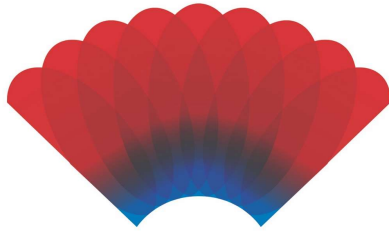


AGENDA

#	Agenda Item	Time Allocated	Planned End Time
	Procedural/Consent Items		
1	Call to Order: T. Georgieff	10:00 am	10:01 am
2	Introductions and Welcome Remarks: T. Georgieff	10:01 am	10:05 am
3	Approval of Board Agenda and Call for Other Business: T. Georgieff	10:05 am	10:06 am
4	Declarations of Conflict of Interest: T. Georgieff	10:06 am	10:07 am
	Discussion and Action Items		
5	Minutes of November 16, 2023, Board Meeting: T. Georgieff <ul style="list-style-type: none"> • Motion to accept the minutes of November 16, 2023 	10:07 am	10:09 pm
6	CPFF Reports <ul style="list-style-type: none"> ➤ Governance: T. Georgieff <ul style="list-style-type: none"> ▪ CPFF AGM <ul style="list-style-type: none"> ○ Directors: Appointment of/or approval to continue in term and year of appointment ○ Chair ○ Vice Chair ○ Treasurer ○ Secretary ○ Governance Chair ○ Communication/Fundraising Chair ○ Advocacy & Support Chair ➤ CPFF Financials (November 2023): V. Pringle & S. Lee <ul style="list-style-type: none"> ▪ Motion to accept the FY 23-24 Budget as present ▪ Motion to accept the recommendation on the hiring of Executive Assistant ➤ Executive Director Report: <ul style="list-style-type: none"> ▪ 2023-2024 Activity Update <ul style="list-style-type: none"> ○ Campaigns: S. Lee 	10:09 am	11:58 am

#	Agenda Item	Time Allocated	Planned End Time
	<ul style="list-style-type: none"> • February Rare Disease Month • September PF Month (June to October) <ul style="list-style-type: none"> ▪ Saskatoon, SK: Jun 15? ▪ Burlington, ON: Aug 10 ▪ Avonmore, ON: Aug 17 ▪ Winnipeg, MB: Aug 24 ▪ Calgary, AB: Sep 14 ▪ Markham, ON: Sep 21 ▪ Montreal, QC: Sep 28 • December Holiday of Gratitude <p>➤ CPFF Committee Reports:</p> <ul style="list-style-type: none"> ▪ Governance & Finance: T. Georgieff & S. Lee <ul style="list-style-type: none"> ○ Nominations Committee <ul style="list-style-type: none"> • Solicitation of new Board members • Solicitation of Committee members ▪ Advocacy & Support: M. Ashcroft, H. Smith & S. Lee <ul style="list-style-type: none"> ○ GR: PMPRB update ○ CORD – Rare Disease Funding ○ PF Connector ▪ Communications & Fundraising: T. Hunter & S. Lee <ul style="list-style-type: none"> ○ 2024 Surveys: S. Lee <ul style="list-style-type: none"> • Patient & Caregiver ▪ Medical Advisory Board (MAB): C. Fell & S. Lee <ul style="list-style-type: none"> ○ Robert Davidson Fellowship awards for 2023 (2 x \$90K) 		
7	<p>New Business</p> <ul style="list-style-type: none"> • In Camera Session (if needed) 		
8	<p>CPFF Board Meeting Dates for FY 23-24:</p> <p>Friday March 1, 2024 Friday May 10, 2024 Friday July 5, 2024 Friday September 13, 2024</p>	11:58 am	12:00 pm

#	Agenda Item	Time Allocated	Planned End Time
9	Adjournment	5:00 pm	



Canadian Pulmonary Fibrosis Foundation

Board Minutes

Held via ZOOM

On Friday November 16, 2023

Commencing at 3:00 pm EST

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

Guest(s): Tom Hunter, Communications & Fundraising Chair
Derek Mastin
Ray Protti

Regrets: None

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 September 1, 2023 Board Meeting

An extension was requested for budgets, timelines and resources for all four outstanding projects in order to include an analysis of how CPFF will be resources to deliver these projects and the rest of the work contemplated.

It was moved and seconded,
That the minutes of the September 1 meeting be approved.

CPFF Board Minutes of November 16, 2023

Carried.

CPFF Financials

Verity presented the September financials. Balance sheet is pretty consistent with last year's, with cash being slightly higher.

It was specified that some of the donations for PF month actually came in in either August or October, but are being considered as part of the \$100,500 PF month revenue.

There were some concerns about fellows not cashing fellowship checks for several months after receiving it, which has caused the timing for the selection of fellows to shift to earlier in the year.

Executive Director Report

Interim Budget

It was pointed out that one of the objectives of the upcoming Board Retreat is to provide direction to Foundation in how it wants to spend its money and resources. As such, an interim budget of \$150,000 was presented to last until January 25th, 2024, at which point the next Board meeting will take place and the Board will be able to decide on a budget for the rest of the fiscal year.

The previous interim budget of \$300,000 meant to last until December was briefly discussed, which induced a short conversation about the cost to run CPFF (i.e. burn rate) and another short conversation about PF month.

It was pointed out that PF Month expenses were included in the previous interim budget, and that they are just slightly higher than the revenue raised.

It was moved and seconded,

That \$150,000 interim budget be approved until January 25th, 2024.

Carried.

Innovation Fund

Briefly discussed during the last Governance & Finance Committee meeting.

It was mentioned that there's currently a need to understand restrictions and contractual obligations before embarking the organization in this project, though no deal-breakers are expected. At the current time, the only company interested in the fund is Boehringer Ingelheim, but that is the foot in the door in getting more companies interested.

I was suggested that financial institutions, such as TD and BMO, be invited to the Board Retreat to present investment plans for a potential Innovation Fund for the Board to consider.

Rare Disease Fund

It was pointed out that no province, besides Quebec, has redacted a Rare Disease policy.

CPFF Board Minutes of November 16, 2023

Nothing has happened at the federal or provincial level in the 9 months since the news broke about this fund, and a new \$550 million investment will take place soon.

CPFF waiting to see what CORD recommends to approach governments as a unified front.

It was mentioned that CPFF is guided by the patient voice, which includes advocating for:

- Equitable access to oxygen and reimbursement of it
- Have new drugs officially added to formulary plans for reimbursement
- Have new therapies looked at, reviewed and funded in Canada

It was agreed that Quebec needs to be the first province to be approached, which has previously been moved at the committee level.

It was moved and seconded,

That \$40,000 be allocated to the creation of materials to raise awareness about pulmonary fibrosis as a rare disease and advocate for equitable access to oxygen, up-to-date formulary plans and innovative therapies in Canada.

Carried.

Patient Navigator

It was mentioned that this project is bigger than initially discussed, which has delayed the development process. An updated proposal has been included in the package, but further discussion at the committee level is needed.

It was pointed out that this project will be scaled down at the beginning with a soft launch (i.e. part-time support at specific locations throughout the country) before considering offering full-time support across the country.

Support Group Leaders' Meeting

The meeting included several topics of discussion, including:

- Interest in having more speakers in the local and national support group meetings;
- Setting up succession plans
- Having support group leaders' contact information re-added to the CPFF website;
- Trouble recruiting members to join in-person meetings and patient forums;
- Training for facilitators;
- Inviting support group leaders to committee meetings; and
- Recurring support group leaders' meetings.

It was agreed that the contact information will be added back to the website with the support group leaders' consent.

It was furthermore agreed some support groups are associated to CPFF, but not owned by the organization, and as such, S. Lee will look into ways to be able to support and fund these groups without any legal liability and insurance issues.

CPFF Board Minutes of November 16, 2023

It was mentioned that the Vancouver support group has managed to address the issue of recruiting for in-person meetings by holding a picnic.

It was pointed out that most support group leaders are volunteers and not professionals, which uncovers a need for facilitation training.

It was proposed that 1 support group leader per month be invited to join the Advocacy & Support committee with a short presentation. On average, a support group leader would meet with the committee once every 18-24 months.

Support group members and community members will be invited to join CPFF at the Board Retreat, either virtually or in-person.

Donor Stewardship

S. Lee has been reaching out to candidates previously vetted by Donna Brown to see what their skillset is and where they're at in their career in the event that they're a good fit for the donor steward role.

It was proposed that nearby Board Directors join S. Lee at informal meetings she may have with candidates, provided that the meeting location is convenient.

A strategic fundraising plan has been drafted, and at this point it is just a matter of finding the right individual to execute it.

It was proposed that CPFF draft a contingency plan that will provide a roadmap in the event of difficult financial times for the foundation. No contingency plan currently exists, but thankfully none has been needed in the last couple of years, which saw strong fundraising numbers.

That being said, with pharma funding decreasing and becoming harder to secure, maintaining the current level of fundraising may prove challenging, so it is only logical to expect the best but prepare for the worst.

Yearly Fundraising Roadmap

A short discussion was entertained about how the staff has mapped out fundraising opportunities and campaigns throughout the year. S. Lee to share with the Board.

Board Retreat

A viable remote link will be available for Board members who are not able to join in person. CPFF staff will aim to secure a more efficient and effective set up from the AV company than the one employed during last year's Board Retreat.

It was pointed out that the overarching goal for the Board Retreat is to come away with an operational plan. The plan is not meant to have all the details sorted out, but instead will provide direction on the 4 outstanding initiatives and determine which ones the organization will prioritize and move forward with. By extension, this will also allow the Board to get a clearer picture of what the budget should include.

CPFF Board Minutes of November 16, 2023

T. Georgieff to schedule a 30-minute individual meeting with all Board members in order to make sure that everyone is on the same page on the January Board Retreat.

The Board will also aim to agree on meeting times during the Board Retreat for the upcoming 2024 Board meetings.

Board members can expect to receive non-onerous homework prior to the Board Retreat, which include feedback on the current Terms of Reference to see if they need updating. The Governance & Finance committee will further discuss this topic during their next meeting.

Board Chair Recognition

K. Morrison's contribution as Board chair for the last 6 years was highlighted and recognized, as he will be stepping down by the time of the next Board meeting.

Vaultt Database Revenue Generation

The meeting package includes Vaultt's responses to CPFF's questions and an updated draft marketing agreement. The Governance & Finance committee will further discuss this topic during their next meeting before bringing this back to the Board.

The potential for having the PFF registry opened up to Canadians was discussed. It was pointed out that if that initiative would start taking shape, the scope of the Vaultt proposal would inherently change, as their app could become the user interface for data gathering for the registry. It was mentioned that this is a major moving piece that needs to be addressed before the Vaultt proposal can move forward.

CPFF's legal counsel will have a look at the documents only after the Board has reviewed it, as per their recommendation.

Robert Davidson Fellowships

The application window for the fellowships is now open until January 12, 2024.

The MAB will present candidates to the Board by February 16, 2024.

Research Grants

The idea for a community patient registry was floated by as a recipient for a research grant. The Board discussed how that initiative could potentially be combined with the PF Care dataset. T. Georgieff to reach out to C. Ryerson about it.

S. Lee has yet to been able to receive an update from C. Fell about what to do with research grants.

It was pointed out that no research grant has been granted in the last 2 years.

CPFF Charitable Status Change

CPFF's legal counsel were provided with photos of the IDs of every Board member which will allow them to move forward the process and hopefully have it completed by January.

CPFF Board Minutes of November 16, 2023

MAB Review & Succession

No updates available.

MAB Meetings

H. Smith offered herself as a patient presence in MAB meetings.

Adjournment

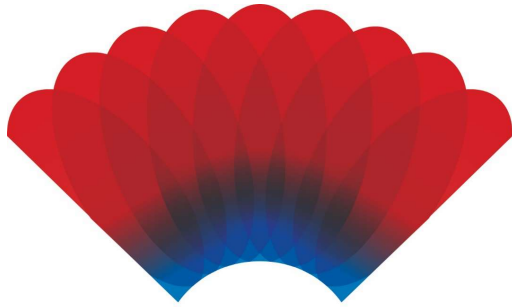
The meeting was adjourned 4:26 pm EST.

Next CPFF Board meeting will be held during the Board Retreat on January 25, 2024.

Certified correct,

SIGNATURE TO BE INCLUDED

Kirk Morrison
CPFF Board Chair



Canadian Pulmonary Fibrosis Foundation

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To: **CPFF Board Directors**
 From: Sharon Lee, Executive Director
 Date: Thursday January 18, 2024
 Subject: Approval of CPFF 2024 Budget

The FY 2024 budget is being presented for approval at the January 25, 2024 board meeting.

The FY 2024 budget revenues forecasts were based on the following assumptions.

	\$	FY 2024 Funding Sources
Donations	\$100,000 \$450,000 \$280,000 \$150,000	Community Walks Possible Bequest Individual donations (includes stocks) FY 2023 Carry-over from BI (Oxygen)
Foundation Grants	\$335,000	BI, Roche? Trevi, Pliant, Chiesi?
Investments	\$20,000	TD Bank & BMO Investments
Consulting Fees Revenue		
Total	\$1,355,000.00	

The FY 2024 budget expenses were based on the following projects – recurring and one-time costs.

	\$	FY 2024 Activities
Patient & Caregiver Support	\$563,725	Community Walks, Support groups, Oxygen, PF month, Rare Disease month, social media
Advocacy	\$429,345	CORD, GR, PMPRB, New Mode, Oxygen, PF month, Rare Disease month, social media
Research	\$220,000	Fellows and Research grants
Education & Awareness	\$239,725	Community Walks, Support groups, Oxygen, PF month, Rare Disease month, social media
Fundraising	\$154,125	Community Walks, Support groups, Oxygen, PF month, Rare Disease month, social media

		Event Mobi, One Cause, Canada Helps, social media
Operations	\$111,700	Salaries (10%), Audit, Bookkeeper, General administration
Total	\$1,718,620	
Net revenue/loss	-\$363,6200	

2024

Revenues

As noted above.

Expenses

SALARIES:

- Total: \$285,000
- Breakdown: 10% (\$28,500) in operations, \$64,125 allocated to each pillar (Support, Advocacy, Education, Fundraising). This includes the PF connector and Executive Assistant

SUPPORT:

- Increased patient & caregiver support (PF connector, Investment in FB Group communications, new resources).

FUNDRAISING:

- Increase investment in donor stewardship (staff & donor communications).
- Introduce new fundraising mechanisms (Tip Tap, Canada Helps, One Cause, etc.).
- Increase fundraising expenses to launch the Innovation Fund.

EDUCATION & AWARENESS:

- Expansion of Community Walks.
- Increase initiatives for early diagnosis - know the signs healthcare professional and public campaigns.
- Develop CTDs & PF Explainer Video.

ADVOCACY:

- O2 access advocacy.
- Conduct a patient & caregiver survey.

Budget Forecast Summary (2025-2027)

The FY 2025, 2026 and 2027 are place holders for discussion at the committee level for later approval.

2025

Revenues

Donations:

- Individual donations from campaigns and from the walk

Foundation Grants

- BI, Roche, Trevi, Pliant, Chiesi
- The above pharma companies should be launching their new drug therapies except for Roche

Investment Interest

- Assuming the same rates from our investments

SALARIES:

- Total: \$400,000
- Allocation: \$100,000 PF Connector, \$60,000 admin, \$60,000 donor, \$180,000 staff.
- Additional \$115,000 from the previous year split amongst the four pillars.

SUPPORT:

- Evolve PF Connector.
- Enhance patient & caregiver support with increased resources.

FUNDRAISING:

- Implement donor recognition and solicitation strategies.
- Develop an annual report/Impact report.
- Evolve fundraising mechanisms and volunteer recruiting.

EDUCATION & AWARENESS:

- Produce CTDs & PF Patient & Dr. Documentary Video.
- Expand community walks.

2026

Revenues

Donations:

- Individual donations from campaigns and from the walk

Foundation Grants

- BI, Roche, Trevi, Pliant, Chiesi

- The above pharma companies should be launching their new drug therapies except for Roche

Investment Interest

- Assuming the same rates from our investments

SALARIES:

- Total: \$400,000
- Allocation: \$100,000 PF Connector, \$60,000 admin, \$60,000 donor, \$180,000 staff.
- 10% operations, remaining split amongst the four pillars.

FUNDRAISING:

- Continue donor recognition and solicitation efforts.
- Evolve fundraising mechanisms and volunteer recruiting.

EDUCATION & AWARENESS:

- Create Diverse Patient & Caregiver Video.
- Increase cross-country community walks with enhanced support, marketing, and fundraising efforts.

2027

Revenues

Donations:

- Individual donations from campaigns and from the walk

Foundation Grants

- BI, Roche, Trevi, Pliant, Chiesi
- The above pharma companies should be launching their new drug therapies except for Roche

Investment Interest

- Assuming the same rates from our investments

SALARIES:

- Total: \$400,000
- Allocation: \$100,000 PF Connector, \$60,000 admin, \$60,000 donor, \$180,000 staff.
- 10% operations, remaining split amongst the four pillars.

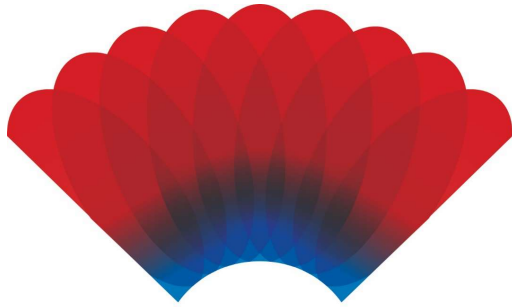
EDUCATION & AWARENESS:

- Increase cross-country community walks with intensified support, marketing, and fundraising initiatives.

FUNDING SOURCES	2021	2022	2023	2024	2025	2026	2027	
Donations	\$405,501	\$612,667	\$896,176	\$1,000,000	\$631,000	\$650,000	\$670,000	3% growth (community walks, campaigns)
Foundation Grants	\$404,409	\$333,107	\$402,600	\$335,000	\$500,000	\$700,000	\$700,000	projection of new drugs being launched
Investment Interest	\$5,787	\$1,083	\$20,705	\$20,000	\$20,000	\$20,000	\$20,000	Bank interest
Consulting Fees			\$3,040					
Total	\$815,697	\$946,857	\$1,322,521	\$1,355,000	\$1,151,000	\$1,370,000	\$1,390,000	

SPENT	2021	2022	2023	2024	2025	2026	2027	
Patient & Caregiver Support	\$107,438	\$235,182	\$210,804	\$563,725	\$270,000	\$450,000	\$300,000	Patient videos, webinars, CPFF walks
Advocacy	\$126,899	\$180,887	\$229,371	\$429,345	\$350,000	\$350,000	\$350,000	based on new drugs being launched & Oxygen
Research	\$220,000	\$270,000	\$180,000	\$220,000	\$220,000	\$220,000	\$220,000	2 Fellows @ 90K and 2 Research @ \$20K
Education & Awareness	\$26,510	\$101,299	\$120,973	\$239,725	\$320,000	\$320,000	\$320,000	PF materials, educational videos, Indigenous
Fundraising	\$5,033	\$0	\$8,609	\$154,125	\$180,000	\$180,000	\$200,000	Donor staff, materials, social media
Operations	\$80,751	\$85,006	\$121,025	\$111,700	\$151,700	\$160,000	\$160,000	Audit, bookkeeper, general admin
Total	\$566,631	\$872,374	\$870,782	\$1,718,620	\$1,491,700	\$1,680,000	\$1,550,000	
Net Revenue/Loss	\$249,066	\$74,483	\$451,739	-\$363,620	-\$340,700	-\$310,000	-\$160,000	

Column E, line 12 should be 2 x \$90k, but one of them was cashed late
Columns B and C are the audited statement results
Column E is the draft audited statement results
Foundation Grants for 2025, 2026 & 2027 include the \$180K from BI



Canadian Pulmonary Fibrosis Foundation

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Memorandum

To: Board of Directors
From: Sharon Lee, Executive Director & Roberto Zapata, Project Coordinator
Date: January 15, 2024
Subject: Approval of an Executive Assistant

The need for an assistant for the Executive Director has been informally discussed between the Executive Director and Board members since early 2023.

Across Board and Committee minutes, the hiring of an executive assistant was never explicitly agreed until January 15, 2024 at the Governance and Finance committee, although it was mentioned a couple of times that more staffing support is needed, indirectly referring to these informal conversations.

Additionally, an expense line for an Executive Assistant was included in the FY23-24 proposed budget which was presented during the 2023 Board Retreat and was furthermore included in the Board Retreat's final report, which was sent to and acknowledged by Board members on July 27, 2023.

While an approval of the budget for the current fiscal year would've confirmed the Board's approval of the hiring of this new staff member, CPFF has been running on interim budgets since the start of the fiscal year, and none of them included the Executive Assistant expense.

On the July 14, 2023 Board of Directors meeting, a \$300,000 interim budget from September to December.

On the November 16, 2023 Board of Directors meeting, a \$150,000 interim budget to last until the January 2024 Board Retreat was approved.

It was ultimately agreed that the official budget for the remainder of the fiscal year would be approved during the Board meeting taking place just before the start of the Board Retreat.

On the January 15, 2024 Governance & Finance Committee meeting, a motion that the budget for the remainder of the fiscal year, which included the Executive Assistant expense, be presented at the January 2024 Board meeting for approval was moved. Furthermore, an explicit discussion about the Executive Assistant was entertained, during which Committee members were in support of the potential hiring of one.

That being said, see below for the trail of proof that the administrative assistant position has been at least explicitly or indirectly mentioned to the Board and Committees, short of being approved.

June 16-17, 2023 - Board Retreat

CPFF Draft Board Retreat Final Report shared with and acknowledged by Board on June 27, 2023 via email.

From proposed FY23-24 budget

1.7 Administrative support for Executive Director	\$ -	\$ 60,000	\$ 60,000				Recruiting administrative assistant to support Executive Director
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From Governance & Finance Work Plan

Governance & Finance Work Plan

Year 1	Year 2	Year 3
STRATEGIC & GOVERNANCE PLANNING [Patient Support, Advocacy, Education & Awareness]		
Strategic planning HR Consultant - Board & ED reviews, Staff Recruitment, HR Plan Board Retreat June 2023 (Hybrid) From Ops to Governance Strat Plan J. Dinner (3-year plan) Board Resource Library Content Executive Assistant for ED (hiring)	Strategic planning HR Consultant - Board & ED reviews, Staff Recruitment, HR Plan Board Retreat June 2024 (Hybrid) From Ops to Governance Strat Plan J. Dinner (3-year plan) Board Resource Library Content	Strategic planning HR Consultant - Board & ED reviews, Staff Recruitment, HR Plan Board Retreat June 2025 (Hybrid) From Ops to Governance Strat Plan J. Dinner (3-year plan) Board Resource Library Content

June 19, 2023 - Governance & Finance Committee Minutes

“The committee shared concerns about all committees being fully engaged with their respective projects/initiatives, and whether they have the necessary resources to see them through.

It was proposed for each committee to have an assigned staff member to manage the projects and move them forward.”

July 14, 2023 - Board of Directors Minutes

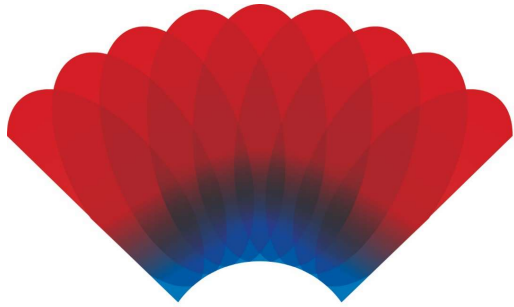
“It was proposed that CPFF’s Board of Directors ought to meet every 2 months to allow more time for committees to progress in their respective projects and initiatives.

It was pointed out that while this is a step in the right direction, committees would also need additional admin and staffing support to get projects done.”

July 17, 2023 - Governance & Finance Committee Minutes

“The committee agreed that the Board’s objective is ultimately oversight of the ongoing projects and initiatives, rather than putting in the work. It is up to the Executive Director and the staff to prepare the work for the committees to vet it and bring forward to the Board.

It was also agreed that despite now having more time to meet in between Board meetings, more administrative and staff support is needed.”



Canadian Pulmonary Fibrosis Foundation

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Memorandum

To: Board of Directors
From: Sharon Lee, Executive Director
Date: January 21, 2024
Subject: Successful Utilization of LinkedIn Network for Executive Assistant Recruitment

Dear Board Directors,

I am pleased to share an update on my recent efforts to leverage my LinkedIn network for the recruitment of the Executive Assistant position at the Canadian Pulmonary Fibrosis Foundation (CPFF).

Background:

In line with our commitment to securing a highly qualified individual for this critical role, I recognized the value of harnessing my professional network to identify candidates who align with CPFF's mission and possess the requisite skills and experience.

Strategy:

1. LinkedIn Search:
Conducting targeted searches on LinkedIn using keywords like "Executive Assistant," "Nonprofit," and "Charity Management," I successfully identified individuals with a proven track record in executive support roles, particularly those with experience in the nonprofit sector.
1. Engagement:
Following the identification of potential candidates, I engaged with them through personalized messages, emphasizing the unique opportunity CPFF presents. I highlighted the organization's mission and the pivotal role the Executive Assistant would play in advancing that mission.
2. Sharing Job Posting:
I shared the official job posting on my LinkedIn profile and requested my network to spread the word. This not only heightened the visibility of the position but also encouraged referrals from within my network.

Results:

The application of this strategy yielded several high-quality leads. These individuals boast diverse experiences, including executive support roles in the nonprofit sector, making them well-suited for the responsibilities outlined in the job description.

Next Steps:

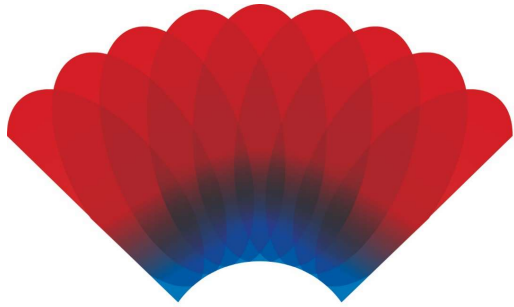
I compiled a shortlist of potential candidates who have expressed interest in the position. Subsequently, I coordinated interviews to assess their suitability for the role. Following this process, I narrowed down the selection to two finalists. To finalize the decision, I invited Todd Georgieff to meet with them and provide valuable insights.

I will be using the offer template letter that Carters created for CPFF when I had hired Roberto Zapata.

I appreciate your ongoing support in this recruitment process and look forward to welcoming Shelly Monaghan (she has a connection, as her sister died from IPF), as a valuable addition to our CPFF team.

Best regards,

Sharon Lee



Canadian Pulmonary Fibrosis Foundation

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Who We Are

The Canadian Pulmonary Fibrosis Foundation (CPFF) is a registered Canadian charity established to provide hope and support for people affected by pulmonary fibrosis (PF). Our charitable registration is 850554858 RR0001.

Our Vision

A world free of pulmonary fibrosis.

Our Mission

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

Position Overview

We are seeking a dynamic and highly organized Executive Assistant to support the Executive Director. The successful candidate will play a critical role in ensuring the smooth and efficient functioning of the Executive Director's office, handling a wide range of administrative responsibilities and as assigned. This is a unique opportunity to contribute to the success of a mission-driven organization and make a lasting impact.

Responsibilities

1. Administrative Support:
 - Manage the Executive Director's calendar, schedule appointments, and coordinate meetings.
 - Handle incoming calls, emails, and correspondence on behalf of the Executive Director.
 - Prepare and edit documents, reports, and presentations as needed.
2. Logistical Coordination:
 - Arrange travel itineraries, accommodations, and logistics for the Executive Director.
 - Coordinate and support special events, board meetings, and other organizational gatherings.
3. Committee and Board Support:
 - Assist in the preparation and distribution of materials for committee and board meetings.
 - Coordinate meeting logistics, including scheduling, room setup, and technology needs.
 - Record and distribute meeting minutes, ensuring timely follow-up on action items.
 - Support the Executive Director in building and maintaining positive relationships with committee members and board directors.

4. Communication and Relationship Management:
 - Interface professionally with internal and external stakeholders.
 - Maintain positive relationships with donors, board members, and partners.
5. Information Management
 - Organize and maintain confidential files and records.
 - Conduct research and compile information as required.
6. Project Assistance
 - Assist in managing specific projects and initiatives as assigned by the Executive Director.
 - Collaborate with team members to ensure project deadlines are met.

Qualifications:

- Proven experience as an Executive Assistant or similar role.
- Excellent organizational and time management skills.
- Strong written and verbal communication skills.
- Proficiency in Microsoft Office Suite (Word, Excel, PowerPoint).
- Ability to handle sensitive information with discretion and confidentiality.
- Exceptional attention to detail and accuracy.
- Previous experience in a nonprofit or charity setting is preferred.

Education and Experience:

- Bachelor's degree in a relevant field is desirable.
- Minimum of 5 years of executive support experience.

How to Apply:

Interested candidates should submit a resume and cover letter to sharon@cpff.ca
Please include "Executive Assistant Application – [Your Name]" in the subject line.

PROFESSIONAL PROFILE

An accomplished Human Resources professional with many years of providing superior services in both the not-for-profit and private sectors, I enjoy finding creative new ways to achieve the best results. With broad experience in many facets of human resources including talent acquisition and management, employee relations, process improvements, benefits administration, and strategic planning, I also bring with me an ability to view the 'big picture' allows me to provide support to the mission, vision and strategic objectives of the organization I serve. Strong communication and collaboration skills are key to my provision of exceptional customer service, whether internal or external. I am a Certified Human Resources Leader (CHRL) in good standing with the Ontario HRPA Grand Valley Chapter.

BUSINESS EXPERIENCE

Monaghan e-office

Oct 2017 to present

Proprietor

- Currently assisting clients with a variety of administrative and human resources duties.
- Coordinator for a national non-profit organization focused on providing health services in a spiritual setting from July 2020 to June 2022. Main duties included providing support to the Board of Directors, who were spread across Canada, including setting up online meetings, preparing the meeting agenda, taking notes and circulating the meeting minutes. Was able to move the Annual General Meeting to an online format for them, and it continues to be online today. Created or updated many templates to streamline and provide consistency to documentation.
- the creation and distribution of client newsletters; updating website style and content, GDPR requirements; presentations and templates in PPT, conducting webinars and other media/marketing communications.
- Capably provided Human Resources Director coverage at a high-tech firm in Waterloo for an eight-week period to cover a medical leave-of-absence.
- Successfully developed a Participant Guide for a three-day course based on previous twelve-week online offering.

KidsAbility

Aug 2002 to February 2018

Human Resources Senior Generalist

Human Resources CoOrdinator

- Capably coordinated Human Resources management initiatives in a healthcare service firm comprised of over 200 employees in three main and several satellite locations across the assigned catchment area.
- Active member of the HRRIS implementation team, including training staff to utilize self-service options.
- Assisted in researching and compiling data for presentation to the Board of Directors, the Ministry of Health and the Ministry of Children & Youth Services.

- Actively involved in the re-design and deployment of upgrades to the Performance Management system and processes.
- Developed and implemented a two-phase Orientation Program for new employees, which became the organizational standard. Engaged in a redesign of the program to meet evolving organizational needs.
- Core member of team charged with preparation and participation in the WSIB Work Well Audit, for which the organization was well graded.
- Provided appropriate support to members of the Board of Directors, the Leadership Team, and Client Services Team on both a group and individual basis.
- Coordinated with supervisors, managers and the Health and Safety Coordinator to develop appropriate return to work plans for staff.
- Participated in collective bargaining and administered policies in accordance with the collective agreement (OPSEU).

Human Resources/ Executive Coordinator

Aug 2002 – Oct 2006

This role involved a large component of Board support. I worked closely with the CEO to ensure that all information required for monthly board meetings was compiled and distributed, and that meeting minutes were circulated in a timely manner post meetings.

- Successfully refurbished the Annual Report and coordinated with I.T. for placement on the website.
- Influential in many aspects of the Branding Project, including the development of the new website.
- Created and implemented Board Member Orientation process and developed a Board Handbook, which was later turned into an online version.
- Successfully coordinated the annual internal fundraising campaign, which resulted in \$17,000.00 raised over three years.
- Coordinated the annual Service Awards ceremony.

[Metafore](#) (formerly MicroAge), Cambridge, ON

Human Resources Liaison

1995 – 2002

- Competently led Human Resources management initiatives in a multi-service high tech firm comprised of over 500 associates in locations across Canada.

EDUCATION / PROFESSIONAL DEVELOPMENT

- **Ongoing** – various client-specific education and training
- **Entrepreneur Business Workshops**
- **CHRL Designation**, HRPAAO, Grand Valley Chapter
- **CAVA member** (Canadian Association of Virtual Assistants)
- **Certificate** Emergency Mental Health

PROFESSIONAL AFFILIATIONS / VOLUNTEER WORK

- **OWIN Board of Directors (President 2020-2022)** 2019 - present
- **Oxford Women in Networking (OWIN)** -active member. 2018 - present
- **Community Futures Oxford – Mentorship Co-Chair** 2019 - 2021
- **Grand Valley HRPAA Member at Large** 1999 – present
- **Grand Valley HRPAA Senior Human Resources Advisory Group** 2014 – 2017
Contributor to Senior HR group advising the GVHRPA Board of Directors.
- **Grand Valley HRPAA Mentorship Committee** 2008, 2009, 2011
Member of committee matching mentors & protégés and fostering for 10-month program.
- **Grand Valley HRPAA Conference Committee** 2006, 2008, 2010
Co-chair of the Speakers Subcommittee to book keynote & other speakers; general conference planning.
- **Ratho Presbyterian Church Audit Committee** 2005 – present
Member of 2-person committee to audit financials for presentation at the AGM.
- **Relay for Life** 2001 – 2004
Participant and Team Captain for overnight relay to raise funds for cancer research.
- **Ratho Rascals Bowling & Community Group** 2000 – 2010
Active member of local initiative to build and maintain community relationships.
- **[Communitech](#)** 1999 – 2002
Assist to promote awareness of IT in businesses and the community.
- **Citizens on Patrol (COPS)** 1993 - 2000
Provided community surveillance, patrols, and police back-up.

CPFF Innovation Fund

Author: Sharon Lee

Introduction

The CPFF Innovation Fund is a dedicated program designed to foster creativity, drive innovation, and support the development of cutting-edge solutions for the PF community. This proposal outlines the structure, funding sources, expected value, management approach, purpose, funded activities, recipients, and measurements of success for the CPFF Innovation Fund.

Structure and Administrative Requirements

The CPFF Innovation Fund will be structured as a dedicated fund within the organization, governed by a clear set of administrative requirements and guidelines. These guidelines will define the eligibility criteria, application process, and evaluation methodology for project proposals seeking funding from the Innovation Fund. An internal team will be responsible for managing the fund and ensuring compliance with the established guidelines.

Funding Sources

At launch, the CPFF Innovation Fund will be initially seeded with an allocation from the organization's surplus funds, (\$1.4 million from TD bank (currently at \$1,763,776.17, will leave \$363,776.17 in the bank) and \$603,829.37 from BMO) with \$1 million grant from BI, a total of \$3,000,829.37. Over time, additional funding sources will be explored, such as external grants, partnerships, and potential contributions from philanthropic entities interested in supporting innovative initiatives. Efforts will be made to diversify and secure sustainable funding streams to ensure the long-term viability of the Innovation Fund.

Expected Value

At launch, the CPFF Innovation Fund aims to allocate an initial budget of \$90,000 to support the first wave of innovative projects. The expected value of the fund will grow over time as successful projects generate returns on investment and attract external funding. As the fund expands, its impact on the organization's mission and vision will become increasingly significant, creating a culture of innovation, and enhancing our ability to tackle emerging challenges effectively.

Fund Management

The CPFF Innovation Fund will be overseen by an Investment Committee comprising experienced professionals from relevant domains. The committee will be responsible for evaluating project proposals, selecting deserving recipients, and monitoring the progress and impact of funded initiatives. The fund will also have dedicated staff members who will assist in administering the fund, managing project milestones, and facilitating collaboration between recipients and relevant stakeholders.

Purpose

The primary purpose of the CPFF Innovation Fund is to encourage and support the generation of fresh ideas, exploration of new approaches, and development of cutting-edge solutions for the PF community. By investing in innovation, we aim to stay ahead of the curve, address emerging challenges proactively, and maintain our position as a leader in our field. The Innovation Fund aligns with our Mission and Vision by fostering a culture of innovation and providing a platform for our employees to contribute to organizational growth and success.

Activities Funded

To start, the CPFF Innovation Fund will focus on funding one innovative project per funding cycle. This approach allows us to test the effectiveness of the fund and ensure that resources are allocated appropriately. The project selected for funding will be based on its potential to drive significant impact, demonstrate innovation, and align with the strategic objectives of CPFF.

Recipients

At launch, all interested stakeholders in Canada will be eligible to submit project proposals for consideration. This inclusive approach ensures that innovative ideas can come from anywhere within the country. Over time, as the fund expands and demonstrates success, opportunities for global partnerships and collaborations may be explored to further diversify the pool of recipients for the benefit of Canadians with PF.

Measurements of Success

The success of the CPFF Innovation Fund will be measured through a set of key performance indicators (KPIs) aligned with its purpose and objectives. These may include metrics such as the number of projects funded, successful implementation and impact of funded projects, external funding attracted, stakeholder engagement in innovation activities, and the overall contribution of the fund to organizational growth and mission fulfillment. Regular reporting on these KPIs will provide transparency, facilitate accountability, and enable continuous improvement of the Innovation Fund.

Conclusion

The CPFF Innovation Fund presents a unique opportunity to foster creativity, drive innovation, and develop cutting-edge solutions for Canadians living with PF. By establishing a dedicated fund, we can support and encourage stakeholders to generate fresh ideas, explore new approaches, and address emerging challenges proactively. The proposed structure, funding sources, management approach, purpose, funded activities, recipients, and measurements of success provide a solid foundation for the CPFF Innovation Fund.

Resources & Estimated Budget

Resources:

- Overseen by an Investment Committee comprising experienced professionals from relevant domains (current or new volunteer board members).
- Existing staff members will assist in administering the fund, managing project milestones, and facilitating collaboration between recipients and relevant stakeholders.

Budget:

- No additional funds are required. Capital will need to be reserved.
 - CPFF Innovation Fund will be initially seeded with an allocation from the organization's surplus funds.
 - Promotion of the Fund will occur within the year-long social media budget.

We request the Board's approval at the January 2024 meeting to proceed with the establishment of the fund, enabling us to embark on this exciting journey of innovation and growth.

Donor Stewardship Program: Donor Coordinator & Donor Communications

Author: Sharon Lee

Introduction

The Donor Program is a strategic initiative that focuses on nurturing and maintaining strong relationships with the organization's donors. This proposal outlines the approach, target audience, and strategies for donor recruitment and stewardship, with the goal of creating sustainable foundation growth through life-long relationships and beyond with legacy giving.

CPFF will do this by building a donor relations infrastructure with high-touch communications. By prioritizing donors, the organization aims to cultivate long-term partnerships, enhance donor satisfaction, and secure sustainable funding for its initiatives. The creation of the Donor Coordinator position is intended as a first step in building a fulsome donor development department for CPFF.

Job Description Refinement

To ensure effective implementation of the Donor Coordinator, the job description for the team responsible for donor coordination, led by Sharon, will be fine-tuned based on Board feedback. The refined job description will outline the responsibilities, skills, and qualifications required for the team members, emphasizing their role in building, and maintaining strong donor relationships, executing stewardship strategies, and facilitating meaningful engagement with donors.

Target Audience and Approach

In addition to traditional pharma sponsors, the Donor Coordinator will expand its target audience to include non-pharma healthcare organizations such as oxygen providers, equipment manufacturers, and major donors. These tactics play a crucial role in supporting patients with pulmonary fibrosis and can be valuable partners in advancing the organization's mission.

The approach to engage non-pharma healthcare organizations will involve targeted outreach, relationship-building, and collaboration. By highlighting shared goals and mutual benefits, the organization will seek partnerships with these donors, emphasizing how their involvement can make a tangible difference in the lives of pulmonary fibrosis patients. Customized strategies and messaging will be developed to address the specific needs and interests of potential non-pharma sponsors, ensuring meaningful and mutually beneficial partnerships.

Strategies for Donor Program

The Donor Program will implement several key strategies to nurture relationships and enhance donor satisfaction:

- **Gratitude and Recognition:** Donors will receive personalized expressions of gratitude and recognition for their contributions. This may include personalized thank-you letters, certificates of appreciation, and acknowledgement in organizational communications and events.
- **Impact Updates:** Regular and transparent updates will be provided to donors, showcasing the impact of their contributions. This can include impact reports, success stories, and testimonials from patients who have benefited from their support.
- **Donor Engagement Opportunities:** Opportunities will be created for donors to actively participate in the organization's activities. This may include involvement in events, volunteer opportunities, advisory roles, and exclusive networking opportunities with key stakeholders.

- Tailored Communication: Donors will receive tailored communication based on their preferences and interests. This may include newsletters, email updates, and personalized invitations to events or meetings relevant to their areas of interest.

Measurements of Success

The success of the Donor Coordinator will be measured through various indicators, including:

- Lead generation, lead nurturing and conversion.
- Donor retention rates: Tracking the percentage of donors who continue to support the organization over time.
- Increased engagement: Measuring the level of donor involvement and participation in organization activities and events.
- Feedback and satisfaction: Regular surveys and feedback mechanisms will assess donor satisfaction levels and their perception of the organization's stewardship efforts.
- Funding growth: Monitoring the increase in funding from existing donors and the acquisition of new donors as a result of effective stewardship strategies and communications.
- Regular reporting on these measurements will enable continuous evaluation and improvement of the Donor Program.

Conclusion

The Donor Coordinator plays a vital role in nurturing and maintaining strong relationships with donors, expressing gratitude, and ensuring their continued support. By expanding the target audience to include non-pharma healthcare organizations and implementing tailored strategies for donor stewardship, the organization can enhance donor satisfaction, secure sustainable funding, and forge meaningful partnerships.

Resources & Estimated Budget

Donor Coordinator salary \$60,000 (annually)

Donor Communications: \$20,000 (FY 24/25), \$25,000 (FY 25/26), \$30,000 (FY 26/27) **Guesstimates, to be refined once staff is hired and plan has been approved.**

- Communication planning, donor solicitation, donation technology & promotional materials (e.g TipTap) for community walks & retail, gratitude and recognition, impact updates, donor engagement opportunities
- Social media promotion will be covered under year-long social media campaigns and will not be incremental

We seek the Board's approval at the January 2024 meeting to proceed with the implementation of the Donor Program and strengthen the organization's relationship with its donors.

PF Connector Program

Author: Sharon Lee

Editor: Roberto Zapata

Introduction

The PF Connector Program is a vital initiative designed to support patients in navigating the complexities of healthcare systems and accessing the resources they need. This proposal outlines the scope, implementation approach, parameters and other considerations for the PF Connector Program, focusing on providing guidance, information, and advocacy to individuals facing healthcare challenges. The program will be led by Sharon and her team, working closely with healthcare providers, community organizations, and patients themselves to ensure a comprehensive and personalized support system.

Need Assessment

In order to better assess the need for the PF Connector program a two-fold analysis was undertaken, which included:

- CPFF staff's workload that currently falls under the scope of the Patient Connector's proposed workload.
- Canadians Living with Pulmonary Fibrosis Facebook support group posts that require monitoring and possibly guidance.

	#	Weekly average	Timeframe
Emails	132	5.4	June 1st to December 11th
Specifically about support	97	3.9	
Calls	145	5.9	
Facebook messages	12	0.5	
Specifically about support	8	0.3	
Facebook post comments	7	0.3	September 1st to December 11th
CLwPF posts	131	9.1	

It is worth noting that this analysis does not forecast the increase in workload that is bound to happen once word-of-mouth spreads that there's a CPFF staff member dedicated to providing more thorough support than what CPFF's current capacity allows.

Program Scope and Objectives

The PF Connector Program aims to address the information and advocacy needs of individuals within the pulmonary fibrosis (PF) community and beyond.

Scope:

The recruitment of a non-medical live agent and purchase of supporting technology to help patients and caregivers navigate CPFF vetted content and resources.

Objectives

The program will focus on:

- Providing guidance and support to individuals facing healthcare challenges related to PF, including diagnosis, treatment, insurance, and access to support services.

- Offering accurate, reliable, and up-to-date information to patients and their families, helping them make informed decisions about their healthcare.
- Advocating on behalf of patients to ensure their needs are met, coordinating with healthcare providers and community organizations to address barriers and improve the overall healthcare experience.
- Supporting both individuals and PF support groups, providing resources and guidance to enhance the well-being and empowerment of patients within a community setting.

Implementation Approach

Live Virtual Chat

- Patients/caregivers who need assistance can escalate to a live virtual chat.

Live Agent & Call Recording

- Patients/caregivers who need further assistance can book an appointment with a live agent, a conversation which will be recorded for legal purposes.

The PF Connector Live Agent position will be a full time paid non-medical role. This approach will ensure that the individual serving as the PF Connector possesses the necessary expertise, dedication, and time commitment to effectively support patients. Over time, as CPFF grows and the demand for patient support increases, trained volunteers can be considered as supplementary resources to expand the program's reach and impact.

To manage risks and maintain quality standards, the program will start small, with a soft launch in Ontario, and gradually expand based on available resources and organizational capacity. A phased approach will allow for careful monitoring, evaluation, and adjustment of program parameters to ensure optimal effectiveness.

Parameters and Risks

Setting clear parameters for the PF Connector Program is essential to maintain focus, manage risks, and ensure quality service delivery. The following parameters will be established:

- The program will initially focus on individuals affected by PF, but may extend support to other rare lung diseases in the future based on resource availability and organizational priorities.
- The PF Connector will adhere to established ethical guidelines, always maintaining patient confidentiality and privacy.
- To mitigate risks, the PF Connector will provide information and guidance within their scope of expertise, referring patients to appropriate medical professionals or resources for specialized medical advice.
- A comprehensive training and onboarding process will be implemented for the PF Connector to equip them with the necessary knowledge and skills to effectively support patients.
- Regular performance evaluations and patient feedback mechanisms will be put in place to ensure ongoing improvement and quality assurance.
- Call recording software will be implemented to protect the employees and the organization from the risk that arises with providing information to PF patients, in the event that it is misconstrued as medical advice, which the Foundation and its employees cannot provide.

Crafting the Job Description

A Human Resources consultant will be retained to produce the job description for the Patient Connector position, given that a professionally produced job description can help mitigate concerns about the nature of the person and skills required for the position.

Once the Executive Director and the Project Coordinator approve the job description, it can be forwarded to the committee for approval.

Program Soft Launch

A soft launch is proposed to take place in Ontario, in order to implement the service carefully and learn from it.

Until a person is hired for the position, it is proposed that CPFF's national support group facilitators be considered to take part in the soft launch.

Program Reporting & Training

The Patient Connector would report to the Executive Director.

In order to improve the quality and efficiency of their support, the PF Connector would shadow the Project Coordinator and reach out to the National support groups facilitators as necessary. All the aforementioned parties would be involved in the training of the Patient Connector.

It is to be expected that the Patient Connector will go through a learning curve to learn everything there is to know about the disease.

Program Growth and Expansion

As CPFF grows, additional resources will be allocated to support the PF Connector Program. This growth may include expanding the team by hiring additional PF Connectors, recruiting, and training volunteers, and exploring technological solutions to enhance accessibility and reach. The program's expansion will be guided by the evolving needs of the PF community, available resources, and the organization's strategic objectives.

Resources & Program Cost

The expected expenditures for the first year of this program are as follow:

Program Deliverables	23/24	24/25	25/26	26/27
Full-time employee	\$60,000	\$100,000	\$100,000	\$100,000
Call recording software, including implementation	\$1,000	\$1,000	\$1,000	\$1,000
Human Resources Consultant	TBD	\$0	\$0	\$0
Total	\$61,000+	\$101,000	\$101,000	\$101,000

Measurements of Success

The success of the PF Connector Program will be measured through various indicators, including:

- Number of patients supported and their feedback on the program's impact.
- Timeliness and effectiveness of patient advocacy efforts.
- Number of patients referred to appropriate resources and services.

- Growth and engagement of support groups facilitated by the PF Connector.
- Positive impact on patients' healthcare experiences and overall well-being.
- Regular reporting on these measurements will enable continuous evaluation and improvement of the PF Connector Program.

Conclusion

The PF Connector Program fills a critical gap in supporting patients facing healthcare challenges, providing guidance, information, and advocacy to improve their overall healthcare experience. Starting small and expanding gradually, the program will serve as a trusted resource and advocate, enhancing the quality of care and support for individuals within the PF community.

Yearly Budget for Subsequent Fiscal Years = \$100K

We seek the board's approval from the Board to proceed with the implementation of the PF Connector Program, ensuring that the PF community and beyond can benefit from this valuable initiative.

[>> return to main retreat homework package](#)

Call Recording Software Proposal

Author: Roberto Zapata

Introduction

For call recording purposes, there were 3 options that were identified and considered during the discovery process.

- Phone application (Google Play Store & Apple App Store)
- Physical device (Recorder)
- Voice over internet provider (VoIP)

Considerations

Phone Application

While this would have been the easiest and cheapest option to implement, unfortunately both Google/Android and Apple have cracked down on applications that allow users to record conversations due to legal and security concerns.

Based on research, it seems that there still remain some ways that some open-source applications may be used for call recording purposes. However, going down this route requires a higher level of IT expertise and knowledge than CPFF has at its disposal, on top of the fact that the long-term reliability is questionable.

As such, this option is no longer being considered.

Physical Device

This is the most rudimentary of the 3 options identified and the second cheapest. Resorting to this option would entail either plugging a recorder to the headphone jack of a cell phone, or recording a conversation while on speaker.

The 3 main drawbacks of this option are call quality, device failure and increased likelihood of human error (i.e. forgetting to start recording or mention that the call is being recorded).

As such, better options are to be considered, if available.

Voice Over Internet Provider

This is the most expensive of the 3 options, incurring monthly (or annual) expenses for as long as it is being used. While the only identified need for CPFF is call recording, VoIPs offer several features within their packages, which range between \$15 and \$35 (USD) per month, per user.

On the flip side, the higher cost of this option also brings with it more value, such as automatic call recordings and disclaimers, recordings going directly to the library and the ability to store them for an indefinite amount of time.

There were 3 different VoIPs considered.

[Google Voice](#)

Cost: \$20 USD per user billed monthly

This is the top choice, as it is an add-on of Google Workspace, which CPFF already uses. Furthermore, anecdotal evidence during research uncovered several positive reviews, despite being a newer player on the market compared to other options.

[RingCentral](#)

Cost: \$35 USD per user billed monthly or \$300 USD per user billed annually

This the most well-known VoIP and the preferred choice for a lot of people. However, it is also the most expensive of the 3 options presented.

[RingBlaze](#)

Cost: \$19 USD per user billed monthly or \$180 USD per user billed annually

This is a direct competitor to RingCentral who tries to undercut it by being cheaper. It is a much newer VoIP with less anecdotal evidence to back up its quality.

Conclusion

As outlined in the considerations, a VoIP is the best option to record calls in a consistent and sustainable manner.

All 3 of the VoIP options identified could address CPFF's need to record calls. However, preference is being given to Google Voice, given that it is part of Google Workspace meaning that the call recordings would integrate into CPFF's existing storage space within Google.

As Google Voice is billed monthly, should any issues arise with it in the first few months of using it, which is doubtful to begin with, there is nothing stopping CPFF from trying another VoIP.

Sample PF Connector Communications:

PF Patient Request:

On Sat, Jun 17, 2023 at 7:04 PM Holly Smith <hollyjeans@shaw.ca> wrote:

Hello, I thought I should update you on the latest medical diagnosis. As you all know I have IPF. But recently, I have struggled with a number of things which has been diagnosed as a connective tissue disorder/autoimmune disorder. This has resulted in extreme swelling and pain in my hands and feet. Right now they have me on low doses of prednisone to try and get my hands to settle down and put me in remission.

I would like to ask for your help in terms of finding appropriate medication's that will not cause my lung fibrosis to get worse. The rheumatologist has asked my pulmonologist about the usual medication methytrexate for putting this disorder into remission. The answer from Dr. Park was that methytrexate was not something that could be used due to its fibrosing factor. Do any of you have any ideas or contacts for people who have a connective tissue disorder, such as scleroderma, rheumatoid arthritis, lupus, and so on and pulmonary fibrosis. Believe it or not, I've been asked to try and re-search what medication's might be a substitute for methytrexate

As a result of this recent illness and trouble with getting into remission, they put me on palliative care to try to expand the pain medication that I have access to so that I can at least move and continue with my pulmonary rehab. It's also put on hold my trying Ofev so so it's been a sad journey.

At this point in time, I am trying to stay as active as I can. I still co lead the support group here with Martha Hardy. I am quite challenged to be able to be involved with CPFF at this point in time but I am still hesitant to resign. I do hope for complete remission, but I have no idea if I'll ever get my hands back. they are like a little puff balls.

Please don't worry about me know that I am a survivor and I think of you all with great regard. Please pass on this message to the board members past and present in case anyone else has any suggestions regarding medication if you think it is appropriate. I just didn't want anybody to be blindsided. If I take a serious turn for the worst. In my opinion, part of cohesion in the group is staying on task and making sure that everyone is aware emotionally of what's going on with everybody else . Warmest regard Holly.

Dr. Holly Smith she/her

I acknowledge that I live work and play in the unceded land of the Stz'uminus First Nation people

CPFF Response:

Dear Holly,

I want to express my sincere gratitude for sharing your health status with us. Your openness and courage truly inspire me to redouble my efforts in advocating for researchers to find a cure and develop drugs that can effectively support patients like yourself who have comorbidities.

CPFF, receives numerous requests on a daily basis, and as such, the Board recently dedicated considerable time on Friday and Saturday to discuss the inclusion of a PF Connector proposal in our

strategic plan for the upcoming years. Personally, I cannot emphasize enough how invaluable PF Connectors have been in my own experience, helping me secure financial support for my father's care.

While CPFF is a patient organization that cannot provide medical advice, we are dedicated to assisting individuals like you in finding possible solutions. In this regard, I would like to suggest reaching out to the BC Lung Foundation, as they will be hosting a patient support group on Thursday, June 22 at 2 pm PST, tailored to your time zone (I have send you and Mark a calendar request with their Zoom link). By posting your question there, you may connect with fellow patients who may have encountered similar challenges.

I would also like to bring your attention to Fran Schooley, who is associated with Dr. Chris Ryerson and is part of the support group. If she becomes aware of your request, she may be able to offer suggestions or insights into alternative options that CPFF might not be aware of.

Moreover, I would like to share two informative presentations by Dr. Janet Pope, a renowned expert in Rheumatic Diseases, that may be of interest to you. In September 2020, Dr. Pope discussed the effects of Rheumatoid Arthritis and Pulmonary Fibrosis, and you can view the presentation at this link: (<https://cpff.ca/on-demand-videos/sessions-2020/pulmonary-fibrosis-and-rheumatic-diseases-dr-janet-pope-2/>). Additionally, Dr. Pope gave a second presentation in September 2021 on Interstitial Lung Disease in Connective Tissue Diseases and Rheumatoid Arthritis, accessible at this link: (<https://cpff.ca/on-demand-videos/sessions-2021/interstitial-lung-disease-in-connective-tissue-diseases-and-rheumatoid-arthritis-dr-janet-pope/>).

I genuinely hope that these suggested resources and potential solutions will be helpful to you. Please feel free to reach out if you require any further assistance or have any additional questions.

Sending you positive energy as I spend today with my family celebrating Father's Day.

CPFF's Role in the National Strategy for Drugs for Rare Diseases (NSDRD)

Author: Sharon Lee

Introduction

The NSDRD is an initiative dedicated to addressing the unique needs of individuals affected by rare diseases. As part of this overall investment, the Government of Canada will make available up to \$1.5 billion over three years to provinces and territories through bilateral agreements. This funding will help provinces and territories improve access to new and emerging drugs for Canadians with rare diseases, as well as support enhanced access to existing drugs, early diagnosis, and screening for rare diseases.

Rare diseases often receive limited attention and research funding due to their uncommon nature. This proposal outlines CPFF's desired role in the NSDRD, with a focus on representing the pulmonary fibrosis (PF) community's needs, collaborating with relevant organizations, advocating for funding allocation at the provincial level, and prioritizing specific PF projects.

CPFF's Desired Role

CPFF aims to actively participate in the NSDRD to ensure that the needs of pulmonary fibrosis patients are adequately represented. Our organization will collaborate with government agencies, medical professionals, and patient advocacy groups to effectively advocate for funding, research, treatment, and awareness campaigns related to PF. CPFF will leverage its expertise, resources, and community connections to support the fund's goals and objectives.

Representing PF Community Needs

To effectively represent the needs of the PF community, CPFF will focus on one to two PF-specific projects (i.e., oxygen, pulmonary rehab, clinical trials, rare disease policies) that address critical gaps in research, treatment, or patient support. These projects will be selected based on their potential to generate significant impact and benefit pulmonary fibrosis patients and caregivers across Canada. CPFF will use the PF Patient Charter and Breathless for Change Patient & Caregiver Survey Report as a starting point to identify key areas of focus and ensure that the projects align with the community's priorities and aspirations.

Collaboration with CORD

In efforts to avoid duplication and maximize effectiveness, CPFF will collaborate with the Canadian Organization for Rare Disorders (CORD) in policy creation and advocacy efforts. By working together, CPFF and CORD can leverage their respective strengths and expertise to create a unified voice for rare disease patients, including those affected by pulmonary fibrosis. This collaboration will streamline efforts, eliminate redundancies, and increase the overall impact of advocacy initiatives.

Advocacy for Funding Allocation at the Provincial Level

Recognizing the importance of provincial funding, CPFF will focus on high-budget provinces such as Ontario and Quebec to ensure that the needs of pulmonary fibrosis patients in those provinces are addressed adequately. CPFF will conduct thorough research to understand the specific needs and challenges faced by patients in each province. By actively engaging with provincial health authorities, policymakers, and relevant stakeholders, CPFF will advocate for the allocation of funds to support research, treatment, and awareness campaigns targeting pulmonary fibrosis.

Measurements of Success

The success of CPFF's involvement in the NSDRD will be measured through various metrics, including:

- Funding secured for PF-related drugs and projects
- Positive policy changes and increased awareness of pulmonary fibrosis at the federal and provincial levels
- Collaboration and partnership with government agencies, medical professionals, and patient advocacy groups
- Improved access to treatment options for PF patients
- Enhanced support and resources available for the PF community
- Regular reporting on these metrics will provide transparency and allow for continuous evaluation and improvement of CPFF's efforts with the fund.

Conclusion

CPFF's involvement in the NSDRD will enable us to effectively represent the needs of the pulmonary fibrosis community, advocate for funding at the provincial level, and collaborate with key stakeholders. By focusing on specific PF projects, leveraging partnerships with organizations like CORD, and prioritizing high-budget provinces, CPFF can make a significant impact in addressing the challenges faced by pulmonary fibrosis patients.

Resources and Budget (FY 24 = \$250K, FY 25 = \$250K, FY 26 = \$300K & FY 27 = \$300K)

- Government Relations Consultant
- Communications & Government Outreach: GR materials, GR Days of Action, Travel, Collaboration with other organizations

We seek the Board's approval at the January 2024 meeting to proceed with our desired role within the NSDRD and work towards advancing the well-being of individuals affected by pulmonary fibrosis.