Canadian Pulmonary Fibrosis Foundation

Canadian Pulmonary Fibrosis Foundation (CPFF)

5/13/2022

Strategic Plan FY 22-23/23-24/24-25

The Canadian Pulmonary Fibrosis Foundation is a registered Canadian Charitable Foundation established to provide hope and support for people affected by pulmonary fibrosis. The CPFF is a not-for-profit charitable organization. The charitable registration # is 850554858RR0001.

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Executive Summary

The Canadian Pulmonary Fibrosis Foundation (CPFF) provides support for all people affected by pulmonary fibrosis (PF), and is the voice of patients living with PF.

The CPFF works closely with the medical community and with support from Canadians, we hope to achieve our mission and vision.

The CPFF's logo is an open blue and red fan. The fan itself represents movement of air. The gradient colour symbolizes the oxygenation of blood that is necessary for survival. Bright red is the colour of oxygenated blood and blue is un-oxygenated blood.

Our four pillars of focus guide our strategy. They are:

1. Support: Support those affected by PF;
2. Advocacy: Represent Canadians affected by PF to government, healthcare professionals, the media, and the public.
3. Awareness: Educate and raise awareness about PF among Canadians;
4. Research: Raise funds to finance research and Fellowship

Because of the growing needs of the PF community throughout Canada, CPFF intends to expand the services and programs that we deliver. As such a key focus of our short-term strategy is to expand our internal capabilities to deliver these services and programs. We call this "Building the Foundation for the Foundation".

Mission Statement

Educate and Raise Awareness: The CPFF aims to educate patients, their families, and the general public about pulmonary fibrosis through our website, printed materials, support groups, and advocacy initiatives.

i. Support Patients and Caregivers: You are not alone on this journey. The CPFF supports patients and families through in-person and on-line support groups across Canada.
ii. Support Research that Benefits Patients: The CPFF supports Canadian research that will benefit patients through annual research grants. The CPFF also supports the training of the next generation of pulmonary fibrosis medical specialists through the Robert Davidson Fellowship program – which will lead to improved access to care and more research into pulmonary fibrosis.
iii. Give a Voice to Patients: Through our work with local and provincial health authorities, the pharmaceutical industry, and oxygen vendors, the CPFF advocates for the recognition and the rights of Pulmonary Fibrosis patients to access specialized healthcare, medications, oxygen, pulmonary rehabilitation, and support groups.

Vision

Creating hope and giving a voice to the pulmonary fibrosis community.

Pulmonary Fibrosis

Pulmonary fibrosis (PF) is an interstitial lung disease that affects an estimated 30,000 Canadians, with a projected 5,000 deaths each year. In patients with PF, the lung tissue becomes scarred and

over time, thickens and becomes more widespread. In turn, the lungs lose their ability to transfer oxygen to the bloodstream, resulting in shortness of breath and vital organs being deprived of the necessary oxygen to survive.

Symptoms of pulmonary fibrosis usually have a gradual onset and may include:

- Shortness of breath, particularly during or after physical activity
- Spasmodic, dry cough
- Gradual, unintended weight loss or weight gain
- Fatigue and weakness
- Chest discomfort
- Clubbing, or enlargement, of the ends of the fingers (or sometimes the toes) due to a buildup of tissue

PF can be linked to particular causes, such as environmental exposures, chemotherapy or radiation therapy, residual infection, or autoimmune diseases such as scleroderma or rheumatoid arthritis. In the majority of cases of pulmonary fibrosis, the cause is uncertain or unknown and as such is termed idiopathic.

Unfortunately, there is currently no cure for pulmonary fibrosis and there is limited treatment available. Using an oxygen tank can help manage the strain of pulmonary fibrosis, however this varies from case to case and you should consult your doctor to learn more.

Key Elements of our Strategy

Key elements of our strategy are as follows:

1. **Educate Canadians to increase awareness about both PF and the Canadian Pulmonary Fibrosis Foundation (CPFF)**
   - Utilize state of the art communications (including social media) to most effectively reach our community and communicate our story. Increase efforts to reach audiences beyond the CPFF community including those living with PF but unaware, sponsors, donors, media, and medical professionals.
   - Continue to run a national September campaign annually to recognize PF awareness month. This campaign will include, but is not limited, to the following events:
     - Lighting up of buildings and structures in blue and red
     - Obtaining proclamations from all levels of government
     - Hosting of online and/or in person patient forums
     - Hope Breathes Here Walk for Pulmonary Fibrosis (national event)
     - Rollout a community-based CPFF ambassador program that engages and equips the CPFF community to support PF advocacy, awareness, and fundraising.
     - Create opportunities for interested parties to become involved in the Foundation.
     - Leverage and further develop grassroots relationships.

2. **Strengthen the focus on people affected by PF and strengthen the services we provide to them**
   - Build the numbers of people affiliated with the Foundation, using our network of patient support groups as a platform.

- Expand access to our patient support groups by both increasing the number of patient support groups and using technology to allow virtual access to support group meetings and events.
- Continue with our practice of conducting regular surveys of the PF community to identify needs, issues, and priorities.
- Create practical patient and caregiver support tools that help patients get better access to PF informed healthcare professionals, manage their PF, and find joy in daily living.

3. Invest in world-class research to slow and prevent Pulmonary Fibrosis (PF)

- Support and promote our Medical Advisory Board, as a national body of excellence in PF diagnosis, treatment and research.
- Continue to build a critical mass of researchers in Canada that will lead to treatments for PF, while encouraging global collaborations and knowledge transfer.
- Enhance clinical research in Canada.
- Continue to forge strong connections to individuals and families living with PF to ensure a strong base for potential clinical trial participation.
- Continue to award Robert Davidson fellowships and research grants on an annual basis.

4. Advocate for Canadians living with PF and enhance the services we provide to them

- Maximize our connections with families and individuals living with PF.
- Lead efforts to bring earlier diagnoses, and access to treatment (drugs, oxygen, mental health, and pulmonary rehabilitation support).
- Continue our federal and provincial advocacy efforts to earlier diagnoses and access to treatment (drugs and oxygen) and create a safe environment for people to tell their story.
- Collaborate with other organizations to promote efficiency and communicate a coordinated message.
- Research daily living support needs and advocate with community organizations to facilitate PF awareness and specialized service offerings for people living with PF.
- Build advocacy capacity by empowering patients, caregivers, and other committed stakeholders with tools that help them advocate and influence change.

5. Demonstrate local, provincial, and national leadership

- Develop and support PF groups, formally connected to the Foundation, to engage our local communities. These groups will:
  - Be the local source of information on PF for PF patients, their families and caregivers.
  - Liaise with local health authorities, municipalities and provincial ministries of health, and advocate for services and support for the local PF community.
  - Develop new patient support groups and assist existing, local patient support groups with operational issues to allow them to expand and flourish.
  - Expand local volunteer base.
  - Develop and run local events for raising awareness, and fund raising.
  - Manage local components of national events (e.g., local proclamations, building lighting, and bubble blowing for September celebrations).
- Maintain relationships with global PF service providers and organizations, to ensure that we are aware of activities and developments outside of Canada which could benefit the Canadian PF community.
- Inspire engagement and collaboration with internal and external stakeholders.
- Set the example for organizational stability, effectiveness, and excellence.
- Investigate opportunities for joint projects with other service providers.

6. **Build the foundation for the Foundation**
   - As previously noted, using our patient support groups as a platform, develop support group committees throughout the country.
   - Operate efficiently.
     - Ensure that greater than 90% of revenues are used for charitable expenses, specifically for projects aligned with our 4 pillars.
   - Operate transparently:
     - Board to approved annual business plans including 3-year profit & loss, balance sheet and cash flow forecasts.
     - All charitable expense projects to have a Board approved scope of work, budget and schedule.
     - Report to Board of Directors quarterly on charitable project progress relative to approved scope of work, budget and schedule.
     - Prepare an annual report for our PF community.
   - Develop, nurture, and retain a high-performing team
     - Carry out annual performance reviews for Management and the Board of Directors.
     - Develop and maintain succession plans for all Board and key Management positions.
     - Support personal development for Board and Management positions.

7. Build the fundraising capacity of the Foundation
   - Maintain strong relationships with existing corporate donors.
   - Develop fundraising plan which will include but not be limited to:
     - Acknowledgement of contributions of current and historical donors and nurturing relationships.
     - Development of donor data base and management plan.
     - Specific plans for individual calendar events (e.g.: Giving Tuesday, Pay it Forward etc.)
     - Strategy for attracting bequests.
     - Nurture new sponsor/major donor relationships with partners that align with CPFF's vision, beyond the pharmaceutical industry for financial and non-monetary support (e.g.: in-kind goods or services, media coverage, promotional partners).
     - Expand efforts to source funding for existing unfunded CPFF assets (e.g., educational webinars, CPFF events etc.) and create new sponsorable assets.