



The Case for a Canadian IPF Patient Charter

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www.cpff.ca

About the CPFF

Created in 2009, the Canadian Pulmonary Fibrosis Foundation is a registered Canadian Charitable Foundation established to provide hope and support for people affected by idiopathic pulmonary fibrosis (IPF).

The CPFF focuses on raising money to find causes and treatments for IPF, providing education and support for people affected by IPF, and helping answer those non-medical questions frequently asked by those suffering with the disease.

The CPFF is a not-for-profit charitable organization.

CPFF is the “Patient Voice” for PF

Vision

Our vision is make lung transplants the LAST resort for people with idiopathic pulmonary fibrosis (IPF) – not the ONLY resort.

Mission

Our mission is to raise funds to finance the research required to better understand, treat and find a cure for IPF.

Objectives

Our key objectives in the battle against IPF are to:

- Raise public awareness about this fatal disease
- Offer support to those affected by IPF
- Represent Canadians affected by IPF to government, healthcare professionals, the media and the public

Why a Charter? Why Now?

- Idiopathic pulmonary fibrosis (IPF) is a devastating disease to the patients who suffer from it and the caregivers and families that support.
- IPF has no cure, and life expectancy without a lung transplant averages 2-5 years from the date of diagnosis (although some patients have lived for up to 20 years).
- In order to help support IPF patients, their families and their healthcare providers, many countries are turning to **Patient Charters** to increase understanding of IPF and to define what world-class patient care looks like.
- **The CPFF believes the time is ripe for a Canadian IPF Patient Charter.**

Why a Charter? Why Now?

- The CPFF is proposing the creation and adoption of a ***Canadian Idiopathic Pulmonary Fibrosis Patient Charter*** as a way to call upon policymakers, healthcare providers, private payers and provincial governments to help campaign for greater awareness of IPF, establish equal and better standards of care and to improve the quality of and access to care across Canada
- The Charter lays down recommendations for provincial governments, Institutions and healthcare organizations that would ensure improvements in IPF patients' quality of life, while supporting efforts to develop better long-term treatments – and ultimately a cure

A Canadian Patient Charter

The CPFF believes that people with IPF and their families have the right to:

1. Equal levels of care and treatment across Canada based on the current best care practices;
2. Timely and accurate diagnosis and care involving an appropriately skilled, specialist multidisciplinary team;
3. Access to seamless, well-integrated health and social care services, including ambulatory and home oxygen services personalized to the needs of IPF patients;

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The CPFF believes that people with IPF and their families have the right to:

4. High quality and accurate information about the condition, including full details of all treatment, clinical trials, transplant, support and service provision options available to them;
5. Specialist palliative care and end-of-life care;
6. Access to dedicated peer support networks, both for patients and their caregivers, in person or remotely;

A Canadian Patient Charter

The CPFF calls upon Canadian governments and health care leaders to:

7. Increase funding for IPF research to a level that will tackle the considerable, and growing, impact of the disease in Canada;
8. Build and resource clinical networks to ensure seamless care between providers at all stages of the patient pathway, and a coordinated approach to IPF management – including access to clinical trials;

A Canadian Patient Charter

The CPFF calls upon Canadian governments and health care leaders to:

9. Recognize the urgency of need in patients with exacerbations and rapid disease progression, via swift access to specialist care, appropriate prioritization on transplant waiting lists, and prompt social care assessment and response; and
10. Conduct awareness campaigns to improve public and primary care recognition of the condition its symptoms and available treatments, and encourage employers and providers of insurance, travel and financial services to better meet the needs of people with IPF.

QUESTIONS?