

BREATHLESS *for* CHANGE

Living with

PULMONARY FIBROSIS

in Canada



Canadian
Pulmonary Fibrosis
Foundation
Breathing should never be hard work®

2020 INSIGHT REPORT

BREATHLESS *for* CHANGE

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Living with **PULMONARY FIBROSIS** *in Canada*

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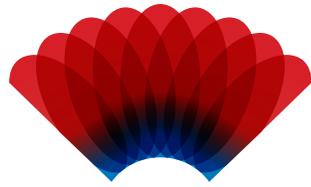
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Canadian Pulmonary Fibrosis Foundation

Breathing should never be hard work®

You told us what you need. We're listening and taking action. You are not alone.

This spring we asked you to help us help you by completing a survey about your experiences living with pulmonary fibrosis (PF), its impact on your life and what you need for your future. More than 640 people living with PF and their caregivers from across the country responded to our call. Thank you!

We are pleased to share with you the key survey results, as well as CPFF's Action Plan to address your concerns, in this report *Breathless for Change*. Most of your responses are not a surprise to us. We know it can take more than two years to be diagnosed. We know that access to treatment is inconsistent across the country and that reliable information and support is hard to find. We know that this disease has a huge impact on you, your family and your community. And COVID-19 has heightened isolation, limited access to support groups and increased stress levels for patients and caregivers.

Thanks to your participation in this survey, we now have the facts, figures and your comments to guide our direction and actions going forward and to share your collective experiences and needs with researchers, health care professionals, the media, the public and policymakers.

To address timely diagnosis we will increase our knowledge transfer activities to help more primary care physicians recognize the symptoms

of PF and make the necessary referrals to ILD respirologists. We will continue to fund clinical research fellowships increasing the number of ILD specialists and research projects.

CPFF will keep working with governments to ensure equal access to drug treatments, therapies and clinical trials for people living with different types of pulmonary fibrosis. We will keep investing in research to deepen our understanding of pulmonary fibrosis, new treatments and an eventual cure.

We'll ramp up our resources and support for people living with PF and their caregivers. New publications and enhanced online channels will help our community stay informed and connected. We'll raise the bar on public awareness to generate widespread support and help people experiencing symptoms to self-advocate.

We will never stop fighting for you. *Because Breathing should never be hard work.®*

Kirk Morrison
Board Chair



Kirk Morrison

Sharon Lee,
Executive Director



Sharon Lee

INSIGHT MATTERS

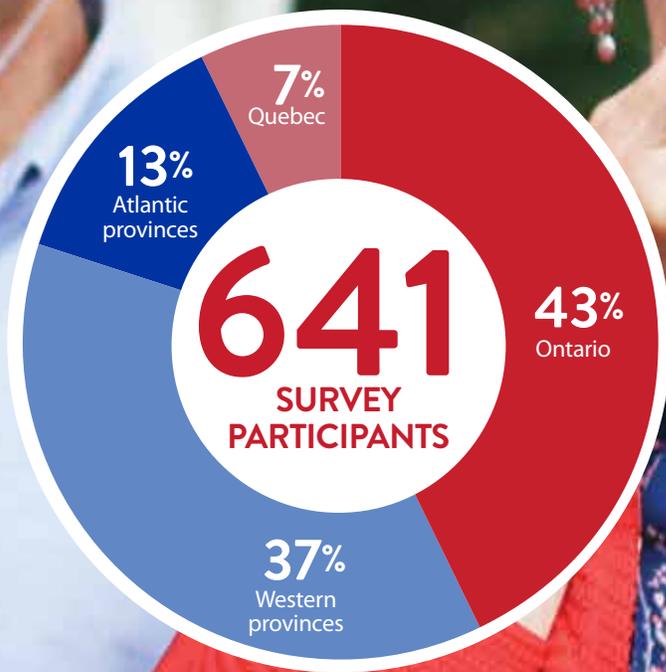
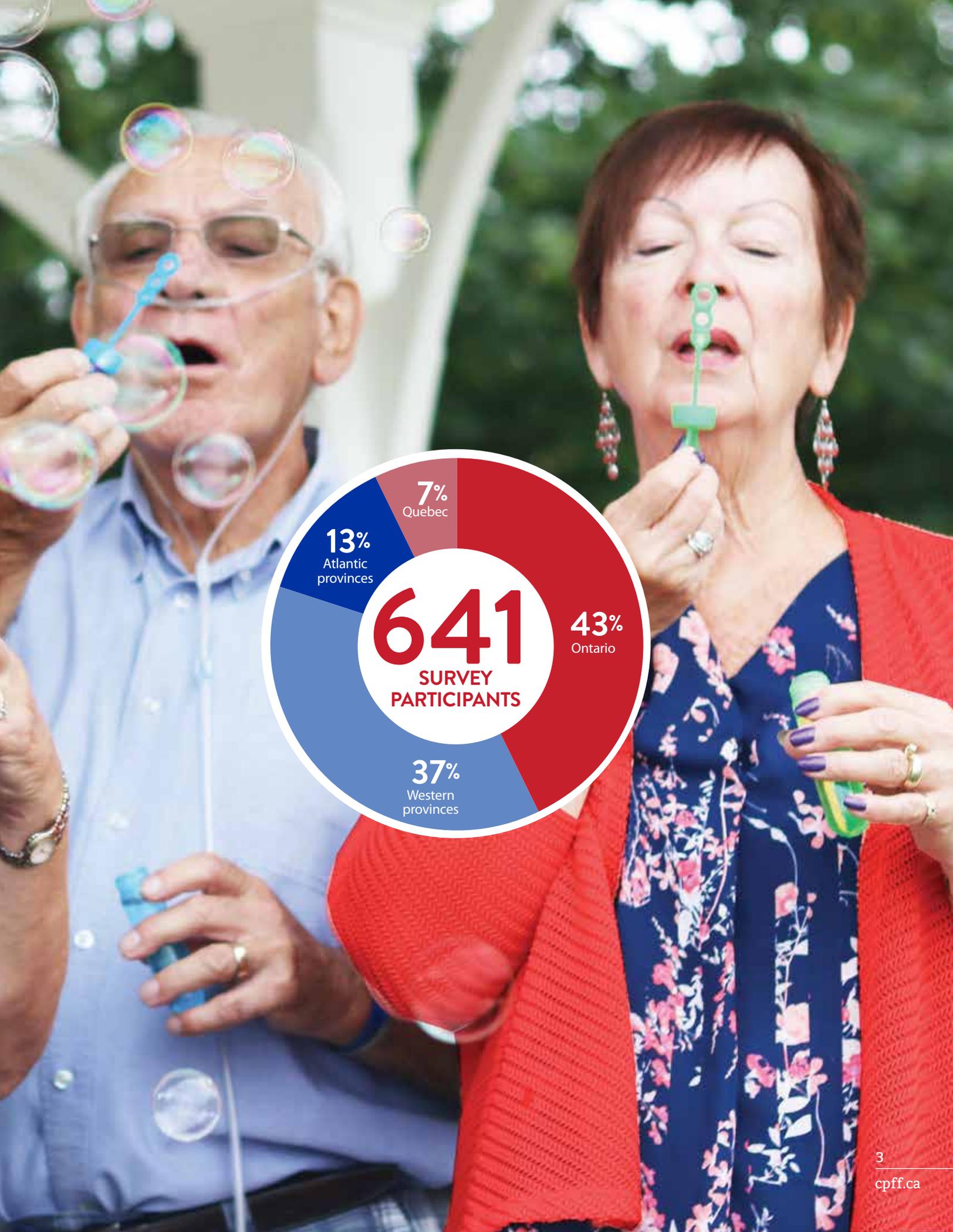
Pulmonary fibrosis (PF) is a lung disease with a survival rate worse than many cancers, averaging two to five years from diagnosis. Over 65% of people who responded to our survey have been living with their disease for 3 years or more. And yet – PF still suffers from limited awareness among the public and even among healthcare professionals, with a patchwork approach across provinces.

Many patients struggle to receive a diagnosis, treatments and therapies, even as their disease makes breathing progressively more difficult. Caregivers struggle to cope with isolation and limited support. Information for patients, caregivers and primary care physicians is lacking. While the majority of respondents were from Ontario and the West, a significant number came from Quebec and the Atlantic provinces.

In order to understand today's PF patient and caregiver experience, the Canadian Pulmonary Fibrosis Foundation (CPFF) conducted a national, bilingual survey. Key survey learnings as well as CPFF's Action Plan are presented in this Report.

To all who participated, a heart-felt thank you (merci!) for your invaluable input. Your testimonials (in 'bubbles' throughout this publication) are an integral part of this Report. We will never stop fighting for you. *“Because breathing should never be hard work®”*





LEARNING HIGHLIGHTS

The survey revealed four significant areas of concern: diagnosis, information scarcity, inconsistent access to treatment and therapy, and overall impact on daily life for both patients and caregivers.



DIAGNOSIS IS LAGGING

- It takes on average two years from the onset of symptoms to be diagnosed with pulmonary fibrosis
- Respiriologists are considered to be most knowledgeable about pulmonary fibrosis
- The majority of diagnoses are made by Respirologists
- Not all patients have access to specialist care and referrals can be slow



TREATMENT ACCESS IS INCONSISTENT

- Over a third of patients do not feel their current treatment/routine is effective in managing their pulmonary fibrosis
- Oxygen therapy is hard to access due to out-of-pocket costs in some provinces
- Rural patients have difficulty accessing needed treatment and therapies
- There are gaps in supplemental insurance to cover counselling and physiotherapy needs



INFO & SUPPORT IS HARD TO FIND

- Patients and caregivers need more information about research, treatments, exercise, lung transplants, and more
- Caregivers need more skills training, support groups and other programs
- Patients and caregivers want to know what to expect as the disease progresses and end-of-life issues, including access to dying with dignity
- Patients and caregivers need help navigating the healthcare system and advocating for themselves
- Almost sixty per cent of respondents feel raising awareness of pulmonary fibrosis across Canada is vitally important



IMPACT IS LIFE-CHANGING

- Two-thirds of patients are not able to work or enjoy leisure or self-care activities as before
- Sixty per cent of patients and almost half of caregivers spend at least two hours per day to care for the patient's pulmonary fibrosis
- Loss of independence and freedom takes a heavy toll on patients and caregivers
- COVID-19 has exacerbated isolation, lack of access to support groups and stress levels for both patients and caregivers



“Feelings of weakness and breathlessness overtake the enjoyment and ability to do much.”

“Coughing all the time is exhausting. I have little energy to do as I like, like spending time with my grandchildren.”

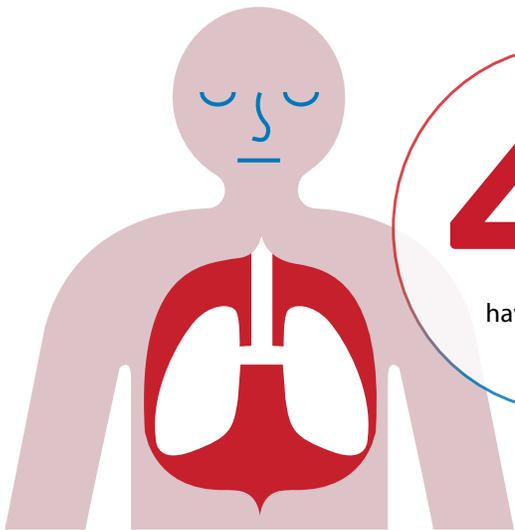
“I have no energy to volunteer any more. I love gardening but am unable to do it.”

The PATIENT

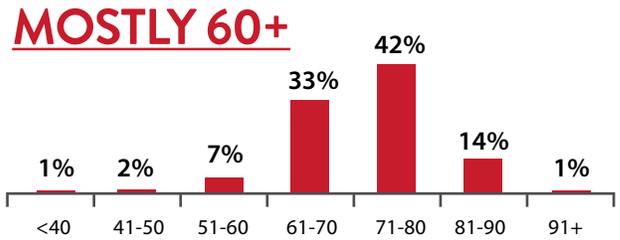


Patients are trying to cope to the best of their ability, but their quality of life being gradually choked off contributes to feelings of anxiety and depression. Many questions remain unanswered.

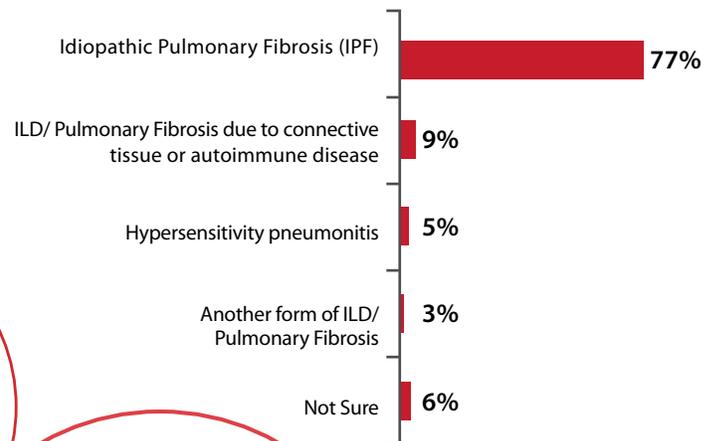
Pulmonary Fibrosis (PF) is a diverse group of diseases that affects the lung tissue via scarring and/or inflammation, often leading to progressive and permanent loss of lung function. PF can be secondary to an underlying disease or exposure (e.g. rheumatoid arthritis), or can develop without a clear cause (e.g. Idiopathic Pulmonary Fibrosis, or IPF). IPF in particular, is a disease that typically occurs after the age of 60, that results in progressive, sometimes rapid, scarring of the lungs.



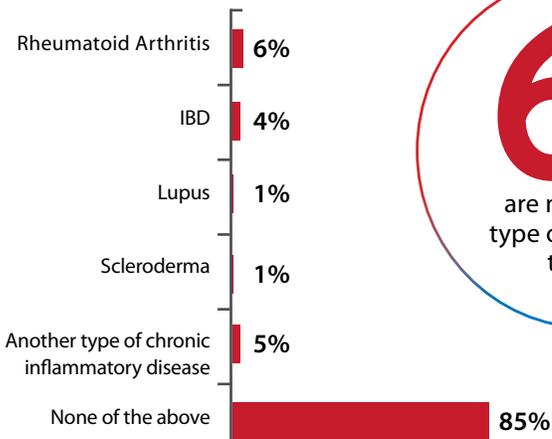
4%
have had a lung transplant



TYPE OF LUNG DISEASE

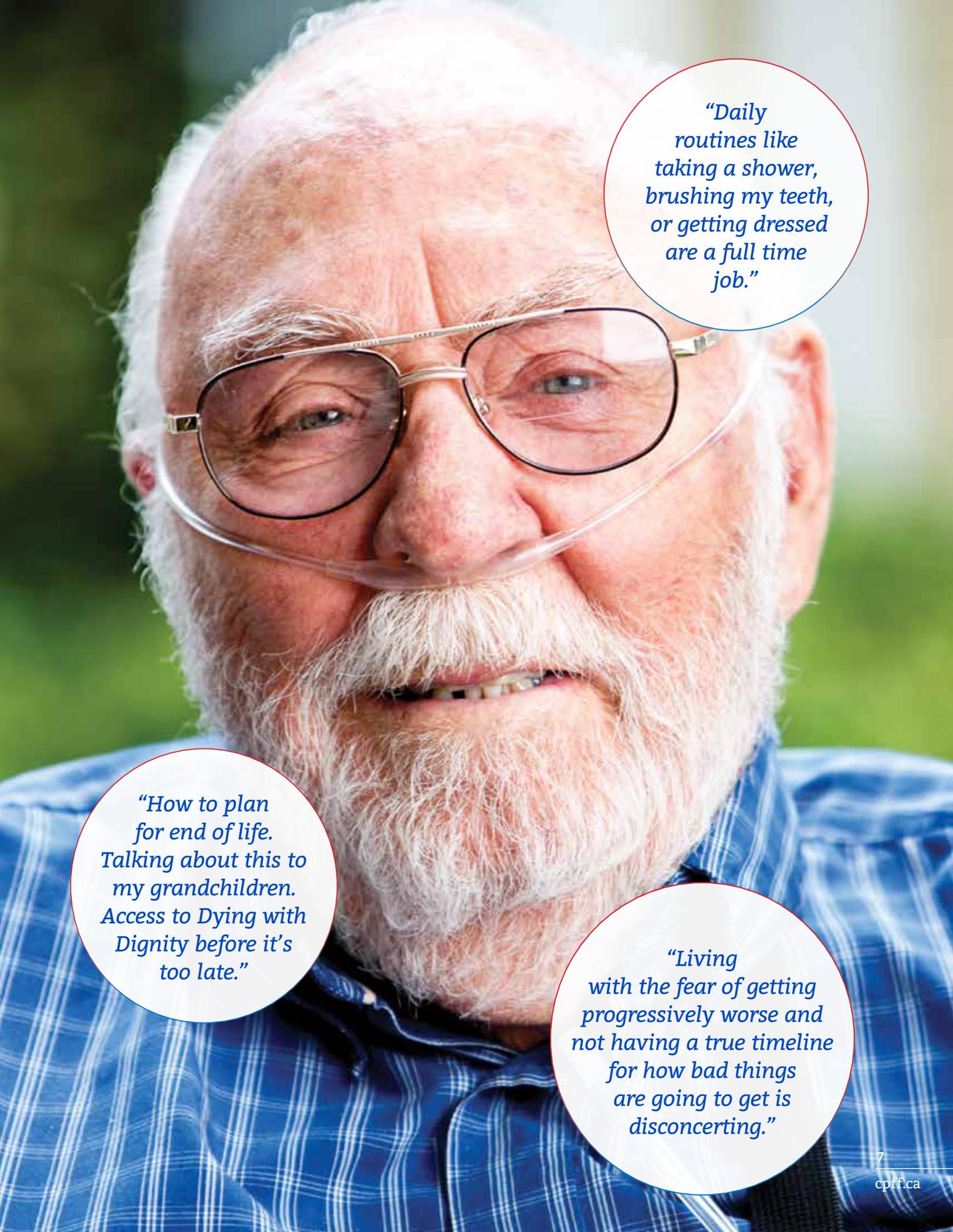


FEW HAD PRE-DISPOSING CONDITIONS



6%
are not sure what type of lung disease they have

44%
of patients are receiving oxygen



“Daily routines like taking a shower, brushing my teeth, or getting dressed are a full time job.”

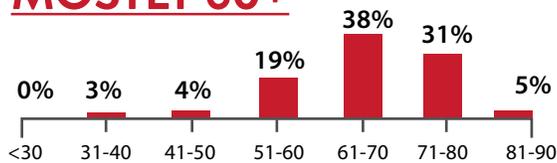
“How to plan for end of life. Talking about this to my grandchildren. Access to Dying with Dignity before it’s too late.”

“Living with the fear of getting progressively worse and not having a true timeline for how bad things are going to get is disconcerting.”

The CAREGIVER

Caregiving has its rewards but it also takes a toll on one's physical and emotional health. Caregiver challenges include impact on physical well being, feelings of hopelessness and/or depression, and taking care of loved ones' day-to-day needs.

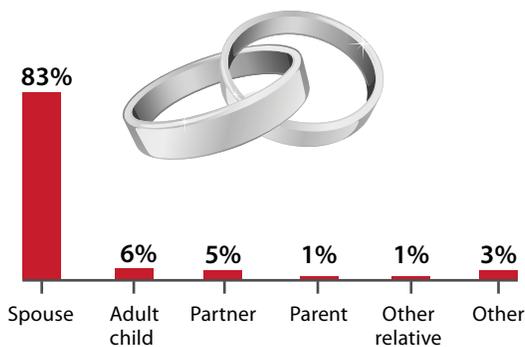
MOSTLY 60+



CAREGIVERS NEED SUPPORT



MOST ARE SPOUSES



CAREGIVING TAKES A TOLL

"I have feelings of hopelessness and/or depression."

"It impacts my physical well-being."

38%

of caregivers are interested in learning more about available support groups.

The need for caregiver support appears even greater in some places than others.

51%

OF CAREGIVERS SPEND
AT LEAST TWO HOURS
PER DAY CARING FOR
THE PATIENT.

*"You make sure
they are not choking from
a cough. You wake up when
their oxygen gets too low.*

*You live for them
to breathe."*



*"COVID-19 has
made life more isolating
due to the compromised
health of my partner
which had already been
compressed by
the illness."*

6

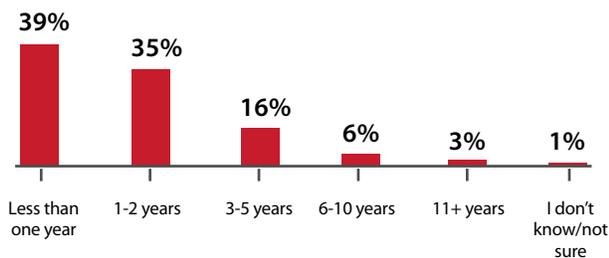
11% SPEND
**HOURS
PER DAY**

*"(Caregivers) need
more information about
advanced stages of the
disease ...progression of
oxygen use as well
as equipment
availability."*

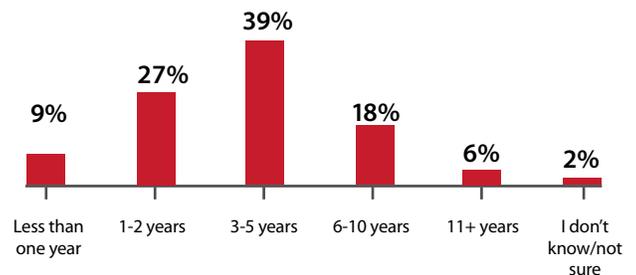
DIAGNOSIS *is* LAGGING

Obtaining an initial diagnosis in a timely manner is often an exercise in frustration. 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.

DELAYS BETWEEN SYMPTOM ONSET & DIAGNOSIS



TIME PASSED SINCE RECEIVING DIAGNOSIS



81%

were diagnosed by a Respirologist

19%

by a Family Doctor

VS.



*“There should be more
information shared with
Family Doctors”*

YEARS

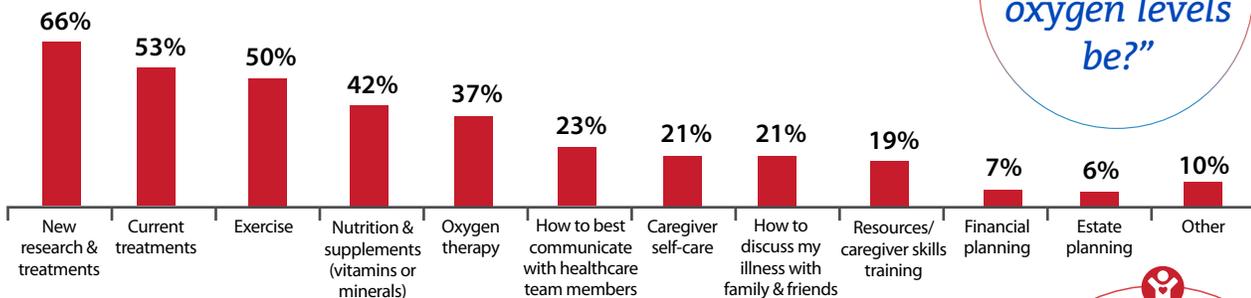
for a confirmed diagnosis

INFO & SUPPORT *are* HARD TO FIND

A dominant theme of the survey findings was that patients and caregivers lack the information they need at every stage of their pulmonary fibrosis journey. Feeling abandoned by the healthcare system, many are exhausted by a constant search for information.



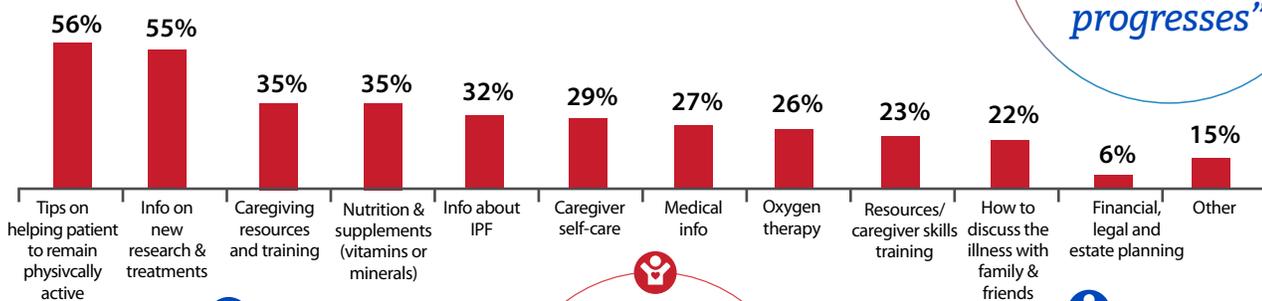
PATIENT INFO NEEDS



“What should my oxygen levels be?”



CAREGIVER INFO NEEDS



“We need more info on what to expect as the disease progresses”

“How long do I have to wait for a lung transplant?”

“Will he have access to dying with dignity?”

“Where can I get info about what it does to the lungs?”



66%

NEED MORE



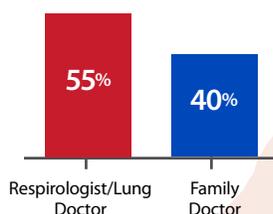
*“What is an
exacerbation
event? Is it
painful?”*

*information about treatments
& new research*

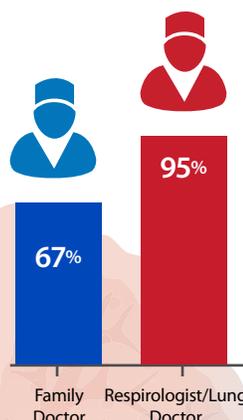
TREATMENT ACCESS *is* INCONSISTENT

Once their diagnosis has (finally) been made, too many PF Patients face additional barriers to “available” treatments and therapies – including access to oxygen – depending on their province’s criteria, their proximity to a city, or their lack of supplemental insurance.

PRIMARY CARE DOCTOR



PATIENTS ARE ASKING THAT PRIMARY CARE DOCTORS RECEIVE INFORMATION REGARDING PULMONARY FIBROSIS

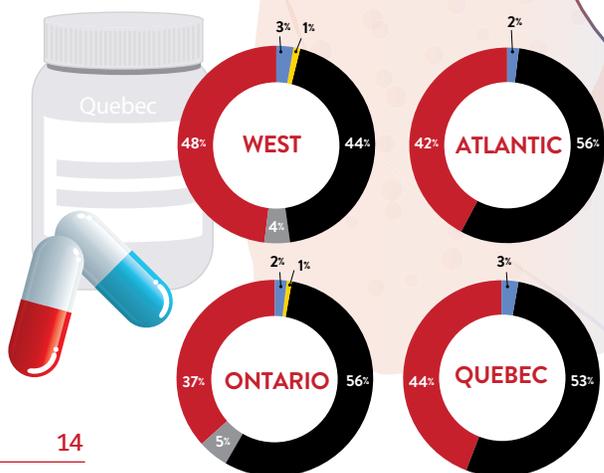


RESPIROLOGISTS ARE RATED AS KNOWLEDGABLE ABOUT THE DISEASE

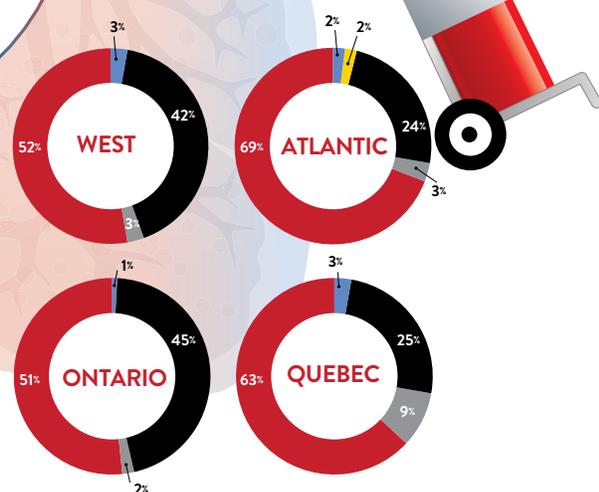
“Getting O₂ would help her, but it is so difficult to get.”

38%
Do not feel their current treatment/routine is effective in helping them manage pulmonary fibrosis.

ANTI-FIBROTIC DRUG



OXYGEN



LEGEND

- Need not covered
- Difficult to access
- Receiving & covered
- Receiving but not covered
- Don't know



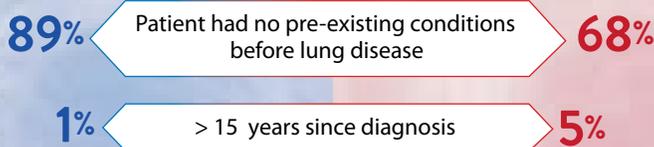
10%
of patients lack access to individual counselling or physiotherapy due to gaps in benefit/insurance coverage or their location.

**78% OF SURVEY RESPONDENTS
IDIOPATHIC PULMONARY
FIBROSIS PATIENTS**

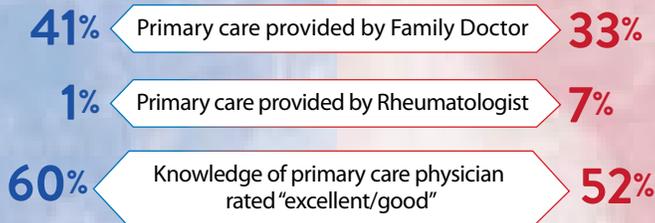
**22% OF SURVEY RESPONDENTS
OTHER TYPES OF
PULMONARY FIBROSIS PATIENTS**



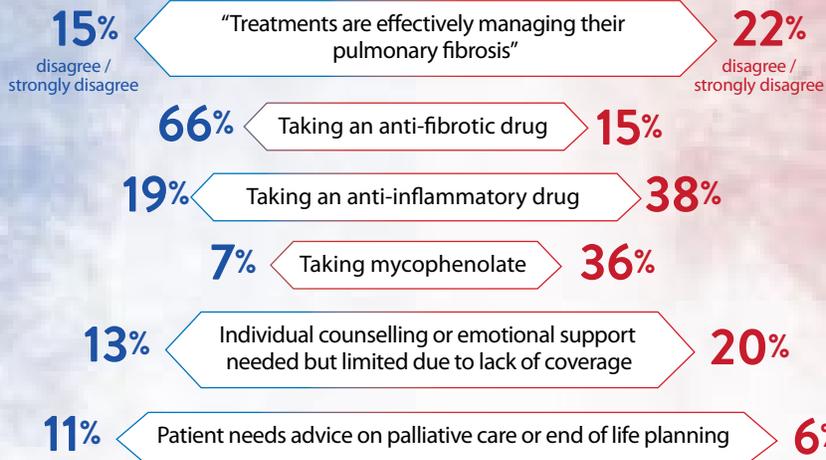
PATIENT HEALTH



PRIMARY CARE EXPERIENCE



TREATMENT



IMPACT *is* LIFE-CHANGING

Patients and Caregivers lives are impacted on every level : physical, psychological, social and emotional. We asked how living with Pulmonary Fibrosis impacts their daily lives:

PATIENTS



58%

Cannot work like before

52%

Cannot enjoy leisure activities like before

50%

Experience shortness of breath

39%

Experience general weakness/fatigue all the time

38%

Are no longer able to care for themselves/their family (ie. housework, meal prep, personal hygiene)

25%

Fear not being able to catch their breath/recover

CAREGIVERS



31%

Physical well-being is impacted

28%

Feel hopeless and/or depressed

27%

Must take care of loved ones day-to-day needs

26%

Must travel to medical appointments

24%

Must advocate for patient

24%

Cannot enjoy leisure activities like before

OVER

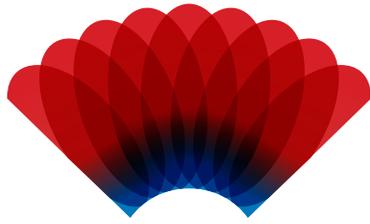
2

“It’s hard to do things that are part of everyday life. Sitting around is easy, everything else requires oxygen.”

3

“What consumes my husband controls my life as well.”

of patients experience symptoms that impact their ability to work, participate in leisure activities, and cause shortness of breath.



Canadian Pulmonary Fibrosis Foundation

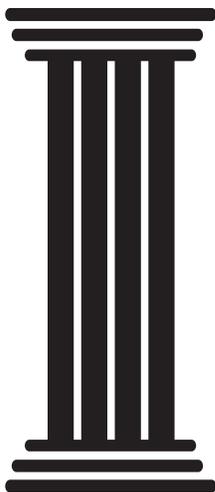
Breathing should never be hard work®

The Canadian Pulmonary Fibrosis Foundation provides support for all people affected by pulmonary fibrosis. Our focus, represented by CPFF's "Four Pillars" is to use these pillars as a basis for CPFF's Action Plan.

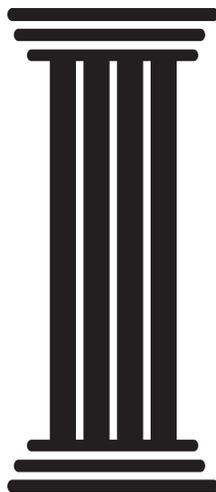
CPFF'S FOUR PILLARS

- Support patients and caregivers
- Educate Canadians about pulmonary fibrosis
- Fund research into understanding PF and finding a cure
- Give voice to families touched by the disease

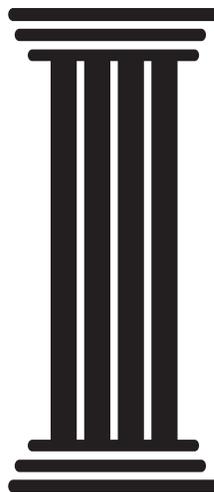
**Patients
& Caregivers**



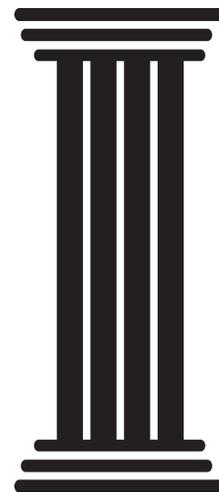
**Educate &
Raise Awareness**



Research



Advocacy



CPFF ACTION PLAN

WE WILL:

1 FIGHT FOR TREATMENT AND THERAPY FOR ALL

More must be done to ensure adequate treatment and therapy, including new drugs and oxygen, are available to all who need them. We will work with all levels of Government to increase inclusive access to drug treatments, therapies, and clinical trials.

2 HELP ACCELERATE RESEARCH

Through fundraising and other initiatives, we will support research into new treatments and a cure for PF.

3 RAMP UP RESOURCES AND SUPPORT

We will expand patient and caregiver resources and support through new publications and enhanced online channels. This will better facilitate the flow of information and the ability to connect to support groups, one-on-one therapies and more.

4 SUPPORT HEALTHCARE PROFESSIONALS TO SPEED UP DIAGNOSIS

We will accelerate knowledge transfer to help more Primary Care Physicians recognize the symptoms of Pulmonary Fibrosis and to make necessary ILD Respiriologist referrals. We will raise funds to facilitate ILD Respiriologist placements in communities.

5 RAISE THE BAR ON RAISING AWARENESS

We're on a mission to educate the public about Pulmonary Fibrosis in order to generate widespread support, and to help Patients self-advocate if they are experiencing symptoms.

“This is an US journey, not a ME journey.”

Barbara Barr (Haylock), Vice-Chair, CPFF



FACES *of* PF

Caregivers, along with patients, truly are heroes.

Thank you to all the family, volunteers, friends, healthcare professionals, donors, researchers, sponsors and organizations working hard to help create positive change.

Learn more about our PF community at

cpff.ca/community



RESOURCES

The Canadian Pulmonary Fibrosis Foundation works tirelessly to bring the latest news about PF research and other information to the PF community, as well as a variety of resources people living with PF can use. To keep up with the latest developments, find the closest clinic, ILD specialist or support group please visit our website cpff.ca and sign up for our newsletter *Hope Breathes Here*.



“Because breathing should never be hard work[®]”



Canadian Pulmonary Fibrosis Foundation

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