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# Written Submission for the Pre-Budget Consultations in Advance of the Upcoming Federal Budget

Submitted by:  
Canadian Pulmonary Fibrosis Foundation

July 2023

## **List of CPFF Recommendations**

- 1. CPFF Recommendation: Improve the Lives of PF Patients with Dedicated Provincial Funding for Health Care Navigator Services**
- 2. CPFF Recommendation: Improve access to support for people with PF in rural, remote, and Indigenous communities**

## Introduction

The Canadian Pulmonary Fibrosis Foundation ([CPFF](#)) appreciates the opportunity to share its recommendations for the 2024 federal budget.

The CPFF is a registered Canadian Charitable Foundation established in 2009 to provide answers, hope and support for people affected by pulmonary fibrosis (PF). It educates and raises awareness about PF; raises funds to invest in research; and represents Canadians affected by PF to governments, healthcare professionals, the media and the public.

PF is a chronic lung disease that makes it progressively harder to breathe. There is no cure, and the prognosis is worse than many types of cancer (with a median survival as low as 5 years).

PF is a rare disease.

### **CPFF Recommendation #1: Improve the Lives of PF Patients with Dedicated Provincial Funding for Health Care Navigator Services**

#### *Context for this recommendation*

Navigating the health care system is hard enough for most people. But for those who fight for every breath every day, and who require home oxygen therapy to get through basic tasks, the last thing they need is the challenge of managing their home oxygen supply and equipment.

In the spring of 2022, CPFF asked Canadians living with PF to complete a survey about their experiences related to living with this rare disease, its impact on their life and what they need for the future. More than 640 people living with PF and their caregivers from across the country responded to our call and the results were summarized in the 2022 Breathless for Change Insight Report. In general, patients feel less able to manage their disease, caregivers are more stressed and depressed, visible minorities feel invisible to the health care system and access to timely oxygen therapy is an issue.

Some of the other findings from the survey:

- Diagnosis is lagging – one in three patients waited over three years for their diagnosis
- The treatment needs of PF patients grew in 2022 – over 1 in 3 are not effectively managing their PF, and 1 in 5 need counselling support; over 50% of visible minority patients feel this way
- Oxygen is unacceptably scarce – 20% of patients did not get an oxygen therapy prescription when needed; 75% of patients did *NOT GET NEEDED OXYGEN* the day it was prescribed and 50% waited a week or more

A PF Healthcare Navigator will assist PF patients:

- Navigate provincial healthcare systems and act as an educational resource
- Manage the various issues around oxygen therapy, including an understating of coverage, eligibility and renewal requirements and requesting changes to their oxygen therapy
- Advance their understanding of how oxygen therapy can be incorporated into daily living and to maintain a high standard of living
- Access the vital supports they need, such as mental health and counselling services.
- Access culturally appropriate programs and services
- Who may live in rural and remote areas of the province, including First Nations communities

**CPFF Recommendation #2: Improve access to support for people with PF in rural, remote, and Indigenous communities**

*Context for this recommendation*

As noted in the 2022 Breathless for Change Insight Report, access to treatment of PF for some is restricted due to a lack of coverage or their remote location. In fact, around 10% reported that their remote location resulted in not receiving anti-fibrotic drug therapy, physiotherapy, or counselling/emotional support.

The CPFF's first recommendation to improve access to supports for people living with PF is for Budget 2024 to include dedicated funding to provincial healthcare systems to **establish more patient support groups in rural, remote, and Indigenous communities.**

**Increasing the number of healthcare professionals with knowledge of interstitial lung diseases** (ILD) like PF is also strongly recommended. The CPFF's fellowship and internship program could be used to train physicians who are interested in furthering their knowledge of PF and working alongside respirologists in communities and ILD centres across Ontario.

We would be pleased to submit a more detailed proposal to support our recommendations. For more information, please contact **Ms. Sharon Lee, Executive Director of the CPFF at [sharon@cpff.ca](mailto:sharon@cpff.ca) or 416-903-6925.**