

Canadian

Foundation

## **SASKATCHEWAN** 2024 ELECTION **ADVOCACY TOOLKIT Pulmonary Fibrosis**



Dear supporters in Saskatchewan,

As you are aware, the Saskatchewan general election is scheduled for October 28, 2024 to elect members to the Legislative Assembly of Saskatchewan.

This election provides an opportunity for the Canadian Pulmonary Fibrosis Foundation (CPFF) and its supporters in Saskatchewanto communicate to all parties and candidates our key messages and recommendations for good public policy as is 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 key message documents on Pages 4-6, 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 Saskatchewan is an opportunity to raise awareness of PF as a rare disease and the challenges faced by people living with it.

1

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

Sharon Lee
Executive Director
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### SASKATCHEWAN ELECTION ADVOCACY TOOLKIT

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# ABOUT THE 2024 SASKATCHEWAN ELECTION

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





Elections Saskatchewan is an independent office of the Legislative Assembly, created to plan, organize, deliver and regulate provincial electoral events for the people of Saskatchewan.

Click on the <u>underlined</u> blue links to go to the corresponding websites.



Voter registration
Voting requirements
Find your constituency
2024 provincial election maps

#### **POLITICAL PARTIES AND CANDIDATES**



Buffalo Party of Saskatchewan (BPSK)



New Democratic Party, Sask.
Section (New Democratic Party
(N.D.P.)



Progressive Conservative Party of Saskatchewan (PC Party of Saskatchewan)



<u>Saskatchewan</u> <u>Green Party (SGP)</u>



Saskatchewan Party (Saskatchewan Party)



Saskatchewan Progress
Party (Sask Progress)



Saskatchewan United
Party (Sask United
Party)



# 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.



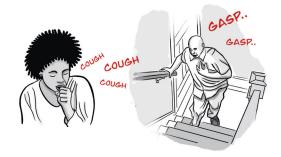


## Many patients face barriers

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.



cpff.ca

## ACCESS TO OXYGEN IN SASKATCHEWAN: CPFF RECOMMENDATIONS

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.

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

18% 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 Over 1 in 3 have no backup oxygen in the event of a power failure

#### General Recommendations

1

All Saskatchewanians 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 the Saskatchewan Aids to Independent Living (SAIL) Home Oxygen Program are reviewed with a focus on developing and implementing strategies to improve access to oxygen by people in rural and remote communities.

2

The federal government's 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 Saskatchewan 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.







Living with Pulmonary Fibrosis in Canada

## BREATHLESS FOR CHANGE

2022 PATIENT & CAREGIVER SURVEY HIGHLIGHTS



Respondents
10%
Indigenous/
visible minority

640 Total

Canadian Pulmonary Fibrosis Foundation 79
Respondents

86%
are women



#### **DIAGNOSIS IS STILL LAGGING**



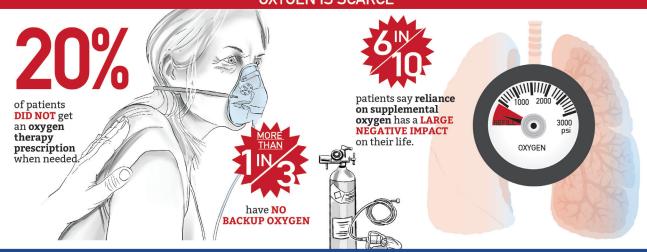
#### TREATMENT NEEDS GREW IN 2021-2022



patients are
NOT EFFECTIVELY MANAGING
their PF.

of visible minority patients feel this way.

### **OXYGEN IS SCARCE**



#### **HEAVIER DEMANDS ON CAREGIVERS**





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







# SAMPLE EMAIL TO CANDIDATES TO REQUEST A MEETING

Subject Constituent meeting request as Cochetch evening living with Dulmanam Fibracia
Subject: Constituent meeting request re: Saskatchewanians 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 Saskatchewanians 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 Saskatchewan and how the healthcare system can best serve Saskatchewanians 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 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 subject areas being discussed in the meeting. 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 onepage 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**

### SASKATCHEWAN HEALTH RESOURCES

Saskatchewan Aids to Independent Living program
Oxygen therapy
Using Oxygen Therapy at Home
Saskatchewan Health Authority
Lung Saskatchewan