

Canadian Pulmonary Fibrosis Foundation Board Meeting February 3, 2023 Via ZOOM 3:30 pm to 5:00 pm EST

# **AGENDA**

#	Agenda Item	Time Allocated	Planned End Time
	Procedural/Consent Items		
1	Call to Order: K. Morrison	3:30 pm	3:31 pm
2	Introductions and Welcome Remarks: K. Morrison	3:31 pm	3:32 pm
3	Approval of Board Agenda and Call for Other Business: K. Morrison	3:32 pm	3:33 pm
4	Declarations of Conflict of Interest: K. Morrison	3:33 pm	3:35 pm
	Discussion and Action Items		
5	Minutes of January 13, 2023, Board Meeting: K. Morrison  • Motion to accept the minutes of November 13, 2023	3:35 pm	3:37 pm
6	CPFF Reports  CPFF Financials (December 2022): V. Pringle & S. Lee  Executive Director Report:  2022-2023 Activity Update  November Board Meeting Follow Up  Mission/Vision Statements  Procurement Policy  Banking Policy  Heather's Contract  Sharon's KPIS  MAB Review and Succession  June 16/17, 2023 Board Retreat (Virtual)  Mar 3, 2023 – Strategic Plan  Apr 14, 2023 - Changes to work plan  May 5, 2023 – Budget  CPFF & Vaultt Database Revenue Generation  Proposal  Letter of Intent  FAQ Vaultt	3:37 pm	4:55 pm

#	Agenda Item	Time Allocated	Planned End Time
	➤ CPFF Committee Reports:  Governance & Finance: T. Georgieff Advocacy & Support: M. Ashcroft, H. Smith & S. Lee  Pucker Up Challenge:  BI Canada  BI Global  BI South America  BI Japan  BI China  BI USA  Canadian Thoracic Society  April 20 – 22, 2023 in Montreal  JAMP Pharma meeting  April 19, 2023 in Montreal  Communications & Fundraising: T. Hunter & S. Lee  DIY fundraisers & funds raised: S. Lee  DIY fundraisers & funds raised: S. Lee  DIY fundraisers & funds raised: S. Lee  April 19, 2023 in Montreal  Communications & Fundraising: T. Hunter & S. Lee  O DIY fundraisers & funds raised: S. Lee  O DIY fundraisers & funds raised: S. Lee  Patient & Caregiver update  Healthcare professionals survey  Oxygen provide survey  Website Update: S. Lee  February – Rare Disease: S. Lee  Global Heroes – National Digital & Print Media in BC & ON  Pucker Up Challenge  Naming of the CPFF Mascot (formerly Bob the Blob) contest  2023 HBH: S. Lee  Events  1. Andre Moran-MacDonald, Half Ironman – July 30, 2023 – Calgary, BC  2. Clarke Walk – Sep 9, 2023 – Calgary, BB  3. Rob Garbutt - ? – Winnipeg, MN  4. Davidson Walk – ? – Markham, ON  5. Georgieff-Fenton/Khan Walk – Sep 23, 2023 – Montreal, QC		

#	Agenda Item	Time Allocated	Planned End Time
	6. Tom Hunter, June 25, 2023 – Half Ironman – Mont- Tremblant  • Greetings (Premiers & Healthcare Ministers)  • Lighting of Buildings across Canada  • Pucker Up Challenge  • Medical Advisory Board (MAB): C. Fell		
7	New Business  • In Camera Session (if needed)		
8	CPFF Board Meeting Dates for FY 22-23:  Friday February 3, 2023  Friday March 3, 2023  Friday April 14, 2023  Board Retreat: Friday June 16, & Saturday June 17, 2023	4:55 pm	4:58 pm
9	Adjournment	5:00 pm	



Board Minutes
Held via ZOOM
On Friday January 13, 2023
Commencing at 3:30 pm EST

Present: Kirk Morrison, Chair

Verity Pringle, Treasurer

Sharon Lee, Executive Director

Todd Georgieff, Vice and Governance & Finance Chair

Mark Ashcroft, Advocacy & Support Co-Chair

Nicole Hilliard Ranjena Maloni Derek Mastin Ray Protti

Guest(s): Dr. Charlene Fell

Regrets: Tom Hunter, Communications & Fundraising Chair

Dr. Holly Smith, Advocacy & Support Co-Chair

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 November 4-5 and December 19, 2022 Board Meetings

It was moved and seconded,

That the minutes of the November 4-5 and December 19, 2022 meetings be approved.

Carried.

#### **CPFF Financials**

V. Pringle presented the November 2022 financials and highlighted a \$209,000 deficit that is the result of the Robert Davidson Fellowships adjustment not yet having been made.

It was moved and seconded,

That the CPFF November financials be approved.

#### Carried.

# **Executive Director Report**

It was proposed that the 2023 Board Retreat dates be changed. It was suggested that the Board Retreat ought to take place from Thursday to Friday, rather than from Friday to Saturday.

R. Zapata and S. Lee will circulate a poll to determine the most optimal date for all Board members.

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

As the new Governance & Finance Chair, T. Georgieff will wait until after he chairs his first committee meeting before presenting a report.

Summary of the Election of the Board of Directors, Officers and Committee Chairs from the January 13, 2023 AGM.

- Acceptance of the Resignations of CPFF Director Dr. Gokul Vidyasankar and CPFF Director and Vice-Chair Moyra Martin. We express our deep gratitude for their contributions to CPFF and thank them for their commitment, passion and service to all those affected by Pulmonary Fibrosis.
- 2. CPFF approved Winston Fiander and Peter Kleinstiver as CPFF Directors in the fall 2022; However, CPFF lost these two members when Peter passed away suddenly and Winston resigned due to poor health. Their interest and desire to be involved will be remembered.
- 3. Confirmation of the following CPFF Directors
  - Kirk Morrison confirmed for the third year of a second 'three-year' term.
  - Verity Pringle confirmed for the third year of a first 'three-year' term.
  - Todd Georgieff confirmed for the first year of a second 'three-year' term.
  - Tom Hunter confirmed for the first year of a second' three-year 'term.
  - Ranjena Maloni confirmed for the third year of a second 'three-year 'term.
  - Holly Smith appointed for the second year of a 'three-year 'term.
  - Ray Protti appointed for the second year of a 'three-year' term.
  - Mark Ashcroft appointed for the second year of a 'three-year 'term.
- Election/Appointment of CPFF Directors
   A motion to appoint the following CPFF Directors to a three-year term as CPFF

# **CPFF Board Minutes of January 13, 2023**

#### **Board of Directors**

- Derek James appointed CPFF Director for the first year of a 'three-year' term.
- Nicole Hilliard appointed CPFF Director for the first year of a 'three-year' term.
- 5. A motion to appoint said officers of CPFF for the 2023/2024 year.
  - Chairperson Kirk Morrison
  - Vice-Chairperson Todd Georgieff
  - Treasurer Verity Pringle
- 6. Secretary Confirmation that Sharon Lee, Executive Director, CPFF (Ex-Officio) will continue as interim Secretary for the CPFF Board of Directors until a Director is appointed.
- 7. Confirmation of CPFF Committee Chairs
  - Communications and Fundraising Committee Tom Hunter
  - Support and Advocacy Committee Mark Ashcroft and Holly Smith
  - Governance and Finance Committee Todd Georgieff
  - Medical Advisory Board Dr. Charlene Fell
  - Medical Advisory Board Director Liaison Vacant

It was moved and seconded.

That the above motions be approved as presented.

#### Carried.

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

M. Ashcroft stated that while his committee is losing a member, two are being gained. This will help with achieving quorum, which has been an issue in the last few months.

The Board discussed the PMPRB. It was mentioned that the organization's chair stepped down on December 7, 2022, and that the organization's intention currently is to fund the cheapest drug possible despite the negative side effects that patients may experience.

It was argued that CPFF must advocate for an appeal mechanism in each province for physicians to recommend name drugs, instead of generic ones, in cases where patients would benefit from it. This option has already been implemented in Alberta.

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

S. Lee provided Communications & Fundraising updates in T. Hunter's absence.

The DIY Fundraising initiative is underway and there is currently 1 active DIY fundraiser, which has so far raised \$4,200.

# **CPFF Board Minutes of January 13, 2023**

The health professionals survey had 43 responses which were respirologists. This represents about 5% of the total respirology workforce in Canada. In turn, the oxygen providers survey had 29 responses in total.

- G. Vidyasankar will complete and provide the oxygen whitepaper by the end of the month of January.
- S. Lee renegotiated with Global Heroes in November to get full spread coverage in February instead of December, while still benefiting from partial coverage during December at no additional cost.

Some updates about the 2023 Hope Breathes Here event was provided:

- A. Moran-Macdonald will run a half triathlon in Calgary on July 30<sup>th</sup>.
- H. Davidson has yet to confirm a date for a walk in Markham.
- The Georgieff-Fenton walk in Montreal will take place either September 23<sup>rd</sup> or 24<sup>th</sup>, and efforts will be made to include the Khan family.
- The Clarke walk in Calgary will take place September 9<sup>th</sup>.
- Depending on the progression of the COVID virus, members of the MAB may be asked to participate in one of the events.

S. Lee has pitched Boehringer Ingelheim Global the idea of the worldwide promotion of the Pucker Up challenge in a contest that will determine how a leftover funding of £100,000 (about CAD\$163,000) will be used. BI is strongly considering it.

It was mentioned that 2023 may be a difficult year for fundraising due to inflation, interest rates and the war in Ukraine. It was suggested that this may be a good opportunity to look into diversifying pharma sponsors.

#### **MAB Report**

C. Fell pointed out that the MAB is at the end of its current 5-year cycle. In light of that, she has sent out a letter to current MAB members, asking whether they would be interested to renew their commitment for another cycle. To date, only 2 members have replied. Active recruitment will take place among community respirologists if she does not hear back from the remaining MAB members before the end of the month.

C. Fell furthermore requested permission from the Board to advertise two 1-year Robert Davidson fellowships of \$90,000 each starting next week. The fellowships would need to be awarded by the beginning of April, and therefore advertisement would need to begin ASAP.

The Board agrees that there's currently money secured for one fellowship, but not yet for a second one. However, it was also agreed that there's enough reserve cash to cover a second one if no funding is secured.

It was furthermore reminded that the Board had previously agreed to use the funding put aside for research grants (\$40,000), in the event that not enough funding is secured for fellowships. It was argued that this should be a last resort option, as research grants are not inconsequential. In any case, the Board agreed that two 1-year Robert Davidson fellowships should be awarded.

It was moved and seconded,

That two 1-year \$90,000 Robert Davidson fellowships be awarded during the 2023 calendar year.

# Carried.

# Adjournment

The meeting was adjourned at 4:41 pm EDT.

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

Certified correct,

# **SIGNATURE TO BE INCLUDED**

Kirk Morrison CPFF Board Chair

# Canadian Pulmonary Fibrosis Foundation Balance Sheet

As of December 31, 2022

			As o	Total of Dec. 31, 2021		
Assets	As of	F Dec. 31, 2022		(PY)		Change
Current Assets						
Cash and Cash Equivalent						
1021 Restricted Cash		130,000.00		130,000.00		0.00
1060 Chequing Bank Account		1,356,662.65		1,463,537.21		-106,874.56
1061 TD Investor Acct		15,258.96		15,128.19		130.77
1062 BMO High Interest Savings		509,449.89		452,018.10		57,431.79
Total Cash and Cash Equivalent		2,011,371.50	\$	2,060,683.50	-\$	49,312.00
1022 Internally Restricted Cash	Ψ	6,027.00	Ψ	6,027.00	-ψ	0.00
1310 Inventory of Items for Resale		1,749.67		1,749.67		0.00
1320 Prepaid Expenses		1,621.00		1,621.00		0.00
2318 PSB Rebate Receivable		26,900.89		12,834.37		14,066.52
Total Current Assets	<b>\$</b>	2,047,670.06	•	2,082,915.54	-\$	35,245.48
Non-current Assets	Φ	2,047,670.06	Ф	2,002,915.54	-φ	35,245.46
Property, plant and equipment						
		2,313.20		2,313.20		0.00
1820 Furniture and Equipment		-2,313.20 -2,313.20		-2,313.20		0.00
1825 Accum Depr - Furn and Equip		0.00	•		\$	
Total Non Courant Aposts	\$			0.00	•	0.00
Total Non Current Assets	\$	0.00		0.00	\$	0.00
Total Assets	\$	2,047,670.06	\$	2,082,915.54	-\$	35,245.48
Liabilities and Equity						
Liabilities						
Current Liabilities						
Accounts Payable (A/P)				040.05		244.00
2100 Accounts Payable		377.13		619.05		-241.92
Total Accounts Payable (A/P)	\$	377.13	\$	619.05	-\$	241.92
Credit Card						
1070 TD Visa 3392		1,961.40		5,856.45		-3,895.05
Total Credit Card	\$	1,961.40	\$	5,856.45	-\$	3,895.05
2000 Current Liabilities						0.00
2220 Vacation Payable		21,760.40		17,120.30		4,640.10
2315 GST/HST Paid on Purchases		-18,977.11		-3,907.85		-15,069.26
Total 2000 Current Liabilities	\$	2,783.29	\$	13,212.45	-\$	10,429.16
2225 Deferred Revenue		8,427.44		0.00		8,427.44
Due to TD Bank		270.00		270.00		0.00
Total Current Liabilities	\$	13,819.26	\$	19,957.95	-\$	6,138.69
Total Liabilities	\$	13,819.26	\$	19,957.95	-\$	6,138.69
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	1,222,497.68	561,032.24		661,465.44
Profit for the year	-168,751.80	521,820.43		-690,572.23
Total Equity	\$ 2,033,850.80 \$	2,062,957.59	-\$	29,106.79
Total Liabilities and Equity	\$ 2,047,670.06 \$	2,082,915.54	-\$	35,245.48

Tuesday, Jan. 24, 2023 08:31:37 p.m. GMT-8 - Accrual Basis

#### CPFF Fiscal July 31, 2023 August 2022 YTD

August 2022 YID			5.00		100%	14%	16.00%	24%	23%	23%	
	July 2022 ACTUAL	2023 budget	YTD BUDGET	VARIANCE	2023 Actual	Admin	Advocay	Education Awairness	Patient Support	Research	
Foundation Grants	882,667	475,000	197,917	(2,427)	195,490	195,490					BI (150,000 + \$90,000) & Roche (45,000 + \$90,000)? & Other Pharma?
Donation and fundraising	332,695	160,000	66,667	126,595	193,261	193,261					General corporate & individual donations
Regional Donations			-			-					
Interst income	18,566		-	100	100	100					
Miscellaneous Income	126					-					
Deferred Revenue						-	-	-	=	-	This amount was accounting entry by the auditors to defer the revenue
	1,234,055	635,000	264,583	124,268	388,851	388,851	-	-	-	-	
1 Grants to charities	80,000	180,000	75,000	(75,000)		-	-	-	-	-	2 Robert Davidson Fellowships funded by BI & Roche restricted
	-	40,000	16,667	198,087	214,753.46	30,065	34,361	51,541	49,393	49,393	Optional 2 Research Grant funded by CPFF
2 Salaries & benefits	97,274	125,000	52,083	(6,085)	45,998	6,440	7,360	11,040	10,580	10,580	ED salary, bonus - CPP, EI, Vacation, Benefits
	64,650	53,000	22,083	6,594	28,677	4,015	4,588	6,883	6,596	6,596	Support staff salary, CPP, EI, benefits
3 Patient support	11,223	500	208	180	388	54	62	93	89	89	Patient Forums, National Summit, Webinars, Regional Committees, etc.
		5,000	2,083	(2,083)		-	-	=	-	=	September PF for full month
		25,000	10,417	(10,417)		-	-	=	-	-	Update paient guidbook, support 21 grps, webinars
		27,000	11,250	(11,250)		-	-	÷.	-	-	\$2K each for 21 support groups
		17,500	7,292	(7,292)		-	-	-	-	-	Additional reserves for new groups and giveaways
4 Communications/Support website costs	342	200,000	83,333	(83,333)		-	-	-	-	-	Web hosting, maintenance, ZOOM, MailChimp, GR, Patient Stories videos, etc.
5 Awareness and advocacy	42,639	10,000	4,167	2,318	6,485	908	1,038	1,556	1,491	1,491	Webinars
		10,000				-	-	-	-	-	
		100,000				-	-	-	-	-	
		20,000				-	-	-	=	-	
6 Fundraising events costs		75,000	31,250	(31,208)	41.92	- 6	- 7	10	10	10	Give aways such as silicon bracelets, baseball caps, mugs, T-shirts
g		75,000	-	(52,200)	12.52	-	- 1	-	-	-	Set up & volunteer costs for Sept Celebrations, Forever Lungs, Clarke Walk, CanadaHelps, PayPal, Benevity, etc.
			-	_		_	_	-	_	_	Advertising in Canadian Donors guide to target potential bequesths
7 Program education and consulting	184,398		_	222,215	222,215	31,110	35,554	53,332	51,109	51,109	
7 Trogram cadeation and consulting	10 1,550		_	222,223	222,223	-	-	-	51,105	-	Media training for the board members and 21 support groups
			_	_	_	_	_	_	_	_	Additional reserves for other opportunities
	480,528	888,000	315,833	202,726	518,559	72,598	82,969	124,454	119,269	119,269	· · · · · · · · · · · · · · · · · · ·
8 Professional fees	16,950	51,000	21,250	(13,798)	7,452	1,043	1,192	1,789	1,714	1,714	
9 office and general	64,433	5,300	2,208	15,265	17,474	2,446	2,796	4,194	4,019	4,019	
10 Travel and meeting costs	36	4,000	1,667	7,565	9,231	1,292	1,477	2,215	2,123	2,123	
11 Telephone/Internet	7,225	6,700	2,792	2,367	5,159	722	825	1,238	1,187	1,187	
12 Insurance	3,813	4,000	1,667	(1,667)		-	-	-	-	-	Director's Liability, General Liability (events, patient groups, contract staff, etc.)
13 Interest and bank charges	1,462		-	(272)		38	- 44	- 65	- 63 -	63	
	93,920	71,000	29,583	9,461	39,044	5,466	6,247	9,371	8,980	8,980	
	659,607	-324,000	-80.833	(87,918)	- 168,752	310,787	-89.216	-133.825	-128,249	-128,249	
	033,007	-324,000	-00,033	(07,918)	- 100,732	310,767	-03,210	-133,023	-120,243	-120,243	

Notes: Note 1

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

Note 2 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 Profit and Loss by Class

August - December, 2022

				Total		
	Aug	- Dec., 2022	Aug	- Dec., 2021 (PY)		Change
INCOME						
4000 Revenue						0.00
4010 Contributions						0.00
4020 Receipted Donations		46,033.33		16,417.03		29,616.30
4026 Receipted Donations- Clark Run				3,300.00		-3,300.00
4027 Rcptd Donations - September Awareness Walks		55,526.25				55,526.25
4030 Donations from Other Charities		1,890.00		285.31		1,604.69
4300 Donations Through Paypal		6,513.00		13,722.00		-7,209.00
4301 Donations Through Canada Helps		73,994.99		102,273.25		-28,278.26
4302 Donations Through CAF Canada		112.00		210.00		-98.00
4303 Donations Through CDN Online Giving		3,526.43		3,626.19		-99.76
4304 Donations Through My Tribute Gift		5,241.25		4,335.00		906.25
4305 Donations Through United Way		423.95		557.18		-133.23
Total 4010 Contributions	\$	193,261.20	\$	144,725.96	\$	48,535.24
4190 Grants Received		195,490.00		540,667.00		-345,177.00
4440 Interest Income		99.73		12.69		87.04
Total 4000 Revenue	\$	388,850.93	\$	685,405.65	-\$	296,554.72
Total Income	\$	388,850.93	\$	685,405.65	-\$	296,554.72
COST OF GOODS SOLD						
5000 Cost of Goods Sold						0.00
5190 Grants Made		210,000.00		20,000.00		190,000.00
5252 Clarke Family run - Expenses		2,753.46				2,753.46
5320 Sponsorship Costs		2,000.00				2,000.00
Total 5000 Cost of Goods Sold	\$	214,753.46	\$	20,000.00	\$	194,753.46
Total Cost of Goods Sold	\$	214,753.46	\$	20,000.00	\$	194,753.46
GROSS PROFIT	\$	174,097.47	\$	665,405.65	-\$	491,308.18

0.00

02. Salaries & Benefits

5410 Wages & Salaries				0.00
5411 Executive Director Salary	38,431.34	33,290.18		5,141.16
5414 Project Coorindator	23,319.98	23,728.25		-408.27
Total 5410 Wages & Salaries	\$ 61,751.32	\$ 57,018.43	\$	4,732.89
5420 El Expense	787.94	315.62		472.32
5430 CPP Expense	2,033.99	726.33		1,307.66
5460 Vacation Accrual	5,749.44	2,684.54		3,064.90
5461 Payroll Admin Expense	401.97	405.82		-3.85
5470 Employee Benefits - Sharon	3,080.23	2,782.50		297.73
5471 Employee Benefits - Roberto	870.70			870.70
Total 02. Salaries & Benefits	\$ 74,675.59	\$ 63,933.24	\$	10,742.35
03. Patient Support	388.16	5,132.61		-4,744.45
5321 Support Group Expenses	0.00	1,000.48		-1,000.48
Total 03. Patient Support	\$ 388.16	\$ 6,133.09	-\$	5,744.93
05. Awareness & Advocacy				0.00
5327 Newsletter Expense	1,439.83	4,896.69		-3,456.86
5530 Awareness & Advocacy	3,273.40	751.54		2,521.86
5615 Advertising and Promotion	1,771.39			1,771.39
Total 05. Awareness & Advocacy	\$ 6,484.62	\$ 5,648.23	\$	836.39
06. Fundraising Events Costs	41.92			41.92
07. Program Education & Consulting				0.00
5511 Patient Education	221,118.19	27,657.60		193,460.59
5515 Consulting	 1,096.92			1,096.92
Total 07. Program Education & Consulting	\$ 222,215.11	\$ 27,657.60	\$	194,557.51
08. Professional Fees				0.00
5610 Accounting & Legal	1,557.08	9,832.68		-8,275.60
5695 Professional Fees	597.64	597.64		0.00
5696 Bookkeeping	4,417.45			4,417.45
5705 Membership fees, dues, subscrip	 880.27	281.38		598.89
Total 08. Professional Fees	\$ 7,452.44	\$ 10,711.70	-\$	3,259.26
09. General & Administrative				0.00
5500 General Administrative Expenses	7,986.09	11,632.74		-3,646.65
5520 Education	326.06			326.06
5525 Conferences	0.00	56.51		-56.51

5571 Website Hosting		226.20			226.20
5640 Courier & Postage		362.99	817.45		-454.46
5650 Staff Equipement - computers		179.35			179.35
5686 Governance		5,366.51	5,197.00		169.51
5700 Office Supplies		666.26	1,234.52		-568.26
5770 Storage		1,533.00	1,521.90		11.10
5890 Credit Card fees		169.72	175.78		-6.06
5891 Other Commissions		54.23	372.13		-317.90
5895 Canada Helps fees		605.88	4,049.39		-3,443.51
5896 PayPal fees		-2.50	601.82		-604.32
Total 09. General & Administrative	\$	17,473.79	\$ 25,659.24	-\$	8,185.45
10. Travel & Meeting Costs		865.21			865.21
5784 Travel		8,365.96	10.44		8,355.52
Total 10. Travel & Meeting Costs	\$	9,231.17	\$ 10.44	\$	9,220.73
11. Telephone/Internet					0.00
5780 Telephone Expense		1,011.81	563.63		448.18
5781 Internet		4,146.92	3,005.54		1,141.38
Total 11. Telephone/Internet	\$	5,158.73	\$ 3,569.17	\$	1,589.56
13. Bank and Interest Charges					0.00
5690 Bank Service Charges		-272.26	262.51		-534.77
Total 13. Bank and Interest Charges	-\$	272.26	\$ 262.51	-\$	534.77
Total Expenses	\$	342,849.27	\$ 143,585.22	\$	199,264.05
PROFIT	-\$	168,751.80	\$ 521,820.43	-\$	690,572.23

# Canadian Pulmonary Fibrosis Foundation Profit and Loss by Class

December 2022

	Adr	min/Fund- 14%	A	dvocacy- 16%	Ed	& Aware 24%	Patient & Care-23%	R	esearch- 23%	TOTAL
INCOME										
4000 Revenue										0.00
4010 Contributions										0.00
4020 Receipted Donations		23,665.00								23,665.00
4300 Donations Through Paypal		280.00								280.00
4301 Donations Through Canada Helps		21,617.72								21,617.72
4302 Donations Through CAF Canada		36.00								36.00
4303 Donations Through CDN Online Giving		811.42								811.42
4304 Donations Through My Tribute Gift		50.00								50.00
4305 Donations Through United Way		58.82								58.82
Total 4010 Contributions	\$	46,518.96	\$	0.00	\$	0.00	\$ 0.00	\$	0.00	\$ 46,518.96
4190 Grants Received		58,540.00								58,540.00
4440 Interest Income		24.75								24.75
Total 4000 Revenue	\$	105,083.71	\$	0.00	\$	0.00	\$ 0.00	\$	0.00	\$ 105,083.71
Total Income	\$	105,083.71	\$	0.00	\$	0.00	\$ 0.00	\$	0.00	\$ 105,083.71
GROSS PROFIT	\$	105,083.71	\$	0.00	\$	0.00	\$ 0.00	\$	0.00	\$ 105,083.71
EXPENSES										
02. Salaries & Benefits										0.00
5410 Wages & Salaries										0.00
5411 Executive Director Salary		978.25		1,118.00		1,677.00	1,607.13		1,607.13	6,987.51
5414 Project Coorindator		593.60		678.40		1,017.60	975.20		975.20	4,240.00
Total 5410 Wages & Salaries	\$	1,571.85	\$	1,796.40	\$	2,694.60	\$ 2,582.33	\$	2,582.33	\$ 11,227.51
5420 EI Expense		13.13		15.01		22.51	21.57		21.57	93.79
5430 CPP Expense		31.69		36.21		54.32	52.06		52.06	226.34
5460 Vacation Accrual		131.78		150.60		225.91	216.49		216.49	941.27
5461 Payroll Admin Expense		10.18		11.64		17.46	16.73		16.73	72.74
5470 Employee Benefits - Sharon		69.54		79.48		119.22	114.25		114.25	496.74
5471 Employee Benefits - Roberto		40.63		46.44		69.66	66.75		66.75	290.23

Total 02. Salaries & Benefits	\$ 1,868.80	\$ 2,135.78	\$ 3,203.68	\$ 3,070.18	\$ 3,070.18	\$ 13,348.62
03. Patient Support	5.90	6.74	10.11	9.69	9.69	42.13
05. Awareness & Advocacy						0.00
5327 Newsletter Expense	78.72	89.97	134.96	129.33	129.33	562.31
5530 Awareness & Advocacy	302.18	345.35	518.03	496.44	496.44	2,158.44
5615 Advertising and Promotion	96.61	110.39	165.60	158.71	158.71	690.02
Total 05. Awareness & Advocacy	\$ 477.51	\$ 545.71	\$ 818.59	\$ 784.48	\$ 784.48	\$ 3,410.77
07. Program Education & Consulting						0.00
5511 Patient Education	6,026.89	6,887.88	10,331.82	9,901.32	9,901.32	43,049.23
5515 Consulting	35.00	40.00	60.00	57.50	57.50	250.00
Total 07. Program Education & Consulting	\$ 6,061.89	\$ 6,927.88	\$ 10,391.82	\$ 9,958.82	\$ 9,958.82	\$ 43,299.23
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	97.42	111.34	167.01	160.05	160.05	695.87
5640 Courier & Postage	16.19	18.50	27.75	26.59	26.59	115.62
5650 Staff Equipement - computers	25.11	28.70	43.04	41.25	41.25	179.35
5700 Office Supplies	26.94	30.79	46.18	44.25	44.25	192.41
5770 Storage	44.09	50.39	75.57	72.43	72.43	314.91
5890 Credit Card fees	6.27	7.17	10.76	10.31	10.31	44.82
5891 Other Commissions	2.35	2.69	4.03	3.87	3.87	16.81
5895 Canada Helps fees	57.85	66.12	99.17	95.04	95.04	413.22
5896 PayPal fees	0.42	0.48	0.72	0.69	0.69	3.00
Total 09. General & Administrative	\$ 276.64	\$ 316.18	\$ 474.23	\$ 454.48	\$ 454.48	\$ 1,976.01
10. Travel & Meeting Costs	10.50	12.00	18.00	17.25	17.25	75.00
5784 Travel	85.25	97.43	146.14	140.05	140.05	608.92
Total 10. Travel & Meeting Costs	\$ 95.75	\$ 109.43	\$ 164.14	\$ 157.30	\$ 157.30	\$ 683.92
11. Telephone/Internet						0.00
5780 Telephone Expense	13.54	15.47	23.21	22.24	22.24	96.70
5781 Internet	22.45	25.66	38.48	36.88	36.88	160.35
Total 11. Telephone/Internet	\$ 35.99	\$ 41.13	\$ 61.69	\$ 59.12	\$ 59.12	\$ 257.05
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
Total Expenses
PROFIT

\$ 7.00	\$	8.00	\$	12.00	\$	11.50	\$	11.50	\$ 50.00
\$ 8,953.17	\$	10,232.21	\$	15,348.30	\$	14,708.77	\$	14,708.77	\$ 63,951.22
\$ 96,130.54	-\$	10,232.21	-\$	15,348.30	-\$	14,708.77	-\$	14,708.77	\$ 41,132.49

Tuesday, Jan. 24, 2023 08:35:35 p.m. GMT-8 - Accrual Basis

# Canadian Pulmonary Fibrosis Foundation Profit and Loss by Class

August - December, 2022

	Admin/Fund- 14%	Ac	dvocacy- 16%	Ed	& Aware 24%	Pat	ient & Care- 23%	Res	earch-23%	TOTAL
INCOME										
4000 Revenue										0.00
4010 Contributions										0.00
4020 Receipted Donations	46,033.33									46,033.33
4027 Rcptd Donations - September Awareness Walks	55,526.25									55,526.25
4030 Donations from Other Charities	1,890.00									1,890.00
4300 Donations Through Paypal	6,513.00									6,513.00
4301 Donations Through Canada Helps	73,994.99									73,994.99
4302 Donations Through CAF Canada	112.00									112.00
4303 Donations Through CDN Online Giving	3,526.43									3,526.43
4304 Donations Through My Tribute Gift	5,241.25									5,241.25
4305 Donations Through United Way	423.95									423.95
Total 4010 Contributions	\$ 193,261.20	\$	0.00	\$	0.00	\$	0.00	\$	0.00	\$ 193,261.20
4190 Grants Received	195,490.00									195,490.00
4440 Interest Income	99.73									99.73
Total 4000 Revenue	\$ 388,850.93	\$	0.00	\$	0.00	\$	0.00	\$	0.00	\$ 388,850.93
Total Income	\$ 388,850.93	\$	0.00	\$	0.00	\$	0.00	\$	0.00	\$ 388,850.93
COST OF GOODS SOLD										
5000 Cost of Goods Sold										0.00
5190 Grants Made	29,400.00		33,600.00		50,400.00		48,300.00		48,300.00	210,000.00
5252 Clarke Family run - Expenses	385.48		440.55		660.83		633.30		633.30	2,753.46
5320 Sponsorship Costs	280.00		320.00		480.00		460.00		460.00	2,000.00
Total 5000 Cost of Goods Sold	\$ 30,065.48	\$	34,360.55	\$	51,540.83	\$	49,393.30	\$	49,393.30	\$ 214,753.46
Total Cost of Goods Sold	\$ 30,065.48	\$	34,360.55	\$	51,540.83	\$	49,393.30	\$	49,393.30	\$ 214,753.46
GROSS PROFIT	\$ 358,785.45	-\$	34,360.55	-\$	51,540.83	-\$	49,393.30	-\$	49,393.30	\$ 174,097.47
EXPENSES										
02. Salaries & Benefits										0.00
5410 Wages & Salaries										0.00

5411 Executive Director Salary	5,380.41	6,149.00	9,223.51	8,839.21	8,839.21	38,431.34
5414 Project Coorindator	3,264.80	3,731.20	5,596.80	5,363.59	5,363.59	23,319.98
Total 5410 Wages & Salaries	\$ 8,645.21	\$ 9,880.20	\$ 14,820.31	\$ 14,202.80	\$ 14,202.80	\$ 61,751.32
5420 El Expense	110.30	126.07	189.11	181.23	181.23	787.94
5430 CPP Expense	284.77	325.44	488.16	467.81	467.81	2,033.99
5460 Vacation Accrual	804.93	919.90	1,379.87	1,322.37	1,322.37	5,749.44
5461 Payroll Admin Expense	56.25	64.32	96.48	92.46	92.46	401.97
5470 Employee Benefits - Sharon	431.23	492.84	739.26	708.45	708.45	3,080.23
5471 Employee Benefits - Roberto	121.90	139.32	208.98	200.25	200.25	870.70
Total 02. Salaries & Benefits	\$ 10,454.59	\$ 11,948.09	\$ 17,922.17	\$ 17,175.37	\$ 17,175.37	\$ 74,675.59
03. Patient Support	54.37	62.10	93.15	89.27	89.27	388.16
05. Awareness & Advocacy						0.00
5327 Newsletter Expense	201.58	230.38	345.55	331.16	331.16	1,439.83
5530 Awareness & Advocacy	458.28	523.74	785.62	752.88	752.88	3,273.40
5615 Advertising and Promotion	248.00	283.41	425.12	407.43	407.43	1,771.39
Total 05. Awareness & Advocacy	\$ 907.86	\$ 1,037.53	\$ 1,556.29	\$ 1,491.47	\$ 1,491.47	\$ 6,484.62
06. Fundraising Events Costs	5.87	6.71	10.06	9.64	9.64	41.92
07. Program Education & Consulting						0.00
5511 Patient Education	30,956.55	35,378.91	53,068.37	50,857.18	50,857.18	221,118.19
5515 Consulting	153.57	175.51	263.26	252.29	252.29	1,096.92
Total 07. Program Education & Consulting	\$ 31,110.12	\$ 35,554.42	\$ 53,331.63	\$ 51,109.47	\$ 51,109.47	\$ 222,215.11
08. Professional Fees						0.00
5610 Accounting & Legal	217.99	249.13	373.70	358.13	358.13	1,557.08
5695 Professional Fees	83.67	95.62	143.43	137.46	137.46	597.64
5696 Bookkeeping	618.45	706.80	1,060.20	1,016.00	1,016.00	4,417.45
5705 Membership fees, dues, subscrip	123.25	140.84	211.26	202.46	202.46	880.27
Total 08. Professional Fees	\$ 1,043.36	\$ 1,192.39	\$ 1,788.59	\$ 1,714.05	\$ 1,714.05	\$ 7,452.44
09. General & Administrative						0.00
5500 General Administrative Expenses	1,118.05	1,277.78	1,916.64	1,836.81	1,836.81	7,986.09
5520 Education	45.64	52.17	78.27	74.99	74.99	326.06
5571 Website Hosting	31.65	36.20	54.29	52.03	52.03	226.20
5640 Courier & Postage	50.81	58.08	87.12	83.49	83.49	362.99
5650 Staff Equipement - computers	25.11	28.70	43.04	41.25	41.25	179.35
5686 Governance	751.31	858.64	1,287.96	1,234.30	1,234.30	5,366.51

5700 Office Supplies		93.27		106.60		159.91		153.24		153.24		666.26
5770 Storage		214.63		245.29		367.90		352.59		352.59		1,533.00
5890 Credit Card fees		23.75		27.15		40.74		39.04		39.04		169.72
5891 Other Commissions		7.59		8.67		13.01		12.48		12.48		54.23
5895 Canada Helps fees		84.82		96.95		145.41		139.35		139.35		605.88
5896 PayPal fees		-0.36		-0.40		-0.60		-0.57		-0.57		-2.50
Total 09. General & Administrative	\$	2,446.27	\$	2,795.83	\$	4,193.69	\$	4,019.00	\$	4,019.00	\$	17,473.79
10. Travel & Meeting Costs		259.31		112.73		169.09		162.04		162.04		865.21
5784 Travel		1,033.04		1,364.26		2,046.40		1,961.13		1,961.13		8,365.96
Total 10. Travel & Meeting Costs	\$	1,292.35	\$	1,476.99	\$	2,215.49	\$	2,123.17	\$	2,123.17	\$	9,231.17
11. Telephone/Internet												0.00
5780 Telephone Expense		141.65		161.88		242.84		232.72		232.72		1,011.81
5781 Internet		580.59		663.50		995.25		953.79		953.79		4,146.92
Total 11. Telephone/Internet	\$	722.24	\$	825.38	\$	1,238.09	\$	1,186.51	\$	1,186.51	\$	5,158.73
13. Bank and Interest Charges												0.00
5690 Bank Service Charges		-38.12		-43.56		-65.34		-62.62		-62.62		-272.26
Total 13. Bank and Interest Charges	-\$	38.12	-\$	43.56	-\$	65.34	-\$	62.62	-\$	62.62	-\$	272.26
Total Expenses	\$	47,998.91	\$	54,855.88	\$	82,283.82	\$	78,855.33	\$	78,855.33	\$	342,849.27
PROFIT	\$ 3	10,786.54	-\$	89,216.43	-\$	133,824.65	-\$	128,248.63	-\$	128,248.63	-\$	168,751.80



#### Introduction

# **Project Overview**

The global COVID19 pandemic, Ukraine war, and Inflation has impacted on all our lives, in particular the revenue streams in supporting the programs and services of CPFF. While we have adapted to using social media and specific campaigns (i.e.: September PF awareness, 21 Days of Gratitude and DIY events), CPFF still needs to concentrate on diversifying our revenues. We are reliant donations from individuals, corporate and pharma to sustain our organization.

Through our partnership with Vaultt, CPFF will receive revenues from the sale of deidentified survey responses from our Pulmonary Fibrosis community.

# **Project Objectives**

The primary objective of this project is to ensure that CPFF has revenues flowing into our coffers to operate our programs, services and administration.

CPFF will receive 25% of revenue generated from the sale of de-identified data which is the industry standard. It is projected that the survey data analytics from a minimum of 500 patients over a set period of time, could generate on average \$150,000 worth of revenue.

IPF/PF patients and caregivers benefit from this project with a free subscription to the Vaultt platform through the CPFF app. This allows them to keep track of their medical records, appointments, and anything they wish to keep track of. This is a savings of \$720 plus HST annually to the patient.

# **Intellectual Property**

Vaultt will retain the ownership of all intellectual property rights in the Platform and will cover all expenses of creating reports, maintenance and improvements/expansions at no cost to CPFF. All data is stored in Canada and follows government guidelines.

# **Ownership of Data**

The private data stored in the Vaultt platform is owned by the IPF/PF patient in perpetuity. Vaultt is the host provider of survey data that is collected, used to



create reports from data disclosed with expressed consent from the owner. Deidentified survey results will be organized, securely stored and protected by Vaultt and be given to CPFF. IPF/PF patients can opt out anytime and have their information deleted and destroyed.

# Alignment to CPFF's Four Pillars

- Patients & Caregivers
- Educate & Awareness
- Research
- Advocacy

This project will support CPFF's four pillars and allow us to add revenues to the Innovation/Future fund in providing programs, service and administration support of the PF community.

# **Budget Considerations**

This project has no expenses associated with it. It is entirely carried funded by Vaultt, with revenues sharing agreement between Vaultt and CPFF. For the initial budget, CPFF will only receive 25% of the revenue generated, which will increase to 50% for the next phase of the partnership.

#### **Success Criteria**

Specific criteria which will be used to measure success will include:

- Increase of engagement activities on:
  - o CPFF app
  - Facebook
  - o Twitter
  - o YouTube
  - Instagram
  - o Website
  - Newsletter
- Increase awareness and benefits to the patient and their caregivers, as the Vaultt app allows them to keep track of their medical records, appointments, wills and end of life wishes plus many other options that they will be able to use.
- To successfully engage our CPFF patients and caregivers in using the Vaultt application within the CPFF app.



- To increase patient/caregiver signup of the CPFF app
- To raise \$150,000 within the next 18 months which CPFF will receive 25% of the revenues
- To increase CPFF's percentage to 50% after the initial partnership phase, as we realize the value of the data collected when sold to government, researchers, universities, corporates and anyone who would be a potential client

# **Scope of Work**

#### **Tasks**

Specific tasks to be completed in the project include:

- Vaultt Platform: to be integrated into the CPFF app by March 31, 2023
- **Testing**: for volunteer patients and caregivers test the platform from April 1<sup>st</sup> to 30<sup>th</sup>, 2023. Ensuring that all kinks are worked out.
- Agreement: Vaultt and CPFF will have signed a legal agreement which has been reviewed by our lawyers and Board Directors by June 15, 2023.
- Campaign Launch: CPFF will have our marketing materials reviewed and vetted by the Communications & Fundraising committee by July 31, 2023. The campaign will launch on August 15, 2023 for a full push in September during PF awareness month. There is no cost to CPFF or the participants.
- Monitoring: Vaultt and CPFF will monitor how many IPF/PF patients and caregivers sign up for the platform from August 15, 2023 to December 31, 2023.
   Our goal is to have 500 patients/caregivers sign up.
- De-identified reports: CPFF and Vaultt will identify data that is need by government, universities, researchers and any other organizations that would interest in purchasing the de-identified reports.

# **Project Team**

The project will be managed by the Executive Director with the Founder of Vaultt.

- Each organization will share data collected from social media, activities within the CPFF app and Vaultt platform to make improvements to the platform and new innovations that is needed by the IPF/PF community.
- It is recommended that CPFF to sign the Letter of Intention (LOI), which has been reviewed by the ED with Carters. They see no liabilities in signing the LOI



- The Communications & Fundraising committee will review the campaign rolling out this project to our IPF/PF community
- CPFF will work with Vaultt in ensuring a smooth integration with our App and their platform.

# **Project Financials**

There are no expenses associated with this project. It's all covered by Vaultt. They have secured funding of this project for the next 24 months.

- To raise a minimum of \$150,000, we will need the participation of 500 IPF/PF patients and caregivers
  - o CPFF app currently has 364 users
  - o CPFF currently has 4,139 followers on Facebook
  - o CPFF currently has 5,000 newsletter subscribers

# Summary

It's the Executive Director's recommended that CPFF moves forward with the partnership with Vaultt. They are the only patient focus tech company to provide this service due to Audrey Bond's experience in managing her parents' chronic illnesses. Vaultt has secured financing for this project to create the platform if CPFF agrees to the partnership. The initial revenue of 25% to CPFF is industry standard for no cash injection into the project. This will increase to 50% after the initial success of the project.



# Vaultt / CPFF Partnership

# STRICTLY PRIVATE AND CONFIDENTIAL

January 24, 2023

Sharon Lee Canadian Pulmonary Fibrosis Foundation 47 Squire Baker's Lane Markham, Ontario L3P 3G8

Re: Proposed partnership between **Vaultt** and the Canadian Pulmonary Fibrosis Foundation (**CPFF**).

Dear Sharon,

Pursuant to our recent discussions and based on information provided to date, Vaultt is pleased to provide you with this letter of intent (the "<u>Letter of Intent</u>") to enter into an agreement between Vaultt and CPFF in the proposed Vaultt CPFF Partnership. It is in the spirit of mutual collaboration, growth and learning that we enter this alliance.

This Letter of Intent reflects only a summary of certain proposed terms. It does not constitute a formal offer and is not intended to create a binding commitment on both parties and no such agreement shall exist until a Definitive Agreement has been executed by the parties.

# **Purpose**

Through the partnership, revenue from the sale of de-identified survey responses from the The Pulmonary Fibrosis Community will help financially support the Canadian Pulmonary Fibrosis Foundation, for projects as identified by them.

#### **Details**

- Through the CPFF, complimentary Vaultt subscriptions will be provided to the community through a custom link which will identify users as being part of The Pulmonary Fibrosis Community.
- The CPFF and Vaultt will together create a set of survey questions that, once answered by members, will provide valuable data sets for researchers and providers.
- Surveys will be sent within the Platform to members for a set period of time.
- Vaultt will collect, de-identify and package survey data.
- Vaultt and the CPFF will work together to present the survey data sets to prospective buyers such as research groups, government, insurance and Pharma.
- Vaultt will complete the sales transaction and provide data sets to customers
- The revenue resulting from The Pulmonary Fibrosis Community and invitees who sign on as a result of the Association's actions will be shared between both the CPFF and Vaultt. These individuals will be identified by using the CPFF specific link. Any data and



revenue from independent subscribers outside of this arrangement would be excluded from this.

# **Revenue Share**

The CPFF will receive commission from the revenue of the sale of the member's data using industry standard metrics, 25% of revenue generated will be paid to the CPFF. After 18 months, we will review the partnership, level of effort on both parties and revise the agreement with an intention to increase the percentage for the CPFF if warranted.

It is projected that the survey data analytics from a minimum of 500 patients over a set period of time, could generate on average \$150,000 worth of shared revenue. This is an assumption from team members who are subject matter experts. This assumption in no way guarantees this amount of revenue. Revenue could be lower or higher than assumed and will be based on survey participation and value to the buyer.

# **Intellectual Property**

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

# Ownership of Data

The private data stored in the Vaultt platform is owned by the Pulmonary Fibrosis individual community members themselves in perpetuity. Vaultt is the host provider of data and may collect, use, and disclose data only with expressed consent from the owner. De-identified survey results will be organized, securely stored, and protected by Vaultt.

# Maintenance, Support, and Operations

Vaultt is responsible for the support, maintenance and operation of all systems of the Platform, including without limitation those required to host the Platform.

# **Platform Technology**

Vaultt will perform continuous improvements to the Platform to increase its value over time and keep up with technological and market advances at no additional cost to CPFF or Customers. In collaboration with CPFF, Vaultt will build useful features based on direct user feedback to increase value to CPFF members.

#### 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.

# **Notification and Dialogue**

The Parties agree to notify and inform each other through open dialogue in a timely manner as required to foster this relationship.

#### **Termination**



This Letter of Intent will terminate automatically upon the execution of the Definitive Agreement, and may be terminated in writing by either Parties.

This Letter of Intent reflects accurately the understanding and agreement of each of the undersigned with respect to the matters set out above and the terms and conditions herein described are hereby accepted.

To confirm the foregoing, please sign this Letter of Intent where indicated below. If a hard or digitally signed copy of this Letter of Intent is not received prior to 5:00 pm (Eastern Daylight Time) on **Friday January 27th**, **2023**, the proposal set forth herein will expire automatically at such time.

We look forward to working with you on the Proposed Partnership.

Yours very truly,

This Letter of Intent reflects accurately the understanding and agreement of the undersigned with respect to the matters set out above.

Confirmed this 27th day of	January	, 2023
VAULTT		
Per:		
DocuSigned by:		

**Audrey Bond Chief Executive Officer** 

Audrey Bond

# CANADIAN PULMONARY FIBROSIS FOUNDATION

Per:	
Sharon Lee Executive Director	



# Vaultt / CPFF Partnership

# **FAQ**

#### What is Vaultt

Vaultt operates an information management and communication mobile application platform built in collaboration with caregivers and patients for caregivers and patients. The CEO of Vaultt, Audrey Bond, created the mobile application platform as she was caregiving for her elderly disabled parents and was looking for a secure solution to help manage the care journey, but none existed.

Vaultt empowers families and patients through the ability to own, organize and easily share vital information. Vaultt's suite of helpful tools empowers patients and caregivers dealing with chronic health issues. The fully encrypted platform was built with privacy at the forefront - keeping user's personal information safe while enabling sharing and collaboration. Vaultt partners with care providers who are looking to elevate the patient experience and improve patient outcomes.

# How did Vaultt and the CPFF first connect?

In 2021, Vaultt consulted with the CPFF patient community and others from the PF community on the enhancement of the platform to support the Pulmonary Fibrosis community at large. After listening to the needs of the patients, Vaultt added such features as My Health Summary<sup>TM</sup>, an emergency checklist, notes for doctors, oxygen logs and enhanced symptom tracking.

# What is the purpose of the CPFF/Vaultt partnership?

During a recent call between the CPFF and Vaultt, it was discussed that patients across Canada are struggling to afford oxygen and other disease related needs. Research groups and Pharma need real-world, patient and caregiver-generated data, however in the past, patients have not been compensated for providing this data. The CPFF lacks the technology to collect health data in a compliant way and de-identify and package it in a way that it can be used by researchers and pharma. Through the partnership, we will be able to collect, de-identify, package, and sell this much needed data. The revenue will be shared between both the CPFF and Vaultt with the goal of raising funds to financially support members of The Pulmonary Fibrosis Community in need.

# What are the benefits for the CPFF and the Pulmonary Fibrosis Community?

The CPFF community will be given a subscription to an extremely valuable platform that helps them manage all aspects of their health journey. This platform is normally \$60/year, however due to the partnership, it will be provided to the patients at no cost to them.

The funds raised through the sale of analysis-based survey data from the CPFF patient community will support the CPFF's mission, and especially the PF community members in need of financial support.

Providing a patient-centric platform that helps to share the patient's voice and their real-world experiences, benefits all stakeholders as we work towards the common goal of better outcomes.



# What's the Capital Expenditure involved for the CPFF?

The CPFF will not be required to invest any amount of money for this Partnership. Vaultt will incur any development expenses related to the partnership. The result will be to bring more funds to the CPFF.

# What are we selling?

For the purpose of this agreement, together, we are selling CPFF patient community's Real-World Data which has been acquired via fully consented surveys to pharma, research, academia, or other organizations. The same dataset can be sold to multiple customers. Survey data is the only data that will be collected and used for the sole purpose indicated. No other data can or will be collected.

# Why is Vaultt the best team for this?

The Vaultt Executive Team is made up of extremely successful tech founders and subject matter experts. The founder and CEO, Audrey Bond has a deep understanding of the patient and caregiver journey and has been an entrepreneur for over 30 years. COO Long Nguyen founded a healthtech company that supported over 500 000 patients and was ultimately acquired in 2020. The technology is now being used by Telus and Walmart. Lead Engineer Shaheryar Ahmad, founded, built, and ran a very successful survey company. Tom Brogan, Vaultt's Health Data advisor was the founder of Brogan Inc. He is the penultimate subject matter expert on health data. He developed e-reporting of patient records and developed the first ever source of Pharma Claims Data for market research & access. The Vaultt Advisory Board also includes Dane Bedward who was VP of Genzyme Corp and Sr. Management at Johnson & Johnson as well as Tushar Menon, Former Director at Vertex USA and currently Director at a US stealth Biotech Startup. Vaultt is also supported by other Strategic Advisors and is an Invest Ottawa Accelerator Company.

# How are we collecting this data?

The CPFF and PF Community will be given a subscription to the Vaultt Platform. They will be offered occasional in-app surveys to complete. Members will opt-in and consent to allowing their survey data to be shared once de-identified.

#### Who is doing the selling?

Vaultt and the CPFF will collaborate on the selling of the data. Vaultt and the CPFF will work together to present the survey data sets to prospective buyers such as research groups, government, insurance, and Pharma. Vaultt will complete the sales transaction and provide data sets to customers.

#### Who owns the Data?

The End Users of the Platform (the members) own the data regardless of affiliation to CPFF or any other organizations. Vaultt is obligated to retain the encrypted user data for 10 years unless otherwise directed by the user to delete. Vaultt is responsible for storing, maintaining, protecting and disposal of user data.



# What about Security?

Vaultt is Secure by Design. Vaultt utilizes best in class security and encryption to protect users' sensitive data. 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 has 3rd parties conduct security audits of our system and regularly implement improvements. The information in your Vaultt is completely secure. Not even Vaultt employees can access users' data.

# Can we add CPFF Resources to the platform?

Vaultt is always refining the platform and adding new features that patients and caregivers ask for. It was discussed that it would be beneficial for members of the CPFF and PF Communities to have an organized location within the Platform for Provincial resources and education. A repository of educational material and resources will be prioritized because of this agreement and can be added as a clause in a Schedule of the Definitive Agreement.