Canadian
PBC Society

A Canadian PBC Patient Charter

What is a Patient Charter?

A common tool used by patient organizations, a Patient Charter is a document that outlines a number of elements of care to which patients have rights. By focusing these elements on the goal of improving care across jurisdictions, the Patient Charter is a tool to engage with governments, institutions, and the healthcare community. By advocating for the contents of the Charter to be implemented in provinces/territories across Canada, the patient community seeks to improve levels of care available, and to eventually find a cure for their disease.

Why is a Patient Charter important for Canada's PBC Community?

The Canadian PBC Patient Charter represents the most important issues to PBC patients, families and caregivers, as identified in our membership consultation during the summer of 2017. In developing the Charter, we have incorporated these issues into a document that acts as a 'call to action' for the entire health system – from government policymakers to private payers – to recognize the impact of PBC among those it affects, and make systemic changes to ensure that PBC patients can receive the best care possible, from coast to coast to coast.

What is PBC?

Primary Biliary Cholangitis (PBC) is a slowly progressive bile duct disease, which results from chronic inflammation of the small bile ducts, the system of small tubes in the liver that helps drain bile. For some people, the inflammation leads to bile duct loss and liver scarring which may, in time, lead to cirrhosis. Although the cause is unknown, PBC is thought to be a rare autoimmune disease where an individual has a genetic predisposition to the disease.

Researchers believe that PBC is likely triggered by a health or environmental factor and is not related to alcohol use. PBC occurs throughout the general population, but has a higher incidence among our First Nations coastal communities.

The main symptoms of PBC are

- Fatigue
- Itch
- Yellowing of skin (Jaundice)
- Dry eyes/mouth (Sjorgen's Syndrome)
- Small white bumps around eyes (Xanthomata)

PBC has no cure, and the road to diagnosis can be a long and challenging process. For those that respond to medication, a normal life expectancy can be achieved; for those that do not, life expectancy is reduced and the need for liver transplantation is increased. Morbidity and mortality rates may be worsened by the more limited access to specialists care in rural and remote locations in which some PBC patients live.

CANADIAN PBC PATIENT CHARTER

We believe that Canadians with PBC, along with their families and caregivers, have the right to:

1. Timely, accurate diagnosis and care
2. Increased educational resources for the medical community
3. Swift access to specialist care
4. Timely access to proven and approved treatments
5. High-quality and accurate information about PBC
6. Dedicated peer support programs
7. Equality in care levels across Canada
8. Improved public awareness of PBC
9. Timely access to professional psychological support
10. Protection against discrimination.

1. Timely, accurate diagnosis and care.

For those with PBC, a timely diagnosis in early disease stages may be life-altering. PBC patients often face uncertainty in the early stages of their disease, as initial diagnosis is difficult. This can be attributed to a range of factors, including insufficient diagnostic tests available and lack of knowledge by primary care providers. Providing medical professionals with education and tools across the health system will ensure accurate, timely diagnosis of PBC and will facilitate the best possible subsequent care plan.

2. Increased educational resources for the medical community.

Primary care physicians are the first point of contact in most PBC patients' journeys, yet they are often unaware of PBC and its symptoms. If front-line physicians are unable to accurately diagnose the disease, PBC patients are left with the risk of disease progression and irreversible liver damage. By providing enhanced education in rare autoimmune liver diseases like PBC, physicians will be better able to diagnose PBC earlier, ensuring that patients can be treated in a timely and effective manner.

3. Swift access to specialist care.

Being placed on a waiting list can have adverse effects on PBC patients. Too often patients are placed in lengthy queues for specialist appointments, while PBC may progress, causing irreversible liver damage. When treatment starts early in the disease course, there are better patient outcomes.

4. Timely access to proven, approved treatments.

One of the most important aspects of PBC is disease management. For years, only one treatment for PBC was available, and a significant number of patients did not respond adequately to it. With numerous new treatments being researched and made available, it is essential that people with PBC receive timely access to all approved treatments. The community also has the right to participate in clinical trials and experimental programs.

5. High-quality and accurate PBC information.

As PBC is a chronic, progressive disease, people living with PBC have the potential for their condition to deteriorate over time. It is vital to ensure that educational materials are made available to them, outlining information about PBC treatment options, disease management guidelines, and support programs available to them.

6. Dedicated peer-support programs.

A diagnosis of PBC can be devastating and confusing. Peer support groups help patients and their families to understand and navigate the journey of living their lives with this chronic, progressive disease. Peer support programs allow PBC patients to connect with each other, share their stories, creating a lifelong support network.

7. Equality in care levels across Canada.

Access to care can vary across the country. For PBC patients, this is problematic; regardless of where they live, patients deserve the same access to care, including regular check-ups, specialist visits and diagnostic and monitoring tools.

8. Improved public awareness of PBC.

Classified as a rare liver disease, PBC is not well-known. With little public awareness of their condition, people living with PBC struggle with the stigma associated with liver disease. The effects of this are wide-ranging and detrimental to the PBC community, leaving patients feeling vulnerable. By increasing awareness of PBC, its symptoms and the effects on patients and their loved ones, patients, families, and caregivers will be better served in their workplaces and communities.

9. Timely access to professional psychological support.

While the physical effects of PBC may be onerous, there is more to PBC than physical symptoms. PBC patients struggle with the psychological effects associated with PBC including social isolation, depression and anxiety. PBC patients need timely access to professional psychological support.

10. Protection against discrimination.

PBC patients may endure judgment and discrimination related to misconceptions about the nature and causes of PBC, specifically related to alcohol abuse. This may negatively affect the patient’s ability to get insurance, pursue a career, get a disability pension, and receive respectful medical care.

About the Canadian PBC Society

The Canadian PBC Society was founded in 2003 as a registered national charity. Our mission is to provide information and education and compassionate support to PBC patients and their families.

We are committed to finding a cure and as such we participate in and sponsor PBC research. We seek to bring awareness to Primary Biliary Cholangitis (PBC), its causes, symptoms, and treatment and to ensure early diagnosis and effective treatments for those living with PBC as we strive for a cure.

We are a volunteer organization with regional coordinators across Canada serving their communities by providing local support. All the money we raise goes toward our extensive information and education programs, as well as supporting PBC research.

How you can join the fight against PBC

- Contact your local MPP, MLA, or MNA to help raise awareness about PBC
- Donate to help find a cure at pbc-society.ca
- Find more information and join the conversation about PBC

Please write, phone or email us at:
CANADIAN PBC SOCIETY
4936 Yonge Street, Suite 221
Toronto, Ontario M2N 6S3
Phone: 416.440.0917
Toll-free: 1.866.441.3643
Email: info@pbc-society.ca

Follow us:
Twitter: PBC_Canada
Facebook: CanadianPBCSociety

Canadian
PBC Society