



Canadian
Pulmonary Fibrosis
Foundation



2023 ELECTION ADVOCACY TOOLKIT





Dear supporters in Alberta,

As you are aware, the Alberta general election will be held on May 29, 2023. The campaign period commenced on May 1 and will last 28 days.

This election provides an opportunity for the Canadian Pulmonary Fibrosis Foundation (CPFF) and its supporters in Alberta **to communicate to all parties and candidates an overview of 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.

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 one-pagers on pages 4-6, and sharing them with local election candidates in your riding and at local events like debates and townhalls. 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 Alberta 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!



A handwritten signature in black ink, appearing to be "SML".

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ALBERTA ELECTION ADVOCACY TOOLKIT

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ABOUT THE 2023 ALBERTA ELECTION

There are several websites and resources to learn more about the 2023 Alberta general election, including party candidates and policy positions, as well as local events such as townhalls and debates. Some of these are listed below.



TIP!

the information on the party websites will likely change daily, so bookmark these websites!



ELECTIONS ALBERTA

Elections Alberta is an independent, non-partisan office of the Legislative Assembly responsible for administering provincial elections, by-elections and referenda. It administers the Election Act and the provincial electoral process in this province, and is responsible for administering elections at the provincial level.

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



[Elections Alberta](#)

[Registering to vote](#)

[Members of the Legislative Assembly of Alberta](#)

POLITICAL PARTIES AND CANDIDATES



[Registered political parties in Alberta](#)



[United Conservative Party \(UCP\)](#)

[Platform](#)

[Candidates](#)



[Alberta NDP](#)

[Commitments](#)

[Candidates](#)



Alberta Party

[Alberta Party](#)

[Vision](#)

[Candidates](#)



[Alberta Liberal Party](#)

[Vision](#)

[Candidates](#)



[Wildrose Independence Party of Alberta](#)

[Platform](#)

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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.



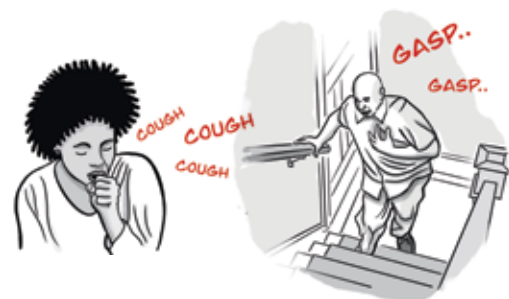

2
YEARS
*for a confirmed
diagnosis on average*

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.



OXYGEN IS SCARCE



People living with PF and other diseases that make breathing difficult experience shortness of breath as the disease progresses. Many describe the feeling like trying to breathe through a drinking straw, while others mention being ‘tethered’ to their supplemental oxygen source.

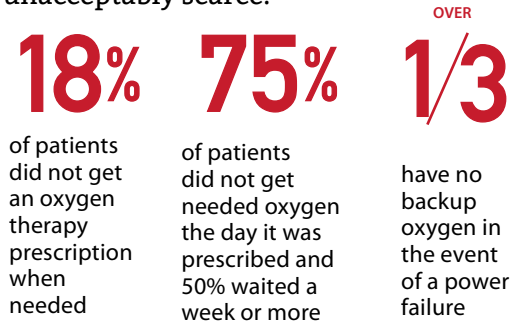


For people living with PF, oxygen is essential as soon as they need it. And yet, getting enough oxygen in a timely manner is not assured.



Patients and Caregivers Survey

CPFF’s 2022 survey of Canadians living with PF found that oxygen is unacceptably scarce:



CPFF RECOMMENDATIONS ON OXYGEN

1

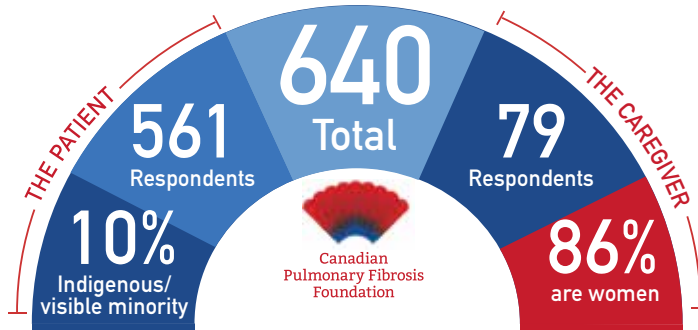
All Albertans that require supplemental oxygen **should have access that is not affected by their location**, whether urban, rural, or remote. CPFF recommends that programs such as Alberta’s Aids to Daily Living (AADL) Respiratory Benefits program are reviewed with a focus on developing and implementing strategies to improve access to oxygen by people in rural, remote and Indigenous communities.

2

The federal government’s recent announcement of a strategy on drugs for rare diseases offers provincial governments the opportunity to **negotiate a set of new and emerging drugs for which coverage would be cost-shared and consistent across the country**. CPFF recommends the next Alberta government use these negotiations to address issues of access to oxygen as well as drugs for medical therapy for pulmonary fibrosis, which is a rare disease.

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.

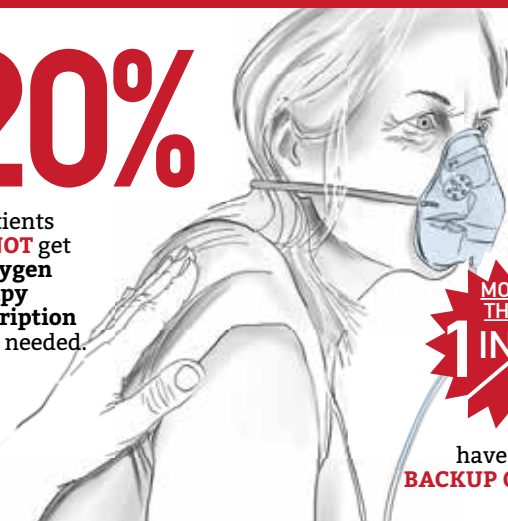


of visible minority patients feel this way.

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.



Canadian Pulmonary Fibrosis Foundation

cpff.ca

SAMPLE EMAIL TO CANDIDATES TO REQUEST A MEETING

Subject: Constituent meeting request re: Albertans 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 Albertans 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 Alberta and how the healthcare system can best serve Albertans 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

THE MEETING

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 three one-pagers, which are 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.



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 Albertans 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

BACKGROUND INFORMATION ON THE ALBERTA AIDS TO DAILY LIVING RESPIRATORY BENEFITS PROGRAM

This program provides oxygen and bi-level positive airway pressure (BPAP) respiratory benefits funding to Albertans living in their homes or supported living facilities.

The program helps Albertans with a long-term disability, chronic illness, or terminal illness stay independent at home or in a supported living facility by providing financial assistance for respiratory equipment and supplies.

Respiratory benefits include oxygen, ventilators, tracheotomy tubes, suction equipment and supplies, and (BPAP) devices. AADL does not provide funding for continuous positive airway pressure (CPAP) machines or supplies.

- The program for respiratory benefits in Alberta provides reimbursement for oxygen costs up to 100% for residents that meet medical criteria
- Financial income of the individual is not considered
- Funding is not disease-specific, and will be provided if medical criteria is met
- Periodic renewals are required to ensure that the patient remains medically eligible for home oxygen

ELIGIBILITY

To access this program, you must:

- be an Alberta resident with a current Alberta Health Care card
- have a long-term disability, chronic illness, or terminal illness
- not be eligible for these types of benefits from another source

SERVICE ACCESS

A healthcare provider or contract AADL (Alberta Aids to Daily Living) specialty supplier will assess what benefits clients are eligible for through the program. Respiratory providers can access resources on the Alberta Blue Cross website.

WAIT TIMES

An estimated wait time will be provided at the time of appointment booking.