

Canadian Pulmonary Fibrosis Foundation Board Meeting Nov 16, 2023 Via ZOOM 3:00 pm to 5:00 pm EDT

# <u>AGENDA</u>

#	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	<ul> <li>Minutes of September 1, 2023, Board Meeting: K. Morrison</li> <li>Motion to accept the minutes of September 1, 2023</li> </ul>	3:35 pm	3:37 pm
6	<ul> <li>Agenda Items</li> <li>CPFF Financials (July 2023): V. Pringle &amp; S. Lee</li> <li>Executive Director Report: <ul> <li>FY 23/24 Budget: S. Lee</li> <li>Motion to approve of interim budget of \$150,000 until January 2024</li> </ul> </li> <li>2023 New Initiatives <ul> <li>Innovation Fund (discussion): T. Georgieff</li> <li>Federal Gov. Rare Disease Fund (Approved): M. Ashcroft</li> <li>Patient Navigator (discussion): M. Ashcroft</li> <li>Donor Stewardship (discussion): T. Hunter</li> </ul> </li> <li>CPFF &amp; Vaultt Database Revenue Generation Update: N. Hilliard, D. Mastin &amp; S. Lee <ul> <li>In progress with Carters &amp; CRA</li> <li>Amended Co-Marketing Agreement</li> </ul> </li> </ul>	3:37 pm	4:55 pm

#	Agenda Item	Time Allocated	Planned End Time
	<ul> <li>CPFF Charitable Status Change (Private to Public): S. Lee         <ul> <li>In progress with Carters</li> </ul> </li> <li>November 2022 Board Meeting Follow Up Updates         <ul> <li>MAB Review and Succession: C. Fell</li> <li>Still in progress</li> </ul> </li> </ul>		
7	<ul> <li>New Business</li> <li>In Camera (if needed)</li> </ul>		
8	CPFF Board Meeting Dates for FY 23-24: January 25, 26 & 27, 2024 Friday March 1, 2024 Friday May 3, 2024 Friday July 5, 2024	4:55 pm	4:58 pm
9	Adjournment	5:00 pm	



Board Minutes Held via ZOOM On Friday September 1, 2023 Commencing at 3:00 pm EDT

Present: Kirk Morrison, Chair Sharon Lee, Executive Director Todd Georgieff, Vice and Governance & Finance Chair Verity Pringle, Treasurer Mark Ashcroft, Advocacy & Support Co-Chair Tom Hunter, Communications & Fundraising Chair Nicole Hilliard Ranjena Maloni Ray Protti

Guest(s): None

Regrets: Derek Mastin Dr. Holly Smith, Advocacy & Support Co-Chair (indefinite medical leave)

Canadian

Pulmonary Fibrosis Foundation

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 August 11, 2023 Board Meeting

The Board had a short discussion to clarify comments made on the Vaultt proposal discussion during the previous meeting.

It was forewarned that donors may have concerns about CPFF selling data in any way, shape or form, which in turn may negatively affect their propensity to donate.

### **CPFF Board Minutes of September 1, 2023**

It was pointed out that the fact that Vaultt sent a contract as a response to the Board's comments to their weak initial LOI is a cause for concern.

Ultimately, it was decided that CPFF will send Vaultt's contract with the US Cystic Fibrosis Foundation to the lawyers in order to amend it with N. Hilliard's comments. Once amended, the contract and the lawyers' feedback will be reviewed by the Governance & Finance committee prior to being sent back to Vaultt for approval.

### It was moved and seconded, That the minutes of the August 11 meeting be approved.

#### Carried.

### **CPFF Financials**

V. Pringle presented the July 2023 financials. The month was pretty quiet with a low amount of donations and most expenses related to the September preparations.

It was mentioned that:

- Assets are up \$200,000 compared to this point last year;
- Year-to-date income statements shows that grants are down and donation are up, though the latter is mainly due to the major legacy gift received;
- Balance sheet is showing a pre-audit profit of \$436,000 for the previous fiscal year.

A fulsome review of FY22 financials has been rescheduled to the November Board meeting.

### Executive Director Report

#### Global Heroes

CPFF was able to negotiate media releases through Global Heroes for 2 months, September and February, for the same price as the previous year.

#### Canadian Thoracic Society

Previous Robert Davidson fellow, Kerri Johannson, is expected to take over as the CTS president during their AGM in Toronto in May 2024. S. Lee is working with her to include CPFF in her speech.

### Winnipeg Patient Conference

S. Lee is scheduled to travel alongside M. Ashcroft to Winnipeg for the patient forum scheduled to take place September 27 and 28. It will be a good opportunity for her to connect with CPFF's contacts in Winnipeg

### Blue Jays Partnership

The Blue Jays have reached out to say that they will not agree to a first pitch, or to a jumbotron appearance, but they are open to receiving a partnership proposal.

### Federal Gov. Rare Disease Fund

It was agreed by the Advocacy & Support committee that in order to secure funding from the rare disease funds recently allocated to each province, pulmonary fibrosis must be first and foremost recognized as a rare disease.

Given CPFF's current resources and capacity, provinces ought to be approached, and secured, in the following order:

- 1. Quebec & Ontario
- 2. British Columbia & Alberta
- 3. Manitoba & Saskatchewan
- 4. Atlantic Provinces

Once that is achieved, the committee ought to consider what exactly CPFF ought to ask money for from each province that has added PF on their rare disease list.

### Patient Connector

More information was requested about the scope and budget for this initiative. It was pointed out that tasks to be overseen by this position are currently being fulfilled jointly by R. Zapata and S. Lee.

It was forewarned that although the position is currently being forecasted as part-time, there is a strong probability that, in practice, the demand for support will require full-time employee.

#### Donor Stewardship

It was pointed out that, in contrast with the other initiatives, this position has a clear costbenefit trade-off, as a better relationship with donors can increase the frequency and the amount of donations.

A budget of \$60,000 was requested for this position.

The Board agreed that its sensible to start looking for candidates. S. Lee to put out an ad in October to hopefully have some candidates lined up prior to the November Board meeting.

Budgets, timelines and resources for all 4 projects/initiative will be provided prior to November Board meeting.

<u>French and Indigenous Support Groups</u> These two new support groups will be starting in September.

David Gourde, a Quebec ILD nurse, will be the leader for the French support group. David previously started a support group at the Association Pulmonaire du Québec.

Justine Fletcher, an indigenous doctor, will be the leader for the Indigenous support group.

MAB Review Nothing to add.

### **CPFF Board Minutes of September 1, 2023**

#### **New Business**

It was reminded that this was the last monthly Board meeting, which will hopefully give more time to the Directors for committee work.

T. Georgieff to send out a G-Form to see if there's another time that would work as well, or better, than the current time, first Friday of the month at 3PM ET.

#### Adjournment

The meeting was adjourned 3:55 pm EDT.

Next CPFF Board meeting will be held on November 3, 2023.

Certified correct,

#### SIGNATURE TO BE INCLUDED

Kirk Morrison CPFF Board Chair

#### CPFF Fiscal July 31, 2024 August 2023 YTD

July 2023		2.00		100%	14%	16.00%	24%	23%	23%
							Education	Patient	
ACTUAL	2024 budget	YTD BUDGET	VARIANCE	2024 Actual	Admin	Advocay	Awairness	Support	Research
479 940	475 000	79 167	101 833	181 000	181 000				
903,676	160,000	26,667	49,080	75,746	75,746				
		-	-		-				
		-	-		-				
20,705		-	67	67	67				
_					-		-	-	
1,404,321	635,000	105,833	150,980	256,813	256,813	-	-	-	-
120 567	180.000	20,000	(20.000)						
120,567									- 23,48
109.163									3,85
71,425	53,000	8,833	2,800	11,633	1,629	1,861	2,792	2,676	2,67
1,939	500	83	1,210	1,294	181	207	311	298	29
	5,000	833	(833)		-	-	-	-	-
	25,000	4,167	(4,167)		-	-	-	-	-
	27,000	4,500	(4,500)		-	-	-	-	-
	17,500	2,917	(2,917)		-	-	-	-	-
134	200,000	33,333	(33,265)	68.37	10	11	16	16	1
22,133	10,000	1,667	6,031	7,698	1,078	1,232	1,847	1,770	1,77
	10,000				-	-	-	-	-
					-	-	-	-	-
	20,000				-	-	-	-	-
42	75.000	12 500	(12 500)		-	-	-	-	-
42	73,000		(12,300)	-	-		_		
		-	-		-	-	-	-	-
370 824			-	124 572	- 17 440	19 932			- 28,65
570,024			124,572	124,572	-	-	-	-	- 20,05
		-	-	-	-		-	-	-
696,229	888,000	126,333	137,808	264,141	36,980	42,263	63,394	60,753	60,75
15.071	F1 000	8 500	(6.425)	2.265	221	270	569	E 4 4	E 4
	-								54 96
	-								96 1,53
	-								1,55
	-		-	-	-	-	-		- 1,05
	4,000	-							2
86,783	71,000	11,833	5,999	17,833	2,497	2,853	4,280	4,101	4,10
621,309	-324,000	-32,333	7,173	- 25,161	217,337	-45,116	-67,674	-64,854	-64,85
	20,705 - - 120,567 - 109,163 71,425 1,939 134 22,133 42 370,824 42 370,824 <b>696,229</b> 15,071 43,943 14,132 8,489 4,799 349	903,676         160,000           20,705         -           1,404,321         635,000           120,567         180,000           -         40,000           109,163         125,000           71,425         53,000           1,939         5000           27,000         17,500           134         200,000           22,133         10,000           100,000         20,000           42         75,000           370,824	903,676         160,000         26,667           20,705         -           -         -           20,705         -           -         -           1,404,321         635,000         105,833           120,567         180,000         -           -         40,000         6,667           109,163         125,000         833           1,939         5000         833           1,939         5000         833           2,5,000         4,167           27,000         4,500           17,500         2,917           134         200,000         33,333           22,133         10,000         1,667           10,000         20,000         -           42         75,000         12,500           370,824         -         -           -         -         -           370,824         -         -           -         -         -           -         -         -           -         -         -           -         -         -           -         -         -	903,676         160,000         26,667         49,000           .         .         .         .           20,705         .         .         .           .         .         .         .           20,705         .         .         .           .         .         .         .           1,404,321         635,000         105,833         150,980           120,567         180,000         30,000         (30,000)           .         40,000         6,667         95,454           109,163         125,000         20,833         (4,077)           71,425         53,000         8,333         2,800           1,939         500         833         (43,500)           5,000         8,333         2,800         1,617           1,434         200,000         33,333         (43,265)           22,133         10,000         1,667         6,031           100,000         .         .         .           20,000         20,000         .         .           370,824         .         12,500         (12,500)           42         75,000         12,503         137	903,676         160,000         26,667         49,080         75,746           .         .         .         .         .         .           20,705         .         .         .         .         .           20,705         .         .         .         .         .           1,404,321         635,000         105,833         150,980         256,813           120,567         180,000         .         .         .         .           .         .         .         .         .         .         .           .         .         .         .         .         .         .         .         .         .           . <td>903,676         160,000         26,667         49,080         75,746         75,746           20,705         -         67         67         67         67           -         -         -         -         -         -           1,404,321         635,000         105,833         150,980         256,813         256,813           120,567         180,000         30,000         (30,000)         -         -           -         40,000         6,667         95,454         102,120.43         14,297           109,163         125,000         20,833         (4,077)         16,756         2,346           71,425         53,000         8,833         2,800         11,633         1,629           1,939         500         833         (433)         -         -           25,000         4,167         (4,167)         -         -           27,000         4,500         (4,500)         -         -         -           17,500         2,917         (2,917)         -         -         -         -           122,133         10,000         1,667         6,631         7,698         1,078         -           1</td> <td>903,676         160,000         26,667         49,080         75,746         75,746                   20,705                1,404,321         635,000         105,833         150,980         256,813         256,813            120,567         180,000                120,567         180,000                120,567         180,000                1404,321         635,000         833         (4,077)         16,756         2,346         2,6681           17,425         53,000         8,833               25,000         833         (4,077)         16,756         2,346         2,681           1,939         500         833         (4,207)              25,000         4,167         (4,500)           </td> <td><math display="block">\begin{array}{c c c c c c c c c c c c c c c c c c c </math></td> <td>479,940       475,000       79,167       101,833       181,000       181,000         903,676       160,000       26,667       49,000       75,746       75,746         20,705       -       67       67       67         -       -       -       -       -         1,404,321       635,000       105,833       150,980       256,813       256,813       -       -         120,567       180,000       30,000       (\$30,000)       -       -       -       -         120,567       180,000       30,000       (\$30,000)       -       -       -       -         120,567       180,000       8,667       95,454       102,120,43       14,297       16,339       24,509       23,488         109,163       125,000       20,833       (4,077)       16,556       2,346       4,021       3,854         1,939       500       833       (\$200)       -       -       -       -       -         25,000       4,167       (\$4,167       -       -       -       -       -       -       -       -       -       -       -       -       -       -       -       -       &lt;</td>	903,676         160,000         26,667         49,080         75,746         75,746           20,705         -         67         67         67         67           -         -         -         -         -         -           1,404,321         635,000         105,833         150,980         256,813         256,813           120,567         180,000         30,000         (30,000)         -         -           -         40,000         6,667         95,454         102,120.43         14,297           109,163         125,000         20,833         (4,077)         16,756         2,346           71,425         53,000         8,833         2,800         11,633         1,629           1,939         500         833         (433)         -         -           25,000         4,167         (4,167)         -         -           27,000         4,500         (4,500)         -         -         -           17,500         2,917         (2,917)         -         -         -         -           122,133         10,000         1,667         6,631         7,698         1,078         -           1	903,676         160,000         26,667         49,080         75,746         75,746                   20,705                1,404,321         635,000         105,833         150,980         256,813         256,813            120,567         180,000                120,567         180,000                120,567         180,000                1404,321         635,000         833         (4,077)         16,756         2,346         2,6681           17,425         53,000         8,833               25,000         833         (4,077)         16,756         2,346         2,681           1,939         500         833         (4,207)              25,000         4,167         (4,500)	$\begin{array}{c c c c c c c c c c c c c c c c c c c $	479,940       475,000       79,167       101,833       181,000       181,000         903,676       160,000       26,667       49,000       75,746       75,746         20,705       -       67       67       67         -       -       -       -       -         1,404,321       635,000       105,833       150,980       256,813       256,813       -       -         120,567       180,000       30,000       (\$30,000)       -       -       -       -         120,567       180,000       30,000       (\$30,000)       -       -       -       -         120,567       180,000       8,667       95,454       102,120,43       14,297       16,339       24,509       23,488         109,163       125,000       20,833       (4,077)       16,556       2,346       4,021       3,854         1,939       500       833       (\$200)       -       -       -       -       -         25,000       4,167       (\$4,167       -       -       -       -       -       -       -       -       -       -       -       -       -       -       -       -       <

Notes:

Note 1

Note 2

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

Deferred Grant from BI of \$149,500 provided to be spent on Advocacy, Education and Research has not been taken in YTD income as of Feb/21

# Canadian Pulmonary Fibrosis Foundation Balance Sheet

As of September 30, 2023

	As of	Sep. 30, 2023	As of	Total f Sep. 30, 2022 (PY)	Change
Assets		000, 2020		(1 1)	onunge
Current Assets					
Cash and Cash Equivalent					
1021 Restricted Cash		270,000.00		270,000.00	0.00
1060 Chequing Bank Account		1,351,746.43		1,136,548.42	215,198.01
1061 TD Investor Acct		15,535.62		15,196.09	339.53
1062 BMO High Interest Savings		603,829.37		521,437.89	82,391.48
Total Cash and Cash Equivalent	\$	2,241,111.42	\$	1,943,182.40	\$ 297,929.02
1320 Prepaid Expenses		1,621.00		1,621.00	0.00
2318 PSB Rebate Receivable		-0.01		14,069.25	-14,069.26
Total Current Assets	\$	2,242,732.41	\$	1,958,872.65	\$ 283,859.76
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	\$ 0.00
Total Non Current Assets	\$	0.00	\$	0.00	\$ 0.00
Total Assets	\$	2,242,732.41	\$	1,958,872.65	\$ 283,859.76
Liabilities and Equity					
Liabilities					
Current Liabilities					
Credit Card					
1070 TD Visa 3392		12,094.36		-1,421.00	13,515.36
Total Credit Card	\$	12,094.36	-\$	1,421.00	\$ 13,515.36
2000 Current Liabilities					0.00
2220 Vacation Payable		31,910.96		24,912.35	6,998.61
2315 GST/HST Paid on Purchases		-13,311.35		-11,281.08	-2,030.27
Total 2000 Current Liabilities	\$	18,599.61	\$	13,631.27	\$ 4,968.34
Due to TD Bank		270.00		270.00	0.00
Total Current Liabilities	\$	30,963.97	\$	12,480.27	\$ 18,483.70
Total Liabilities	\$	30,963.97	\$	12,480.27	\$ 18,483.70
Equity					
3500 Retained Earnings		974,077.92		974,077.92	0.00
3561 Internatlly Restricted Funds		6,027.00		6,027.00	0.00
Retained Earnings		1,256,824.14		635,515.04	621,309.10
Profit for the year		-25,160.62		330,772.42	-355,933.04
Total Equity	\$	2,211,768.44	\$	1,946,392.38	\$ 265,376.06
Total Liabilities and Equity	\$	2,242,732.41	\$	1,958,872.65	\$ 283,859.76

Sunday, Oct. 29, 2023 08:13:41 p.m. GMT-7 - Accrual Basis

# Canadian Pulmonary Fibrosis Foundation Profit and Loss

Sep-23

	Admin/Fun d-14%	Ac	lvocacy- 16%	Ed	& Aware 24%		atient & are-23%	R	esearch- 23%		TOTAL
INCOME											
4000 Revenue											0.00
4010 Contributions											0.00
4020 Receipted Donations	23,783.63										23,783.63
4030 Donations from Other Charities	3,017.87										3,017.87
4300 Donations Through Paypal	52.00										52.00
4301 Donations Through Canada Helps	3,589.00										3,589.00
4302 Donations Through CAF Canada	38.00										38.00
4303 Donations Through CDN Online Giving	585.08										585.08
4304 Donations Through My Tribute Gift	775.00										775.00
4305 Donations Through United Way	146.25										146.25
Total 4010 Contributions	\$ 31,986.83	\$	0.00	\$	0.00	\$	0.00	\$	0.00	\$	31,986.83
4010-2 Fundraising											0.00
4252 Funds Raised - Avonmore Berry Farm	1,750.00										1,750.00
4254 Funds Raised - Markham Walk	200.00										200.00
Total 4010-2 Fundraising	\$ 1,950.00	\$	0.00	\$	0.00	\$	0.00	\$	0.00	\$	1,950.00
4440 Interest Income	33.61										33.61
Total 4000 Revenue	\$ 33,970.44	\$	0.00	\$	0.00	\$	0.00	\$	0.00	\$	33,970.44
Total Income	\$ 33,970.44	\$	0.00	\$	0.00	\$	0.00	\$	0.00	\$	33,970.44
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
5252 Clarke Family run - Expenses	302.34		345.53		518.26		496.69		496.69		2,159.51
5255 Montreal Walk - Expenses	43.75		50.00		74.99		71.88		71.88		312.50
Total 5000 Cost of Goods Sold	\$ 12,946.09	\$	14,795.53	\$	22,193.25	\$	21,268.57	\$	21,268.57	\$	92,472.01
Total Cost of Goods Sold	\$ 12,946.09	\$	14,795.53	\$	22,193.25	\$	21,268.57	\$	21,268.57	\$	92,472.01
GROSS PROFIT	\$ 21,024.35	-\$	14,795.53	-\$	22,193.25	-\$	21,268.57	-\$	21,268.57	-\$	58,501.57
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 Coorindator	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 El 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
04. COMMUNICATION / SUPPORT WEBSITE COSTS						0.00
5335 Website Development	9.58	10.94	16.39	15.73	15.73	68.37
Total 04. COMMUNICATION / SUPPORT WEBSITE COSTS	\$ 9.58	\$ 10.94	\$ 16.39	\$ 15.73	\$ 15.73	\$ 68.37
05. Awareness & Advocacy						0.00
5327 Newsletter Expense	18.96	21.66	32.47	31.14	31.14	135.37
5530 Awareness & Advocacy	410.99	469.70	704.51	675.19	675.19	2,935.58
5615 Advertising and Promotion	34.81	39.79	59.66	57.19	57.19	248.64
Total 05. Awareness & Advocacy	\$ 464.76	\$ 531.15	\$ 796.64	\$ 763.52	\$ 763.52	\$ 3,319.59
07. Program Education & Consulting						0.00
5511 Patient Education	8,871.38	10,138.72	15,208.04	14,574.40	14,574.40	63,366.94
5515 Consulting	97.58	111.52	167.27	160.31	160.31	696.99
Total 07. Program Education & Consulting	\$ 8,968.96	\$ 10,250.24	\$ 15,375.31	\$ 14,734.71	\$ 14,734.71	\$ 64,063.93
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	65.38	74.72	112.05	107.41	107.41	466.97
5525 Conferences	48.52	55.45	83.17	79.71	79.71	346.56
5686 Governance	23.73	27.12	40.67	38.99	38.99	169.50
5700 Office Supplies	39.14	44.73	67.06	64.30	64.30	279.53
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	9.97	11.39	17.05	16.37	16.37	71.15

5895 Canada Helps fees	18.84		21.53		32.26		30.95		30.95		134.53
5896 PayPal fees	0.24		0.26		0.42		0.40		0.40		1.72
Total 09. General & Administrative \$	254.14	\$	290.42	\$	435.48	\$	417.50	\$	417.50	\$	1,815.04
10. Travel & Meeting Costs	338.17		386.48		579.69		555.57		555.57		2,415.48
5784 Travel	439.17		501.91		752.84		721.50		721.50		3,136.92
Total 10. Travel & Meeting Costs \$	777.34	\$	888.39	\$	1,332.53	\$	1,277.07	\$	1,277.07	\$	5,552.40
11. Telephone/Internet											0.00
5780 Telephone Expense	16.39		18.74		28.08		26.93		26.93		117.07
5781 Internet	554.13		633.29		949.91		910.36		910.36		3,958.05
Total 11. Telephone/Internet \$	570.52	\$	652.03	\$	977.99	\$	937.29	\$	937.29	\$	4,075.12
12. Insurance											0.00
5685 Insurance	111.31		127.21		190.77		182.86		182.86		795.01
Total 12. Insurance \$	111.31	\$	127.21	\$	190.77	\$	182.86	\$	182.86	\$	795.01
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 \$	13,170.97	\$	15,052.49	\$	22,578.23	\$	21,637.94	\$	21,637.94	\$	94,077.57
PROFIT \$	7,853.38	-\$	29,848.02	-\$	44,771.48	-\$	42,906.51	-\$	42,906.51	-\$	152,579.14

Friday, Sep. 29, 2023 08:04:20 p.m. GMT-7 - Accrual Basis

# Canadian Pulmonary Fibrosis Foundation Profit and Loss

August - September, 2023

	Ad	min/Fund- 14%	Ac	lvocacy- 16%	Ed	& Aware 24%	atient & are-23%	Re	esearch- 23%	TOTAL
INCOME										
4000 Revenue										0.00
4010 Contributions										0.00
4020 Receipted Donations		53,719.94								53,719.94
4030 Donations from Other Charities		3,017.87								3,017.87
4300 Donations Through Paypal		1,495.72								1,495.72
4301 Donations Through Canada Helps		12,221.50								12,221.50
4302 Donations Through CAF Canada		38.00								38.00
4303 Donations Through CDN Online Giving		1,187.16								1,187.16
4304 Donations Through My Tribute Gift		1,010.00								1,010.00
4305 Donations Through United Way		146.25								146.25
Total 4010 Contributions	\$	72,836.44	\$	0.00	\$	0.00	\$ 0.00	\$	0.00	\$ 72,836.44
4010-2 Fundraising										0.00
4252 Funds Raised - Avonmore Berry Farm		1,750.00								1,750.00
4253 Funds Raised - Clarke Walk		200.00								200.00
4254 Funds Raised - Markham Walk		730.00								730.00
4255 Funds Raised - Montreal Walk		230.00								230.00
Total 4010-2 Fundraising	\$	2,910.00	\$	0.00	\$	0.00	\$ 0.00	\$	0.00	\$ 2,910.00
4190 Grants Received		181,000.00								181,000.00
4440 Interest Income		67.01								67.01
Total 4000 Revenue	\$	256,813.45	\$	0.00	\$	0.00	\$ 0.00	\$	0.00	\$ 256,813.45
Total Income	\$	256,813.45	\$	0.00	\$	0.00	\$ 0.00	\$	0.00	\$ 256,813.45
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
5252 Clarke Family run - Expenses		1,577.32		1,802.62		2,703.93	2,591.29		2,591.29	11,266.45
5255 Montreal Walk - Expenses		119.56		136.61		204.95	196.43		196.43	853.98
Total 5000 Cost of Goods Sold	\$	14,296.88	\$	16,339.23	\$	24,508.88	\$ 23,487.72	\$	23,487.72	\$ 102,120.43

Total Cost of Goods Sold	\$ 14,296.88	\$	16,339.23	\$	24,508.88	\$	23,487.72	\$	23,487.72	\$ 102,120.43
GROSS PROFIT	\$ 242,516.57	-\$	16,339.23	-\$	24,508.88	-\$	23,487.72	-\$	23,487.72	\$ 154,693.02
EXPENSES										
02. Salaries & Benefits										0.00
5410 Wages & Salaries										0.00
5411 Executive Director Salary	1,956.50		2,236.00		3,354.02		3,214.26		3,214.26	13,975.04
5414 Project Coorindator	1,187.20		1,356.80		2,035.20		1,950.40		1,950.40	8,480.00
5415 Payables Coordinator - Heather	52.08		59.52		89.28		85.56		85.56	372.00
Total 5410 Wages & Salaries	\$ 3,195.78	\$	3,652.32	\$	5,478.50	\$	5,250.22	\$	5,250.22	\$ 22,827.04
5420 El Expense	62.24		71.09		106.64		102.21		102.21	444.39
5430 CPP Expense	172.05		196.60		294.95		282.66		282.66	1,228.92
5460 Vacation Accrual	299.18		341.92		512.86		491.50		491.50	2,136.96
5461 Payroll Admin Expense	22.62		25.86		38.76		37.16		37.16	161.56
5470 Employee Benefits - Sharon	111.30		127.20		190.80		182.86		182.86	795.02
5471 Employee Benefits - Roberto	111.30		127.20		190.78		182.86		182.86	795.00
Total 02. Salaries & Benefits	\$ 3,974.47	\$	4,542.19	\$	6,813.29	\$	6,529.47	\$	6,529.47	\$ 28,388.89
03. Patient Support	181.14		206.99		310.52		297.59		297.59	1,293.83
04. COMMUNICATION / SUPPORT WEBSITE COSTS										0.00
5335 Website Development	9.58		10.94		16.39		15.73		15.73	68.37
Total 04. COMMUNICATION / SUPPORT WEBSITE COSTS	\$ 9.58	\$	10.94	\$	16.39	\$	15.73	\$	15.73	\$ 68.37
05. Awareness & Advocacy										0.00
5327 Newsletter Expense	35.28		40.28		60.44		57.95		57.95	251.90
5530 Awareness & Advocacy	926.00		1,058.26		1,587.39		1,521.28		1,521.28	6,614.21
5615 Advertising and Promotion	116.40		133.03		199.53		191.23		191.23	831.42
Total 05. Awareness & Advocacy	\$ 1,077.68	\$	1,231.57	\$	1,847.36	\$	1,770.46	\$	1,770.46	\$ 7,697.53
07. Program Education & Consulting	144.81		165.47		248.25		237.91		237.91	1,034.35
5511 Patient Education	17,197.76		19,654.56		29,481.84		28,253.46		28,253.46	122,841.08
5515 Consulting	97.58		111.52		167.27		160.31		160.31	696.99
Total 07. Program Education & Consulting	\$ 17,440.15	\$	19,931.55	\$	29,897.36	\$	28,651.68	\$	28,651.68	\$ 124,572.42
08. Professional Fees										0.00
5695 Professional Fees	83.67		95.61		143.44		137.46		137.46	597.64
5696 Bookkeeping	247.38		282.72		424.08		406.40		406.40	1,766.98
Total 08. Professional Fees	\$ 331.05	\$	378.33	\$	567.52	\$	543.86	\$	543.86	\$ 2,364.62
09. General & Administrative										0.00

PROFIT	\$ 217,336.89	-\$	45,115.53	-\$	67,673.46	-\$	64,854.26	-\$	64,854.26	-\$	25,160.62
Total Expenses	\$ 25,179.68	\$	28,776.30	\$	43,164.58	\$	41,366.54	\$	41,366.54	\$	179,853.64
Total 13. Bank and Interest Charges	\$ 14.00	\$	16.00	\$	24.00	\$	23.00	\$	23.00	\$	100.00
5690 Bank Service Charges	14.00		16.00		24.00		23.00		23.00		100.00
13. Bank and Interest Charges											0.00
Total 11. Telephone/Internet	\$ 630.42	\$	720.46	\$	1,080.68	\$	1,035.70	\$	1,035.70	\$	4,502.96
5781 Internet	595.26		680.28		1,020.42		977.93		977.93		4,251.82
5780 Telephone Expense	35.16		40.18		60.26		57.77		57.77		251.14
11. Telephone/Internet											0.00
Total 10. Travel & Meeting Costs	\$ 935.36	\$	1,068.95	\$	1,603.41	\$	1,536.67	\$	1,536.67	\$	6,681.06
5784 Travel	597.19		682.47		1,023.72		981.10		981.10		4,265.58
10. Travel & Meeting Costs	338.17		386.48		579.69		555.57		555.57		2,415.48
Total 09. General & Administrative	\$ 585.83	\$	669.32	\$	1,004.05	\$	962.38	\$	962.38	\$	4,183.96
5896 PayPal fees	11.22		12.79		19.24		18.43		18.43		80.11
5895 Canada Helps fees	64.30		73.47		110.19		105.63		105.63		459.22
5891 Other Commissions	13.19		15.04		22.57		21.66		21.66		94.12
5890 Credit Card fees	8.46		9.66		14.46		13.88		13.88		60.34
5770 Storage	44.09		50.39		75.57		72.43		72.43		314.91
5700 Office Supplies	66.04		75.44		113.17		108.49		108.49		471.63
5686 Governance	23.73		27.12		40.67		38.99		38.99		169.50
5640 Courier & Postage	78.18		89.32		134.02		128.43		128.43		558.38
5525 Conferences	48.52		55.45		83.17		79.71		79.71		346.56
5500 General Administrative Expenses	228.10		260.64		390.99		374.73		374.73		1,629.19

Sunday, Oct. 29, 2023 08:06:53 p.m. GMT-7

# Canadian Pulmonary Fibrosis Foundation Profit and Loss

August - September, 2023

	Aug	- Sep., 2023	Aug - S	Sep., 2022 (PY)		Change
INCOME						
4000 Revenue						0.00
4010 Contributions						0.00
4020 Receipted Donations		53,719.94		17,169.35		36,550.59
4027 Rcptd Donations - September Awareness Walks				53,325.73		-53,325.73
4030 Donations from Other Charities		3,017.87		1,790.00		1,227.87
4035 Rcptd Donations - Donated Prop				11,988.00		-11,988.00
4300 Donations Through Paypal		1,495.72		3,867.00		-2,371.28
4301 Donations Through Canada Helps		12,221.50		32,075.11		-19,853.61
4302 Donations Through CAF Canada		38.00				38.00
4303 Donations Through CDN Online Giving		1,187.16		1,217.97		-30.81
4304 Donations Through My Tribute Gift		1,010.00		5,066.25		-4,056.25
4305 Donations Through United Way		146.25		287.91		-141.66
Total 4010 Contributions	\$	72,836.44	\$	126,787.32	-\$	53,950.88
4010-2 Fundraising						0.00
4252 Funds Raised - Avonmore Berry Farm		1,750.00				1,750.00
4253 Funds Raised - Clarke Walk		200.00				200.00
4254 Funds Raised - Markham Walk		730.00				730.00
4255 Funds Raised - Montreal Walk		230.00				230.00
Total 4010-2 Fundraising	\$	2,910.00	\$	0.00	\$	2,910.00
4190 Grants Received		181,000.00		270,000.00		-89,000.00
4440 Interest Income		67.01		36.86		30.15
Total 4000 Revenue	\$	256,813.45	\$	396,824.18	-\$	140,010.73
Total Income	\$	256,813.45	\$	396,824.18	-\$	140,010.73
COST OF GOODS SOLD						
5000 Cost of Goods Sold						0.00
5190 Grants Made		90,000.00		20,000.00		70,000.00
5252 Clarke Family run - Expenses		11,266.45				11,266.45

5255 Montreal Walk - Expenses	853.98				853.98
5313 Misc Fundraising Expenses	0.00				0.00
Total 5000 Cost of Goods Sold	\$ 102,120.43	\$	20,000.00	\$	82,120.43
Total Cost of Goods Sold	\$ 102,120.43	\$	20,000.00	\$	82,120.43
GROSS PROFIT	\$ 154,693.02	\$	376,824.18	-\$	222,131.16
EXPENSES					
02. Salaries & Benefits					0.00
5410 Wages & Salaries					0.00
5411 Executive Director Salary	13,975.04		13,975.04		0.00
5414 Project Coorindator	8,480.00		8,153.84		326.16
5415 Payables Coordinator - Heather	372.00				372.00
Total 5410 Wages & Salaries	\$ 22,827.04	\$	22,128.88	\$	698.16
5420 El Expense	444.39		452.45		-8.06
5430 CPP Expense	1,228.92		1,199.96		28.96
5460 Vacation Accrual	2,136.96		2,117.40		19.56
5461 Payroll Admin Expense	161.56		145.46		16.10
5470 Employee Benefits - Sharon	795.02		1,291.75		-496.73
5471 Employee Benefits - Roberto	795.00		290.24		504.76
Total 02. Salaries & Benefits	\$ 28,388.89	\$	27,626.14	\$	762.75
03. Patient Support	1,293.83		81.07		1,212.76
5321 Support Group Expenses	0.00		0.00		0.00
Total 03. Patient Support	\$ 1,293.83	\$	81.07	\$	1,212.76
04. COMMUNICATION / SUPPORT WEBSITE COSTS					0.00
5335 Website Development	68.37				68.37
Total 04. COMMUNICATION / SUPPORT WEBSITE COSTS	\$ 68.37	\$	0.00	\$	68.37
05. Awareness & Advocacy					0.00
5327 Newsletter Expense	251.90		234.42		17.48
5530 Awareness & Advocacy	6,614.21		-5,197.00		11,811.21
5615 Advertising and Promotion	831.42		905.37		-73.95
Total 05. Awareness & Advocacy	\$ 7,697.53	-\$	4,057.21	\$	11,754.74
07. Program Education & Consulting	1,034.35				1,034.35
5511 Patient Education	122,841.08		4,287.19		118,553.89
5515 Consulting	696.99		0.00		696.99
Total 07. Program Education & Consulting	\$ 124,572.42	\$	4,287.19	\$	120,285.23

08. Professional Fees				0.00
5610 Accounting & Legal	0.00			0.00
5695 Professional Fees	597.64	597.64		0.00
5696 Bookkeeping	1,766.98	1,766.98		0.00
5705 Membership fees, dues, subscrip		880.27		-880.27
Total 08. Professional Fees	\$ 2,364.62	\$ 3,244.89	-\$	880.27
09. General & Administrative				0.00
5500 General Administrative Expenses	1,629.19	970.63		658.56
5525 Conferences	346.56	0.00		346.56
5571 Website Hosting		226.20		-226.20
5640 Courier & Postage	558.38	247.37		311.01
5650 Staff Equipement - computers	0.00	0.00		0.00
5686 Governance	169.50	5,197.00		-5,027.50
5700 Office Supplies	471.63	143.74		327.89
5770 Storage	314.91	588.27		-273.36
5890 Credit Card fees	60.34	63.87		-3.53
5891 Other Commissions	94.12	-61.01		155.13
5895 Canada Helps fees	459.22	0.00		459.22
5896 PayPal fees	80.11	-12.75		92.86
Total 09. General & Administrative	\$ 4,183.96	\$ 7,363.32	-\$	3,179.36
10. Travel & Meeting Costs	2,415.48	160.68		2,254.80
5784 Travel	4,265.58	4,446.30		-180.72
Total 10. Travel & Meeting Costs	\$ 6,681.06	\$ 4,606.98	\$	2,074.08
11. Telephone/Internet				0.00
5780 Telephone Expense	251.14	620.64		-369.50
5781 Internet	4,251.82	2,228.74		2,023.08
Total 11. Telephone/Internet	\$ 4,502.96	\$ 2,849.38	\$	1,653.58
12. Insurance				0.00
5685 Insurance	0.00			0.00
Total 12. Insurance	\$ 0.00	\$ 0.00	\$	0.00
13. Bank and Interest Charges				0.00
5690 Bank Service Charges	100.00	50.00		50.00
Total 13. Bank and Interest Charges	\$ 100.00	\$ 50.00	\$	50.00
otal Expenses	\$ 179,853.64	\$ 46,051.76	\$	133,801.88

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### -\$ 25,160.62 \$ 330,772.42 -\$ 355,933.04

Sunday, Oct. 29, 2023 08:11:18 p.m. GMT-7 - Accrual Basis

### **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.

### 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.

#### **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.

#### **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, 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 & 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 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.

### **Program Cost**

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

Program Deliverables	Cost	
Full-time employee	\$60,000	
Chatbot, including implementation	\$5,000	
Call recording software, including implementation	\$1,000	
Total	\$66,000	

### **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 = \$100K

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.

#### **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 methyltrexate for putting this disorder into remission. The answer from Dr. Park was that methyltrexate 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 scleraderma, 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 methyltrexate

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.

# 1. Personal Health Information (PHI)

The CPFF is concerned about privacy law and the collection of what could be deemed personal health information ("PHI"). Can you please provide guidance on the legal risks the Organization should consider in terms of collecting PHI, including record retention, storing PHI in the "Cloud", whether the Organization has a specific duty to disclose it is collecting PHI, and whether the Organization would have any increased legal obligations as a potential custodian of PHI. For greater certainty, would using the app to collect PHI trigger any legal duties that must be considered before accepting the attached contract?

# Answer:

Vaultt is the risk owner and is liable for such risks being the sole contractor to both endconsumer (Users) and Customer (pharma, research institutes, and other payers). Users and Customers will agree to Vaultt's Terms of Service, Privacy Policy, and Master Service Agreement which places all legal obligations onto Vaultt.

CPFF will not be collecting, storing, or disclosing PHI as this responsibility is solely on Vaultt. Vaultt may share de-identified or anonymized aggregate datasets with CPFF as part of the contract. Since CPFF has collected its own patient surveys in the past, this information does not add any new risk to the organization.

For clarity, CPFF will enter into a Co-Marketing Agreement with Vaultt, and summarily will be compensated for Marketing and Sales efforts to both Users and Customers.

# 2. Storage and Exposure

What exposure could the Organization face due to storage of PHI or other similar data in the "Cloud"? How could any identified risks be mitigated?

# Answer:

As stated above, risks associated with PHI storage is Vaultt's responsibility. Vaultt reduce PHI risks by architecting our app to the highest security standards as outlined in section 2.10 of the Agreement. We have edited Section 2.10 of the latest version of the Agreement for clarity: "Vaultt utilizes best in class security and encryption to protect users' sensitive data, whether in-transit or at-rest. End-to-end encryption, a standard much higher than most other health platforms use, ensures data is always safe and secure. This higher level of security assures total privacy and protection, exceeding the security of today's standard mobile banking apps. Vaultt employs cloud-based intrusion and threat detection, as well as access restrictions at every level. Vaultt procure services from suppliers who meet privacy regulations such as PHIPA, PIPEDA, and HIPAA. Vaultt has 3rd parties conduct security audits, penetration tests of our system, and regularly implement improvements."

Furthermore, we outsource storage responsibility to AWS, which adheres to strict privacy polices such as PIPEDA, PHIPA, and HIPAA. Links to their compliance here: <a href="https://aws.amazon.com/compliance/pipeda/">https://aws.amazon.com/compliance/pipeda/</a> <a href="https://aws.amazon.com/compliance/pipeda/">https://aws.amazon.com/compliance/pipeda/</a> <a href="https://aws.amazon.com/compliance/pipeda/">https://aws.amazon.com/compliance/pipeda/</a>

# 3. "Exclusively hosted in Canada"

It notes that: "Canada: Vaultt warrants that the Platform and any information it collects from Canadian Users is and will continue to be exclusively hosted in Canada. For clarity, this provision does not apply to End- Users accessing the Solution from outside Canada." What privacy issues must the CPFF consider if the app is accessed, and survey data completed outside of Canada?

# Answer:

Vaultt protects our User's privacy by implementing the strongest industry security practices such as encryption at-rest as described in the Storage question above. We also implement best practices when Users access our app anywhere around the world using TLS encryption in-transit and at rest. Vaultt is HIPAA, PIPEDA and GDPR compliant. To note, neither HIPAA nor GDPR specifies storage location mandates. Please see our security promise here:<u>https://www.vaultt.com/security/</u>

# 4. Retention and Ownership

It states Vaultt retains intellectual property ("IP") rights in its Platform. Are there any IP rights the CPFF should consider when integrating its app with Vaultt? What about ownership of survey questions created in collaboration with Vaultt?

# Answer:

The roadmap for app integration with Vaultt is currently not in scope but can certainly be addressed once we see an uptake from members. Section 2.6 of the Agreement does state reciprocal IP acknowledgments. Regarding ownership of patient survey data, as stated in the agreement, this information will always belong to the respondent. They grant Vaultt the license to collect, store, and disseminate de-identified or anonymized data to help the cause to improve health outcomes of those affected by cystic fibrosis.

# 5. Data Removal

While the contract confirms data remains the property of the survey respondent, could the CPFF be exposed to legal liability if Vaultt refuses to remove a respondent's data from the Platform if so requested. Further, what legal risks exist should Vaultt fail to deidentify survey data that is later sold/shared or revealed in a data breach? Sixth, if a survey respondent never requests that their data be deleted, could Vaultt retain the survey results in perpetuity?

# Answer:

As stated in the first question, Vaultt is solely responsible for agreements between the End User and Vaultt. Vaultt has a two-step approach to safeguarding Survey data. a) We have a De-Identification Policy and Procedure that is disseminated internally, and b) We have architected the survey storage system separate from the main app. In the unlikely possibility of a data breach, the survey storage would show numeric IDs and no other identifiable information such as name or address.

If no request is received to delete User data, then Vaultt is obligated to store survey information so long as the account is active and in good standing.

# 6. Conflict of Interest

Would the Organization face legal risk and/or does a conflict of interest exist if Vaultt sells survey data to Companies that provide funding to the CPFF for research purposes/scholarships?

# Answer:

The Co-Marketing Agreement was set up to allow arm's length transactions between Vaultt and Companies/Customers so there should not be any conflicts of interest. Circling back to the fact that it is Vaultt and the Customer who will enter into a sales agreement for survey data, and there will be no mention of CPFF in the MSA for the sale of the data. In addition, Vaultt's CEO has spoken to representatives from various Pharmaceutical Manufacturers, and they have indicated that they were supportive of this collaboration. Does CPFF have agreements with specific Companies at this time and are there any written exclusions?

# 7. Consent

Last, how could the CPFF gain express consent from survey participants to disclose survey data? Would a "click and accept the terms" option suffice?

# Answer:

Correct, in the current digital age, a consent checkbox is sufficient and is pervasive in all mobile app design. Vaultt uses best practice in our UX/UI approach and follows guidelines here: <u>https://www.priv.gc.ca/en/privacy-topics/technology/mobile-and-digital-devices/mobile-apps/gd\_app\_201210/</u>

Note: Vaultt is asking for consent, not CPFF.



# **CO-MARKETING AGREEMENT**

**THIS AGREEMENT** is made as of November 1, 2023 (the "**Effective Date**") between Vaultit Inc. having a place of business at 441 MacLaren St, Ottawa, ON, Canada K2P 2H3 ("**Vaultt**") and Canadian Pulmonary Fibrosis Foundation having its head office at 47 Squire Baker's Lane, Markham, Ontario, L3P 3G8 ("**CPFF**").

**WHEREAS** Vaultt operates an information management and communication platform built for caregivers and patients to organize, collaborate, and share vital information (the "**Solution**");

**WHEREAS** Vaultt collects and stores sensitive information such as User responses to surveys and other Personal Information that Users have voluntarily consented to share (the "Data"). Ownership of Data remains the property of the respective Users indefinitely;

**WHEREAS** CPFF is a registered charity established to provide hope and support for people affected by pulmonary fibrosis (PF);

**WHEREAS** Vaultt and CPFF wish to enter into a co-marketing and revenue sharing arrangement with respect to the Community Members of CPFF;

**NOW THEREFORE**, in consideration of the mutual covenants set forth in this Agreement and the exchange of other good and valuable consideration by and between the Parties (the receipt and sufficiency of which are hereby acknowledged by each Party), the Parties hereby agree as follows:

### **1. INTERPRETATION**

### 1.1. Definitions

In addition to other terms defined throughout this Agreement, the following terms have the following meanings:

- (a) "Affiliate" means an affiliated body corporate (as so defined) of a Party and any partnership or other unincorporated association in which a "Party" has a controlling interest;
- (b) "Agreement" means this Agreement, including all Schedules attached hereto, all as amended or replaced by the Parties in writing from time to time;
- (c) "Applicable Law(s)" means all applicable federal, provincial, state, municipal and local law, statutes, by-laws, ordinance, rule, regulation, judgment, order, decree, arbitration award, agency requirement, opinion, franchise, license, or permit of any governmental authority or common law applicable to which the Parties are subject to in performance of this Agreement, including, without limitation, all Canadian, and Provincial laws regulating health or wellness applications and uses thereof, data protection laws and privacy laws;
- (d) "Claim" means any actual, threatened or alleged claim, action, suit, proceeding or demand of whatsoever nature;

- (e) "Community Member(s)" means a User who has a direct relationship with the CPFF.
- (f) "Confidential Information" means any technical, business, marketing, financial, scientific, or other information of a Party or its Affiliates that, at the time of disclosure, is designated confidential (or a like designation), or is disclosed in circumstances of confidence, or would generally be understood by an individual exercising reasonable business judgment to be confidential or proprietary in nature. The following information is not Confidential Information (i) information that was known by the Receiving Party prior to its disclosure (as evidenced by its records); (ii) information that was lawfully in the public domain prior to its disclosure or becomes publicly available other than through a breach of this Agreement; (iii) information that was disclosed to the Receiving Party by a third party provided such third party is not in breach of any confidentiality obligation in respect of such information; (iv) information that is independently developed by the Receiving Party (as evidenced by its records). Confidential Information also includes Personal Information the Solution may collect and store.
- (g) "**Customer(s)**" means an organization such as a research institution, government body, or pharmaceutical company who has entered into a Customer Agreement with Vaultt;
- (h) "Customer Agreement(s)" means a written agreement between Vaultt and a Customer regarding the sale of Data to the Customer.
- (i) "Party" means a party to this Agreement and "Parties" means Vaultt and CPFF;
- (j) "**Personal Information**" means all information that is about an identifiable individual, including any personal health information and other sensitive information, which is protected from unauthorized disclosure pursuant to Applicable Laws;
- (k) **"Marks"** means the trademarks, logos, pictures, images, graphics or other designations of source owned or licensed by Vaultt or CPFF from time to time.
- (1) **"Solution**" means the application software owned and licensed by Vaultt pursuant to this Agreement including but not limited to the following features:
  - (i) The secure storage of Personal Information
  - (ii) Appointment scheduling
  - (iii) Task assignments
  - (iv) My Health Summary: A summary of pertinent health information in case of an emergency
  - (v) Medication and adherence reminders
  - (vi) Symptom trackers
  - (vii) Configurable and Custom Categories and Records
  - (viii) Collaborators and family member invitations
  - (ix) Family social postings

- (x) Surveys and questionnaires
- (xi) Including all documentation, improvements, enhancements, new releases, new versions, and bug or error fixes thereto made from time to time by Vaultt;
- (m) "Taxes" means any and all applicable federal, provincial, municipal, local or other governmental authority taxes including all sales, use, excise, personal property, utility, goods, services, value-added, gross receipts, and services taxes, now in force or enacted in the future associated with this Agreement, provided however, that in no event shall Taxes include taxes on net income or capital.
- (n) **"User"** means an end-user who is authorized by Vaultt to access or use the Solution from time to time.

# 2. ARRANGEMENT

### 2.1. Grant

Subject to the terms and conditions of this Agreement, Vaultt hereby grants to CPFF a nonexclusive, non-transferable, non-sublicensable and revocable right to advertise, market, and promote the Solution and gather the Data, on the terms and conditions set out in this Agreement. As a condition of this grant, the Parties agree as follows:

- a) Subsidized subscriptions to the Solution will be provided to Users through a custom link or unique identifier which will recognize them as Community Members.
- b) CPFF and Vaultt will together create a set of survey questions that, once answered by Community Members, will provide the Data for use by researchers, pharmaceuticals, and health care providers.
- c) Surveys will be sent within the Solution to Community Members for a set period of time.
- d) Vaultt will collect, de-identify and package the Data.
- e) Vaultt and the CPFF will work together to present the Data to prospective Customers such as research groups, government, insurance companies and pharmaceutical companies.
- f) The revenue resulting from Community Members and invitees who sign on as a result of the CPFF's actions will be shared between both the CPFF and Vaultt, as set out in Section 3.1 below. Any Data and revenue from Users that are not Community Members are excluded from this Agreement, in terms of the rights and obligations of the Parties under this Agreement.
- g) Vaultt will be responsible for completing all sales transactions with Customers and to providing de-identified Data to Customers.

# 2.2. Roles & Responsibilities

Schedule B of this Agreement outlines the Roles and Responsibilities of each Party. The Parties agree to execute activities in a timely manner which will be mutually beneficial to this covenant.

# 2.3. Branding

The Solution will be distributed under the Marks. The Parties hereby grant each other a limited, non-exclusive, non-transferable, non-sublicensable, non-royalty bearing license to use each other's Marks for the purpose of this Agreement, provided that any such use shall be pre-approved by the other Party in writing. Ownership of the Marks will always remain with their respective Parties.

### 2.3 Marketing Plan

The parties each agree to appoint a primary contact who will be responsible for the development and implementation of a marketing plan to be agreed upon by the parties. Both parties agree to attend meetings as needed and make such introductions to potential customers or other interested persons as required, with the goal of acquiring customers and generating income pursuant to section 3.1.

# 2.4 Contracting Process

Distribution of the Data by Vaultt to Customers will be made through a Customer Agreement drafted and supported by Vaultt in its exclusive discretion. CPFF is responsible for providing Vaultt in writing with any specific terms and conditions it recommends adding to the Customer Agreement given the specific nature of the Data. Vaultt will consider those terms and conditions and ensure that similarly protective terms are included in the Customer Agreements. CPFF will not be a party to the Customer Agreements.

### 2.5 Maintenance, Support, and Operations

At no additional cost to CPFF, Customers, or Community Members, Vaultt is responsible for the support, maintenance, and operation of all systems of the Solution, including without limitation those required to host the Solution. Vaultt warrants that it has implemented reasonable industry-appropriate separation measures that ensure that User data is physically or logically segregated and stored separately from other User data and the User data backups are made on systems that are logically and/or physically separate.

### 2.6 Intellectual Property

CPFF acknowledges and agrees that Vaultt retains ownership of all rights, title, and interests, including all intellectual property rights, in the Solution and its Marks. This Agreement does not grant to CPFF any right, title, or interest in, or to the Solution or its Marks other than the limited rights granted herein.

Vaultt acknowledges and agrees that CPFF retains ownership of all rights, title, and interests, including all intellectual property rights, in its Marks. This Agreement does not grant to Vaultt any right, title, or interest in, or to its Marks other than the limited rights granted herein.

# 2.7. Non-Exclusivity

This Agreement does not create an exclusive relationship between the Parties. Without limiting the generality of the foregoing, Vaultt retains its right to enter into similar co-marketing and revenue sharing arrangements with patient advocacy groups, other than CPFF.

### 2.8 Marketing Materials

Any marketing material to be developed by the Parties in connection with the Solution or this Agreement shall be developed at each Parties own cost.

# 2.9 Qualifications and References

CPFF will provide Vaultt access to reference Customers to support Vaultt's sales and marketing efforts, as reasonably required by Vaultt. The Parties may agree to produce and publish (with prior approval of the other Party) case studies or secure testimonials regarding the successful use of the Solution and sale of Data.

# 2.10 Security

Vaultt utilizes best in class security and encryption to protect users' sensitive data, whether intransit or at-rest. End-to-end encryption, a standard much higher than most other health platforms use, ensures data is always safe and secure. This higher level of security assures total privacy and protection, exceeding the security of today's standard mobile banking apps. Vaultt employs cloud-based intrusion and threat detection, as well as access restrictions at every level. Vaultt procure services from suppliers who meet privacy regulations such as PHIPA, PIPEDA, and HIPAA. Vaultt has 3rd parties conduct security audits, penetration tests of our system, and regularly implement improvements.

# **3. PRICING AND PAYMENTS**

### 3.1. Commission Fee

Vaultt will pay CPFF a commission fee 50% of monies received by it resulting from any sale of Data obtained from one or more Community Member pursuant to a Customer Agreement (the "Fees"). In calculating the Fees, Vault shall use as a basis the Price List set out in Schedule "A" to this Agreement. After The Initial Term as defined in Section 6.1 below, the Parties may review this Agreement, and having regard to the circumstances and make such adjustments to the Fees as they may agree upon in writing.

Vaultt will pay all Fees due and payable within forty-five (45) days of it receiving payment form a Customer under a Customer Agreement.

# 3.2. List Prices

Schedule "A" to this Agreement sets out Vaultt's initial list for all chargeable items associated with the Solution and the sale of Data to Customers. Vaultt may update the Price List on an annual basis. To the extent an updated Price List increases fees payable, such increases will only apply to Customer Agreements entered after the date of the update. For this partnership, CPFF Community Members will be provided with the Vaultt platform at no cost.

# 3.3. Currency

Unless otherwise provided, all references in this Agreement to dollar amounts are to Canadian Dollars.

# 4. CONFIDENTIALITY

### 4.1. Obligation of Confidentiality

Except as permitted hereunder, neither Party shall use the other Party's Confidential Information without the other Party's written consent or disclose the other Party's Confidential Information except: (a) to employees, contractors or consultants only if they have a need to know about it for purposes of this Agreement and subject to the confidentiality obligations similar to the ones set out herein, or (B) if required to comply with a court order or other government demand that has the force of law, in which case the Party shall seek the highest level of protection available and, when possible, give the other Party enough prior notice to provide a reasonable chance to seek a protective order.

### 4.2. Protection

Each Party shall: (i) take reasonable steps to safeguard the other Party's Confidential Information, which steps shall be at least as protective as those the Party takes to protect its own confidential information; and (ii) cooperate in any reasonable way to help the other Party regain control of the Confidential Information and prevent further unauthorized use or disclosure.

### 4.3. Return of Information

Without prejudice to any other rights provided herein, upon termination of this Agreement, each Party shall return to the other Party all Confidential Information of the other Party in its possession or control, or at the other Party's option, destroy such Confidential Information, including any copies or reproductions thereof, with such destruction confirmed in writing. Notwithstanding the foregoing obligation to return or destroy the Confidential Information of the other party, receiving Party may electronically retain Confidential Information in its e-mail and other archival systems, subject to the obligations not to disclose or use such Confidential Information and to use at least the same degree of care in safeguarding the Confidential Information as receiving Party uses for its own confidential and proprietary information, but with no less than reasonable care.

### 4.4. Public Statements

Either Party may issue press releases, or public statements with respect to the execution, delivery, or performance of this Agreement, subject to the prior written approval of the other Party which approval shall not be unreasonably withheld.

### 4.5. Compliance with Applicable Laws

Each Party is responsible for complying with Applicable Laws including without limitation, pertaining to the protection of Personal Information.

# 5. INDEMNIFICATION AND LIABILITY

### 5.1. Indemnification

The Parties will defend, indemnify and hold harmless each other, its respective directors, officers, employees, contractors and agents (collectively, the "**Indemnified Parties**") from and against any and all loss, liability or damage (including reasonable professional costs and expenses and all interest charges) incurred by some or all of the Indemnified Parties in connection with or relating to any actual Claim associated with the Solution, a breach of this Agreement by either Party or the services Vaultt provides in connection with this Agreement.

# 5.2. Limitation of Liability

Notwithstanding anything to the contrary herein, neither Party's total and cumulative liability in connection with this Agreement shall not exceed an amount equivalent to the fees paid by Vaultt to CPFF hereunder in the twelve (12) months preceding the event giving rise to the claim.

### 5.3. Damages

In no event will either Party be liable to the other Party or to any other entity for any special, consequential, exemplary, indirect, incidental, punitive or reliance damages, however caused, lost profits, lost data or lost revenues, under any theory, whether or not foreseeable, whether or not advised of the possibility of such damage, and notwithstanding the failure of essential purpose of any limited remedy.

### 5.4. Disclaimer

Except as expressly set forth herein, the Solution and the Data, information or services accessed or provided in connection with this Agreement are provided "as is" and "as available". Vaultt disclaims all statutory representations, conditions and warranties, express or implied, including but not limited to any implied warranties of merchantability, accuracy, integrity, freedom, noninfringement or fitness for a particular purpose, or arising from course of performance or course of dealing, or that services or the application will provide error-free or uninterrupted functionalities.

### 5.5. Insurance

Throughout the Term, Vaultt shall maintain sufficient insurance coverage to satisfy their respective obligations under this Agreement.

### 6. TERM AND TERMINATION

### 6.1. Term

Unless earlier terminated in accordance with this Agreement, the term of this Agreement will begin on the Effective Date and continue for a period of 12 months (the "**Initial Term**") At the end of the Initial Term, the term of this Agreement will automatically renew for additional periods of twelve (12) months (each, a "**Renewal Term**") unless either Party provides the other Party with notice of non-renewal at least sixty (60) days' prior to the end of the Initial Term or then current Renewal Term, as the case may be. The Initial Term and any Renewal Term(s) (if any) shall be collectively referred to as the "**Term**".

# 6.2. Termination for Convenience

Either party may at any time, for any reason, terminate this Agreement upon 180 days prior written notice to the other Party.

# 6.3. Termination on Material Breach

Either Party may terminate this Agreement, by written notice delivered to the other Party, upon a material breach of a Party's material representations, warranties, or obligations under this Agreement, upon failure of the breaching Party to cure the alleged breach within thirty (30) calendar days after receipt of the non-breaching Party's written notice of material breach.

### 6.4. Insolvency

This Agreement may be immediately terminated by either Party in the event that the other Party ceases to operate or becomes insolvent or is declared bankrupt by a court of competent jurisdiction or becomes the subject of any reorganization (other than a corporate reorganization effected in the ordinary course of business and not arising out of any insolvency) or winding up, receivership or dissolution, bankruptcy or liquidation proceeding, or any proceeding or action similar to one or more of the above (each, an "**Event of Insolvency**") in which case termination will be effective upon written notice to the other Party. The failure of either Party to give notice of termination upon obtaining knowledge of any such Event of Insolvency will not be interpreted as a waiver of such Party's rights under this Section and such Party reserves the right to exercise any such rights at any time after the occurrence of any such Event of Insolvency.

# 6.5. Effects of Termination

Promptly following termination or expiry of this Agreement, the Parties will work together on a transition plan to terminate the Customer Agreements.

### 6.6. Survival

The following provisions will survive the expiration of the Term or the termination of this Agreement: Articles 4, 5, 6, and 7 and those other provisions that, by the nature of their terms, would apply after termination of this Agreement.

# 7. GENERAL PROVISIONS

### 7.1. No Waiver

The failure of either Party to insist upon strict performance of any of the terms and conditions of this Agreement will not be deemed a waiver of any rights or remedies that either Party has and will not be deemed a waiver of any subsequent default of the terms and conditions of this Agreement.

### 7.2. Assignment

Vaultt may assign this Agreement or the rights and obligations it creates without the prior written consent of CPFF. This Agreement will enure to the benefit of and be binding upon the Parties and their respective successors and permitted assigns.

# 7.3. Governing Law

This Agreement is governed and interpreted exclusively in accordance with the laws of the Province of Ontario and the laws of Canada applicable therein.

# 7.4. No Partnership or Ability to Bind

Nothing in this Agreement or in the relationship between the Parties will be construed, implied or deemed to create a partnership, joint venture, agency or employment relationship between the Parties. Except as expressly permitted herein, neither Party will have the authority to serve as agent for the other Party, to make any statement, representation or commitment of any kind on behalf of the other Party nor to take any action which may be binding on the other Party. Each Party is solely responsible for its employees, including terms of employment, wages, hours, required insurance, and daily direction and control.

### 7.5. Audit

Each Party will maintain complete and accurate records of all amounts billable to and payments made by Vaultt in respect of all Customer Agreements, in accordance with generally accepted accounting principles. Each Party will have the right at such Party's expense to appoint an auditor or auditors, who may or may not be employees of such Party, who will have access to the audited party's systems and activities during regular business hours during the Term and for a period of three (3) years following the termination or expiry of this Agreement, to the books, statements, accounts and records of the Provider relating to this Agreement. Such access will be for the sole purpose of assessing the audited Party's compliance with the provisions of this Agreement. Performance of any audit will not release the other Party from any of its obligations under this Agreement.

### 7.6. Amendment

Except as permitted by the other provisions of this Agreement, no provision of this Agreement may be changed, modified, or amended from time to time without the express written agreement of the Parties executed by their authorized representatives.

### 7.7. Counterparts

This Agreement may be executed in counterpart, each of which, when so executed, will be deemed to be an original copy hereof, and all such counterparts together will constitute but one single agreement. Either Party may deliver a counterpart signature page by facsimile or other means of electronic transmission.

### 7.8. Precedence in the Event of Conflict

If there is any conflict with or inconsistency between the provisions of the main body of this Agreement and the provisions of any Schedule attached hereto, then the provisions of the main body of this Agreement will take precedence over the provisions of any Schedule to the extent of such conflict.

### 7.9. Severability

If any provision of this Agreement is held to be unenforceable, then such provision will be deleted from this Agreement and the remaining provisions will continue in full force and effect. The Parties will in good faith negotiate a mutually acceptable and enforceable substitute for the unenforceable provision, which substitute will be as consistent as possible with the original intent of the Parties.

# 7.10. Entire Agreement

This Agreement constitutes the entire agreement between the Parties and supersedes all prior understandings and communications between the Parties, oral or written.

### [THE REMAINDER OF THIS PAGE IS LEFT BLANK INTENTIONALLY. SIGNATURE PAGE TO FOLLOW]

IN WITNESS WHEREOF each of the Parties has executed this Agreement to have effect as of the Effective Date.

### VAULTIT INC.

# CANADIAN PULMONARY FIBROSIS FOUNDATION

Per:	Per:
Name:	Name:
Title:	Title:

# **Schedule A: Pricing**

Solution pricing is as follows:

Vaultt will discount the full cost of the Solution to Community Members of CPFF. There will be no monthly charge to the CPFF Community.

Solution Licensing Fees:	
Monthly Subscription for non-members	\$5.99/month
Yearly Subscription for non-members	\$60/year
Subscription for CPFF Community members	\$0/year

Data pricing is as follows:

Data Fees:	
Data Revenue (per User or Tiered):	Market Price

### **Revenue Sharing:**

Subject to Article 3 of this Agreement, for each active Customer Agreement Vaultt will pay CPFF a dollar amount equivalent to the listed share in percent of the invoiced amounts to the Customer as listed in the table within:

Description	Paid By Customer	Vaultt Share in Percent	CPFF Share in percent
Data Revenue	100%	50%	50%

# Schedule B: Assignment of Roles & Duties

Task	Owner
Vaultt Platform Technology: Development & Maintenance, Data Storage, Data Security & Protection, Compliance	Vaultt
End User Onboarding (Phase 1 Pilot & Phase 2 Community)	Vaultt & CPFF
End User Support (technical and non-technical)	Vaultt
Marketing to CF Community	CPFF & Vaultt
Marketing to Potential Customers (Survey Data)	CPFF & Vaultt
Survey Creation	Vaultt
Survey Deployment	Vaultt
Sale of Data to Pharma, Research, Vendors etc.	CPFF & Vaultt
Customer Contract, Legal Agreement, Invoicing	Vaultt
Data Packaging & Delivery	Vaultt
Customer Support (technical & non-technical)	Vaultt