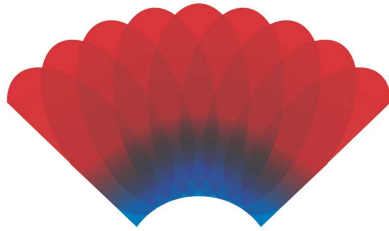




AGENDA

#	Agenda Item	Time Allocated	Planned End Time
	Procedural/Consent Items		
1	Call to Order: K. Morrison	3:30 pm	3:31 pm
2	Introductions and Welcome Remarks: K. Morrison	3:31 pm	3:32 pm
3	Approval of Board Agenda and Call for Other Business: K. Morrison	3:32 pm	3:33 pm
4	Declarations of Conflict of Interest: K. Morrison	3:33 pm	3:35 pm
	Discussion and Action Items		
5	Minutes of August 11, 2023, Board Meeting: K. Morrison <ul style="list-style-type: none"> • Motion to accept the minutes of August 11, 2023 	3:35 pm	3:37 pm
6	Agenda Items <ul style="list-style-type: none"> ➤ CPFF Financials (July 2023): V. Pringle & S. Lee ➤ Executive Director Report: <ul style="list-style-type: none"> ▪ FY 23/24 Budget: S. Lee (Deferred to November board meeting) ▪ 2023 New Initiatives <ul style="list-style-type: none"> ○ Innovation Fund (discussion): T. Georgieff ○ Federal Gov. Rare Disease Fund (discussion): M. Ashcroft ○ Patient Navigator (discussion): M. Ashcroft ○ Donor Stewardship (discussion): T. Hunter ▪ CPFF & Vaultt Database Revenue Generation Update: N. Hilliard, D. Mastin & S. Lee <ul style="list-style-type: none"> ○ In progress with Carters & CRA ○ Co-Marketing Agreement ▪ November Board Meeting Follow Up Updates <ul style="list-style-type: none"> ○ MAB Review and Succession: C. Fell <ul style="list-style-type: none"> • Still in progress 	3:37 pm	4:55 pm

#	Agenda Item	Time Allocated	Planned End Time
7	New Business <ul style="list-style-type: none"> • In Camera (ED Review) 		
8	CPFF Board Meeting Dates for FY 23-24: Friday November 3, 2023 Friday January 12, 2024 Friday March 1, 2024 Friday May 3, 2024 Friday July 5, 2024	4:55 pm	4:58 pm
9	Adjournment	5:00 pm	



Canadian Pulmonary Fibrosis Foundation

Board Minutes

Held via ZOOM

On Friday August 11, 2023

Commencing at 3:00 pm EDT

Present: Kirk Morrison, Chair
Sharon Lee, Executive Director
Todd Georgieff, Vice and Governance & Finance Chair
Mark Ashcroft, Advocacy & Support Co-Chair
Ranjena Maloni
Derek Mastin
Ray Protti

Guest(s): None

Regrets: Verity Pringle, Treasurer
Dr. Holly Smith, Advocacy & Support Co-Chair (indefinite medical leave)
Tom Hunter, Communications & Fundraising Chair
Nicole Hilliard

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 July 14, 2023 Board Meetings

It was moved and seconded,
That the minutes of the May 5 meeting be approved.

Carried.

CPFF Board Minutes of August 11, 2023

CPFF Financials

V. Pringle was not in attendance to present the June 2023 financials, though it was said that there was nothing remarkable to point out.

A fulsome review of FY22 financials will take place on the September 1st Board meeting.

Executive Director Report

Procurement Policy

The procurement policy was amended as the incorrect table was presented at the July Board meeting.

It was moved and seconded,

That the Procurement Policy be approved as amended.

Carried.

FY23/24 Budget

The complete budget, including revenues, expenditures and a balance sheet will be presented at the September Board meeting.

Some concerns were shared about timelines for work to be done on projects/initiatives.

It was mentioned that risk needs to be looked at for each project independently and the Board must decide if it's worth it. S. Lee and R. Protti to set up a time to talk about risk assessment.

It was also mentioned that CPFF does not have the capacity to take on these projects unless new staff members are hired to match the increased capacity needed.

Fellowship & Research grant Update

Next MAC meeting in which a talk about grants will take place has yet to be scheduled by C. Fell.

GR Report Update

Daniel MacDonald, Director General of Drugs for Rare Diseases, will put CPFF on his list and send an invite to participate to next meeting. It was mentioned that he's shown considerable interest in what CPFF is doing, including surveys.

Boehringer Ingelheim Canada

S. Lee is scheduled to meet with Dr. Rasha Abdelazim Eldessouky, Regional Medical Manager Europe and Canada at Boehringer Ingelheim, VP of Medical & Compliance at BI Canada.

The purpose of their meeting is to talk about what kind of support BI can provide from the medical side.

CPFF & Vaultt Database Revenue Generation Update

It was mentioned that Vaultt currently has a contract with the US Cystic Fibrosis Foundation, which is being used as a template for CPFF's Vaultt proposal. S. Lee to contact the US CF Foundation to see how they feel about their experience with Vaultt.

CPFF Board Minutes of August 11, 2023

It was mentioned that some questions have yet to be addressed by Vaultt's LOI, which was reviewed by CPFF's lawyers. The lawyers have advised CPFF to send Vaultt a draft proposal for their review, rather than a reviewed LOI, to expedite the process and save on legal fees.

After much discussion, it was agreed that a first level assessment of the Vaultt proposal will take place at the Governance and Finance committee and then, if all goes well, the ongoing implementation and maintenance of this app would most likely move over to the Support and Advocacy committee.

Furthermore, it was clarified that a potential partnership with Vaultt will require little to no capacity from CPFF's staff, as the app is completely Vaultt's responsibility.

September Events Update

To date, triathlons from Queen's students and T. Hunter, as well as the Avonmore Berry Farm, Run the Farm for PF event have taken place. Over \$31,000 have been raised, with the Avonmore Berry Farm having raised over \$25,000.

Walks in Calgary, Markham and Montreal are scheduled to take place during the month of September.

The media campaign for the month of September will include:

- 31 days of Embracing Hope
- Social Media campaign
- Media Interviews

Oxygen Paper Update

It was mentioned that the survey for healthcare professionals has finally reached the target number of submissions.

S. Lee to meet with G. Vidyasankar prior to meeting with medical writer to clarify the direction of the paper.

It was clarified that the \$25,000 set aside for distribution would allow the document to be an open article that anyone can view. Short of investing that sum, anyone wanting access to the paper will find it behind a paywall.

2023 Board Retreat – New Initiatives

It was reminded that rough budgets for each of the initiatives were shared during the Board retreat, and that they still align with the scope of each initiative following the production of the draft proposals.

Budgets will be polished following the review of the draft proposals by the respective committees.

Governance & Finance Report

Nothing to report at this time.

CPFF Board Minutes of August 11, 2023

Advocacy & Support Report

Support Group Leaders meeting – Sept 26

It was mentioned that H. Smith is scheduled to be the moderator for the support group leaders meeting. M. Ashcroft will also be in attendance, and will act as the backup moderator in the event of any unforeseen circumstances.

Winnipeg Support Group Sponsorship

It was mentioned that the Winnipeg support group is once again hosting a conference and that they are asking if CPFF can contribute some money and swag, like last year.

The Board agreed on renewing the sponsorship, provided that receipts are provided for each expenditure for which CPFF money is used, and that under no circumstances that money be used as honorariums for speakers.

It was moved and seconded,

That CPFF sponsor the Winnipeg Support Group conference with a monetary donation not exceeding \$2,100 and provide 175 pens and bracelets as giveaways.

Carried.

Furthermore, it was added that the Winnipeg support group is offering CPFF 15 minutes of podium time to talk about the Foundation. The Board agrees that M. Ashcroft ought to be the speaker, should he agree to it, which he did.

Communications & Fundraising Report

The Board discussed having a CPFF presence at upcoming respiratory health events:

Pulmonary Fibrosis Foundation Conference November 9 – 11, 2023 (Orlando, FL)
Canadian Thoracic Society (CTS) Conference April 20 – 22, 2024 (Toronto, ON)
Canadian Society of Respiratory Therapists May 3 – 5, 2024 (Banff, AB)
American Thoracic Society (ATS) Conference May 17 – 22, 2024 (San Diego, CA)
European Respiratory Society (ERS) September 7 – 11, 2024 (Vienna, AUS)

It was agreed that:

- Each event has a specific objective to achieve;
- Most of the events do not require CPFF to go in numbers – only 1 or 2 people;
- A booth would only be beneficial at the CTS conference.

MAB Report

Nothing to report, as C. Fell not in presence.

Adjournment

The meeting was adjourned 4:10 pm EDT.

Next CPFF Board meeting will be held on September 1, 2023.

CPFF Board Minutes of August 11, 2023

Certified correct,

SIGNATURE TO BE INCLUDED

Kirk Morrison
CPFF Board Chair

Canadian Pulmonary Fibrosis Foundation

Balance Sheet

As of July 31, 2023

	As of Jul. 31, 2023	Total As of Jul. 31, 2022 (PY)	% Change
Assets			
Current Assets			
Cash and Cash Equivalent			
1021 Restricted Cash	270,000.00	270,000.00	0.00%
1060 Chequing Bank Account	1,314,178.19	1,181,500.01	11.23%
1061 TD Investor Acct	15,468.61	15,159.23	2.04%
1062 BMO High Interest Savings	509,449.89	509,449.89	0.00%
Total Cash and Cash Equivalent	\$ 2,109,096.69	\$ 1,976,109.13	6.73%
1320 Prepaid Expenses	1,621.00	1,621.00	0.00%
2318 PSB Rebate Receivable	5,641.81	14,069.25	-59.90%
Total Current Assets	\$ 2,116,359.50	\$ 1,991,799.38	6.25%
Non-current Assets			
Property, plant and equipment			
1820 Furniture and Equipment	2,313.20	2,313.20	0.00%
1825 Accum Depr - Furn and Equip	-2,313.20	-2,313.20	0.00%
Total Property, plant and equipment	\$ 0.00	\$ 0.00	
Total Non Current Assets	\$ 0.00	\$ 0.00	
Total Assets	\$ 2,116,359.50	\$ 1,991,799.38	6.25%
Liabilities and Equity			
Liabilities			
Current Liabilities			
Credit Card			
1070 TD Visa 3392	-12,251.29	-13,502.36	9.27%
Total Credit Card	-\$ 12,251.29	-\$ 13,502.36	9.27%
2000 Current Liabilities			
2110 Accrued Liabilities	0.00	96,581.33	-100.00%
2220 Vacation Payable	29,774.00	22,794.95	30.62%

2315 GST/HST Paid on Purchases	-43,982.79	35.50	-123995.18%
Total 2000 Current Liabilities	-\$ 14,208.79	\$ 119,411.78	-111.90%
2225 Deferred Revenue	0.00	270,000.00	-100.00%
Due to TD Bank	270.00	270.00	0.00%
Total Current Liabilities	-\$ 26,190.08	\$ 376,179.42	-106.96%
Total Liabilities	-\$ 26,190.08	\$ 376,179.42	-106.96%
Equity			
3500 Retained Earnings	974,077.92	974,077.92	0.00%
3561 Internatly Restricted Funds	6,027.00	6,027.00	0.00%
Retained Earnings	635,515.04	561,032.24	13.28%
Profit for the year	526,929.62	74,482.80	607.45%
Total Equity	\$ 2,142,549.58	\$ 1,615,619.96	32.61%
Total Liabilities and Equity	\$ 2,116,359.50	\$ 1,991,799.38	6.25%

Monday, Aug. 28, 2023 08:22:17 p.m. GMT-7 - Accrual Basis

CPFF Fiscal July 31, 2023
August 2022 YTD

			12.00		100%	14%	16.00%	24%	23%	23%
	July 2022 ACTUAL	2023 budget	YTD BUDGET	VARIANCE	2023 Actual	Admin	Advocay	Education Awairness	Patient Support	Research
Foundation Grants	882,667	475,000	475,000	4,940	479,940	479,940				
Donation and fundraising	332,695	160,000	160,000	669,692	829,692	829,692				
Regional Donations			-	-		-				
Interst income	18,566		-	309	309	309				
Miscellaneous Income	126					-				
Deferred Revenue						-				
	1,234,055	635,000	635,000	674,941	1,309,941	1,309,941	-	-	-	-
1 Grants to charities	80,000	180,000	180,000	(180,000)	-	-	-	-	-	-
	-	40,000	40,000	80,567	120,567.31	16,879	19,291	28,936	27,730	27,730
2 Salaries & benefits	97,274	125,000	125,000	(15,837)	109,163	15,283	17,466	26,199	25,108	25,108
	64,650	53,000	53,000	18,425	71,425	10,000	11,428	17,142	16,428	16,428
3 Patient support	11,223	500	500	1,439	1,939	271	310	465	446	446
		5,000	5,000	(5,000)		-	-	-	-	-
		25,000	25,000	(25,000)		-	-	-	-	-
		27,000	27,000	(27,000)		-	-	-	-	-
		17,500	17,500	(17,500)		-	-	-	-	-
4 Communications/Support website costs	342	200,000	200,000	(199,866)	134.08	19	21	32	31	31
5 Awareness and advocacy	42,639	10,000	10,000	12,133	22,133	3,099	3,541	5,312	5,091	5,091
		10,000				-	-	-	-	-
		100,000				-	-	-	-	-
		20,000				-	-	-	-	-
						-	-	-	-	-
6 Fundraising events costs		75,000	75,000	(74,958)	41.92	6	7	10	10	10
			-	-		-	-	-	-	-
			-	-		-	-	-	-	-
7 Program education and consulting	184,398		-	370,824	370,824	51,915	59,332	88,998	85,290	85,290

			-	-	-	-	-	-	-	-
			-	-	-	-	-	-	-	-
	480,528	888,000	758,000	(61,771)	696,229	97,472	111,397	167,095	160,133	160,133
8 Professional fees	16,950	51,000	51,000	(35,929)	15,071	2,110	2,411	3,617	3,466	3,466
9 office and general	64,433	5,300	5,300	38,643	43,943	6,152	7,031	10,546	10,107	10,107
10 Travel and meeting costs	36	4,000	4,000	10,132	14,132	1,978	2,261	3,392	3,250	3,250
11 Telephone/Internet	7,225	6,700	6,700	1,789	8,489	1,189	1,358	2,037	1,953	1,953
12 Insurance	3,813	4,000	4,000	799	4,798.57	672	768	1,152	1,104	1,104
13 Interest and bank charges	1,462		-	349	349	49	56	84	80	80
	93,920	71,000	71,000	15,783	86,783	12,150	13,885	20,828	19,960	19,960
	659,607	-324,000	-194,000	720,930	526,930	1,200,320	-125,282	-187,923	-180,093	-180,093

Notes:

Note 1

All expenses allocated under pillars have been proportioned in accordance with the percentage resources approved by organization

Canadian Pulmonary Fibrosis Foundation

Profit and Loss by Class

August 2022 - July 2023

	Admin/Fund- 14%	Advocacy-16%	Ed & Aware 24%	Patient & Care- 23%	Research-23%	TOTAL
INCOME						
4000 Revenue						0.00
4010 Contributions						0.00
4020 Receipted Donations	92,188.00					92,188.00
4027 Rcptd Donations - September Awareness Walks	55,526.25					55,526.25
4030 Donations from Other Charities	58,632.63					58,632.63
4040 Unreceipted Donations	1,152.00					1,152.00
4195 Bequests Received	496,247.22					496,247.22
4300 Donations Through Paypal	9,075.28					9,075.28
4301 Donations Through Canada Helps	101,838.70					101,838.70
4302 Donations Through CAF Canada	250.00					250.00
4303 Donations Through CDN Online Giving	7,621.81					7,621.81
4304 Donations Through My Tribute Gift	6,736.25					6,736.25
4305 Donations Through United Way	423.95					423.95
Total 4010 Contributions	\$ 829,692.09	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 829,692.09
4190 Grants Received	479,940.00					479,940.00
4440 Interest Income	309.38					309.38
Total 4000 Revenue	\$ 1,309,941.47	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 1,309,941.47
Total Income	\$ 1,309,941.47	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 1,309,941.47
COST OF GOODS SOLD						
5000 Cost of Goods Sold						0.00
5190 Grants Made	15,400.00	17,600.00	26,400.00	25,300.00	25,300.00	110,000.00
5252 Clarke Family run - Expenses	385.48	440.55	660.83	633.30	633.30	2,753.46
5313 Misc Fundraising Expenses	813.94	930.22	1,395.31	1,337.19	1,337.19	5,813.85
5320 Sponsorship Costs	280.00	320.00	480.00	460.00	460.00	2,000.00
Total 5000 Cost of Goods Sold	\$ 16,879.42	\$ 19,290.77	\$ 28,936.14	\$ 27,730.49	\$ 27,730.49	\$ 120,567.31
Total Cost of Goods Sold	\$ 16,879.42	\$ 19,290.77	\$ 28,936.14	\$ 27,730.49	\$ 27,730.49	\$ 120,567.31
GROSS PROFIT	\$ 1,293,062.05	-\$ 19,290.77	-\$ 28,936.14	-\$ 27,730.49	-\$ 27,730.49	\$ 1,189,374.16

EXPENSES

02. Salaries & Benefits							0.00
5410 Wages & Salaries							0.00
5411 Executive Director Salary	12,717.30	14,534.00	21,801.04	20,892.68	20,892.69	90,837.71	
5414 Project Coordinator	7,718.14	8,820.74	13,231.10	12,679.80	12,679.80	55,129.58	
5415 Payables Coordinator - Heather	198.66	227.04	340.56	326.37	326.37	1,419.00	
Total 5410 Wages & Salaries	\$ 20,634.10	\$ 23,581.78	\$ 35,372.70	\$ 33,898.85	\$ 33,898.86	\$ 147,386.29	
5420 EI Expense	379.00	433.07	649.57	622.53	622.54	2,706.71	
5430 CPP Expense	952.57	1,088.64	1,632.96	1,564.91	1,564.91	6,803.99	
5460 Vacation Accrual	1,926.84	2,202.10	3,303.14	3,165.50	3,165.49	13,763.07	
5461 Payroll Admin Expense	175.76	200.91	301.38	288.81	288.82	1,255.68	
5470 Employee Benefits - Sharon	848.50	969.72	1,454.58	1,393.95	1,393.95	6,060.70	
5471 Employee Benefits - Roberto	365.68	417.96	626.92	600.78	600.77	2,612.11	
Total 02. Salaries & Benefits	\$ 25,282.45	\$ 28,894.18	\$ 43,341.25	\$ 41,535.33	\$ 41,535.34	\$ 180,588.55	
03. Patient Support	194.43	222.16	333.24	319.35	319.34	1,388.52	
5321 Support Group Expenses	77.06	88.07	132.07	126.60	126.60	550.40	
Total 03. Patient Support	\$ 271.49	\$ 310.23	\$ 465.31	\$ 445.95	\$ 445.94	\$ 1,938.92	
04. COMMUNICATION / SUPPORT WEBSITE COSTS							0.00
5335 Website Development	18.78	21.46	32.16	30.84	30.84	134.08	
Total 04. COMMUNICATION / SUPPORT WEBSITE COSTS	\$ 18.78	\$ 21.46	\$ 32.16	\$ 30.84	\$ 30.84	\$ 134.08	
05. Awareness & Advocacy							0.00
5327 Newsletter Expense	402.56	460.09	690.12	661.37	661.37	2,875.51	
5530 Awareness & Advocacy	2,031.95	2,718.66	4,077.98	3,908.07	3,908.07	16,644.73	
5615 Advertising and Promotion	365.84	418.07	627.10	601.02	601.01	2,613.04	
Total 05. Awareness & Advocacy	\$ 2,800.35	\$ 3,596.82	\$ 5,395.20	\$ 5,170.46	\$ 5,170.45	\$ 22,133.28	
06. Fundraising Events Costs	5.87	6.71	10.06	9.64	9.64	41.92	
07. Program Education & Consulting							0.00
5511 Patient Education	51,524.36	58,884.97	88,327.39	84,647.11	84,647.10	368,030.93	
5515 Consulting	391.10	446.97	670.45	642.51	642.51	2,793.54	
Total 07. Program Education & Consulting	\$ 51,915.46	\$ 59,331.94	\$ 88,997.84	\$ 85,289.62	\$ 85,289.61	\$ 370,824.47	
08. Professional Fees							0.00
5610 Accounting & Legal	371.16	424.18	636.27	609.77	609.77	2,651.15	
5695 Professional Fees	131.31	150.07	225.12	215.73	215.73	937.96	
5696 Bookkeeping	1,484.28	1,696.32	2,544.48	2,438.40	2,438.40	10,601.88	

5705 Membership fees, dues, subscrip	123.25	140.84	211.26	202.46	202.46	880.27
Total 08. Professional Fees	\$ 2,110.00	\$ 2,411.41	\$ 3,617.13	\$ 3,466.36	\$ 3,466.36	\$ 15,071.26
09. General & Administrative						0.00
5500 General Administrative Expenses	2,807.53	3,208.60	4,812.85	4,612.37	4,612.35	20,053.70
5520 Education	45.64	52.17	78.27	74.99	74.99	326.06
5525 Conferences	145.39	166.15	249.20	238.81	238.81	1,038.36
5571 Website Hosting	67.43	77.11	115.65	110.83	110.83	481.85
5640 Courier & Postage	88.25	100.88	151.27	145.01	145.01	630.42
5650 Staff Equipement - computers	474.21	541.97	812.92	779.07	779.07	3,387.24
5686 Governance	1,031.31	1,178.64	1,767.96	1,694.30	1,694.30	7,366.51
5700 Office Supplies	413.14	472.17	708.22	678.75	678.75	2,951.03
5770 Storage	525.44	600.51	900.64	863.18	863.18	3,752.95
5790 Utilities	0.64	0.73	1.10	1.06	1.06	4.59
5890 Credit Card fees	54.31	62.09	93.13	89.26	89.28	388.07
5891 Other Commissions	71.97	82.25	123.35	118.23	118.22	514.02
5895 Canada Helps fees	425.88	486.74	730.09	699.69	699.70	3,042.10
5896 PayPal fees	0.84	1.00	1.43	1.43	1.42	6.12
Total 09. General & Administrative	\$ 6,151.98	\$ 7,031.01	\$ 10,546.08	\$ 10,106.98	\$ 10,106.97	\$ 43,943.02
10. Travel & Meeting Costs	259.31	112.73	169.09	162.04	162.04	865.21
5784 Travel	1,591.39	2,002.38	3,003.56	2,878.42	2,878.42	12,354.17
5789 Travel - non refundable	127.75	145.99	218.94	209.86	209.86	912.40
Total 10. Travel & Meeting Costs	\$ 1,978.45	\$ 2,261.10	\$ 3,391.59	\$ 3,250.32	\$ 3,250.32	\$ 14,131.78
11. Telephone/Internet						0.00
5780 Telephone Expense	279.38	319.27	478.93	458.98	458.99	1,995.55
5781 Internet	909.19	1,039.01	1,558.50	1,493.58	1,493.59	6,493.87
Total 11. Telephone/Internet	\$ 1,188.57	\$ 1,358.28	\$ 2,037.43	\$ 1,952.56	\$ 1,952.58	\$ 8,489.42
12. Insurance						0.00
5685 Insurance	671.80	767.77	1,151.65	1,103.67	1,103.68	4,798.57
Total 12. Insurance	\$ 671.80	\$ 767.77	\$ 1,151.65	\$ 1,103.67	\$ 1,103.68	\$ 4,798.57
13. Bank and Interest Charges						0.00
5690 Bank Service Charges	48.90	55.88	83.83	80.33	80.33	349.27
Total 13. Bank and Interest Charges	\$ 48.90	\$ 55.88	\$ 83.83	\$ 80.33	\$ 80.33	\$ 349.27
Total Expenses	\$ 92,444.10	\$ 106,046.79	\$ 159,069.53	\$ 152,442.06	\$ 152,442.06	\$ 662,444.54
PROFIT	\$ 1,200,617.95	-\$ 125,337.56	-\$ 188,005.67	-\$ 180,172.55	-\$ 180,172.55	\$ 526,929.62

Monday, Aug. 28, 2023 08:23:54 p.m. GMT-7 - Accrual Basis

Canadian Pulmonary Fibrosis Foundation

Profit and Loss by Class

July 2023

	Admin/Fund- 14%	Advocacy- 16%	Ed & Aware 24%	Patient & Care-23%	Research- 23%	TOTAL
INCOME						
4000 Revenue						0.00
4010 Contributions						0.00
4020 Received Donations	8,422.59					8,422.59
4030 Donations from Other Charities	4,246.23					4,246.23
4040 Unreceived Donations	150.00					150.00
Total 4010 Contributions	\$ 12,818.82	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 12,818.82
4440 Interest Income	31.54					31.54
Total 4000 Revenue	\$ 12,850.36	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 12,850.36
Total Income	\$ 12,850.36	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 12,850.36
COST OF GOODS SOLD						
5000 Cost of Goods Sold						0.00
5190 Grants Made	12,600.00	14,400.00	21,600.00	20,700.00	20,700.00	90,000.00
Total 5000 Cost of Goods Sold	\$ 12,600.00	\$ 14,400.00	\$ 21,600.00	\$ 20,700.00	\$ 20,700.00	\$ 90,000.00
Total Cost of Goods Sold	\$ 12,600.00	\$ 14,400.00	\$ 21,600.00	\$ 20,700.00	\$ 20,700.00	\$ 90,000.00
GROSS PROFIT	\$ 250.36	-\$ 14,400.00	-\$ 21,600.00	-\$ 20,700.00	-\$ 20,700.00	-\$ 77,149.64
EXPENSES						
02. Salaries & Benefits						0.00
5410 Wages & Salaries						0.00
5411 Executive Director Salary	978.25	1,118.00	1,677.01	1,607.13	1,607.13	6,987.52
5414 Project Coordinator	593.60	678.40	1,017.60	975.20	975.20	4,240.00
5415 Payables Coordinator - Heather	26.04	29.76	44.64	42.78	42.78	186.00
Total 5410 Wages & Salaries	\$ 1,597.89	\$ 1,826.16	\$ 2,739.25	\$ 2,625.11	\$ 2,625.11	\$ 11,413.52
5420 EI Expense	35.84	40.94	61.38	58.84	58.84	255.84
5430 CPP Expense	89.04	101.76	152.64	146.28	146.28	636.00
5460 Vacation Accrual	149.59	170.96	256.43	245.75	245.75	1,068.48
5461 Payroll Admin Expense	11.31	12.93	19.38	18.58	18.58	80.78
Total 02. Salaries & Benefits	\$ 1,883.67	\$ 2,152.75	\$ 3,229.08	\$ 3,094.56	\$ 3,094.56	\$ 13,454.62

03. Patient Support	0.00	0.00	0.00	0.00	0.00	0.00
5321 Support Group Expenses	77.06	88.07	132.07	126.60	126.60	550.40
Total 03. Patient Support	\$ 77.06	\$ 88.07	\$ 132.07	\$ 126.60	\$ 126.60	\$ 550.40
04. COMMUNICATION / SUPPORT WEBSITE COSTS						0.00
5335 Website Development	18.78	21.46	32.16	30.84	30.84	134.08
Total 04. COMMUNICATION / SUPPORT WEBSITE COSTS	\$ 18.78	\$ 21.46	\$ 32.16	\$ 30.84	\$ 30.84	\$ 134.08
05. Awareness & Advocacy						0.00
5327 Newsletter Expense	22.26	25.44	38.14	36.57	36.57	158.98
5530 Awareness & Advocacy	209.49	239.42	359.10	344.16	344.16	1,496.33
5615 Advertising and Promotion	15.97	18.25	27.36	26.24	26.24	114.06
Total 05. Awareness & Advocacy	\$ 247.72	\$ 283.11	\$ 424.60	\$ 406.97	\$ 406.97	\$ 1,769.37
07. Program Education & Consulting						0.00
5511 Patient Education	4,934.81	5,639.79	8,459.65	8,107.19	8,107.19	35,248.63
Total 07. Program Education & Consulting	\$ 4,934.81	\$ 5,639.79	\$ 8,459.65	\$ 8,107.19	\$ 8,107.19	\$ 35,248.63
08. Professional Fees						0.00
5696 Bookkeeping	123.69	141.36	212.04	203.20	203.20	883.49
Total 08. Professional Fees	\$ 123.69	\$ 141.36	\$ 212.04	\$ 203.20	\$ 203.20	\$ 883.49
09. General & Administrative						0.00
5500 General Administrative Expenses	47.87	54.70	82.03	78.63	78.63	341.86
5640 Courier & Postage	1.43	1.64	2.43	2.35	2.35	10.20
5650 Staff Equipment - computers	394.68	451.07	676.58	648.40	648.40	2,819.13
5700 Office Supplies	35.22	40.25	60.34	57.86	57.86	251.53
5770 Storage	44.09	50.39	75.57	72.43	72.43	314.91
5890 Credit Card fees	4.23	4.83	7.23	6.94	6.94	30.17
5891 Other Commissions	4.81	5.49	8.22	7.89	7.89	34.30
5895 Canada Helps fees	16.66	19.04	28.53	27.36	27.36	118.95
Total 09. General & Administrative	\$ 548.99	\$ 627.41	\$ 940.93	\$ 901.86	\$ 901.86	\$ 3,921.05
10. Travel & Meeting Costs						0.00
5784 Travel	172.28	196.89	295.32	283.03	283.03	1,230.55
5789 Travel - non refundable	22.38	25.57	38.34	36.76	36.76	159.81
Total 10. Travel & Meeting Costs	\$ 194.66	\$ 222.46	\$ 333.66	\$ 319.79	\$ 319.79	\$ 1,390.36
11. Telephone/Internet						0.00
5780 Telephone Expense	22.58	25.81	38.68	37.10	37.10	161.27
5781 Internet	192.45	219.94	329.88	316.16	316.16	1,374.59

Total 11. Telephone/Internet	\$ 215.03	\$ 245.75	\$ 368.56	\$ 353.26	\$ 353.26	\$ 1,535.86
12. Insurance						0.00
5685 Insurance	489.76	559.72	839.57	804.60	804.60	3,498.25
Total 12. Insurance	\$ 489.76	\$ 559.72	\$ 839.57	\$ 804.60	\$ 804.60	\$ 3,498.25
13. Bank and Interest Charges						0.00
5690 Bank Service Charges	7.00	8.00	12.00	11.50	11.50	50.00
Total 13. Bank and Interest Charges	\$ 7.00	\$ 8.00	\$ 12.00	\$ 11.50	\$ 11.50	\$ 50.00
Total Expenses	\$ 8,741.17	\$ 9,989.88	\$ 14,984.32	\$ 14,360.37	\$ 14,360.37	\$ 62,436.11
PROFIT	-\$ 8,490.81	-\$ 24,389.88	-\$ 36,584.32	-\$ 35,060.37	-\$ 35,060.37	-\$ 139,585.75

Monday, Aug. 28, 2023 08:23:27 p.m. GMT-7 - Accrual Basis

Canadian Pulmonary Fibrosis Foundation
Profit and Loss by Class
August 2022 - July 2023

	Aug. 2022 - Jul. 2023	Total Aug. 2021 - Jul. 2022 (PY)	% Change
INCOME			
4000 Revenue			
4010 Contributions			
4010-1 Other Charities Donations		500.00	-100.00%
4020 Receipted Donations	92,188.00	35,265.08	161.41%
4026 Receipted Donations- Clark Run		6,300.00	-100.00%
4027 Rcptd Donations - September Awareness Walks	55,526.25		
4030 Donations from Other Charities	58,632.63	948.81	6079.60%
4035 Rcptd Donations - Donated Prop		56,917.91	-100.00%
4040 Unreceipted Donations	1,152.00	15.84	7172.73%
4195 Bequests Received	496,247.22	500.00	99149.44%
4300 Donations Through Paypal	9,075.28	21,743.84	-58.26%
4301 Donations Through Canada Helps	101,838.70	188,324.64	-45.92%
4302 Donations Through CAF Canada	250.00	500.00	-50.00%
4303 Donations Through CDN Online Giving	7,621.81	9,202.04	-17.17%
4304 Donations Through My Tribute Gift	6,736.25	10,250.70	-34.28%
4305 Donations Through United Way	423.95	2,511.74	-83.12%
Total 4010 Contributions	\$ 829,692.09	\$ 332,980.60	149.17%
4010-2 Fundraising			
4107 Merchandise Sales		31.40	-100.00%
Total 4010-2 Fundraising	\$ 0.00	\$ 31.40	-100.00%
4190 Grants Received	479,940.00	612,667.00	-21.66%
4420 Sundry Income		94.73	-100.00%
4440 Interest Income	309.38	1,082.61	-71.42%
Total 4000 Revenue	\$ 1,309,941.47	\$ 946,856.34	38.35%
Total Income	\$ 1,309,941.47	\$ 946,856.34	38.35%
COST OF GOODS SOLD			

5000 Cost of Goods Sold			
5190 Grants Made	110,000.00	270,000.00	-59.26%
5252 Clarke Family run - Expenses	2,753.46		
5313 Misc Fundraising Expenses	5,813.85		
5320 Sponsorship Costs	2,000.00		
Total 5000 Cost of Goods Sold	\$ 120,567.31	\$ 270,000.00	-55.35%
Total Cost of Goods Sold	\$ 120,567.31	\$ 270,000.00	-55.35%
GROSS PROFIT	\$ 1,189,374.16	\$ 676,856.34	75.72%
EXPENSES			
02. Salaries & Benefits			
5410 Wages & Salaries			
5411 Executive Director Salary	90,837.71	0.00	
5414 Project Coordinator	55,129.58	0.00	
5415 Payables Coordinator - Heather	1,419.00		
5516 Payroll - Research (Reclass)		37,242.55	-100.00%
5526 Payroll - Awareness (Reclass)		64,769.64	-100.00%
5527 Wages and Salaries - admin		22,669.37	-100.00%
5528 Payroll - Patient Support		37,242.55	-100.00%
Total 5410 Wages & Salaries	\$ 147,386.29	\$ 161,924.11	-8.98%
5420 EI Expense	2,706.71	0.00	
5430 CPP Expense	6,803.99	0.00	
5460 Vacation Accrual	13,763.07	0.00	
5461 Payroll Admin Expense	1,255.68	0.00	
5470 Employee Benefits - Sharon	6,060.70	0.00	
5471 Employee Benefits - Roberto	2,612.11	0.00	
Total 02. Salaries & Benefits	\$ 180,588.55	\$ 161,924.11	11.53%
03. Patient Support			
5321 Support Group Expenses	550.40	6,050.48	-90.90%
5529 Patient Support (RECLASS)		63,953.69	-100.00%
Total 03. Patient Support	\$ 1,938.92	\$ 70,842.13	-97.26%
04. COMMUNICATION / SUPPORT WEBSITE COSTS			
5335 Website Development	134.08	342.45	-60.85%
5572 Support Website Cost (RECLASS)		38,928.33	-100.00%
Total 5335 Website Development	\$ 134.08	\$ 39,270.78	-99.66%

Total 04. COMMUNICATION / SUPPORT WEBSITE COSTS	\$	134.08	\$	39,270.78	-99.66%
05. Awareness & Advocacy					
5327 Newsletter Expense		2,875.51		5,698.02	-49.53%
5530 Awareness & Advocacy		16,644.73		4,893.48	240.14%
5531 Awareness & Advocacy (RECLASS)				111,223.81	-100.00%
5615 Advertising and Promotion		2,613.04		3,020.09	-13.48%
Total 05. Awareness & Advocacy	\$	22,133.28	\$	124,835.40	-82.27%
06. Fundraising Events Costs		41.92			
07. Program Education & Consulting					
5511 Patient Education		368,030.93		81,759.80	350.14%
5515 Consulting		2,793.54		102.92	2614.28%
5517 Program Education + Consutling (RECLASS)				63,953.69	-100.00%
Total 07. Program Education & Consulting	\$	370,824.47	\$	145,816.41	154.31%
08. Professional Fees					
5610 Accounting & Legal		2,651.15		10,192.68	-73.99%
5695 Professional Fees		937.96		3,460.90	-72.90%
5696 Bookkeeping		10,601.88		4,350.47	143.70%
5705 Membership fees, dues, subscrip		880.27		646.38	36.18%
Total 08. Professional Fees	\$	15,071.26	\$	18,650.43	-19.19%
09. General & Administrative					
5500 General Administrative Expenses		20,053.70		10,885.96	84.22%
5520 Education		326.06			
5525 Conferences		1,038.36		236.51	339.03%
5571 Website Hosting		481.85		130.69	268.70%
5640 Courier & Postage		630.42		1,492.13	-57.75%
5650 Staff Equipement - computers		3,387.24		1,305.14	159.53%
5686 Governance		7,366.51		0.01	73665000.00%
5700 Office Supplies		2,951.03		3,065.28	-3.73%
5770 Storage		3,752.95		3,595.26	4.39%
5790 Utilities		4.59			
5890 Credit Card fees		388.07		396.76	-2.19%
5891 Other Commissions		514.02		1,078.56	-52.34%
5895 Canada Helps fees		3,042.10		5,680.95	-46.45%
5896 PayPal fees		6.12		630.45	-99.03%

Total 09. General & Administrative	\$	43,943.02	\$	28,497.70	54.20%
10. Travel & Meeting Costs		865.21			
5784 Travel		12,354.17		35.62	34583.24%
5789 Travel - non refundable		912.40			
Total 10. Travel & Meeting Costs	\$	14,131.78	\$	35.62	39573.72%
11. Telephone/Internet					
5780 Telephone Expense		1,995.55		1,361.98	46.52%
5781 Internet		6,493.87		5,863.16	10.76%
Total 11. Telephone/Internet	\$	8,489.42	\$	7,225.14	17.50%
12. Insurance					
5685 Insurance		4,798.57		3,813.48	25.83%
Total 12. Insurance	\$	4,798.57	\$	3,813.48	25.83%
13. Bank and Interest Charges					
5690 Bank Service Charges		349.27		1,462.34	-76.12%
Total 13. Bank and Interest Charges	\$	349.27	\$	1,462.34	-76.12%
Total Expenses	\$	662,444.54	\$	602,373.54	9.97%
PROFIT	\$	526,929.62	\$	74,482.80	607.45%

Monday, Aug. 28, 2023 08:24:20 p.m. GMT-7 - Accrual Basis

Donor Coordinator

Author: Sharon Lee

Introduction

The Donor Coordinator 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 this 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.

Budget = \$60K

We seek the board's approval at the September 2023 meeting to proceed with the implementation of the Donor Program and strengthen the organization's relationship with its donors.

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 benefit from the expertise of a well-established financial management company. With a team of seasoned professionals well-versed in investment strategies and portfolio management, this company will play a pivotal role in guiding the fund's growth and sustainability.

One of the core contributions of the financial management company will be to provide strategic financial advice to the Investment Committee. This guidance will be invaluable in optimizing investment decisions, managing risk, and ensuring alignment with the fund's objectives. By leveraging the financial management company's insights, the committee can make well-informed choices that amplify the impact of the CPFF Innovation Fund.

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.

Budget = \$0

It is noteworthy that the expenses associated with the financial management services will be seamlessly covered by the fund itself. This approach underscores our commitment to efficient resource utilization, as the returns generated by the fund will facilitate the continued engagement of these professional services without straining our financial resources.

We request the board's approval at the September 2023 meeting to proceed with the establishment of the fund, enabling us to embark on this exciting journey of innovation and growth.

PF Connector Program

Author: Sharon Lee

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, and parameters 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.

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

Smart Chatbot

- Patients/caregivers start at cpff.ca, input questions into a chatbot which sends automated responses on predetermined categories of questions

Live Virtual Chat

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

Live Agent

- Patients/caregivers who need further assistance can book an appointment for a live agent

The PF Connector Live Agent position will be a 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 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.

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.

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.

Budget = \$40K

We seek the board's approval at the September 2023 Board meeting to proceed with the implementation of the PF Connector Program, ensuring that the PF community and beyond can benefit from this valuable initiative.

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.

Budget = \$40K

We seek the board's approval at the September 2023 meeting to proceed with our desired role within the NSDRD and work towards advancing the well-being of individuals affected by pulmonary fibrosis.