

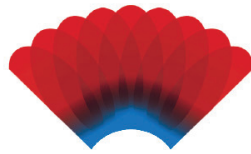
BRITISH COLUMBIA



Canadian
Pulmonary Fibrosis
Foundation

2024 ELECTION ADVOCACY TOOLKIT





Canadian
Pulmonary Fibrosis
Foundation

Dear supporters in British Columbia,

As you are aware, British Columbia's general election is scheduled for October 19, 2024 to elect members of the Legislative Assembly to serve in the 43rd parliament.

This election provides an opportunity for the Canadian Pulmonary Fibrosis Foundation (CPFF) and its supporters in British Columbia to **communicate to all parties and candidates our key messages and recommendations for good public policy as it relates to pulmonary fibrosis (PF)** as a rare disease and the need for equitable access to oxygen therapy and pulmonary rehabilitation.

This toolkit has been designed to provide you with **a simple and practical way to communicate** CPFF's key messages by printing off the handy key message documents on Pages 4-7, and sharing them with candidates in your riding and at local events like debates and town hall meetings. You may also want to keep the one-pagers handy near your front door to share with any candidates canvassing in your neighbourhood. It's an easy way to raise PF's profile among election candidates and political parties!

It is only with the tremendous efforts of **people like you** that we can ensure that Canadians across the country living with PF have access to the supports they need. Your advocacy and willingness to engage with your election candidates is just one way to achieve this. It is also very much appreciated, and on behalf of everyone here at the national office, I want to **thank you for your advocacy, your passion, and your commitment!**

But our work is not done, and the provincial election in British Columbia is an opportunity to **raise awareness of PF** as a rare disease and the challenges faced by people living with it.

Thank you again for your advocacy work and support of CPFF!



Sharon Lee
Executive Director
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Tel: 416-903-6925

BC ELECTION ADVOCACY TOOLKIT

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ABOUT THE 2024 BC ELECTION

There are several websites and resources to learn more about the 2024 British Columbia general election, including party candidates and policy positions, as well as local events such as townhalls and debates. Some of these are listed below.



ELECTIONS BC Province of British Columbia

Elections BC “administers provincial general elections, by-elections, recall petitions, initiative petitions, initiative votes, referenda and plebiscites, and oversees campaign financing and advertising rules at the local level.”

Click on the underlined blue links to go to the corresponding websites.



[Registering to vote](#)

[Candidate list](#)

[Find your electoral district](#)

[2024 Provincial election maps](#)

[Registered political parties](#)

[Current party standings in the BC Legislature](#)

ABOUT THE CANADIAN PULMONARY FIBROSIS FOUNDATION (CPFF)

The Canadian Pulmonary Fibrosis Foundation (CPFF) is Canada's **ONLY** national organization supporting people affected by pulmonary fibrosis. The CPFF was created to raise money to research causes and treatments for PF, provide education and support for people affected by PF and their caregivers, raise awareness about PF, and represent Canadians affected by PF to governments, healthcare professionals, the media, and the public.

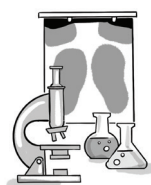
SUPPORT



EDUCATE



RESEARCH

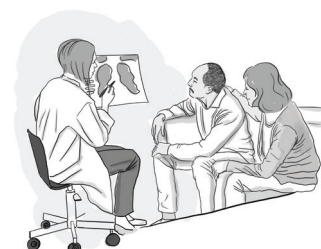


ADVOCATE



What is pulmonary fibrosis?

Pulmonary Fibrosis (PF), is a rare disease in which the lungs become scarred. Over time, normal lung tissue is destroyed, making them unable to provide the body with sufficient oxygen. Although currently there is no cure, many people living with PF can be helped with proper treatment and for some, lung transplantation.



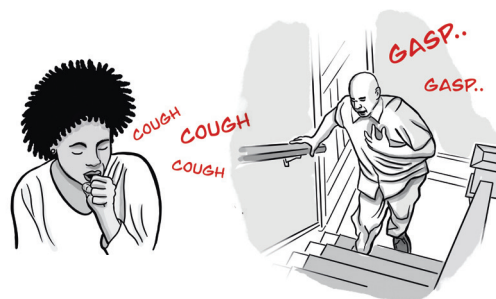

2
YEARS
*for a confirmed
diagnosis on average*

Many patients face barriers

PF suffers from limited awareness among the public and even among healthcare professionals, with a patchwork approach across Canada. Too many patients face years-long delays in accessing specialists due to unequal access to respirologists across the country and/or needed referrals from primary care physicians.

What are the symptoms?

Progressively worsening shortness of breath to complete tasks requiring exertion and/or a persistent cough are common symptoms.



BARRIERS TO ACCESSING OXYGEN IN BRITISH COLUMBIA AND CPFF'S RECOMMENDATIONS

1

Inconsistencies across health authorities - *Though BC residents may travel to and receive care in any health authority, there is inconsistency in qualifying for supplemental oxygen therapy among them.*

- ▶ Patients need to qualify for oxygen therapy in their health authority. This may cause confusion because patients may find themselves at a hospital outside their health authority where clinicians may be unaware of differences in qualifying criteria among authorities.
- ▶ For patients who require oxygen for ambulation, there may be differences in the process used by clinicians when conducting a walk test. While some clinicians will walk patients for 6 full minutes, others may do so until a blood oxygen level of <88% for 1 minute is reached. The length of the test impacts the total distance walked. Consequently, the distance walked with supplemental oxygen, which can often show improvement, is also affected.

CPFF recommendation – ensure consistency across all health authorities in the interpretation of qualifying criteria and when conducting tests.



2

Home oxygen - *Someone may receive supplemental oxygen when in the hospital but may not necessarily be qualified to receive it at home.*

- ▶ Hospitals generally give oxygen to keep O2 >92%.
- ▶ To qualify for resting home oxygen, the patient must meet certain criteria. This often means that a patient will be given oxygen while in hospital and then be sent home without.

CPFF recommendation - patients who require and are provided oxygen at the hospital also be qualified to receive at-home oxygen.



3

Pulmonary rehabilitation (PR) - *Lack of access to PR is a barrier to healthy living.*

- ▶ Most PR programs in British Columbia are offered at larger hospitals and have long wait lists, which serves to restrict access to many residents in BC, particularly those outside major cities.
- ▶ Patients are not generally referred to PR upon diagnosis, but only when the disease progresses. PR teaches self-management, healthy living strategies, breathing techniques, secretion clearance, energy management, exercise and many other tools that will help people to stay healthy, reduce exacerbations, and stay out of hospital.

CPFF recommendation - everyone diagnosed with a chronic lung condition should be referred to and have access to a PR program in their area.

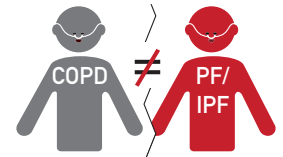
BARRIERS TO ACCESSING OXYGEN IN BRITISH COLUMBIA AND CPFF'S RECOMMENDATIONS

4

Chronic Obstructive Pulmonary Disease

- ▶ The qualifying criteria for supplemental oxygen for PF is based on COPD and were based on mortality studies rather than on quality of life.

CPFF recommendation – research is needed to assess oxygen levels, quality of life differences and reduction in hospital visits for various lung conditions such as COPD, pulmonary fibrosis, etc.



5

After qualifying for oxygen

- ▶ Rules concerning the equipment required (prongs, regulators, etc) are overly restrictive; people can only have two oxygen systems - e.g. if they have one large concentrator at home, and one portable concentrator for excursions, they cannot also get tanks. For those who enjoy traveling, this may pose a problem as they may require a different device.
- ▶ Only a certain number of tanks are provided; if too many are used, they may be required to pick up the tanks themselves, or they must restrict their activities so they don't use as much oxygen and run out completely
- ▶ Funding only covers use of oxygen when outside of the home and not for activities inside the home.

CPFF recommendation – Oxygen for ambulation should be provided for ambulation regardless of location, either within the home or outside the home.

6

Qualifying criteria for exertional oxygen

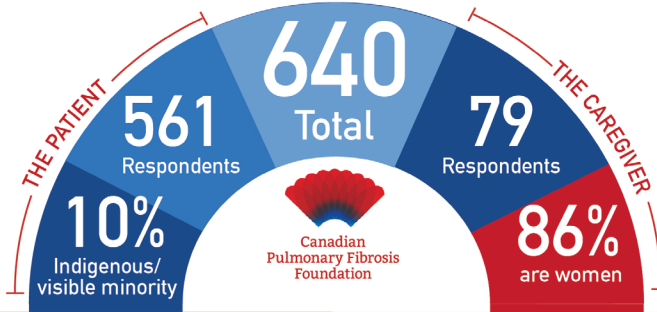
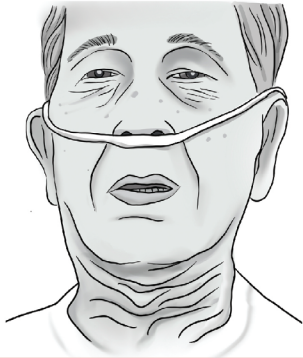
- ▶ Oxygen saturation is a vital parameter to define blood oxygen content. For adults, the normal range is 95 – 100%. A value of less than 90% is considered low oxygen saturation.
- ▶ To qualify for exertional oxygen in British Columbia, oxygen saturation must be at 80% or lower.

Long term exertional oxygen should be funded when a person's oxygen saturation drops below 88% for at least one minute while walking (same criteria as short term exertional oxygen).

Physical exertion - exertional oxygen should be funded when the oxygen saturation drops below 88% and remains at that level for one minute of exercise (resistance training and aerobic activity) to allow clients to maintain a healthy active lifestyle and decrease sedentary time. This recommendation is per the Canadian 24-hour Movement Guidelines and is meant to achieve lower risks of mortality, cardiovascular disease, hypertension, type 2 diabetes, several cancers, anxiety, depression, dementia, weight gain, and adverse blood lipid profile. The benefits include improved bone health, cognition, quality of life and physical function.

BREATHLESS FOR CHANGE

2022 PATIENT & CAREGIVER SURVEY HIGHLIGHTS



DIAGNOSIS IS STILL LAGGING

TREATMENT NEEDS GREW IN 2021-2022



patients waited **OVER 3 YEARS** for their diagnosis



patients are **NOT EFFECTIVELY MANAGING** their PF.

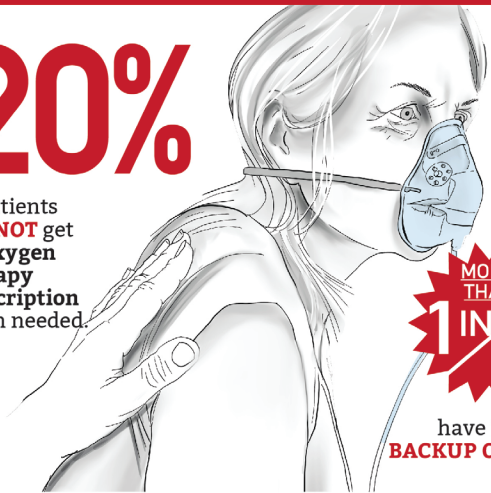


of visible minority patients feel this way.

OXYGEN IS SCARCE

20%

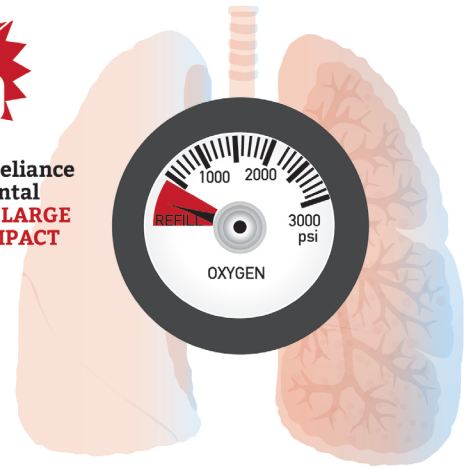
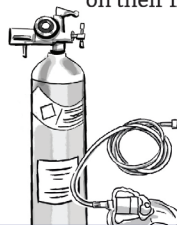
of patients **DID NOT** get an oxygen therapy prescription when needed.



have **NO BACKUP OXYGEN**



patients say **reliance on supplemental oxygen** has a **LARGE NEGATIVE IMPACT** on their life.



HEAVIER DEMANDS ON CAREGIVERS



caregivers are **no longer able** to work and do all their activities.



caregivers who spend **4+HOURS/DAY** caregiving.



SAMPLE EMAIL TO CANDIDATES TO REQUEST A MEETING

Subject: Constituent meeting request re: British Columbians living with Pulmonary Fibrosis

Dear Mr./Ms./Dr. [Last Name],

I am writing to request a brief meeting to introduce you to the work of the Canadian Pulmonary Fibrosis Foundation (CPFF) and the challenges faced by British Columbians living with pulmonary fibrosis (PF), a rare disease.

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).

I would appreciate 15 to 20 minutes to learn more about your views as they relate to healthcare in British Columbia and how the healthcare system can best serve British Columbians living with or caring for someone living with PF.

Please let me know when would be best for your schedule.

Thank you,

[Your name]

[Your postal code]

DELIVER CPFF'S KEY MESSAGES

DELIVERING CPFF'S KEY MESSAGES

Now that you have secured a meeting with a candidate, the meeting should be focused on educating them on CPFF as a patient-focused organization and our key messages. You are encouraged to use any, or all, of the pages included in this package, to deliver the key messages in meetings with candidates. CPFF encourages volunteers and supporters – provided they feel comfortable doing so – to share their personal stories and lived experiences as they relate to the subjects being discussed. Perhaps you can share your challenges with accessing needed supports like oxygen or other therapy, or navigating the healthcare system for a loved one with PF.

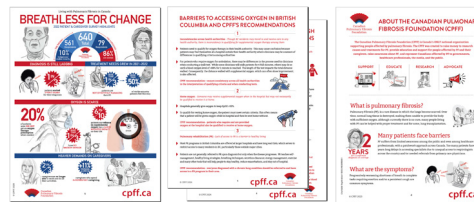
THE MEETING



Introduce yourself and why you wanted to meet – e.g. to share your experience as someone living with or caring for someone living with PF; the unique challenges faced by people with PF such as having difficulty breathing, etc.



Mention your involvement with CPFF



Focus on delivering the points from the one-page documents and relating them back to why they are important to you



Ask if the candidate has any questions

Let them know that you would be happy to provide any additional information and that more information is available at cpff.ca.

SAMPLE FOLLOW-UP EMAIL/LETTER

After meeting with a candidate, express your appreciation for their time by sending a follow-up email or letter. This is also another opportunity to emphasize the key issues you spoke about in your meeting. Feel free to personalize this thank you by including more details about what you discussed in your meeting:

Subject: Thank you for making time for this important issue.

Dear Mr./Ms./Dr. [Last Name]

I would like to thank you for taking the time to learn more about the CPFF and the issues faced by people living with or caring for people living with pulmonary fibrosis, which is a rare disease.

I also want to encourage the new government to assess how British Columbians with PF can best be supported and how to use the new federal strategy on drugs for rare diseases to raise the profile of PF as a rare disease and the need to cover the drugs and therapies to treat it.

I greatly appreciate your time, and if I can provide any additional information, please do let me know.

Sincerely,
[Your name]

APPENDIX

BRITISH COLUMBIA HEALTH RESOURCES

[BC Home Oxygen Program - Medical eligibility](#)

REGIONAL HEALTH AUTHORITIES:

VANCOUVER COASTAL HEALTH

[Home Oxygen Program](#)

FRASER HEALTH AUTHORITY

[Home Oxygen Program](#)

INTERIOR HEALTH

[Home Oxygen Program](#)

ISLAND HEALTH

[Home Oxygen Program](#)

NORTHERN HEALTH

[Home Oxygen Program](#)

THERE ARE 5 HOME OXYGEN PROVIDERS IN BC THAT COVER THE PROVINCE'S 5 HEALTH AUTHORITIES:

[VitalAire*](#)

[Respiratory Homecare Solutions](#)

[MedPro Respiratory Care*](#)

[Medigas](#)

[Lakeside Medical Supplies](#)

*Liquid oxygen available