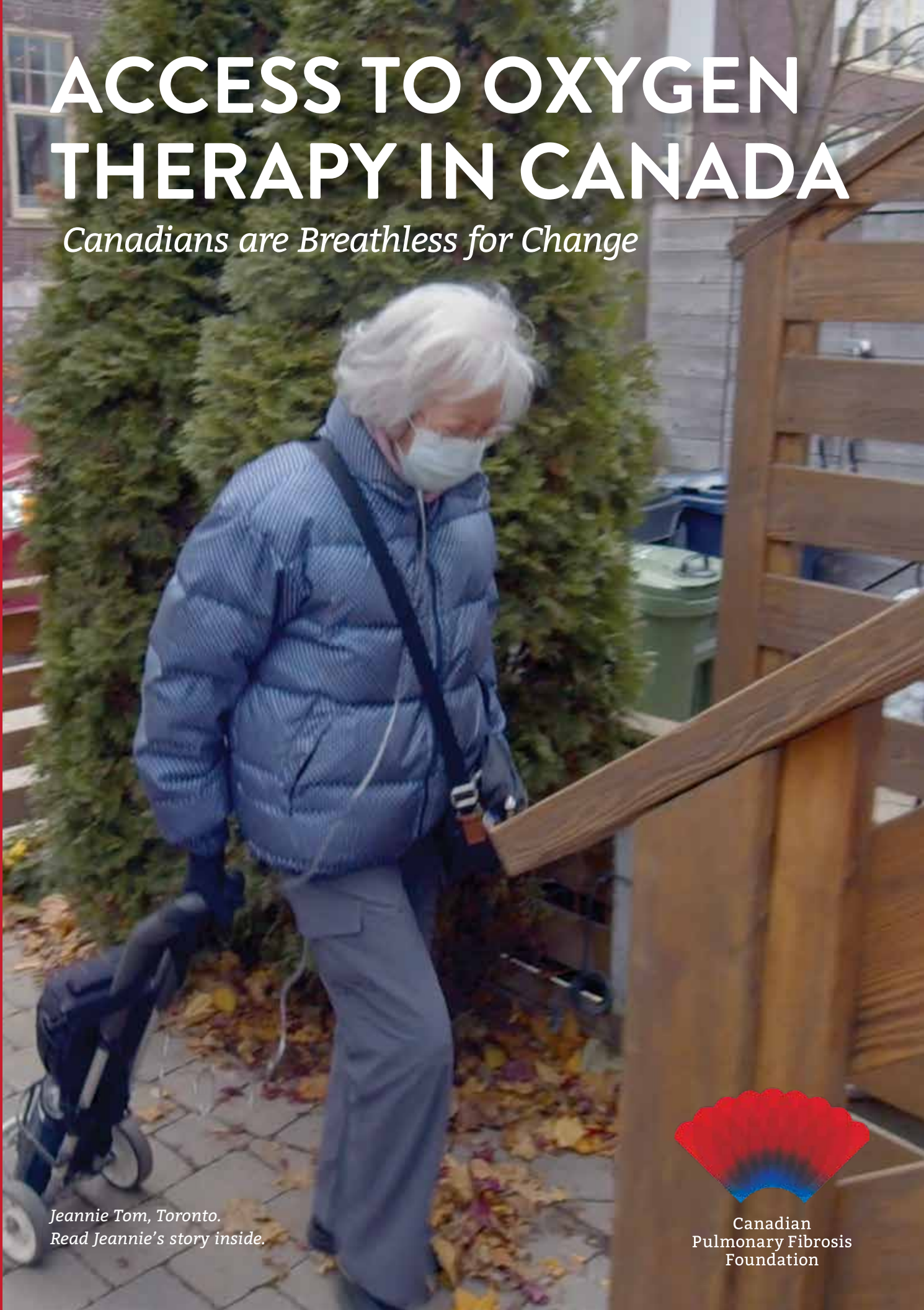




ACCESS TO OXYGEN THERAPY IN CANADA | 2023 REPORT

ACCESS TO OXYGEN THERAPY IN CANADA

Canadians are Breathless for Change



*Jeannie Tom, Toronto.
Read Jeannie's story inside.*



Canadian
Pulmonary Fibrosis
Foundation



“I had to fight to get oxygen supplies.”
PATIENT

1 IN 5

PATIENTS WERE UNABLE TO RECEIVE AN OXYGEN THERAPY PRESCRIPTION WHEN NEEDED

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A 360° VIEW

In 2022 the Canadian Pulmonary Fibrosis Foundation (CPFF) asked Canadians living with pulmonary fibrosis (PF) and their caregivers to complete a survey about the impact of the disease on their lives, and their needs for the future. Many of our respondents felt worse off in 2022 than they did in 2020. One issue, above all others, demanded further attention: **timely and equitable access to home oxygen therapy.**

Breathing is a fundamental human right. Home oxygen therapy is crucial for people with PF to exercise that right. And yet, twenty per cent of respondents did not get an oxygen therapy prescription when needed. Six in ten said that supplemental oxygen had a large negative impact on their lives. More than a third have no backup oxygen in the event of a power failure. While some of these increasing gaps in care during the past three years might be attributable to the pandemic, it cannot account for them all.



Patients and Caregivers



Healthcare Professionals



Oxygen Providers

To understand all aspects of this issue, we knew we needed to do more. CPFF commissioned **two groundbreaking national research surveys – with medical professionals and with oxygen providers**, to gain their valuable perspectives. Additionally, a collective of prominent physicians including Dr. Kerri A. Johannson (*Department of Medicine, Department of Community Health Sciences, and Interstitial Lung Disease Program, University of Calgary*) undertook a **detailed review of the issues at hand** that guide (and restrict) access to oxygen therapy for patients in need.

Insights were gathered from all of these sources in this comprehensive **O2 Access in Canada Summary Report**. We are grateful to all who stepped up to participate and share their valuable expertise. Our research confirmed what patients and others have been telling us for years: access to oxygen varies dramatically across Canada. Medical criteria to qualify for oxygen therapy vary widely, frustrating patients, caregivers, medical professionals, and oxygen providers alike. People with PF must navigate a patchwork system with few supports. Canada can, and must, do better.

One of CPFF's four pillars, advocacy, requires specialized knowledge, skills, and a facts-based approach. This data-rich report provides us with valuable proof to advocate for the oxygen therapy needs of people living with PF.

The time to act is now.

Patients and medical professionals are speaking out about the **barriers to oxygen therapy access** and needed improvements. As the voice of pulmonary fibrosis patients across Canada, CPFF is dedicated to working with all stakeholders to make meaningful change for more equitable access to oxygen. **No Canadian should be left without the treatment they need to breathe.**

To learn more about pulmonary fibrosis and CPFF, please visit our website: cpff.ca

Kirk Morrison
Board Chair

Sharon Lee,
Executive Director



RESEARCH & PARTICIPANTS

THREE CPFF SURVEYS



Patients and Caregivers



Healthcare Professionals



Oxygen Providers

PHYSICIAN RESEARCH OF O2 ISSUES



OBJECTIVE & METHODOLOGY

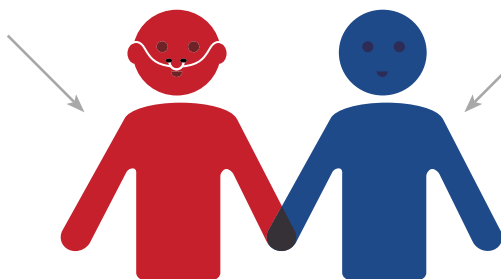
CPFF's objective with this research is to provide insights to help us advocate for better access to home oxygen therapy for patients living with PF. Insights were gathered from three CPFF surveys and research from clinicians with specific expertise in managing patients with PF.

Survey respondents were identified through CPFF's database and network across all Canadian provinces and territories, and were solicited through CPFF's communication channels (newsletter, social media, and associations).

640

PULMONARY FIBROSIS PATIENTS AND CAREGIVERS

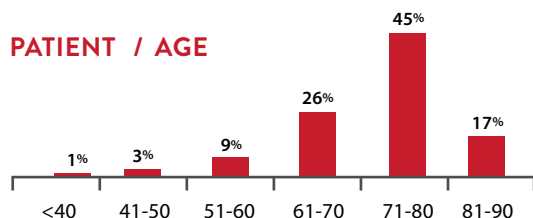
561
PATIENTS



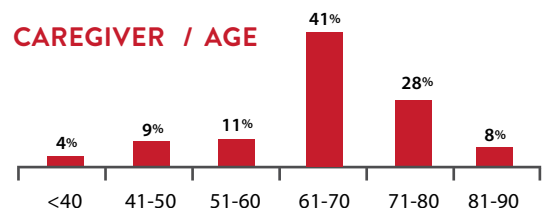
79
CAREGIVERS

Since our last survey in 2020 conditions for pulmonary fibrosis patients have worsened in all parts of the country. Most caregivers are women over 60 caring for patients who are older on average than in previous CPFF surveys.

PATIENT / AGE

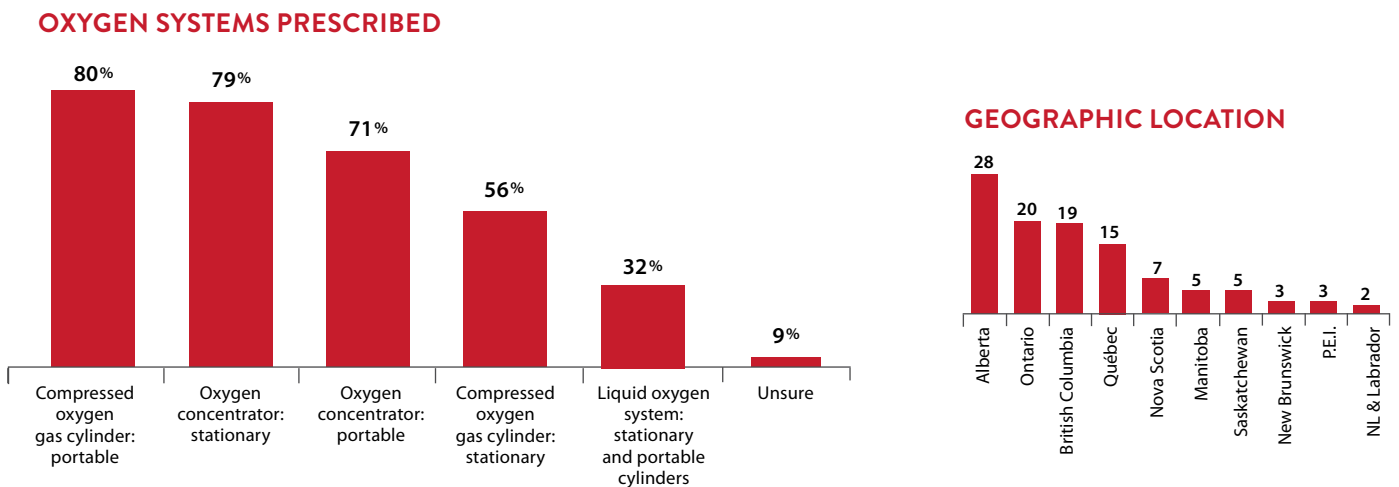
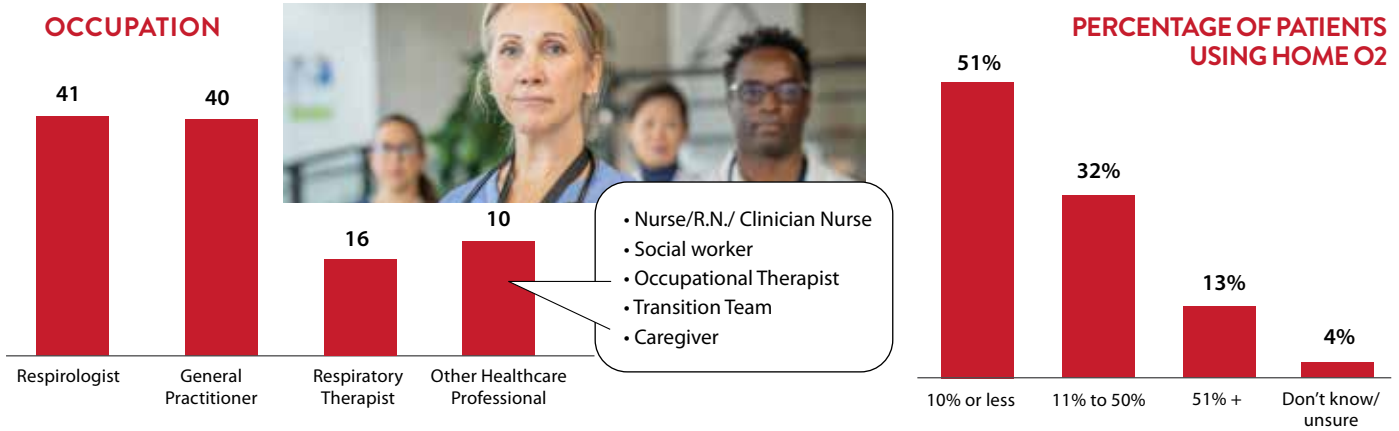


CAREGIVER / AGE



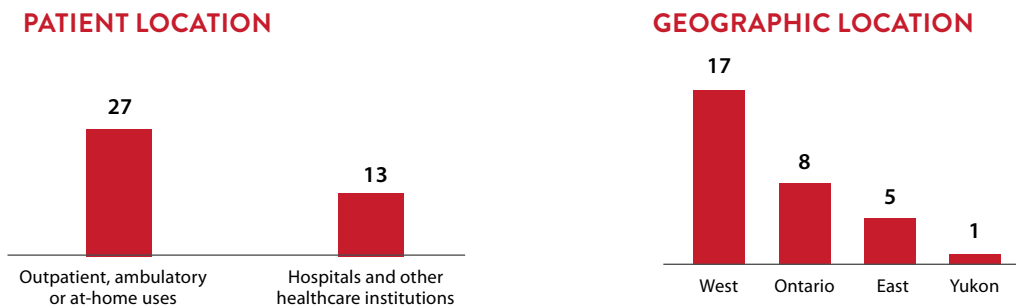
HEALTHCARE PROFESSIONALS

Respirologists, general practitioners, respiratory therapists, and other healthcare professionals are frustrated by how patchwork reimbursement systems and qualifying medical criteria limit their ability to provide optimal care.



OXYGEN PROVIDERS

Oxygen providers are professionals on the front lines of oxygen therapy. Their direct contact with patients allow them an unparalleled look into the realities faced by people living with PF.



“We need more government funding for pulmonary fibrosis treatment. I feel it’s left behind on quicker access to treatment and transplant in comparison to other serious, deadly diseases.

It’s a long delay for such a deadly disease, which is a death sentence”

PULMONARY FIBROSIS PATIENT

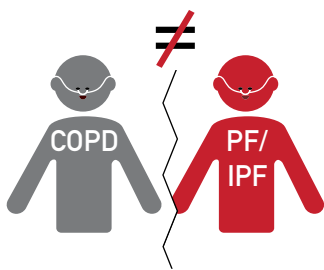


LEARNING HIGHLIGHTS



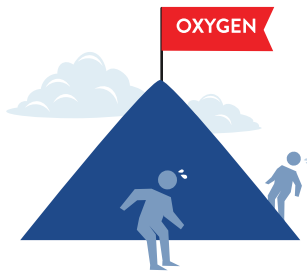
OXYGEN ACCESS IS INSUFFICIENT FOR PULMONARY FIBROSIS PATIENTS

Most pulmonary fibrosis patients will require oxygen therapy to support breathing, but the current patchwork of policies across the country creates barriers for some.



QUALIFYING FOR OXYGEN THERAPY IS DIFFICULT

Medical criteria to qualify for oxygen therapy are rigid or unsuitable, relying on testing protocols based on the needs of those with COPD. With exertion, PF patients require more oxygen. Physicians are scarce in rural/remote areas and eastern Canada.



WHERE YOU LIVE IN CANADA DETERMINES WHAT YOU GET

Differing provincial guidelines create inequity. Where you live in Canada determines what percentage of home oxygen therapy costs are reimbursed. Fourteen percent of pulmonary fibrosis patients say they pay at least some of their oxygen costs out-of-pocket, which can be thousands of \$\$\$ per year.



PULMONARY FIBROSIS PATIENTS IN CANADA HAVE A RIGHT TO:

- Disease-specific qualifying criteria.
- Reimbursement for all.
- O2 in all communities.

1 IN 2

OXYGEN ACCESS IS INSUFFICIENT

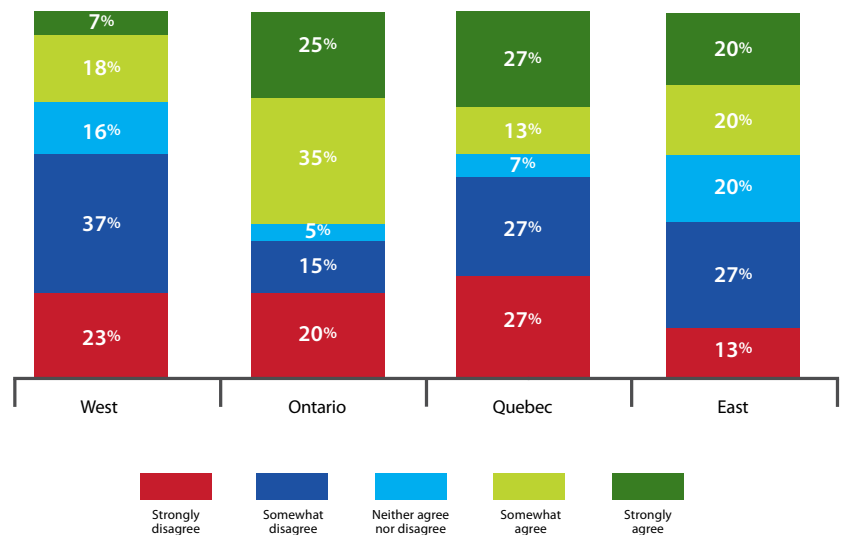
Regulated at the provincial/territorial level, home oxygen funding in Canada varies widely. If O2 is clinically needed but not covered due to restrictive qualification criteria, patients often must cover the cost themselves, causing significant financial strain.

HEALTHCARE PROFESSIONALS SAY PROVINCIAL GUIDELINES DO NOT ALLOW THEM TO PRESCRIBE OXYGEN THERAPY TO ALL WHO NEED IT



REGIONAL BREAKDOWN

Q: Agree or disagree: "My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all who need it"



Note: National sample size is statistically valid. Province-specific insights are directional only due to provincial sample sizes. Provinces with less than N=5 have been removed from this chart.

WHERE YOU LIVE IN CANADA DETERMINES WHAT YOU GET

OUT-OF-POCKET COSTS CAN BE THOUSANDS OF \$\$\$ PER YEAR

14% of patients say that they pay at least some of their oxygen costs **OUT-OF-POCKET**

50%

of healthcare professionals say provincial reimbursement guidelines **DO NOT ALLOW** doctors to prescribe oxygen therapy to all patients in need.

"IPF patients must be covered by respirology in another province... We have no visiting respirologist."

HEALTHCARE PROFESSIONAL,
YUKON

"Criteria for O2 access in Quebec are based on very old COPD literature and not at all applicable to ILD patients."

RESPIROLOGIST,
QUEBEC

"The Ontario government has cut funding so severely that we are having a hard time seeing our patients as often as we would like."

OXYGEN PROVIDER,
ONTARIO

"Unfortunately there is a family physician shortage in Newfoundland."

OXYGEN PROVIDER,
NEWFOUNDLAND

+50% 

of oxygen providers say patients **DO NOT HAVE EQUAL ACCESS** to timely oxygen deliveries



**“TO MANAGE
MY DAY TO DAY
ACTIVITIES I
NEED TO PLAN
EVERYTHING OUT
IN GREAT DETAIL.
I WISH I COULD
BE MORE
SPONTANEOUS
AND JUST GET UP
AND GO.”**

JEANNIE TOM

JEANNIE'S STORY

Jeannie Tom of Toronto was typical of many people living with pulmonary fibrosis in that she was a healthy, active individual prior to her diagnosis. Like many people who eventually learn they have PF, Jeannie spent years living with bronchial symptoms that seemed relatively benign. Many doctors are not familiar with a rare disease that at first resembles other less serious conditions.

In the ensuing years Jeannie dealt with multiple episodes of the flu and pneumonia, “Nobody ever mentioned PF,” she says. It was 2011 when Jeannie was finally diagnosed with pulmonary hypertension and pulmonary fibrosis (PF) secondary to scleroderma. “I went through a mourning period,” says Jeannie, “for all the things I could no longer do.” Jeannie’s ordeal didn’t end with her diagnosis. “I asked about treatment options and learned that two recommended medications would cost upwards of \$30,000 a year. I was shocked!” It is only recently that the two medications shown to slow the progression of PF have been covered by governments across the country for all types of

progressing pulmonary fibrosis, including the kind Jeannie has.

Jeannie was eventually prescribed oxygen therapy – a major adjustment. “When I first had to use oxygen I was worried about having to be tethered to an oxygen tank. I felt very self-conscious.” Today, she is sad about its limitations. “To manage my day to day activities I need to plan everything out in great detail. I wish I could be more spontaneous and just get up and go.” Jeannie is not one to sit and focus on what she has lost for long, and feels empowered by using her story to raise awareness about PF. “I think that awareness of pulmonary fibrosis for lung patients, the general public, and the government is very important. Ensuring equitable coverage when new treatments are developed, is essential for us.”

Jeannie hopes that sharing her story can help ensure that more people know about pulmonary fibrosis, leading to earlier diagnosis, better treatment, and increased access to the oxygen they need to breathe. We thank Jeannie for being an important voice in the PF community.



Recently hospitalized to fight a virus and low O₂ levels, Jeannie stays positive. Here she is participating in an online pulmonary rehab exercise session.

OVER

1

IN

3

PATIENTS SAY
KNOWING
HOW TO GET
CHANGES TO
THEIR OXYGEN
THERAPY IS
THEIR BIGGEST
CHALLENGE

QUALIFYING FOR OXYGEN IS DIFFICULT

Barriers to oxygen therapy weigh heavily on patients fighting to breathe. Medical criteria for the prescription of home oxygen vary widely across Canada, causing great distress.

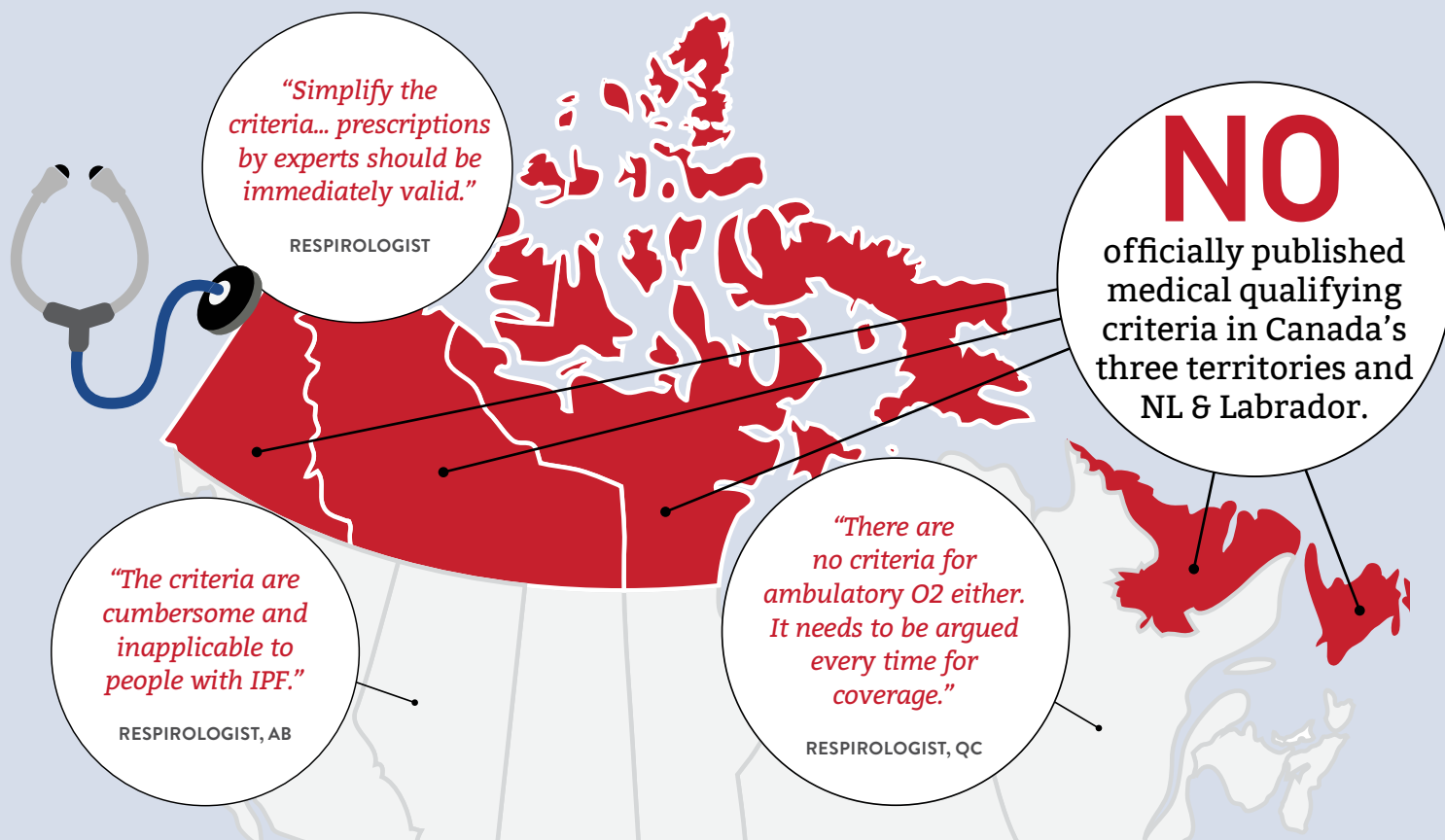


MEDICAL CRITERIA TO QUALIFY FOR OXYGEN THERAPY ARE RIGID, UNSUITABLE, OR NON-EXISTENT

PROVINCIAL GUIDELINES CREATE UNACCEPTABLE INEQUITY

“Criteria for qualifying for oxygen in this province is not suitable for patients with exertional dyspnea which is primarily what our patients struggle with”

ILD REGISTERED NURSE



*For adults, the normal range of SaO2 is 95 – 100%. A value <90% is considered low O2 saturation.

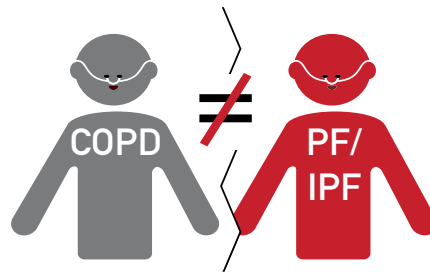
OXYGEN NEEDED FOR EXERTION IS AN ISSUE

Most studies investigating home oxygen therapy focus on chronic obstructive pulmonary disease (COPD). This data is then extrapolated to other respiratory diseases, including pulmonary fibrosis. The reality is that PF patients tend to require more oxygen upon exertion than COPD patients. Unfortunately, this data has been used to create the current guidelines for oxygen therapy prescriptions for all, regardless of need.

75%

OF OXYGEN PROVIDERS SAY PULMONARY FIBROSIS PATIENTS NEED SIGNIFICANTLY MORE O2 THAN COPD PATIENTS

PROOF POSITIVE

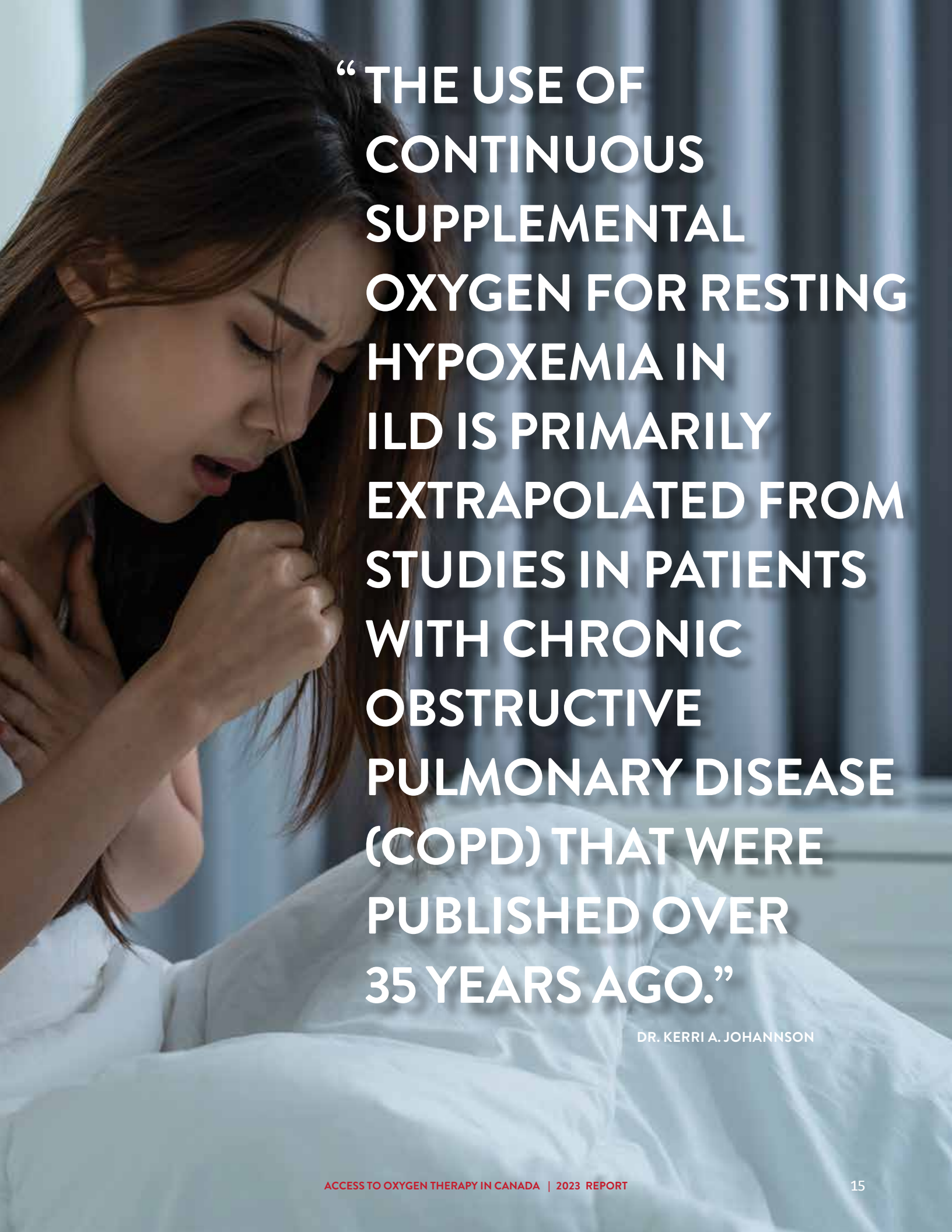


“Experts recommend oxygen use in cases of symptomatic exertional desaturation, highlighting the different approach to oxygen prescription for patients with fibrotic ILD compared with patients with COPD.”

DR. KERRI A. JOHANNSON
Department of Medicine, Department of Community Health Sciences, and Interstitial Lung Disease Program, University of Calgary, Calgary, Alberta, Canada.

“Criteria for O2 access in Quebec are based on very old COPD literature and not at all applicable to ILD patients.”

RESPIROLOGIST, QC



**“THE USE OF
CONTINUOUS
SUPPLEMENTAL
OXYGEN FOR RESTING
HYPOXEMIA IN
ILD IS PRIMARILY
EXTRAPOLATED FROM
STUDIES IN PATIENTS
WITH CHRONIC
OBSTRUCTIVE
PULMONARY DISEASE
(COPD) THAT WERE
PUBLISHED OVER
35 YEARS AGO.”**

DR. KERRI A. JOHANNSON

SURVEY RESPONDENTS WEIGH IN ON HOW TO IMPROVE HOME OXYGEN THERAPY

Common themes of affordability/coverage, qualifying criteria, and better equipment netted the most responses. Each group of respondents also raised additional concerns.

	 IMPROVE COVERAGE	 MEDICAL CRITERIA BARRIERS	 BETTER EQUIPMENT
 <p>PATIENTS & CAREGIVERS</p>	<p>“Coverage for portable tanks is only three tanks per month (six hrs outside my home.) Any extra, I pay out of pocket.”</p> <p>“I try to keep active but the government only pays for 10 small tanks. After that I have to pay. This limits my outings as I can’t afford it.”</p>	<p>“Easier access to other suppliers, comprehensive listing of provincial/national suppliers.</p> <p>In Ontario, change regulations to allow purchase of portable concentrators.”</p> <p>“The level of qualification should be lowered so people can get the oxygen they need.”</p>	<p>“A small portable oxygen concentrator would be much better than the compressed oxygen tanks.”</p> <p>“I cannot fly with a tank which lasts for less than two hours, it limits my time out of the house.”</p> <p>“Portable, lighter options that for easier travel.”</p>
 <p>HEALTHCARE PROFESSIONALS</p>	<p>“Relax funding criteria. Get rid of obstructionist policies... Currently it takes 2-3 months to obtain exertional funding.”</p> <p>REGISTERED NURSE, AB</p> <p>“Allow funding for anyone with dyspnea and O2 sat on exertion.”</p> <p>RESPIROLOGIST</p>	<p>“Lower the bar for exertional oxygen.”</p> <p>RESPIROLOGIST</p> <p>“Clarify qualification guidelines, simplify application. Special considerations for certain patients.”</p> <p>GENERAL PRACTITIONER</p> <p>“Have different rules for PF patients than for COPDs.”</p> <p>RESPIRATORY THERAPIST</p>	<p>“Access should be made available as soon as possible for patients requiring oxygen therapy. Perhaps a provincial registry?”</p> <p>GENERAL PRACTITIONER</p>
 <p>OXYGEN PROVIDERS</p>	<p>“Provinces should offer home O2 services to patients or at least provide coverage under provincial plan.”</p> <p>NEWFOUNDLAND</p> <p>“Increase reimbursement and enhance fairness...making client choice a legal right.”</p> <p>ALBERTA</p> <p>“Increase funding for high flow needs.”</p> <p>PEI</p>	<p>“Increase access to funding by removing the hoops that patients need to jump through to qualify.”</p> <p>ALBERTA</p> <p>“Create territorial home oxygen program with medically sound criteria for funding.”</p> <p>YUKON</p> <p>“Update qualification criteria.”</p> <p>ALBERTA</p>	<p>“Pulmonary fibrosis patients often require higher litre flows than other patients with respiratory diseases.”</p> <p>NEWFOUNDLAND</p> <p>“We hope that technology will continue to develop and we will get portable units that can give higher flows that last longer.”</p> <p>ALBERTA</p>

PATIENTS & CAREGIVERS



PROVIDE PATIENT SUPPORT /
INFORMATION

“There is no counselling on oxygen therapy, other than if your level falls below 90 you should use oxygen.”

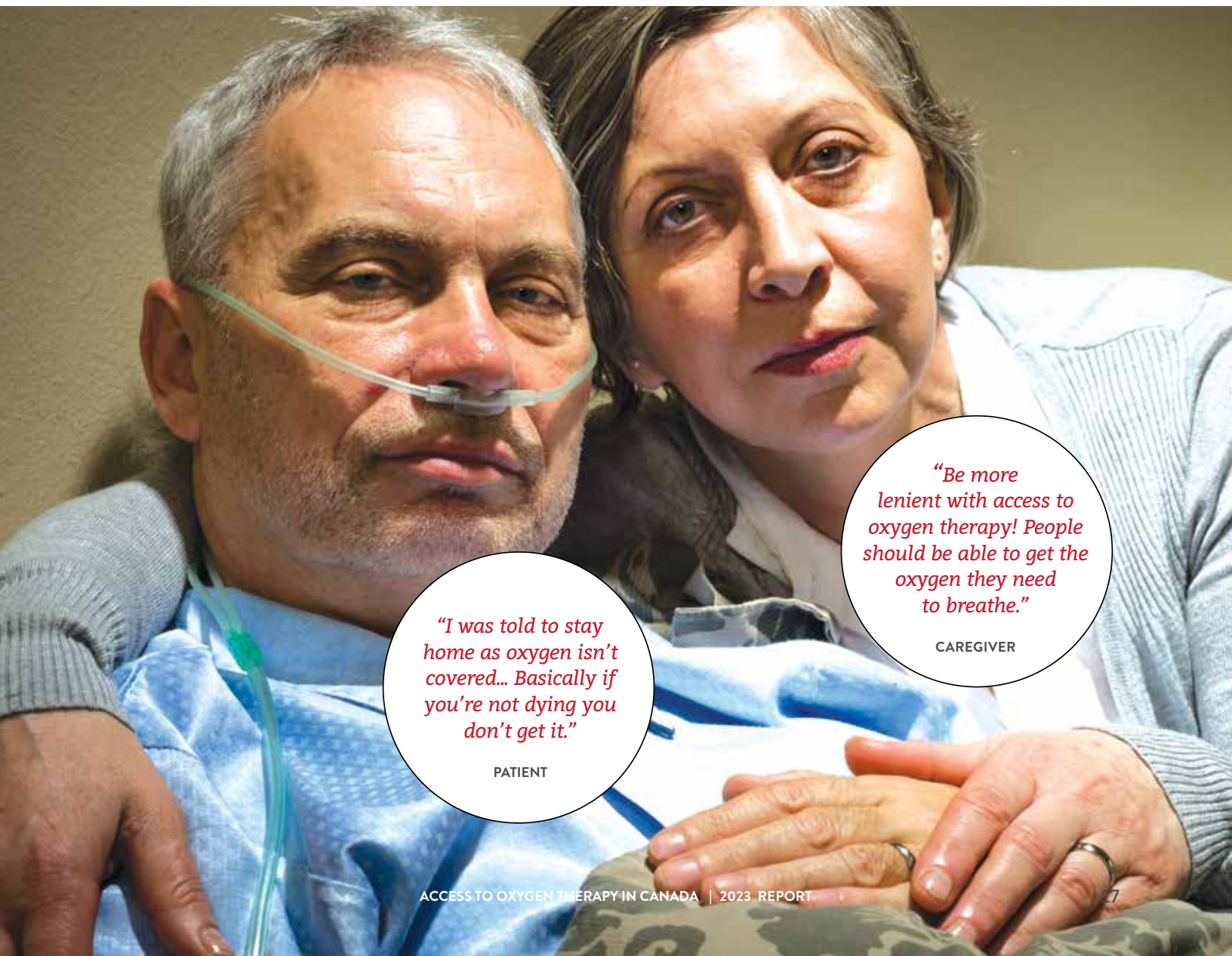
“I was not informed that I could increase the oxygen allowed. Initially I was told 8 cylinders every 2 weeks. When my husband pushed how important my oxygen is for exercise they increased the amount. I worry I’ll run out.”



ENABLE REMOTE OXYGEN
ADJUSTING / MONITORING

“Remote monitoring and adjustment of oxygen equipment.”

“While using my home system, it would be beneficial to have a remote control to adjust amount of oxygen.”



“I was told to stay home as oxygen isn’t covered... Basically if you’re not dying you don’t get it.”

PATIENT

“Be more lenient with access to oxygen therapy! People should be able to get the oxygen they need to breathe.”

CAREGIVER

HEALTHCARE PROFESSIONALS



EDUCATION & TRAINING

“More education on managing desaturations especially during exercise. Ways to adjust flow rate without having to go to the concentrator when it is stationary.”

RESPIROLOGIST

“More patient education”

GENERAL PRACTITIONER

“Make the O2 provider responsible for providing education on oxygen therapy - as well as more responsible for meeting the changing needs of their clients.”

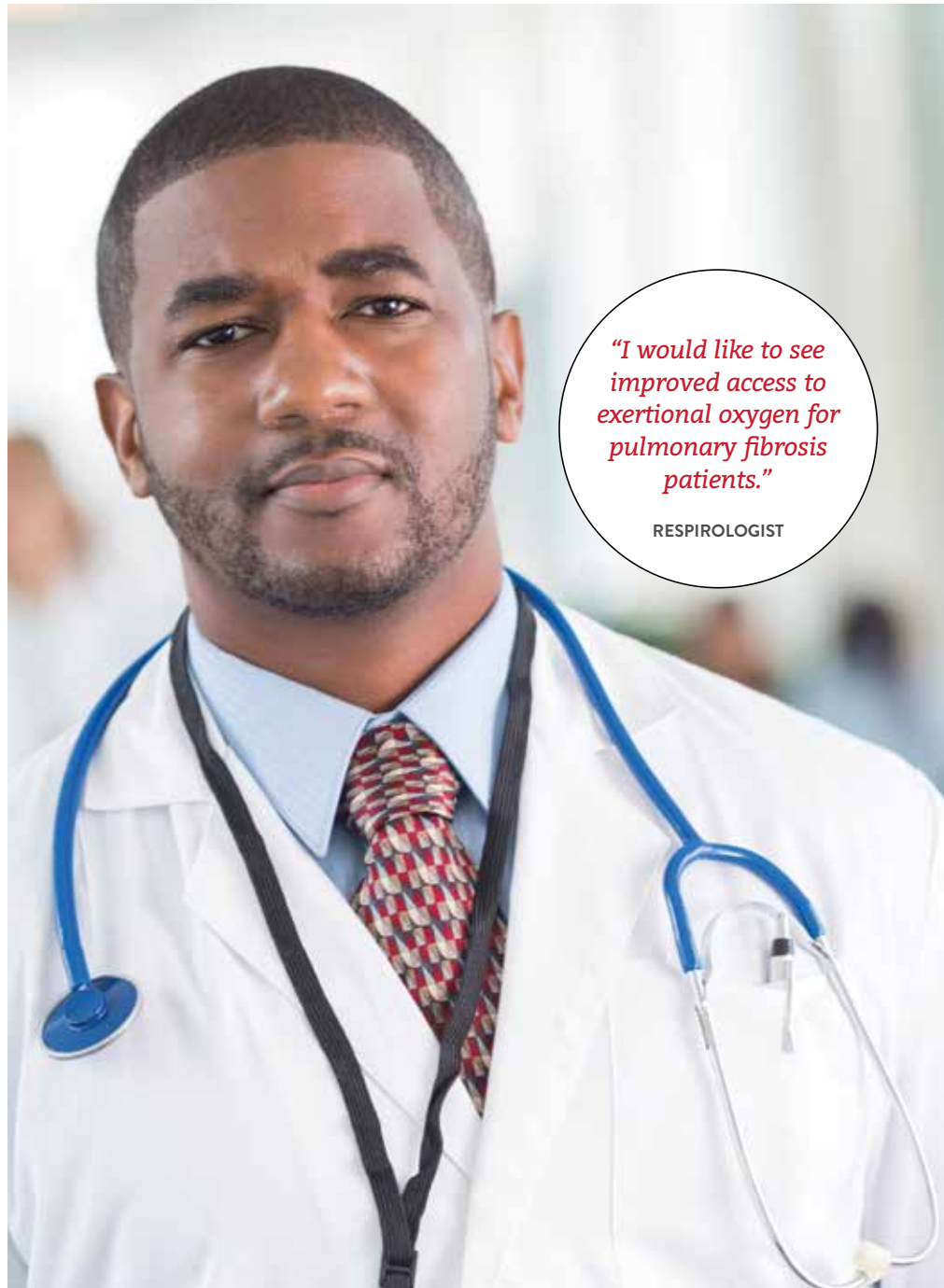
RESPIRATORY THERAPIST

“Qualifying for oxygen is beyond challenging!! Exertional oxygen funding requires desaturation 22 months, then they need to go through the whole requalification process.”

RESPIROLOGIST

“Alberta’s oxygen policy for exertional desaturation is horrible and unacceptable.”

RESPIROLOGIST



“I would like to see improved access to exertional oxygen for pulmonary fibrosis patients.”

RESPIROLOGIST

“Criteria for O2 access in Quebec are based on very old COPD literature and not at all applicable to ILD patients. There are no criteria for ambulatory O2 either.”

RESPIROLOGIST

OXYGEN PROVIDERS



EQUAL ACCESS

“Ensure equal access that doesn’t depend on where you live. Private pricing to some isolated areas would be far too expensive for a senior to pay.”

NEWFOUNDLAND

“Increase the monthly rate, ensure all providers are accredited/ISO certified, the people should take steps to verify that providers comply with the terms of their vendor agreements to ensure all patients have equal access to quality care.”

ONTARIO

“In some remote communities deliveries can be slightly delayed, however most providers provide systems and quantities to allow for that so that the patient is not impacted.”

ONTARIO

“We will always do our best to service each and every client to the best of our ability, but there can be situations where a little extra time and notice is required in order for us to arrange deliveries adequately.”

ALBERTA

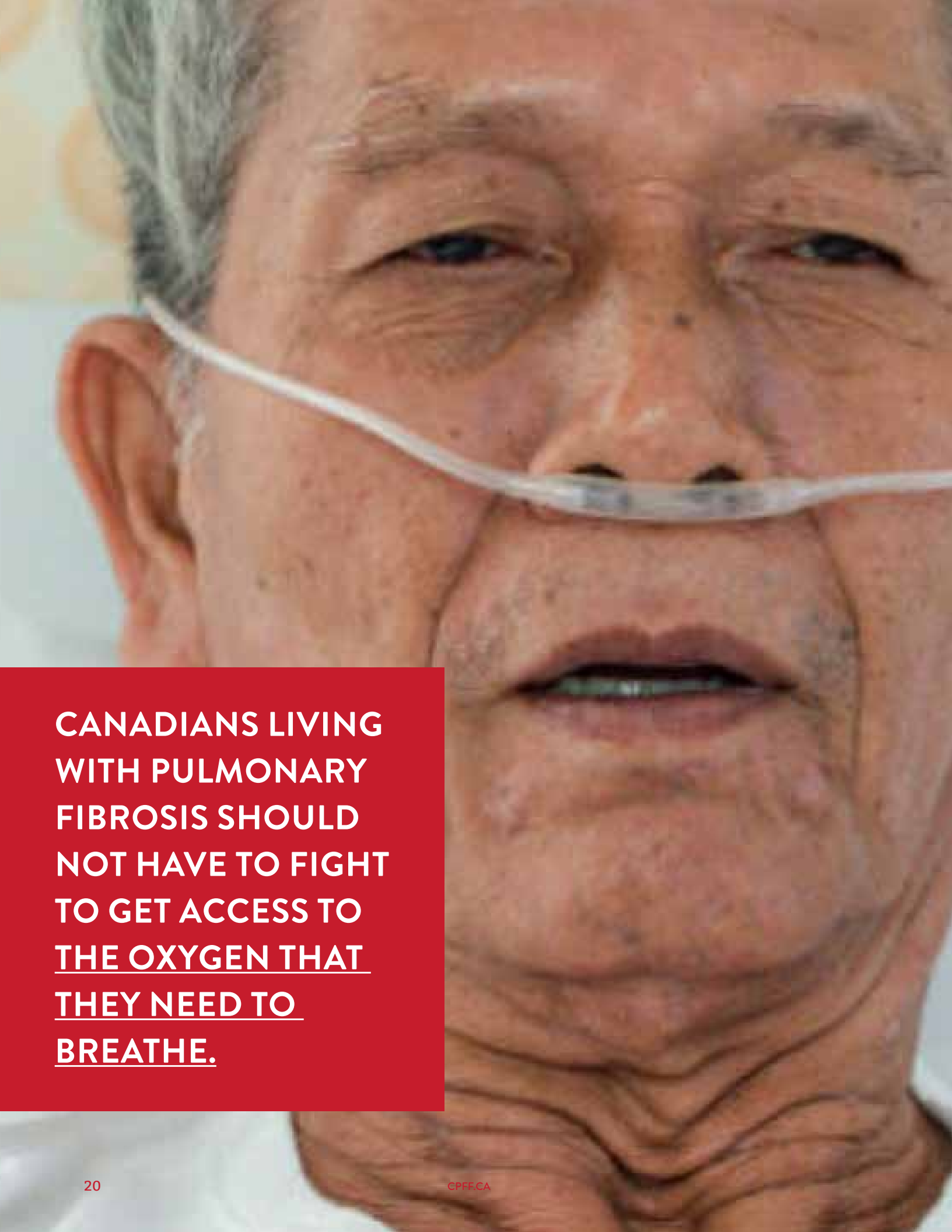


“Make oxygen therapy more funded by the government for all people.”

ALBERTA

“Clients are expected to improve both in O2 saturation and metres walked in two walking tests (with and without O2), done back-to-back the same day. This is a lot of exertion for many, who fail due to fatigue.”

RESPIRATORY THERAPIST

A close-up, high-resolution photograph of an elderly man's face. He has grey hair and deep wrinkles, particularly around his eyes and mouth. A clear plastic nasal cannula is inserted into his nostrils, with the tube extending across his upper lip. The background is a soft, out-of-focus light color. A red rectangular box is overlaid on the lower-left portion of the image, containing white text.

**CANADIANS LIVING
WITH PULMONARY
FIBROSIS SHOULD
NOT HAVE TO FIGHT
TO GET ACCESS TO
THE OXYGEN THAT
THEY NEED TO
BREATHE.**

PULMONARY FIBROSIS PATIENTS HAVE A RIGHT TO:



Disease-specific Qualifying Criteria

- Many Canadians living with pulmonary fibrosis (PF), must complete a resource-intensive “six-minute walk” test to qualify for supplemental oxygen. This test is not suitable for patients with PF who often require higher flow rates of oxygen when active.
- Medical criteria to qualify for supplemental O2 are based on unsuitable COPD data. Exertional needs specific to pulmonary fibrosis are not covered.

Patients and medical professionals are calling for standardized medical criteria based on the unique needs of pulmonary fibrosis patients.



Reimbursement for All

- Misaligned provincial policies mean reimbursement for home oxygen therapy is inconsistent nationally. This is contrary to Canada’s commitment to an accessible universal healthcare system for all.
- O2 is classified as a drug in Canada, however in many aspects it is managed and funded as a medical device. As a result, access to a provincially-funded drug plan does not guarantee access to funding for home oxygen equipment.
- Patients are not always provided the equipment they need to maintain their oxygen levels outside the home. Without portable equipment, they may be housebound.

Patients and medical professionals are asking that costs be fully reimbursed for ALL people receiving home oxygen therapy.

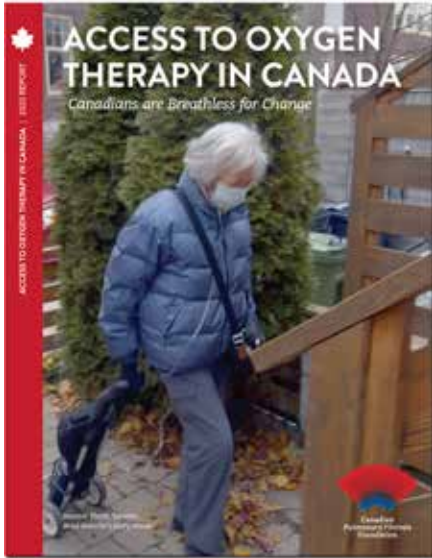


O2 in All Communities

- Oxygen delivery to Canadians living with pulmonary fibrosis is a national issue, especially in rural and remote areas.
- Patients struggle to access the quantity of oxygen they need outside the home for higher flow needs (> 10 cylinders per month).

Patients and medical professional are pleading for the health system to provide the oxygen therapy patients need, regardless of where they live.

READ THE REPORTS



Access to Oxygen Therapy in Canada Report

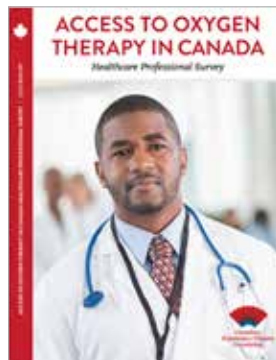
OXYGEN SUMMARY REPORT

The CPFF *Access to Oxygen Therapy in Canada Report* summarizes the research we conducted with all stakeholder groups in 2022 and 2023. Individual stakeholder group reports delve into more detail for each of the groups surveyed.

STAKEHOLDER REPORTS



Patients and Caregivers Report



Healthcare Professionals Report



Oxygen Providers Report

TWO RESEARCH PAPERS

CPFF Oxygen Reports were also informed by:



Supplemental Oxygen in Interstitial Lung Disease: An Art in Need of Science



Oxygen in Patients with Fibrotic Interstitial Lung Disease: an International Delphi Survey

Scan to read the reports and the research papers:





The Canadian Pulmonary Fibrosis Foundation is a registered charity established in 2009 by Robert Davidson. 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.

The Canadian Pulmonary Fibrosis Foundation works tirelessly to:



For more information, please contact:

info@cpff.ca

or

905-294-7645

cpff.ca



Canadian
Pulmonary Fibrosis
Foundation

The Canadian Pulmonary Fibrosis Foundation works tirelessly to bring the latest news about PF research, resources and more to people living with pulmonary fibrosis as well as the larger community. For more information, please contact:

info@cpff.ca