

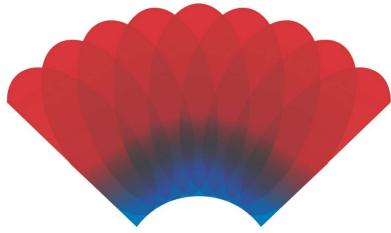
AGENDA

#	Agenda Item	Time Allocated	Planned End Time
	Procedural/Consent Items		
1	Call to Order: K. Morrison	3:30 pm	3:31 pm
2	Introductions and Welcome Remarks: K. Morrison	3:31 pm	3:32 pm
3	Approval of Board Agenda and Call for Other Business: K. Morrison	3:32 pm	3:33 pm
4	Declarations of Conflict of Interest: K. Morrison	3:33 pm	3:35 pm
	Discussion and Action Items		
5	Minutes of March 3, 2023, Board Meeting: K. Morrison <ul style="list-style-type: none"> • Motion to accept the minutes of March 3, 2023 	3:35 pm	3:37 pm
6	CPFF Reports <ul style="list-style-type: none"> ➤ CPFF Financials (February 2023): V. Pringle & S. Lee ➤ Executive Director Report: <ul style="list-style-type: none"> ▪ 2022-2023 Activity Update <ul style="list-style-type: none"> ○ November Board Meeting Follow Up Updates <ul style="list-style-type: none"> • Procurement Policy (Governance Review): K. Morrison • Banking Policy (Governance Review) • Sharon's KPIs (Governance Review) • MAB Review and Succession: C. Fell ○ June 16/17, 2023 Board Retreat (Virtual) <ul style="list-style-type: none"> ✓ Mar 3, 2023 – Strategic Plan (see attached) • Apr 14, 2023 – Draft Work plan based on Strategic plan • May 5, 2023 – Budget ▪ CPFF & Vaultt Database Revenue Generation Update: N. Hilliard, D. Mastin & S. Lee (in progress with Carters) 	3:37 pm	4:55 pm

#	Agenda Item	Time Allocated	Planned End Time
	<ul style="list-style-type: none"> ➤ CPFF Committee Reports: <ul style="list-style-type: none"> ▪ Governance: T. Georgieff & S. Lee <ul style="list-style-type: none"> ○ Policies with John Dinner ▪ Advocacy & Support: M. Ashcroft, H. Smith & S. Lee <ul style="list-style-type: none"> ○ Pucker Up Challenge (see report from Communications & Fundraising) ○ Canadian Organization for Rare Disorders (CORD) – March 27 – 29, 2023 in Ottawa update ○ Canadian Thoracic Society: S. Lee <ul style="list-style-type: none"> • April 20 – 22, 2023 in Montreal • Meeting with Respiriologists ○ JAMP Pharma meeting: S. Lee <ul style="list-style-type: none"> • April 19, 2023 in Montreal ▪ Communications & Fundraising: T. Hunter & S. Lee <ul style="list-style-type: none"> ○ 2022 Surveys for Oxygen White Paper: S. Lee <ul style="list-style-type: none"> ✓ Patient & Caregiver survey • Healthcare professionals survey (in progress with CTS and CSRT) ✓ Oxygen providers survey ○ Pucker Up Challenge: S. Lee <ul style="list-style-type: none"> ✓ BI Argentina ✓ BI Global ✓ BI Canada ✓ Honourable Audrey Gordon, Manitoba Minister of Health • PF organizations from around the globe <ul style="list-style-type: none"> ▪ Shorten Video & Multi-language captions <ul style="list-style-type: none"> ▪ Japanese ▪ Spanish ▪ Portuguese ▪ Chinese ▪ English ▪ French • CTS Round Table Collaboration: S. Lee <ul style="list-style-type: none"> ▪ Lung Associations across Canada ▪ COPD Canada ▪ Asthma Canada 		

#	Agenda Item	Time Allocated	Planned End Time
	<ul style="list-style-type: none"> ○ 2023 HBH: S. Lee <ul style="list-style-type: none"> ● Events <ol style="list-style-type: none"> 1. Tom Hunter, June 25, 2023 – Half Ironman – Mont-Tremblant 2. Queens Varsity Team (20 members) – Toronto Triathlon Event – July 23, 2023 3. Andre Moran-MacDonald, Half Ironman – July 30, 2023 - Calgary, BC 4. Avonmore Berry Farm for CPFF – Aug 12, 2023 5. Clarke Walk – Sep 9, 2023 – Calgary, AB 6. In memory of Rob Garbutt - ? – Winnipeg, MN 7. Davidson Walk – Sep 16 – Markham, ON 8. Khan Family Walk for CPFF– Sep 23, 2023 – Montreal, QC ● Greetings (Premiers & Healthcare Ministers) ● Lighting of Buildings across Canada ● Paralympics 2024 <ul style="list-style-type: none"> ▪ Presentation of Hope & Courage in support of PF patients ▪ Medical Advisory Board (MAB): C. Fell <ul style="list-style-type: none"> ○ April 3, 2023 – Fellowship Reviews <ul style="list-style-type: none"> ● Kristen Nessel (Hamilton Firestone with Dr. Nate Hambly) ● Alex Campbell (UBC with Dr. Chris Ryerson) ● Motion: to accept Kristen Nessel and Alex Campbell as the 2023 Fellows with a \$90K grant each as recommended by the MAB. 		
7	New Business		

#	Agenda Item	Time Allocated	Planned End Time
	<ul style="list-style-type: none"> <li data-bbox="326 310 727 342">• In Camera Session (if needed) 		
8	<p data-bbox="277 422 760 453">CPFF Board Meeting Dates for FY 22-23:</p> <p data-bbox="277 478 505 510">Friday May 5, 2023</p> <p data-bbox="277 516 954 548">Board Retreat: Friday June 16, & Saturday June 17, 2023</p> <p data-bbox="277 554 496 585">Friday July 7, 2023</p> <p data-bbox="277 592 550 623">Friday August 11, 2023</p> <p data-bbox="277 630 581 661">Friday September 8, 2023</p> <p data-bbox="277 667 548 699">Friday October 6, 2023</p> <p data-bbox="277 705 574 737">Friday November 3, 2023</p> <p data-bbox="277 743 906 774">Friday December 1, 2023 – CPFF Virtual Open House</p>	4:55 pm	4:58 pm
9	Adjournment	5:00 pm	



Canadian Pulmonary Fibrosis Foundation

Board Minutes

Held via ZOOM

On Friday March 3, 2023

Commencing at 3:00 pm EST

Present: Kirk Morrison, Chair
Sharon Lee, Executive Director
Verity Pringle, Treasurer
Todd Georgieff, Vice, and Governance & Finance Chair
Mark Ashcroft, Advocacy & Support Co-Chair
Dr. Holly Smith, Advocacy & Support Co-Chair
Ranjena Maloni

Guest(s): None

Regrets: Tom Hunter, Communications & Fundraising Chair
Dr. Charlene Fell
Nicole Hilliard
Derek Mastin
Ray Protti

Minutes: Roberto Zapata

Call to Order

The meeting was called to order by K. Morrison.

Introductions and Welcome

K. Morrison welcomed everyone.

Approval of the Board Agenda

It was moved and seconded,
That the Board agenda be approved as amended.

Carried.

Declarations of Conflict of Interest

There were no declarations of conflict.

Minutes of February 3, 2023 Board Meetings

It was moved and seconded,
That the minutes of the February 3 meeting be approved.

Carried.

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CPFF Financials

V. Pringle presented the January 2023 financials and pointed out that donations for the month totaled, give, or take, \$32,000.

It was pointed out by R. Zapata and S. Lee that this amount is almost triple the 5-year average for January donations, which sits at \$11,046, as well as the 5-year maximum, which sat at \$13,560. This success highlights CPFF efforts to improve donor engagement and fundraising in historically slower months.

Executive Director Report

Vision & Mission Statements

The Board discussed the new CPFF proposed vision and mission statements.

OUR VISION

A world free of pulmonary fibrosis.

OUR MISSION

We improve the lives of people living with pulmonary fibrosis by providing compassionate support, leading advocacy, raising awareness, funding research, and inspiring hope.

The Board believes the statements resonate well, but agree that mission statement should have a mention of Canada.

It was moved and seconded,

That Canadian content be added to the mission statement.

Carried.

Procurement Policy & CPFF KPIs

It was mentioned that the Governance & Finance committee ought to have a look at the Procurement policy and the proposed KPIs in order to analyze and formalize them.

June Retreat

It was mentioned that, following the event, it would be important to take note of, and provide the Board with, information regarding what was approved during the retreat, and what is still outstanding. This would allow all Directors to follow up on any related progress, and it would also allow any new Directors to catch up on what has happened.

FY23-24 Strategic Plan

The Board briefly discussed the proposed strategic plan, which garnered no objections.

MAB Review and Succession

It was mentioned that, so far, only one MAB has agreed to join the 2023 Robert Davidson fellowship review meeting. It was pointed out, and agreed, that only MAB members without a conflict of interest should review proposed fellows for full transparency.

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Furthermore, the Board agrees that even if there are not more applications than the available number of fellowships to award, CPFF staff should at the very least verify that the fellows meet the minimum application criteria.

Innovation Fund

The Board briefly discussed the Innovation Fund. It was reminded that a priority for the fund is to have flexibility in how to use it, so CPFF may use it in case of emergency, such as the foundation running low on funds on a down year.

It was mentioned that the auditor has advised CPFF to create a separate line for the fund on financial statements and to designate it as internally restricted.

It was agreed that potential fund donors ought to be informed that the internal restriction is in the spirit of the fund.

It was mentioned that, once the fund is formalized, the Board can decide to put money into it depending on the fiscal year results.

It was pointed out that CPFF currently has the liquidity to invest into the fund, but a matching partner is still being prospected. It was added that once a matching partner is secured, their contribution could be used as a fundraising tool, as matching opportunities are usually great to boost fundraising.

CPFF & Vaultt Database Revenue Generation Update

Actions from February 2023 meeting are still being worked on.

Governance & Finance Report

T. Georgieff mentioned his work, alongside R. Zapata, to organize the accepted and outstanding CPFF documents on Google Drive, including their current status.

At the moment, there are 25 documents, with 11 of them being completed and the rest being in different states of completion.

The next step is to determine where each document belongs and what the review cycle for each is.

T. Georgieff took the opportunity to commend M. Martin's work as former Governance & Finance chair, in particular the number of policies she worked on and helped finalize.

Advocacy & Support Report

Oxygen Advocacy

The Board was reminded of the important to continue the oxygen advocacy and its impact on patients and caregivers.

Canadian Organization for Rare Diseases

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It was mentioned that S. Lee will join CORD leadership in Ottawa to ask the prime minister and federal minister of health on the status of billion dollars that was promised for rare diseases and how those funds can be accessed.

Canadian Thoracic Society Conference

It was pointed out that:

- For \$1,000, CPFF will have 3 registrations and 1 booth at the CTS conference in April;
- It is the hope that CPFF will be allowed to participate in the ILD committee meetings, since it is a good place to give out the new patient guidebook;
- The conference could be streamed live on Zoom, through CPFF's website, to garner more community engagement;
- The conference is a great place to create relationships with community respirologists and solicit for 2 positions – 1 for the Board and 1 for the MAB.

Jamp & Sandoz

It was pointed out that Jamp:

- Has participated to the Pucker Up challenge and has uploaded a video on their social media;
- Is planning to produce generic nintedanib once OFEV's patent runs out;
- Has developed a good patient program that is cognisant of the current pitfalls in drug coverage for patients.

S. Lee has asked Jamp for \$10,000 grant and is currently working on stewarding CPFF's relationship with them.

As for Sandoz, it was pointed out that they have not been forthcoming and do not seem to want to work with CPFF.

It was suggested that a pulmonary rehabilitation study, similar to the oxygen study currently underway, could be an activity for future years, and should be considered in the upcoming strategic planning work.

Communications & Fundraising Report

DIY Fundraising

It was mentioned that Skott Taylor's DIY fundraiser managed to surpass its goal of \$10,000, and that hopefully he'll be able to share the good experience he had doing so.

Oxygen Advocacy – Healthcare Professionals Survey

It was mentioned that it seems that Action for PF (UK) has uncovered a similar problem pattern to the one experienced in Canada through their own surveying, with rural areas having trouble accessing oxygen.

As for CPFF's healthcare professionals survey, it was pointed out that about 60 more survey submissions would be needed to make the study worthwhile. It was suggested that healthcare professionals ought to be remunerated for their submission to entice them to fill out the survey, as the lack of submissions probably stems from the perceived opportunity cost of their time.

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In order to keep the project on schedule and finish up by May, this were the proposed steps:

1. Update and finish the healthcare professionals survey;
2. Include both surveys results (healthcare professionals and oxygen providers) in the whitepaper;
3. Have the whitepaper endorsed by CTS;
4. Have the whitepaper published in a recognized medical journal;
5. Use the whitepaper as messaging for advocacy.

Global Heroes

It was pointed out that the digital version of the publication was great, while the physical version left much to be desired. Should CPFF partner with Global Heroes once again in the future, an exclusively digital strategy ought to be employed.

Pucker Up Challenge

It was pointed out that the PU Challenge has not yet garnered the desired traction amongst the community.

The Board was asked to participate in it and to send a video to CPFF staff so they may compile them into a video.

Other Boehringer Ingelheim divisions, including Argentina and Greece, have agreed to participate in the challenge.

Once the challenge picks up, the idea is to do an around-the-world compilation.

CPFF Mascots

Following community input, it was decided that the CPFF mascots will be named Hope and Gen (or Jen).

The Board briefly discussed the utility of trademarking the mascots, which would prevent anyone from using their likeness as they see fit.

2023 Hope Breathes Here PF Month Fundraising

An update was provided about the secured events.

Queen's triathlon team, composed of 20 medical students including Andres Moran-Macdonald, have agreed to fundraise for CPFF in exchange of having their triathlon registration fees covered. Their goal is for each triathlete to raise \$1,000. Most of them will participate in the Toronto triathlon, while Andres will participate in the Calgary one.

The Calgary Clarke Walk has been booked.

Several volunteers have been secured for the Markham Walk.

The Montreal Walk will potentially be hosted by the Kahn family instead this year, with no objection from T. Georgieff and his spouse, N. Fenton.

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On the topic of naming the individual walks, the Board was cautioned against giving them personal names. It is easier to attract the community without that level of personalisation as a new walk starts up. Instead, the following formula was suggested:

CPFF (city name) Walk hosted by the (family name) family

Further discussion on the topic to take place in the Communications & Fundraising committee.

Last, but not least, paralympic athletes have been invited to participate in the walks and to give a presentation about hope and determination.

MAB Report

Beyond what was mentioned in the Executive Director report, with C. Fell's absence, there was nothing to add.

Adjournment

The meeting was adjourned at 4:33 pm EST.

Next CPFF Board meeting will be held April 14, 2023.

Certified correct,

SIGNATURE TO BE INCLUDED

Kirk Morrison
CPFF Board Chair



Canadian Pulmonary Fibrosis Foundation (CPFF)

3/3/2023

Strategic Plan FY23-24

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

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

We improve the lives of **Canadians** living with pulmonary fibrosis by providing compassionate support, leading advocacy, raising awareness, funding research, and inspiring hope.

Vision

A world free of pulmonary fibrosis

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
 - 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
 - Encouraging bubble blowing across the country
 - Clarke Walk for Pulmonary Fibrosis (national event)
 - 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.
- 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 and oxygen)
- 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.

5. Demonstrate local, provincial and national leadership

- Develop and support Regional Committees, formally connected to the Foundation, to engage our local communities. These committees 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 (eg. 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 Regional 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 Expenses 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

▪ **Create CPF Innovation Fund**

- Support fund with earned income for continued growth
- Annual review of funds by Board for alignment with strategic goals
- Internal restrictions as determined by Board for disbursement of interest earned
- 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.: Rare Disease Day, September PF, etc.)
 - Strategy for attracting bequests.