed to date.*

What are the symptoms of PBC?

Many individuals are without symptoms at diagnosis. The two most common symptoms are:

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

Other symptoms may include:

- **Xanthomata, small white bumps under the skin, especially around the eyes**
- **Jaundice, a yellow discoloration to the skin & eyes can also occur (this is now very rare)**
- **Sjorgens syndrome, dry eyes & dry mouth**
- **Dental issues**
- **Non-specific abdominal discomfort**

How is PBC diagnosed?

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

Blood test findings include:

- **AMA (antimitochondrial antibody) are found in approximately 90% of patients.**
- **Increased alkaline phosphatase (an enzyme) is the most 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 increasingly many doctors are not using it because the diagnosis can normally be made by blood tests alone. The stage of disease at presentation for the majority of people now is early, and therefore a biopsy doesn't help for the most part in working out the best treatment or follow up.**

How is PBC treated?

There are good treatments for the majority. A bile salt, ursodeoxycholic acid, (UDCA or Urso) has been shown to significantly slow progression of the disease. There doesn't appear to be any significant difference between generic Urso and the original Urso.

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 many individuals, the disease may remain silent (asymptomatic) and never become serious. Other patients may not manifest symptoms for decades. The response to Urso may predict the progression of disease. For a small proportion of patients that progress and develop liver failure, liver transplant may be needed.

What lifestyle changes may be helpful with PBC?

People with PBC are encouraged to live a normal lifestyle. Fatigue can be a troublesome symptom. Pacing daily activities will help 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, skin care, regular dental examinations and artificial tears for dry eyes.

Alcohol can usually be consumed in moderation. Smoking is very bad for the liver and people with PBC who smoke may have more scarring.

It is wise to consult with your doctor before taking any medication, including painkillers, over the counter drugs and herbal medications. 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 as they occur to you to ask at your next visit.

Questions

- **How severe is the liver damage?**
- **What treatment do you recommend? Will this slow the progression of the disease?**
- **Will any medication be prescribed? What are the side effects?**
- **Have I responded to the treatment and do I need any additional treatment should they become available?**
- **Should I change my diet?**
- **Are there any supplements you would suggest I take?**
- **What can be done to relieve my symptoms?**
- **If cirrhosis develops, is transplantation going to be needed?**
- **Is there a local hepatologist (specialist in liver disease) or gastroenterologist I should see who looks after people with PBC?**