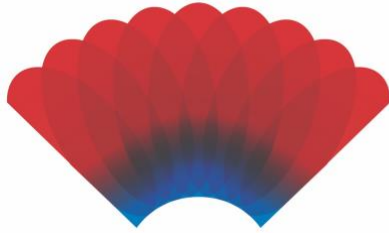


## AGENDA

| # | Agenda Item  | Time Allocated | Planned End Time |
|---|--|----------------|------------------|
|   | <b>Procedural/Consent Items</b>  |                |                  |
| 1 | Call to Order: K. Morrison   | 2:00 pm        | 2:01 pm          |
| 2 | Introductions and Welcome Remarks: K. Morrison   | 2:01 pm        | 2:02 pm          |
| 3 | Approval of Board Agenda and Call for Other Business: K. Morrison  | 2:02 pm        | 2:03 pm          |
| 4 | Declarations of Conflict of Interest: K. Morrison  | 2:03 pm        | 2:05 pm          |
|   | <b>Discussion and Action Items</b>   |                |                  |
|   | <b>Treasurer's Report: V. Pringle</b>  |                |                  |
| 5 | <ul style="list-style-type: none"> <li>• CPFF Draft Audited Statements FY 21-22: V. Pringle, S. Lee, N. Jilani &amp; H. Ng               <ul style="list-style-type: none"> <li>○ Motion to accept the 2021-2022 Audited Statements</li> </ul> </li> <li>• Appointment of Auditors for the 2022-2023 fiscal year               <ul style="list-style-type: none"> <li>○ Motion to the appoint Schwartz Levitsky Feldman LLP, Chartered Accounts as Auditors for the 2022-2023 fiscal year</li> </ul> </li> </ul> | 2:05 pm        | 2:27 pm          |
| 6 | <b>New Business</b> <ul style="list-style-type: none"> <li>• In Camera Session (if needed)</li> </ul>  | 2:27 pm        | 2:28 pm          |
| 7 | <b>CPFF Board Meeting Dates for FY 22-23:</b><br>Friday January 13, 2023 (AGM & Board Meeting)<br>Friday February 3, 2023<br>Friday March 3, 2023  | 2:28 pm        | 2:30 pm          |
| 8 | <b>Adjournment</b>   | 2:30 pm        |                  |



# Canadian Pulmonary Fibrosis Foundation

## **Board Minutes**

**Held in Vancouver, BC via ZOOM and In-person**

**On Friday and Saturday November 4-5, 2022**

**Commencing at 2:30 pm PDT on Friday and 9:00 am PDT on Saturday**

Present: Kirk Morrison, Chair  
Moyra Martin, Vice & Governance Chair  
Verity Pringle, Treasurer  
Sharon Lee, Executive Director

Mark Ashcroft, Advocacy & Support Co-Chair (Via Zoom)

Todd Georgieff, Communications & Fundraising Co-Chair  
Nicole Hilliard (Via Zoom)  
Tom Hunter, Communications & Fundraising Co-Chair (Via Zoom)  
(Joined @ 9:23 am and left @ 10:30 am)  
Ranjena Maloni  
Derek Mastin (Via Zoom)  
Ray Protti  
Dr. Gokul Vidyasankar

Guest(s): Dr. Charlene Fell

Regrets: Dr. Holly Smith, Advocacy & Support Co-Chair  
Peter Kleinstiver  
Winston Fiander

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.

## **CPFF Board Minutes of November 4-5, 2022**

### **Minutes of October 7, 2022 Board Meeting**

It was noted that a copy of the Robert Davidson Fellowships has yet to be sent to N. Hilliard and D. Mastin for review. A copy will be sent to each electronically during the following week.

It was moved and seconded,

**That the minutes of the October 7, 2022 Board meeting be approved.**

**Carried.**

### **CPFF Overview**

#### **History of CPFF**

M. Martin provided a detailed summary of CPFF's history. This served as an introduction to the new directors, and a refresher for the veteran directors.

In 2009, Robert Davidson went for health check-up as part of his soccer referee certification. This is where Robert was diagnosed with pulmonary fibrosis, which at the time had very little information available online.

Due to the scarcity of information and support, Robert decided to start a foundation which would bridge that gap. Most of the CPFF's start up investments came from Robert's own pocket.

M. Martin first met Robert in 2013, as he traveled West to advocate for the coverage of Esbriet in all of Canada.

CPFF started as a provincial foundation, but Robert's goal was to expand it across Canada, and so it was federally registered.

It is important to recognize the past directors who stepped away from the Board for personal reasons or who passed away.

- Stephen Binch (passed)
- Barbara Barr (passed)
- Doug Barber (passed)
- Darlene Gallant
- George Kaminsky

### **CPFF Structure**

S. Lee provided a detailed summary of CPFF's structure. This served as an introduction to the new directors, and a refresher for the veteran directors.

The following topics were discussed:

- Organizational structure (directors, non-directors and staff)
- Vision, mission and objectives (and their pending update)
- The 4 Pillars, their history and what they comprise:
  - Support of Patients & Caregivers
    - Support groups

## CPFF Board Minutes of November 4-5, 2022

- CPFF App
- Staff ready to help
  
- Education & Awareness
  - Website
  - Educational webinars
  - Patient stories and Breathless for Change documentary
  - Hope Breathes Here Newsletter
  
- Research
  - Fellowships and grants (and previous fundings awarded)
  - Mention of the presentation by Chris Ryerson and fellows on Friday morning
  
- Advocacy
  - OFEV for all PF-ILD patients and thank you letters to Ministers
  - Ambassador program
  - Oxygen whitepaper
  - Previous successes (The Burden of IPF report, Breathless for Change 2020 report, Provincial presence (Greeting & Proclamations), Canadian IPF Charter, Initial OFEV Advocacy for IPF patients)

It was mentioned that if the Boehringer Ingelheim's and Roche's upcoming drugs pass to phase 3, CPFF will take up advocating for their equitable coverage across Canada.

It was added that in-person support group meetings, prior the pandemic, is a success that was not discussed but that should be noted.

### **Carter's Report**

K. Morrison provided some key highlights of the 2015 Carter's report. He furthermore encourages the rest of the Board to read the 27-page report themselves.

#### Highlights

Page 5 - CPFF is a charitable corporation that:

- Is not owned by the Members of Directors;
- Does not own/issue share capital;
- Cannot be operated for pecuniary gain of Members.

Page 6 & 14 - CPFF must conduct a yearly audit, as it is a soliciting corporation with a non-designated revenue greater than \$250,000.

Page 8 - CPFF's purpose is to:

- Receive and maintain funds and apply all or part of principal and income to charitable organizations;
- Promote health;
- Advance education;
- Undertake other activities that will further help achieve its charitable purposes.

## CPFF Board Minutes of November 4-5, 2022

Page 9 - CPFF's structure requires an Annual General Meeting (AGM) within 6 months of its fiscal year's end (July 31, therefore by January 31) during which:

- Reports are reviewed;
- Financials and budgets are reviewed and approved;
- Directors are elected;
- Past actions are approved;
- Other business is transacted.

Page 11 - CPFF's governance, administration and management of the Corporations entails that:

- Directors are accountable to Members and furthermore cannot receive remuneration;
- Executive Director is accountable to Directors and responsible for management and day-to-day operations;
- Meeting must take place in person or electronically;
- Documents must be executed by 2 Officers or others designated by Board;
- Page 15 - Board must consider adopting policies on matters of important applications, particularly where the Corporation needs to protect potential victims;
- Page 14 - Books and records must be kept at the registered office for the following:
  - Certificate of continuance, articles of amendment and by-laws
  - Register of Members and Directors
  - Meeting minutes
  - Minute book.

Page 15 - CPFF's obligations under the Income Tax Act entail that maintaining charitable status is the responsibility of the Members.

Page 16-23 - CPFF has federal and provincial reporting requirements.

Page 24-26 - CPFF's Directors' duties and liabilities entails that Directors:

- Are the "directing minds of the Corporation" and so may be responsible for "misdeeds of the Corporations in certain instances";
- Must be reasonably prudent and have a duty to act honestly and in good faith with a view of the best interest of the Corporations;
- Are potentially liable for 6 months of unpaid wages;
- Must have provisions for resignation in the event of a conflict.

It was pointed out by S. Lee that CPFF became a public foundation in 2020 and can apply for government grants.

### **Strategic Plan Review**

#### **Plan Review**

Highlights about S. Lee and R. Zapata were provided.

S. Lee urged the members of the Board to **ASK** themselves how CPFF can **GROW** by being a **STAR**.

### *Attitude, Skills and Knowledge*

### *Goals, Realistic, Opportunities, Will/Way*

### *Situation, Tactics, Analysis and Results*

This process entails:

- Rethinking policies, procedures and protocols;
- Creating comprehensive plans with Board and staff to share with key stakeholders, funders, volunteers and donors.
  - Goal timelines
  - Communication tools
  - Expansion plans

#### **Discussion and approval of draft Mission and Vision statement from May Board Retreat**

It was noted that the FY 22-23 Strategic Plan was approved with drafts of these requiring resolution. It was pointed out that the vision was already revamped in 2019, and that the Board had spent quite some time on it.

It was furthermore pointed out that the proposed vision looks more like a mission. A vision isn't an action, a mission is. The Board had voted online without significant input. The vision should be the state the Foundation aspires to achieve.

The work done in 2019 and recently (by Etal Marketing) will be further reviewed before further action on this topic.

It was mentioned that it is not up to Etal Marketing to come up with CPFF's vision. It was however rebutted that Etal did not create CPFF's vision, they merely help pull together the results of the votes done by the Directors.

The discussion was tabled. S. Lee to coordinate finalizing the Mission and Vision statements.

#### **FY22-23 Strategic Plan Overview**

The previously accepted strategic plan and budget for the current fiscal year was overviewed and discussed by the Board.

It was pointed out that, and discussed how, working with some key associations has proven challenging, if at all possible.

It was mentioned that about half of the strategic plan's \$1,393,302 budget has already been raised to avoid working in deficit as much as possible.

The Board was reminded to **ASK** themselves how CPFF can **GROW** by being a **STAR**.

#### **Innovation Fund Discussion**

## **CPFF Board Minutes of November 4-5, 2022**

It was mentioned that CPFF have been asked by Boehringer Ingelheim Global division to request funding from the United States, Pacific and China divisions, as they are only willing to offer \$500,000 of the \$3,000,000 goal for the fund. The Canada division is also offering \$500,000.

S. Lee has requested to meet with the Boehringer Ingelheim family to personally ask for the Global division to match the \$1,000,000 that CPFF is willing to invest in this fund.

It was clarified that:

- The Innovation Fund's goal is to only spend the money from the interest earned to fund unplanned, innovative and exceptional projects that no one else would be willing to fund;
- It should nonetheless be flexible enough that an exception can be made in the event that funds are needed to keep the Foundation afloat in exceptional circumstances;
- This funding would be in addition to what Boehringer Ingelheim already contribute yearly; it would not be a final, book-closing, grant;
- The scope of the fund includes, but goes beyond, research.

General support was expressed for this type of matched funding, as there are few organizations for patient support and that dollars contemplated could assure that long term financial stability for CPFF.

It was furthermore mentioned that this funding could take away the stress of whether CPFF can afford fellowship funding every year, as it wouldn't need to come out of the operating fund.

Some Board members were not keen on calling this initiative the "Innovation" Fund.

The Board agrees that this fund would be doable, but would require some scoping and branding, and could definitely benefit from a top-up campaign.

The next course of action would be to define how the fund would be named and what it's spirit would be so CPFF's auditors and lawyers can be advised on CPFF's intentions.

V. Pringle was proposed as the lead this project on behalf of the Governance committee, to figure out the financial feasibility of this project and define how the fund proceeds should be spent with T. Georgieff and T. Hunter volunteering to support this project as part of the communications and fundraising committee.

It was pointed out that convincing Boehringer Ingelheim to fund this project would give CPFF more leverage with ongoing talks with Roche.

### **CPFF Financials**

The Board briefly discussed the need to get 3 quotes for the fulfilment of all projects. It was argued that not all projects require 3 quotes, but the process needs to be clarified to define the cut-offs.

### **September 2022 Financials**

V. Pringle provided an update on CPFF's financials.

## **CPFF Board Minutes of November 4-5, 2022**

Revenue currently sits at \$115,000, while it was at \$49,000 at this time last year.

It currently looks like CPFF is running on a deficit, but it is just because of the timing of the expenses related to PF Awareness Month.

It was pointed out that CPFF needs to be able to forecast its annual fundraising targets, despite how challenging it is to do so due to the nature of the donor base (95.7% of donors in the previous 5 years have donated once or twice).

### **Banking: Re: Heather Davidson**

It was pointed out that H. Davidson remains with signing authority despite the motion that was previously passed to remove it.

Several Board members agreed that, having an individual who is neither a director nor an employee accessing our bank exposes CPFF to tremendous liability, and that this needs to be resolved as soon as possible.

It was mentioned that H. Davidson is interested in coming back as Board member despite recently stepping down.

It was pointed out that, according to the by-laws, there's a limit to how many Directors can be on the Board, and that thinking should furthermore be rational and not emotional.

It was also noted that CPFF is currently using the Davidson's home as our corporate address. The Board agrees that CPFF's mailing address needs to be changed ASAP. Mail forwarding was proposed to ensure all CPFF-related mail ceases to arrive at the Davidson residence. S. Lee to develop a plan for this.

It was proposed that H. Davidson could be hired as a part-time employee and she could donate her wages if she wishes, just so there's a reciprocal relationship.

It was also proposed that she could become a volunteer for the Governance & Finance committee.

K. Morrison will contact H. Davidson to further discuss the topic, and will report back to the Board. S. Lee to draft a policy/procedure on banking including, but not limited to payroll, accounts payable and deposits and bring it forward to the Board for review as soon as possible.

### **Day 1 Adjournment**

The meeting was adjourned at 5:42 pm PDT.

The meeting was scheduled to resume at 8:30 am PDT on the following day.

### **Governance & Finance Committee Report**

#### **Board of Director Makeup, Terms, Planned Departures & Succession Planning**



## **CPFF Board Minutes of November 4-5, 2022**

The Board was urged to think and prepare to take action about the succession planning for K. Morrison as Chair in 2024, and the other Directors who are scheduled to leave in 2023. Notably, the Board will have the difficult task of trying to replace G. Vidyasankar as a community respirologist Board member.

Additionally, the Board was urged to think about the human resources needs of CPFF, in terms of Directors, volunteers and staff in order to bridge the skill gaps in the organization and begin working towards a Board that takes on a more governing than working role.

It was pointed out that volunteer policy is needed for volunteers to sit at the committee level, since the current needs seem to outweigh the Board's output capacity.

### **Board Manual**

It was clarified that the Board Manual project entails putting together a handbook that would be available on a portal for all current and future Directors.

The document would be editable so S. Lee and R. Zapata can update it as new relevant documents become available.

It was moved and seconded,

**That Etal Marketing will be hired to create a digital repository handbook at a cost of \$5,932.50.**

**Carried.**

### **December CPFF Virtual/Face-to-Face Open House**

S. Lee provided a summary of what was done last year.

A virtual Community Open House took place where sponsors and other guests were invited. Once the sponsors left, attendees were asked:

- What do you know of CPFF?
- What do you think we did well?
- What are the gaps?

A report came out of this event stating what CPFF did well and what could be improved. It was shared with the Board and discussed at the May Board Retreat.

For this year, it is proposed that 2 separate events take place on the same day:

- Appreciation luncheon to thank sponsors, MAB doctors, departing directors and H. Davidson
- Meeting similar to last year at 1:30 pm EST

Ideally, 5 individuals from each province would take part in the event.

## **CPFF Board Minutes of November 4-5, 2022**

Similar to last year, a report would come out of this event that ought to be reviewed and discussed in May. The results will help consolidate or shift CPFF's strategic plan.

### **Advocacy & Support Committee Report**

#### **Support Group Policy**

It was clarified that the Support Group policy would provide a guideline for the expectation of both parties (CPFF and the support groups).

However, it was urged that the expectations must be reasonable as it would be unwise to have potential new support group leaders thinking that the endeavour is onerous and give up as a result.

#### **Oxygen Advocacy**

It was mentioned that the results from the 3 surveys (patients & caregivers, oxygen providers and respirologists) should be used to create some copy that would be sent to MLAs through NewMode.

G. Vidyasankar is writing up the whitepaper from the medical research papers, although, he stated that there was little research on the use of oxygen.

Some Board Directors felt a bit uncomfortable on how Etal Marketing sensationalized headlines from the Breathless for Change survey. It was agreed that the Communications & Fundraising committee, as well as the Board, should find a balance between the patient voice and the need to bring awareness.

The Board debated on whether the MAB should be asked for feedback on the Breathless for Change report, as it was not a medical report but a reflection of patient voices.

S. Lee and C. Fell to have conversation offline to address concerns.

### **Communications & Fundraising Committee Report**

#### **Social Media Management Plan**

The Board was presented with a 1-year social media management plan that would allow CPFF to have an efficient and effective social media presence year-round.

It was clarified that the goal of the plan is not to aggressively fundraise year-round, but rather to maintain a connection with the community in non-campaign months while including very subtle, non-invasive asks.

To address some concerns, it was pointed out that the ideas are those of CPFF, and that the Foundation is the decision-maker. However, CPFF has asked Etal Marketing for help in fulfilling those ideas and furthermore open to their suggestions.

The Board overviewed the proposed plan, which included the following campaigns:

- Year of Positivity
- 30 Days of Gratitude
- Rare Disease Day

## **CPFF Board Minutes of November 4-5, 2022**

- Oxygen Advocacy

Overall, the Board is pleased with the proposed campaigns.

For the Year of Positivity, the Board agrees that having a mascot would be great idea, but the name requires further thought.

It was pointed out that enough feedback needs to be requested from the community before executing these campaigns with the social media management plan.

During the discussion the need to finalize our draft Procurement Policy and Foundation KPI's was noted. S. Lee to finalize.

It was moved and seconded,

**That Etal Marketing will be hired to execute a 1-year social media management plan for \$16,800 plus HST.**

**Carried.**

### **Global Heroes**

S. Lee has renegotiated the deal with Global Heroes to receive more value for the \$5,000 investment. The new deal includes the original digital media exposure for December 2022 and an additional digital and print exposure during February 2023 (Toronto Star, Globe & Mail).

This will assist the planned Rare Disease Day campaign.

### **MAB Report**

It was pointed out that only 3 of the 7 ILD specialists on the MAB routinely participate. As such, CPFF must actively discuss and put in place succession planning for the MAB.

It was mentioned that MAB members ought to be thanked for their commitment and this ought to be taken as an opportunity to assess their interest in staying on, and on becoming a Director with G. Vidyasankar leaving.

It was pointed out that patient presence is crucial on the MAB, and Murray Walz inclusion is a great step forward. It was added that the MAB ought to be more inclusive of patient presence, and as such should be more welcoming.

It was mentioned that representation from the Prairies and Quebec would be welcomed and invaluable on the MAB. It was also proposed to include at least one fellow as part of the MAB.

C. Fell mentioned that a CPFF email would be crucial in helping her achieve her endeavours as MAB Chair. Furthermore, she added that scheduling must be set in place for 4 annual meetings to take place (1 each quarter).

The Board discussed the possibility of including Respiratory Therapists on the MAB.

**CPFF Board Minutes of November 4-5, 2022**

It was pointed out that Dr. Chris Ryerson, Dr. Alyson Wong, Dr. Daniel Marinescu and Dr. Alec Campbell ought to be thanked for their time and for their invaluable presentation. Furthermore, CPFF ought to consider Dr. Ryerson's request and make the videos in question.

**Day 2 Adjournment**

The meeting was adjourned at 11:41 am PDT.

Next CPFF Board meeting will be held on December 2, 2022.

Certified correct,

A handwritten signature in blue ink, appearing to read 'K. Morrison', with a long horizontal stroke extending to the right.

Kirk Morrison  
CPFF Board Chair