Canadian Pulmonary Fibrosis Foundation

Board Minutes
Held via ZOOM
On Friday April 1, 2022
Commencing at 3:00 pm EST

Present:	Kirk Morrison, Chair Moyra Martin, Vice & Governance Chair Verity Pringle, Treasurer Sharon Lee, Executive Director Mark Ashcroft Todd Georgieff Tom Hunter Ranjena Maloni (joined @ 3:48 pm) Ray Protti Dr. Holly Smith Dr. Gokul Vidyasankar
Guest(s):	Dr. Charlene Fell, MAB Chair (joined @ 3:15 pm)
Regrets:	N/A
Minutes:	Sharon Lee, Board Secretary

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.

Carried.

Declarations of Conflict of Interest
There were no declarations of conflict.

Minutes of March 11, 2022 Board Meeting

It was moved and seconded,

That the minutes of March 11, 2022 be approved.

Carried.

CPFF Reports

CPFF Financials
V. Pringle reviewed the financials reports. She reported that was nothing out of the normal.

CPFF Strategic Plan & Virtual Board Retreat
K. Morrison reviewed the planning process leading up to the May 2022 Board retreat.

- The Strategic Plan has been updated based on feedback from the December 2021 Community meeting, which was reviewed at the February Board meeting. A draft update was circulated in the Board package for today's meeting.
- Outstanding items from the Strategic Plan:
    - Feedback from December 2021 Community Meeting was that the Mission and Vision statements could use a refresh, and so a survey to receive input on content will be sent out to Board members before the Board Retreat.
    - Should consider whether or not to address the establishment of a reserve type fund in the plan.
- A draft 3-year workplan has been prepared based on work being discussed at the Committee meetings, and was circulated in today's Board package. Comments from Committees (and Board members) on this workplan would be appreciated.
- Based on this workplan, a draft 3-year financial plan will be reviewed in advance of the May Board Retreat via a Google survey.
- All of the above will be reviewed at the Board retreat, with a view to approval at the June Board meeting.

S. Lee reminded everyone the time and dates for the May board retreat based on the feedback from the Doodle Poll. Etal Marketing will send out prep-work two week before the Board retreat.

- Friday **May 13**, 2022 from **1 pm EST** *(10 am PST, 11 MST & 2:30 pm AST)* to **4 pm EST** (*1:00 pm PST, 2 pm MST & 5:30 pm AST*)
- Saturday **May 14**, 2022 from 10 am EST (*7 am PST, 8 am MST & 11:30 am AST*) to **12 noon EST** (*9 am PST, 10 am MST & 1:30 pm AST)*

Communications
T. Georgieff reviewed the timing on the work of combining CPFF.CA & HopeBreathesHere.COM, and the exploration of what capabilities desired of the APP in support of CPFF's events in conjunction to the needs of the other committees (Advocacy & Support and Fundraising). He discussed how the committee would like to add Clinical trials on the website, and to have things automatically updated without CPFF having to do. CPFF simply provide a direct link to the website where the information is hosted as this will be less of a burden and cost to CPFF.

T. Georgieff reviewed the status of the three surveys – 1) Patient & Caregiver, 2) Canadian Respirologists and 3) Canadian Oxygen Providers. S. Lee noted that she was able to provide the survey questions from EU IPFF and the Oxygen research result from the US funded by Three

Lakes Foundation. T. Georgieff said that this was greatly appreciated, as it will enhance CPFF's surveys in gathering useful results.

S. Lee reported that the patient & caregiver survey will be translated into French and be reviewed by Dr. David Langlais and Dr. Deborah Assayag, from McGill University.

T. Georgieff informed the Board that the patient & caregiver survey will be launched after May 24th due to long weekend – Victoria Day across the country.

Fundraising
T. Hunter reported on the committee's plans for next three years in supporting CPFF's fundraising goals. He indicated that V. Pringle and S. Lee would investigate and bring back information on how best to create a CPFF innovation Fund where only the interest earned from the principle will be used for CPFF programs and services.

S. Lee reviewed the data profile of CPFF's donors with the Board. She noted the breakdown of CPFF's donors. She reminded everyone that CPFF unlike other charities, have the one-time donors (99.6%) who we will not be able to convert into long term donors due to the lack of connection to the organization, as it was donated through someone dying from IPF/PF. Even our event attendees are usually a one-time donor who gives because someone they know asked them.

Donor Profiles
0.1% are lapsed monthly donors
0.1% are active monthly donors
0.1% are legacy donors (a gift from their estate)
0.1% are stock donors
99.6% are one-time donors (they gave due to knowing someone who died from IPF/PF)

Dollar Amount Donated

- 1% donated between $25 to $49.99
- 3% donated between $50 to $99.99
- 6% donated between $100 to $199.99
- 4% donated between $200 to $499.99
- 15% donated between $500 or more
- 2% of the donations are from PayPal Giving Fund
- 69% of the donations are from Grants (BI, Roche and other charities, with the bulk from pharma)

Advocacy & Support
M. Ashcroft informed the Board that committee members will take on one or two support groups and connect with them with the same questions from last year. He had asked Governance Chair, M. Martin to request John Dinner to help CPFF with a patient support group policy.

The support group responses will be shared with CPFF staff and they will create a summary chart for the committee's review who will then share the results with the Board at the next Board meeting.

Governance
M. Martin presented her report which was included in the Board package.

Medical Advisory Board (MAB)
Dr. Fell presented the Fellowship recommendation of the MAB for a $60,000 grant.

- Dr. Alec Campbell from UBC, with Dr. Chris Ryerson and Scott Tebbutt, PhD
- Dr. Bohyung Min from U of C, with Drs. Charlene Fell and Kerri Johannson
- Dr. Leigh Minuk from UHN, with Drs. Shane Shapera and Jolene Fisher

Dr. Fell informed the Board that Dr. Amanda Grant-Orser is returning for the second year of her fellowship at $90,000. She was off on maternity leave. Dr. Grant-Orser is under the supervision of Drs. Fell and Johannson.

The discussion then moved on to how fellows may apply for a second year. The Board asked Dr. Fell what's the dollar amount to be grant? Dr. Fell will consult with the MAB members and will bring a recommendation on the dollar amount needed for the fellows at the Board retreat. The Board will then discuss whether CPFF would make the commitment if they did not receive pharma support.

Adjournment
The meeting was adjourned at 4:30 pm EST

May Board meeting date has been replaced with the Board Retreat on the 13th and 14, 2022. Next CPFF Board meeting will be held on June 3, 2022.

Certified correct,

Kirk Morrison
CPFF Board Chair