Canadian Pulmonary Fibrosis Foundation

CPFF Board Retreat 2022

MAY

13TH & 14TH

FINAL REPORT

May 19, 2022

Canadian Pulmonary Fibrosis Foundation

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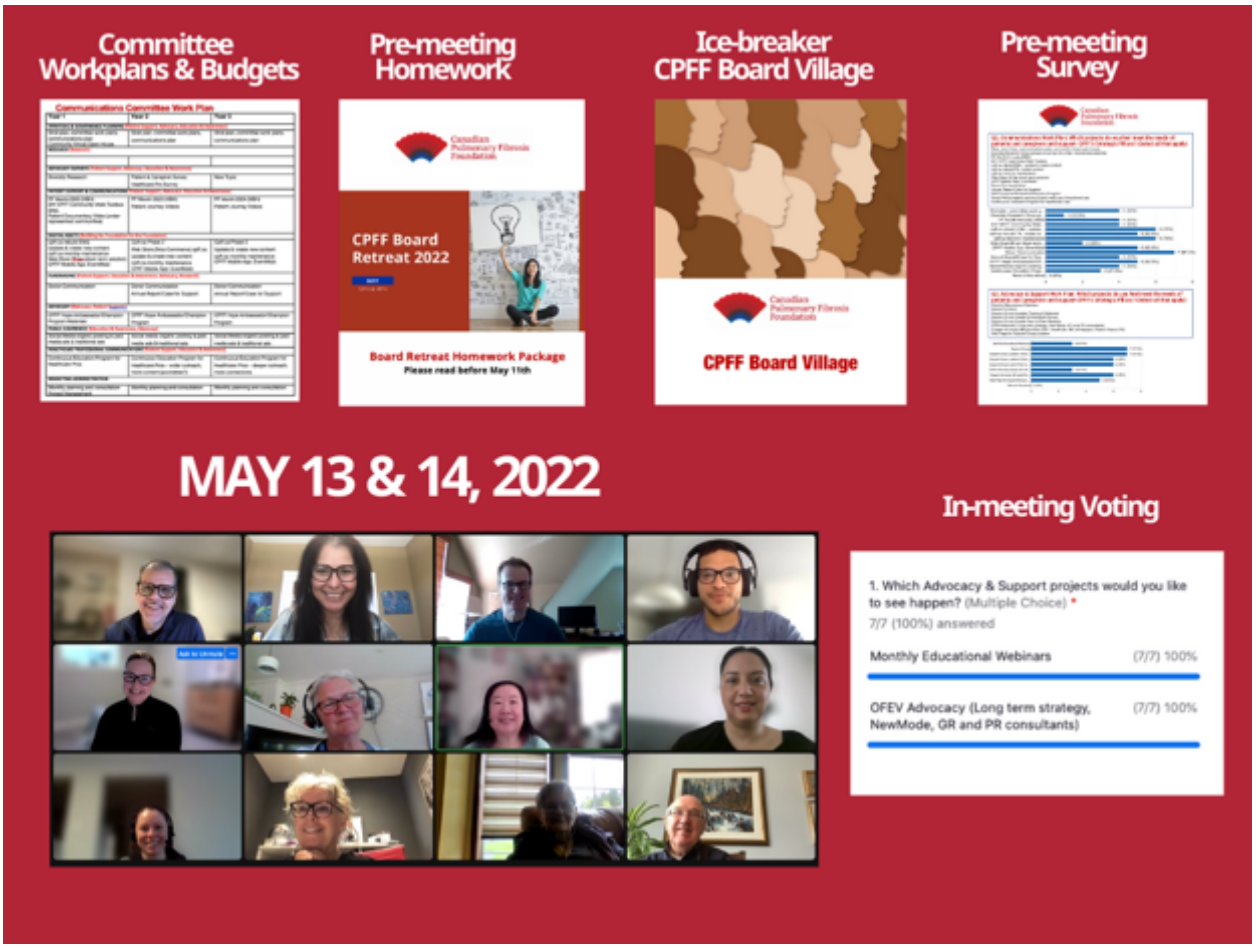


KEY COMPONENTS

1. Pre-meeting

Homework Package

- CPFF Strategic Plan FY22-23 edits
- Committees work plans & budgets
- Survey: Vote on 3-year annual focus and high priority projects for each committee work plan

Personal Bios

- Board personal bios
- Output – CPFF Village e-book

2. Meeting Facilitation

PowerPoint: Pre-meeting Survey Results & committee workplans

Meeting Activity Design and Facilitation

4. Report

Approved committee workplans and projects, draft implementation plans, June Board meeting follow ups

CPFF BOARD MEETING MAY 2022 – OBJECTIVES & KEY OUTCOMES

Meeting Objectives

Refine CPFF's FY 22-23 Strategic Plan and 3-year work plans.

Participants

Board Members

Mark Ashcroft, Charlene Fell, Todd Georgieff, Ranjena Maloni, Moyra Martin, Kirk Morrison, Verity Pringle, Raymond Protti, Holly Smith

Staff

Sharon Lee, Roberto Zapata

Support

Kelly Mills

Facilitator

Tina Finelli

Executive Summary - Key Outcomes

CPFF Board reviewed and voted on CPFF's FY 22-23 Strategic Plan

Most agreed with edits that were made to for "Key Elements of Strategy" and prioritization of strategic pillars with some minor edits requested. Copy edits for key elements of strategy to be further refined and presented at June 2022 Board meeting. *See appendix for pre-retreat survey results for FY 22-23 Strategic Plan.*

Mission & Vision

Mission statement options were provided along with recommendations to consider vision statement edits. These items will be further explored at June 2022 Board meeting. *See appendix for Mission statement options.*

Committee Work Plans – Priority Projects

Draft budgets and committee workplans were presented prior to the May 2022 Board meeting.

Priority projects were identified, voted upon, and approved for each committee. Budgets to be refined for June 2022 Board Meeting. *See appendix for voting results.*

Implementation plans were started for each committee.

A request was made to make Research an official CPFF Committee that should be appropriately resourced.

APPROVED PROJECTS
DRAFT IMPLEMENTATION PLANS

Communications

Advocacy & Support

Fundraising & Events

Governance & Finance

Research, Fellowships & Grants

CPFF BOARD MEETING MAY 2022 – APPROVED PROJECTS + IMPLEMENTATION PLANS

Communications Committee Work Plan

Year 1	Year 2	Year 3
STRATEGIC & GOVERNANCE PLANNING [Patient Support, Advocacy, Education & Awareness]		
Strat plan, committee work plans, communications plan Community Virtual Open House	Strat plan, committee work plans, communications plan	Strat plan, committee work plans, communications plan
ADVOCACY SURVEYS [Patient Support, Advocacy, Education & Awareness]		
Diversity/Under-represented Communities (survey year 1 & support year 2 with programming, translations, materials etc.) Preliminary agreement to further explore in future discussions. The following items need to be evaluated: 1/Is budget too high? 2/ Is there a need for primary research or can CPFF tap into secondary research that is already available?	Patient & Caregiver Survey Healthcare Pro Survey	New Topic
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]		
PF Month 2022 (HBH) DIY CPFF Community Walk Toolbox Patient Documentary Video (under-represented communities). Contingent on future discussions for Diversity.	PF Month 2023 (HBH) Patient Journey Videos (under-represented communities). Contingent on future discussions.	PF Month 2024 (HBH) Patient Journey Videos Contingent on future discussions.
DIGITAL ASSETS [Building the Foundation for the Foundation]		
cpff.ca rebuild ENG. Update & create new content cpff.ca monthly maintenance Web Store BCap (approved with minimal budget $2500) CPFF Mobile App: EventMobi	Cpff.ca Phase 2 Update & create new content cpff.ca monthly maintenance CPFF Mobile App: EventMobi	Cpff.ca Phase 3 Update & create new content cpff.ca monthly maintenance CPFF Mobile App: EventMobi
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]		
Donor Communication	Donor Communication Annual Report/Case for Support	Donor Communication Annual Report/Case for Support
ADVOCACY [Advocacy, Patient Support]		
CPFF Hope Ambassador/Champion Program Materials	CPFF Hope Ambassador/Champion Program	CPFF Hope Ambassador/Champion Program
PUBLIC AWARENESS [Education & Awareness, Advocacy]		
Social Media organic posting AND paid social media ads & traditional ads to reach new audiences.	Social Media organic posting AND paid social media ads & traditional ads to reach new audiences.	Social Media organic posting AND paid social media ads & traditional ads to reach new audiences.
HEALTHCARE PROFESSIONAL COMMUNICATIONS [Patient Support, Education & Awareness]		
~~Continuous Education Program for Healthcare Pros~~	~~Continuous Education Program for Healthcare Pros –~~	~~Continuous Education Program for Healthcare Pros~~
MARKETING ADMINISTRATION		
Monthly planning and consultation Project Management	Monthly planning and consultation	Monthly planning and consultation

Communications Committee Implementation Plan

Next Steps

Year 1 Project Plan – Indicate deadlines and key milestones for each of the deliverables
Year 1 Calendar of External Events – map out external facing events by in-market dates

Keep on Track – Project Management

Use a Trello Board as a project management tool. Progress reports will be downloaded and shared prior to committee meetings.

How Projects Will be Resourced

Sharon, Roberto, Etal Marketing Team will support most projects. There may be other projects that require the communications committee to resource projects beyond this team including the possible expansion of internal staff resources.

Key Performance Indicators

Communications committee will identify 4-5 KPIs that will be refreshed quarterly and shared with the board. Some activities already have baselines, and some will be set this year.

Individual activity KPIs will be rolled up and related to two high-level categories:

Engagements – How many people are connecting with us and how are they connecting with us. Example KPIs: how many people are looking at website, engaging with the app, web page views etc.

Actions –Relates to the action that people who are engaging with CPFF take. Example KPIs: sign up for events, click through to read more, donate, volunteer, share etc.

CPFF BOARD MEETING MAY 2022 – APPROVED PROJECTS + IMPLEMENTATION PLANS

Advocacy & Support Work Plan

Year 1	Year 2	Year 3
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]		
Educational Webinars (3-5 throughout the year + September) Support Groups Support Group Leaders training & materials Support Group Leader and Participant Survey Support Group Leader Peer-to-Peer meet ups.	Monthly Educational Webinars (7) Support Groups Support Group Leaders Communications (resources, recruitment, training & materials) Support Group Leader Peer-to-Peer meet ups.	Monthly Educational Webinars (7) Support Groups Support Group Leader Communications (resources, recruitment, training & materials) Support Group Leader Peer-to-Peer meet ups.
DIGITAL ASSETS [Building the Foundation for the Foundation]		
Webpage Support Group Leaders	Update support group webpage with new Support Group materials	Update support group webpage with new Support Group materials
ADVOCACY [Advocacy, Patient Support]		
Advocacy (drug therapy, treatments, and other high priority patient needs) Oxygen	Advocacy (drug therapy, treatments, and other high priority patient needs) Oxygen	Advocacy (drug therapy, treatments, and other high priority patient needs) Oxygen

Advocacy and Support Implementation Plan

Key Performance Indicators

Support Groups

- Expand number of support groups throughout the country. Goal is to have one in every province of the country including a francophone resource. KPI: % growth of support groups.
- Support leader training. KPI: % participation?

Government Relations

- 1 meeting per year (in-person or Zoom) in as many provinces as possible. KPI: # of government official meetings.

Respirologists – 3-year Plan

- Year 1: Identify who/how many are out there.
- Year 2: Determine how to engage them so that they know about CPFF and what the organization offers.
- Year 3: Identify any gaps in the plan.
- KPI: Plan completion.

Drug & Therapy Advocacy

- OFEV Advocacy – KPI: Number of provinces to add OFEV for PF-ILD on provincial formularies.
- Oxygen Therapy Advocacy – KPIs: Year 1 Survey completed & whitepaper published. Year 2: Get at least two provinces on board to improve O2 access. Year 3 Increase the number of provinces on board for improved O2 access.

Resourcing

- Managed by a CPFF staff member

Fundraising & Events Work Plan

Year 1	Year 2	Year 3
DIGITAL ASSETS [Building the Foundation for the Foundation]		
Text to Donate	Text to Donate	Text to Donate
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]		
Rare Disease Campaign Scleroderma & PF Campaign PF Month Events & Fundraising Do-it-yourself (DIY) Campaigns DIY Fundraising Platform (OneCause) CPFF Innovations Fund	Rare Disease Campaign Scleroderma & PF Campaign PF Month Events & Fundraising Do-it-yourself (DIY) Campaigns DIY Fundraising Platform (OneCause) CPFF Innovations Fund	Rare Disease Campaign Scleroderma & PF Campaign PF Month Events & Fundraising Do-it-yourself (DIY) Campaigns DIY Fundraising Platform (OneCause) CPFF Innovations Fund

Fundraising and Events

Not discussed. Chair absent.

Example KPIs for consideration by Fundraising & Event Committee:

Fundraising

- Gifts secured
- Donor & donation growth
- Donor retention rate
- Average gift size
- Fundraising ROI
- # of DIY fundraisers & # of events hosted

Events

- CPFF event and webinar participation
- Event satisfaction (via polls)

CPFF BOARD MEETING MAY 2022 – APPROVED PROJECTS + IMPLEMENTATION PLANS

Governance and Finance Work Plan

Year 1	Year 2	Year 3
STRATEGIC & GOVERNANCE PLANNING [Patient Support, Advocacy, Education & Awareness]		
HR Consultant - Board & ED reviews, Staff Recruitment Board Retreat Nov 2022 (Face-to-Face) Board Retreat May 2023 From Ops to Governance Strat Plan J. Dinner (3-year plan)	HR Consultant - Board & ED reviews, Staff Recruitment Board Retreat Nov 2023 (Face-to-Face) Board Retreat May 2024 Governance Policies J. Dinner	HR Consultant - Board & ED reviews, Staff Recruitment Board Retreat Nov 2024 (Face-to-Face) Board Retreat May 2025 Governance Policies J. Dinner

Governance and Finance

Key Performance Indicators & Workplan

Centred around time and completion of work.

Governance Document Building

Governance document completion: KPI: Working with John Dinner have documents completed within 6 months and completed on time.

Board Selection

Application submission deadline June 15, 2022. KPI: 2 new board members in place by fall 2022.

Recruitment and selection process. KPI: Chair selection process and succession plan put in place by Spring 2023.

Evaluations & Appraisals:

- Board Evaluation: KPI: complete by Spring 2023.
- Executive Director Appraisal: KPI: complete by Spring 2023.
- Satisfaction: KPI increase satisfaction ratings for Board, ED, and employees. Use baseline data from the last 2 years and set future goals.

HR Consultant:

- Investigation into the hiring of an HR consultant. KPI: hiring complete by the Fall of 2022 so HR documents can be ready for Spring 2023 appraisals and evaluations.

- Documents used for ED, Board, and employees will align with the mandates from governance documents.

Future Meetings (retreats, workshops, face to face meetings):
Committee proposed that the Governance committee (along with Board Chair and ED) has a consultative role to play in developing the approach for strategic planning and overseeing of feedback and information.

Research, Fellowships & Grants Work Plan

Year 1	Year 2	Year 3
RESEARCH [Research]		
Robert Davidson Fellows CPFF Research Grants	Robert Davidson Fellows CPFF Research Grants	Robert Davidson Fellows CPFF Research Grants

2 Fellowships $180k (1x1-year, 1x 2-year)

2 Research projects $20,000 each.

10-15% holdback until delivery of report and presentation

Other success metrics to be determined

Budget to be evaluated annually based on financial status of CPFF

Research, Grants and Fellowships Implementation Plan

Key Performance Indicators

How often to assess these? Annually? Twice per year?

1. Acknowledgements by Fellow & grant recipients in publications resulting from work funded by CPFF (abstracts, posters, publications, talks)
2. Participation in CPFF events & communications
    a. September awareness
    b. Speak to support groups around the country
    c. Local advocacy (ie, Fellow based in TO would be asked to participate in an event at the Ontario Legislature)
    d. Update on progress in lay terms for publication in the CPFF Newsletter
3. For Robert Davidson Fellowships: number of Fellows who go on to work in an ILD Clinic or establish a practice with the focus on ILD
    a. Geographic location of the Fellows practices? – infographic using map of Canada on web?
    b. ? Number of Fellows who become donors or board members? – maybe have the fellows join MAB as junior members
4. For all award recipients: list of publications which were the result of work completed during the grant period

CPFF BOARD MEETING MAY 2022 – APPROVED PROJECTS + IMPLEMENTATION PLANS

Research, Fellowships & Grants: 12-month Workplan

	RD Fellowships: $90K/Fellow/yr	Research Grants: $20K/Grant/yr
January: 1st week January 15-ish	Finalize budget: # 1-year Fellowships # 2-year Fellowships: year 1 # 2-year Fellowships: year 2 Announce competition & deadlines	Finalize budget: # 1-year Research Grants Announce competition & deadlines
February	Highlight a Fellow in Newsletter	Highlight a Research Grant awardee in Newsletter
March: 1st week 2nd week 4th week	Deadline for applications Distribute packages to MAB MAB meets to discuss/rank	Deadlines for applications Distribute packages to MAB MAB meets to discuss/rank
April 1st week 2nd week April 15-ish	MAB makes recommendation at Board mtg CPFF Contacts new Fellows CPFF Announces new Fellows	MAB makes recommendation at Board mtg CPFF Contacts awardees CPFF Announces awardees
May	Announce Fellows in Newsletter Contracts are signed	Contracts are signed
June	Propose Budget for next cycle at Board meeting/retreat	Announce Research Grant awardees in Newsletter
July	Most new Fellows start July 1	Reports from finishing projects
August	Reports from Fellows who ended June 30	
September	? Each Fellow is asked to give a seminar?	1 hour seminar for Grant Awardees to explain research to public?
October	? apply for $ from pharma for next cycle?	Highlight a Research Grant awardee in Newsletter?
November	Highlight a Fellow in Newsletter?	
December		

Research, Fellowships & Grants: 12-month Workplan

Robert Davidson Fellowship Award Recipitnets

Year	Fellow	Program Length (years)	Training Institution	Project	Status	Link to publication arising from project	Where are they now?	Link to Website
	Dr. Jolene Fisher		UofT		Completed		University of Toronto and University Health Network	https://www.uhn.ca/Surgery/Clinics/Interstitial_LungDisease_Clinic
	Dr. Tiffany Winstone	2	Harvard		Completed		Fraser Health Authority, Burnaby, BC	
	Dr. Lee Fiddler		UofT		Completed		University of Toronto and Sunnybrook Health Sciences Centre	https://sunnybrook.ca/team/member.asp?t=19&page=24030&m=928
2017	Dr. Veronica Marcoux	1	UofC	Mobile Health Monitoring in Patients with IPF	Completed	https://doi.org/10.1513/AnnalsATS.201904-335BL	University of Saskatchewan	https://medicine.usask.ca/profiles/department-of-medicine/saskatoon/respirology-critical-care-and-sleep-medicine/veronica-marcoux.php
2018	Dr. Alyson Wong	2	UBC	Effects of comorbidities on lung function and survival in ILD	Completed	https://doi.org/10.1186/s12931-020-01579-7	UBC & St. Paul's Hospital	
2018	Dr. Andrei Vagaon	1	UofT	QI: Increase use of antacids in ILD pts	Completed		The Toronto Lung Care Clinic & Toronto East Health Network	
2019	Dr. Stacey LOK	1	UofC	Malignancy Risk Associated with the use of MMF in ILD	Completed	https://doi.org/10.1016/j.chest.2021.12.636	University of Saskatchewan	https://medicine.usask.ca/profiles/department-of-medicine/saskatoon/respirology-critical-care-and-sleep-medicine/lok_s.php
2020	Dr. Colin Adams		UofT	Development of a prognostic score for progressive ILD	Completed			
2020	Dr. Amanda Grant-Orser	2	UofC	Perceptions on Genetic Testing in IPF	In Progress			
2020	Dr. Daniel Marinescu		Vancouver	Genetic Risk Factors for Progression in Fibrotic ILD	In Progress			
2020	Dr. Sarah MacIsaac	2 (completed 1)	McMaster	Optimization of ILD patient care: referral times and lung cancer in ILD	Completed			
2021	Dr. Kelly Sun	1	UofT	Health care utilization of patients with PF-ILD	In Progress			
2022	Dr. Alex Campbell	1 (wants 2)	UBC	scMRNAs for early diagnosis of ILD	to start			
2022	Dr. Bohyung Min	1	UofC	CBC as a biomarker for disease progression in ILD	to start			
2022	Dr. Leigh Minuk	1	UofT	Development of a staging system to predict progression in non-IPF ILD	to start			
						* Most projects have a lay summary in the CPFF Newsletter we can link. Some have YouTube videos (via CPFF) we can link		

Implementation Planning Framework

Each committee gathered and used the following questions as a guide to build their implementation plans

What are the next steps for each committee?

Who will be responsible?

What is the timing?

How will projects be resourced? (volunteers, paid staff, contractors?)

How will committees stay on track?

What are the Key Performance Indicators?

Note: Refined budget to be presented at June 2022 board meeting

For Discussion at June Board Meeting

Strategic Plan

- Edits & Board Feedback
- Mission Statement Options
- Vision Statement Discussion

Refined CPFF 3-Year Workplan Focus

Workplan items for further discussion:

- Diversity/Under-represented Communities (survey year 1 & support year 2 with programming, translations, materials etc.) Preliminary agreement to further explore in future discussions. The following items need to be evaluated:
    - 1/Is budget too high?
    - 2/ Is there a need for primary research or can CPFF tap into secondary research that is already available?

Refined Committee Implementation Plans

Refined Committee Budgets

APPENDIX

Draft CPFF 3-Year Work Plan Annual Focus

Provided within board retreat homework package

Draft CPFF 3-Year Workplan & Budget

Provided within board retreat homework package

Draft Committee Workplans

Provided within board retreat homework package

Prioritizing Initiatives - Project Votes

Pre-Meeting Vote Summary – Determine High and Low Priority Projects
In-meeting Votes – Determine which Low Priority Projects need to be removed from plan
Detailed Pre-Meeting Participant Survey

CPFF Board Village

Personal Bios

CPFF 3-Yr. Work Plan – Annual Focus Areas (Draft)

+ Foundation for the Foundation

Year 1:

I) Focus on building the foundation for the foundation with cpff.ca rebuild, new fundraising platform (OneCause), and event engagement app (EventMobi).
II) Empower patients and caregivers self-advocate with Do-it-yourself (DIY) Platforms (NewMode – Government Relations & OneCause – Fundraising and Community Engagement).
III) Identify Patient Support Group leaders and participants needs with a survey, provide training/leadership resources, and facilitate peer-to-peer connections for leaders
IV) Gain insights on Oxygen and PF journeys + advocate for OFEV and oxygen.
V) Continue engagement through PF Month (Hope Breathes Here) with a hybrid model (in-person + online).
VI) Launch CPFF Hope Ambassador program.
VII) Increase knowledge transfer for healthcare professionals with continuing education projects.

Year 2:

I) Continue with advocacy for OFEV and Oxygen and any other uncovered challenges from patient and caregiver study.
II) Refine foundation for the foundation - phase II of cpff.ca
III) Provide training/leadership resources and facilitate peer-to-peer connections for Support Group Leaders. Ramp up Leader Recruitment efforts.
IV) Ramp up DIY fundraising program.
V) Evolve PF month and other community events to include more face to face.
VI) Gain insights on under-represented communities through surveys and focus groups (Indigenous, South Asians, Muslims etc.).
VII) Start converting social media followers and event participants to become donors.
VIII) Continue recruitment for and growth of CPFF Hope Ambassador Program.
IX) Ramp up Continuing Education Program for Healthcare Pros – wider outreach, more content (accredited?).

Year 3

I) Address needs of under-represented communities.
II) Provide training/leadership resources, and facilitate peer-to-peer connections for Support Group Leaders
III) Ramp up CPFF Hope Ambassador Program and volunteer recruitment/training initiatives.

IV) Rollout alternate online or in-person fundraising events – e.g. Gala, meal in a box delivery, online auction etc.
V) Deepen Continuing Education Program for Healthcare Pros – deeper outreach, more connections.
VI) Strategic Planning for next 3-year plan 2025/26, 2026/27, 2027/28.
VII) Ramp up converting social media followers and event participants to become donors.

(Draft) CPFF 3-Yr. Work Plan & Budget– Year 1

	Budget	Gov. & Fin	Fund. & Eve.	Comms	Adv. & Sup.	Explanation
YEAR 1: August 1, 2022 to July 31, 2023						
STRATEGIC & GOVERNANCE PLANNING [Patient Support, Advocacy, Education & Awareness]						
Strat plan, committee work plans, communications plan	$ 10,000	X	X	X	X	
HR Consultant - Board & ED reviews, Staff Recruitment	$ 40,000	X				Pay as you go HR Services or give an honorarium to Donna Brown
Board Retreat Nov 2022 (Face-to-Face)	$ 40,000	X				Flights, hotel, meals, gas, facilitator, BOD & staff
Board Retreat May 2023	$ 5,000	X				Preparation & Facilitation (Strat Plan & Communications)
From Ops to Governance Strat Plan J. Dinner (3-year plan)	$ 30,000	X				New Policies & Edits / Director's Manual / Workshop on Governance
CPFF Community Virtual Open House	$ 20,000	X		X		Board, Community, Sponsors & Patients
	$ 145,000					
RESEARCH [Research]						
Robert Davidson Fellows	$ 180,000		X			Will CPFF fund this if Pharma does not?
CPFF Research Grants	$ 40,000		X			2 Research projects at $20,000 each
	$ 220,000					
ADVOCACY SURVEYS [Patient Support, Advocacy, Education & Awareness]						
Diversity Research	$ 150,000		X	X	X	Indigenous patient/caregiver focus groups and survey for other under-represented patients. (South Asians, Muslims etc.)
Support Group Leader and Participant Survey	$ 20,000				X	Survey support group leaders to understand how CPFF can better support them + survey participants to gain insights on how to better meet their needs.
	$ 170,000					
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]						
PF Month 2022 (Hope Breathes Here)	$ 70,000		X	X	X	Etal Marketing with CPFF: 11 Webinars, peer to peer meetups & socials, 1 National Hybrid webinar, One Interactive challenge, Social media marketing, PR, GR (NewMode), Wrap up Slide Show, Final Report (Mobile App in Digital Assets)
DIY CPFF Community Walk Toolbox ENG.	$ 16,000		X	X		Editable poster, social media graphics, how-to-guides, web page
DIY Fundraising Platform (**OneCause** + **Etal)**.	$ 19,000		X			OneCause ($9k Total): Platform $7.5k ($5.5k USD)+ One-time Setup $1.5k ($1,095 USD). Etal: Initial Design, SetUp, Facilitation ($10K)
Monthly Educational Webinars (7)	$ 8,400			X	X	

Support Groups	$ 22,000	X	X	X	X	
Patient Documentary Video	$ 65,000			X		Indigenous and under-represented communities

	Budget	Gov. & Fin	Fund & Eve	Comms	Adv. & Sup.	
Support Group Leader peer-to-peer meet ups	$ 10,000				X	Facilitate, host nation-wide or province-wide Support Group Leader meetups + education webinars.
Support Group Leaders training & materials	$ 15,000			X	X	
	$ 225,400					
DIGITAL ASSETS [Building the Foundation for the Foundation]						
cpff.ca rebuild ENG.	$ 50,000			X		
Update content, create new content	$ 20,000		X	X	X	
cpff.ca monthly maintenance	$ 6,720			X		(7 hours a month) CPFF Administration
Support Group Leader web page	$ 0			X	X	part of cpff.ca budget
Web Store BCap (short term solution)	$ 2,500			X		
CPFF Mobile App: EventMobi	$ 24,000			X		**Event Mobi $14,000** **+ ETAL MARKETING FEES** $10,000 Setup, design & content
EventMobi Live Streaming Fees	$ 2,500			X		
	$ 105,720					
ADVOCACY [Advocacy, Patient Support]						
OFEV Advocacy	$ 30,000			X	X	Long term strategy as we advocate with government. New Mode, GR (Puneet), PR
Oxygen Advocacy	$ 150,000		X	X	X	Received Grant from BI in Dec 2021. NewMode (covered in OFEV), GR, Whitepaper, Patient & Caregiver Videos, PR
CPFF Hope Ambassador/Champion Program	$ 50,000			X	X	Ambassador program strategy, training guidebooks, training program & videos, advocacy materials, resource library, live practice webinars with GR consultant for patients and caregivers
	$ 230,000					
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]						
Rare Disease Campaign	$ 10,000		X		X	ED & Fundraising Committee
Scleroderma & PF Campaign	$ 10,000		X		X	
Holiday DIY Campaign	$ 5,000		X		X	
Donor Communication	$ 25,100		X	X	X	Thank you letters, donor welcome package, volunteer recruitment $12.6k + Annual Report $12.5k

CPFF Innovations Fund	$ 0					
	$ 50,100					

	Budget	Gov. & Fin	Fund & Eve	Comms	Adv. & Sup.	
PUBLIC AWARENESS [Education & Awareness, Advocacy]						
Social Media (mentoring Roberto)	$ 5,500		X	X	X	
Social Media Ads for key fundraising months	$ 4,500		X	X		
	$ 10,000					
HEALTHCARE PROFESSIONAL COMMUNICATIONS [Patient Support, Education & Awareness]						
Continuous Education Program for Healthcare Pros	$ 66,100			X	X	Continuous Ed. Program strategy, whiteboard video for health pros (from diagnosis to palliative care), training videos, webinars for healthcare pros, digital guidebook, resource library
	$ 66,100					
MARKETING ADMINISTRATION						
Monthly planning and consultation fee $2000/month (20 hours per month)	$ 24,000.00	X				CPFF Administration
Project Management. Monthly resource management, project coordination and quality assurance, monthly budget reconciliation. $1000/month (20 hours/month)	$ 12,000.00	X				CPFF Administration
	$ 36,000					
Subtotal	**$ 1,258,320**					
HST	**$ 134,982**	(No HST for Grants & Fellowships)				
TOTAL	**$ 1,393,302**					

(Draft) CPFF 3-Yr. Work Plan – Year 2

YEAR 2: August 1, 2023 to July 31, 2024						
	Budget	Gov & Fin	Fund. & Eve.	Comms	Adv. & Sup.	Explanation
PLANNING						
Strategic planning, committee work plans, communications plan	$ 10,000	X	X	X	X	
Board Retreat Nov 2023 (Face-to-Face)	$ 40,000	X				Flights, hotel, meals, mileage, facilitator, (10-12) BOD & (2-3) staff
Board Retreat May 2024	$ 5,000					Virtual - Preparation & Facilitation (Strat Plan & Communications)
Governance Policies w/John Dinner	$ 15,000	X				Revisions & Updates of Policies + Facilitation of Nov Board Retreat
HR Consultant for Board & ED Review + Staff Recruitment	$ 35,000	X				Pay as you go or an Honorarium for Donna Brown
	$ 70,000					
RESEARCH [Research]						
Robert Davidson Fellows	$ 180,000					ED, Staff & MAB
CPFF Research Grants	$ 40,000					ED, Staff & MAB
	$ 300,000					
ADVOCACY SURVEYS [Patient Support, Advocacy, Education & Awareness]						
Patient & Caregiver Survey	$ 90,000			X	X	All patients and caregivers
Healthcare Professional Survey	$ 60,000			X	X	Includes pharmacists, rheumatologist, other specialists, GPs, mental health, nurses etc.
	$ 150,000					
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]						
PF Month (Hope Breathes Here) 2023	$ 110,000		X	X	X	More face-to-face includes event materials for live events.
Monthly Educational Webinars	$ 8,400				X	Webinar production (7 Virtual webinars), CPFF Staff with Etal Marketing
Support Groups	$ 22,000	X	X	X	X	Rental of meeting rooms, snacks and drinks plus PF materials + Zoom
Support Group Leaders Communications	$ 15,000					Resources, recruitment, training & materials

	Budget	Gov. & Fin	Fund & Eve	Comms	Adv. & Sup.	
Support Group Leader Peer-to-Peer Meetups & Education	$ 10,000					Facilitate, host nation-wide/province-wide Support Group Leader meetups + education webinars.
Patient Videos	$ 50,000			X		
	$ 215,400					
ADVOCACY [Advocacy, Patient Support]						
Advocacy Cause #1 (New Mode, GR, PR)	$ 30,000			X	X	Long term strategy as we advocate with government
Advocacy Cause #2	$ 30,000			X	X	Oxygen advocacy
CPFF Hope Ambassador/Champion Program	$ 20,000			X	X	Ensure enough Hope Ambassadors are in the pipeline and trained. Ongoing communications and script updates.
	$ 80,000					
DIGITAL ASSETS [Building the Foundation for the Foundation]						
cpff.ca Phase 2 (pricing tbc)	$ 35,000		X	X	X	CPFF Administration - Fr. , Webstore, Other page updates
Web Store (Woo Commerce)	$ 7,000		X	X	X	Built on cpff.ca
Update content, create new content	$ 15,000		X	X	X	CPFF Administration
cpff.ca monthly maintenance (7 hours a month)	$ 6,720					CPFF Administration
CPFF Mobile App: EventMobi	$ 24,000					CPFF Administration
EventMobi Live Streaming	$ 2,500			X		CPFF Administration
	$ 90,220					
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]						
DIY Fundraising Campaigns (PF Month + 2 Others)	$ 40,000		X	X	X	$9k platform + 2 Campaigns
Rare Disease Campaign	$ 10,000		X	X	X	ED & Fundraising Committee
Scleroderma & PF Campaign	$ 10,000		X	X	X	ED & Fundraising Committee
Donor Communication	$ 12,000		X	X		Converting social media fans & event participants to donors
Annual Report/Case for Support	$ 12,500		X	X		Stewardship of CPFF Donors
CPFF Innovations Fund	$ 0					
	$ 84,500					
PUBLIC AWARENESS [Education & Awareness, Advocacy]						
Social Media (mentoring Roberto & graphics)	$ 5,500		X	X	X	CPFF & Etal Marketing
Social Media Ads for key fundraising months	$ 4,500		X	X	X	CPFF & Etal Marketing
	$ 10,000					

	Budget	Gov. & Fin	Fund & Eve	Comms	Adv. & Sup.	
HEALTHCARE PROFESSIONAL COMMUNICATIONS [Patient Support, Education & Awareness]						
Continuous Education Program for Healthcare Pros - Phase II	$ 65,000			X	X	Expand program with more content and a bigger reach to more professionals
	$ 65,000					
MARKETING ADMINISTRATION						
Monthly planning and consultation fee $2000/month (20 hours/month)	$ 24,000					CPFF Administration
Project Management. Monthly resource management, project coordination and quality assurance, monthly budget reconciliation. $1000/month (20 hours/month)	$ 12,000					CPFF Administration
	$ 36,000					
Subtotal	**$ 1,101,120**					
HST	**$ 104,146**					
TOTAL	**$ 1,205,266**					

(Draft) CPFF 3-Yr. Work Plan – Year 3

YEAR 3: August 1, 2024 to July 31, 2025

	Budget	Gov. & Fin	Fund. & Eve.	Comms	Adv. & Sup.	Explanation
PLANNING						
Strategic planning, committee work plans, communications plan	$ 20,000	X	X	X	X	3-year plan 2025/26, 2026/27, 2027/28
Board Retreat Nov 2024 (Face-to-Face)	$ 40,000	X				Flights, hotel, meals, mileage, facilitator, (10-12) BOD & (2-3) staff
Board Retreat May 2025	$ 5,000					Virtual - Preparation & Facilitation (Strat Plan & Communications)
Governance Policies w/John Dinner	$ 15,000	X				Revisions & Updates of Policies + Facilitation of Nov Board Retreat
HR Consultant for Board & ED Review + Staff Recruitment	$ 35,000	X				Pay as you go or an Honorarium for Donna Brown
	$ 80,000					
RESEARCH [Research]						
Robert Davidson Fellows	$ 180,000					ED, Staff & MAB
CPFF Research Grants	$ 40,000					ED, Staff & MAB
	$220,000					
ADVOCACY SURVEYS [Patient Support, Advocacy, Education & Awareness]						
New Topic	$ 50,000			X	X	
	$ 50,000					
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]						
PF Month (Hope Breathes Here) 2024:	$ 110,000		X	X	X	Hybrid Model
Monthly Educational Webinars (7)	$ 8,400		X	X	X	
Support Groups	$ 25,000		X	X	X	Room Rentals, snacks & drinks, PF materials + Zoom
Support Group Leaders Communications	$ 15,000				X	Resources, recruitment, training & materials
	Budget	**Gov. & Fin**	**Fund & Eve**	**Comms**	**Adv. & Sup.**	
Support Group Leader Peer-to-Peer meet ups	$ 10,000					Facilitate, host nation-wide/province-wide Support Group Leader meetups + education webinars.
Patient Journey Videos	$ 50,000			X	X	

	$ 218,400					
ADVOCACY [Advocacy, Patient Support]						
Advocacy Cause #1 (New Mode, GR, PR)	$ 30,000			X	X	Long term strategy as we advocate with government
Advocacy Cause #2	$ 30,000			X	X	Oxygen advocacy
CPFF Hope Ambassador/Champion Program	$ 35,600		X	X	X	
	$ 95,600					
DIGITAL ASSETS [Building the Foundation for the Foundation]						
cpff.ca Phase 3 (pricing tbc)	$ 15,000					
Update content, create new content	$ 15,000					CPFF Administration, Includes adding new support group materials
cpff.ca monthly maintenance (7 hours a month)	$ 6,720					
CPFF Mobile App: EventMobi	$ 24,000					
EventMobi Live Streaming Fees	$ 2,500					
	$ 63,220					
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]						
DIY Fundraising Campaigns (PF Month + 2 Others)	$ 40,000		X	X	X	$20k platform + 2 Campaigns
Rare Disease Campaign	$ 10,000			X	X	ED & Fundraising Committee
Scleroderma & PF Campaign	$ 10,000		X	X	X	
Donor Communication	$ 12,000		X	X		Converting social media fans & event participants to donors
Annual Report/Case for Support	$ 12,500		X	X		Stewardship of CPFF Donors
CPFF Innovations Fund	$ 0					
	$ 84,500					

	Budget	Gov. & Fin	Fund & Eve	Comms	Adv. & Sup.	
PUBLIC AWARENESS [Education & Awareness, Advocacy]						
Social Media (mentoring Roberto & graphics)	$ 5,500		X	X	X	CPFF & Etal Marketing
Social Media Ads for key fundraising months	$ 4,500		X	X	X	CPFF & Etal Marketing
	$10,000.00					
HEALTHCARE PROFESSIONAL COMMUNICATIONS [Patient Support, Education & Awareness]						
Continuous Education Program for Healthcare Pros	$ 58,100.00			X	X	Raising awareness and educating specialists (Rheumatologists, Pharmacists, Community Respirologists, Family Physicians, Respiratory Therapists, Nurses
	$58,100.00					
MARKETING ADMINISTRATION						
Monthly planning and consultation fee $2000/month (20 hours per month)	$ 24,000.00					CPFF Administration
Project Management. Monthly resource management, project coordination and quality assurance, monthly budget reconciliation. $1000/month (20 hours/month)	$ 12,000.00					CPFF Administration
	$36,000.00					
Subtotal	$ 915,820					
HST	$ 90,457					
TOTAL	$ 1,006,277					

(Draft) Communications Committee Work Plan

Year 1	Year 2	Year 3
STRATEGIC & GOVERNANCE PLANNING [Patient Support, Advocacy, Education & Awareness]		
Strat plan, committee work plans, communications plan Community Virtual Open House	Strat plan, committee work plans, communications plan	Strat plan, committee work plans, communications plan
RESEARCH [Research]		
ADVOCACY SURVEYS [Patient Support, Advocacy, Education & Awareness]		
Diversity Research	Patient & Caregiver Survey Healthcare Pro Survey	New Topic
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]		
PF Month 2022 (HBH) DIY CPFF Community Walk Toolbox ENG. Patient Documentary Video (under-represented communities)	PF Month 2023 (HBH) Patient Journey Videos	PF Month 2024 (HBH) Patient Journey Videos
DIGITAL ASSETS [Building the Foundation for the Foundation]		
cpff.ca rebuild ENG. Update & create new content cpff.ca monthly maintenance Web Store BCap (short term solution) CPFF Mobile App: EventMobi	Cpff.ca Phase 2 Web Store (Woo Commerce) cpff.ca Update & create new content cpff.ca monthly maintenance CPFF Mobile App: EventMobi	Cpff.ca Phase 3 Update & create new content cpff.ca monthly maintenance CPFF Mobile App: EventMobi
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]		
Donor Communication	Donor Communication Annual Report/Case for Support	Donor Communication Annual Report/Case for Support
ADVOCACY [Advocacy, Patient Support]		
CPFF Hope Ambassador/Champion Program Materials	CPFF Hope Ambassador/Champion Program	CPFF Hope Ambassador/Champion Program
PUBLIC AWARENESS [Education & Awareness, Advocacy]		
Social Media organic posting & paid media ads & traditional ads	Social Media organic posting & paid media ads & traditional ads	Social Media organic posting & paid media ads & traditional ads
HEALTHCARE PROFESSIONAL COMMUNICATIONS [Patient Support, Education & Awareness]		
Continuous Education Program for Healthcare Pros	Continuous Education Program for Healthcare Pros – wider outreach, more content (accredited?)	Continuous Education Program for Healthcare Pros – deeper outreach, more connections
MARKETING ADMINISTRATION		
Monthly planning and consultation Project Management	Monthly planning and consultation	Monthly planning and consultation

(Draft) Advocacy & Support Work Plan

Year 1	Year 2	Year 3
STRATEGIC & GOVERNANCE PLANNING [Patient Support, Advocacy, Education & Awareness]		
RESEARCH [Research]		
ADVOCACY SURVEYS [Patient Support, Advocacy, Education & Awareness]		
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]		
Monthly Educational Webinars (7) Support Groups Support Group Leaders training & materials Support Group Leader and Participant Survey Support Group Leader Peer-to-Peer meet ups.	Monthly Educational Webinars (7) Support Groups Support Group Leaders Communications (resources, recruitment, training & materials) Support Group Leader Peer-to-Peer meet ups.	Monthly Educational Webinars (7) Support Groups Support Group Leader Communications (resources, recruitment, training & materials) Support Group Leader Peer-to-Peer meet ups.
DIGITAL ASSETS [Building the Foundation for the Foundation]		
Webpage Support Group Leaders	Update support group webpage with new Support Group materials	Update support group webpage with new Support Group materials
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]		
ADVOCACY [Advocacy, Patient Support]		
OFEV Oxygen	Cause 1 (Oxygen?) & Cause 2	Cause 1 (Oxygen?) & Cause 2
PUBLIC AWARENESS [Education & Awareness, Advocacy]		
HEALTHCARE PROFESSIONAL COMMUNICATIONS [Patient Support, Education & Awareness]		
MARKETING ADMINISTRATION		

(Draft) Fundraising & Events Work Plan

Year 1	Year 2	Year 3
STRATEGIC & GOVERNANCE PLANNING [Patient Support, Advocacy, Education & Awareness]		
RESEARCH [Research]		
ADVOCACY SURVEYS [Patient Support, Advocacy, Education & Awareness]		
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]		
DIGITAL ASSETS [Building the Foundation for the Foundation]		
Text to Donate	Text to Donate	Text to Donate
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]		
Rare Disease Campaign Scleroderma & PF Campaign PF Month & other DIY Campaigns CPFF Innovations Fund	Rare Disease Campaign Scleroderma & PF Campaign PF Month & other DIY Campaigns CPFF Innovations Fund	Rare Disease Campaign Scleroderma & PF Campaign PF Month & other DIY Campaigns CPFF Innovations Fund
ADVOCACY [Advocacy, Patient Support]		
PUBLIC AWARENESS [Education & Awareness, Advocacy]		
HEALTHCARE PROFESSIONAL COMMUNICATIONS [Patient Support, Education & Awareness]		
MARKETING ADMINISTRATION		

(Draft) Governance and Finance Work Plan

Year 1	Year 2	Year 3
STRATEGIC & GOVERNANCE PLANNING [Patient Support, Advocacy, Education & Awareness]		
HR Consultant - Board & ED reviews, Staff Recruitment Board Retreat Nov 2022 (Face-to-Face) Board Retreat May 2023 From Ops to Governance Strat Plan J. Dinner (3-year plan)	HR Consultant - Board & ED reviews, Staff Recruitment Board Retreat Nov 2023 (Face-to-Face) Board Retreat May 2024 Governance Policies J. Dinner	HR Consultant - Board & ED reviews, Staff Recruitment Board Retreat Nov 2024 (Face-to-Face) Board Retreat May 2025 Governance Policies J. Dinner
RESEARCH [Research]		
ADVOCACY SURVEYS [Patient Support, Advocacy, Education & Awareness]		
PATIENT SUPPORT & COMMUNICATIONS [Patient Support, Advocacy, Education & Awareness]		
DIGITAL ASSETS [Building the Foundation for the Foundation]		
FUNDRAISING [Patient Support, Education & Awareness, Advocacy, Research]		
ADVOCACY [Advocacy, Patient Support]		
PUBLIC AWARENESS [Education & Awareness, Advocacy]		
HEALTHCARE PROFESSIONAL COMMUNICATIONS [Patient Support, Education & Awareness]		
MARKETING ADMINISTRATION		

(Draft) Research, Fellowships & Grants Work Plan

Year 1	Year 2	Year 3
STRATEGIC & GOVERNANCE PLANNING **[Patient Support, Advocacy, Education & Awareness]**		
RESEARCH **[Research]**		
Robert Davidson Fellows CPFF Research Grants	Robert Davidson Fellows CPFF Research Grants	Robert Davidson Fellows CPFF Research Grants
ADVOCACY SURVEYS **[Patient Support, Advocacy, Education & Awareness]**		
PATIENT SUPPORT & COMMUNICATIONS **[Patient Support, Advocacy, Education & Awareness]**		
DIGITAL ASSETS **[Building the Foundation for the Foundation]**		
FUNDRAISING **[Patient Support, Education & Awareness, Advocacy, Research]**		
ADVOCACY **[Advocacy, Patient Support]**		
PUBLIC AWARENESS **[Education & Awareness, Advocacy]**		
HEALTHCARE PROFESSIONAL COMMUNICATIONS **[Patient Support, Education & Awareness]**		
MARKETING ADMINISTRATION		

Canadian Pulmonary Fibrosis Foundation

CPFF BOARD MEETING MAY 2022 – COMMITTEE WORKPLANS

Summary: Voting Results

Voting Approach

Pre-meeting Vote:
CPFF Board voted on which projects should move forward.
Projects with a majority vote of 51-100% were ranked as high priority.
Projects with a 0-50% of vote were ranked as low priority projects.

In-meeting Vote:
Low priority projects were discussed and voted upon.

Results:
Projects with a majority vote at the end of the May 2022 Board Retreat were considered high priority and approved. See conditions and notes in individual committee work plans

Communications Work Plan

COMMITTEE WORK PLANS - COMMUNICATIONS

Pre-retreat Voting Results

51-100%
HIGHEST PRIORITY PROJECTS
Donor Communication **7 (87.5%)**
cpff.ca rebuild ENG., update & create content **6 (75%)**
cpff.ca monthly maintenance **6 (75%)**
cpff.ca FR., create content **5 (62.5%)**
CPFF Mobile App: EventMobi **5 (62.5%)**
CPFF Hope Ambassador/Champion Program **5 (62.5%)**

0-50%
LOWER PRIORITY PROJECTS
Strat, committee, communications plans & community open house **4 (50%)**
PF Month Annually (HBH) **4(50%)**
DIY CPFF Community Walk Toolbox **4(50%)**
Annual Report/Case for Support **4 (50%)**
Social Media organic posting & paid media ads & traditional ads **4 (50%)**
Continuous Education Program for Healthcare Pros **3 (37.5%)**
Diversity Research **1 (12.5%)**

(Day 1)

Canadian Pulmonary Fibrosis Foundation

Communications
Low Priority Projects
Voting Results

1. Which Communications projects would you like to see happen? (Multiple Choice) *
7/7 (100%) answered

Strategic, communications, committee work plans & community virtual open house	(5/7) 71%
PF Month Annually (HBH)	(7/7) 100%
DIY CPFF Community Walk Toolbox	(5/7) 71%
Social media & traditional ads	(2/7) 29%
Annual Report/Case for Support	(4/7) 57%
Continuous Education Program for Healthcare Pros	(1/7) 14%
Webstore	(0/7) 0%
Diversity Research	(0/7) 0%

Projects that were voted as low priority

CPFF Board Retreat 2022

(Day 2)

1. Which Communications projects would you like to see happen? (Multiple Choice) *
9/9 (100%) answered

Social media (FB, IG, Twitter are the only means of advertising right now and are successful)	(9/9) 100%
Webstore (to support DIY events & HBH walk)	(8/9) 89%
Diversity (survey Year 1 & support Year 2-3 with programming, translations, materials etc)	(6/9) 67%

Advocacy & Support Work Plan

COMMITTEE WORK PLANS – ADVOCACY & SUPPORT

Pre-retreat Voting Results

51-100%

HIGHEST PRIORITY PROJECTS

Support Groups **7 (87.5%)**
Support Group Leaders Training & Materials **7 (87.5%)**
Support Group Leader & Participant Survey **6 (75%)**
Support Group Leader Peer-to-Peer Meetups **6 (75%)**
Oxygen Advocacy (BI grant/Dec 2021. NewMode, GR, Whitepaper, Patient Videos, PR) **6 (75%)**
Web Page for Support Group Leaders **5 (62.5%)**

0-50%

LOWER PRIORITY PROJECTS

Monthly Educational Webinars **3 (37.5%)**
OFEV Advocacy (Long term strategy, New Mode, GR and PR consultants) **3 (37.5%)**

(Day 1)

All projects were approved with edits

Advocacy & Support Low Priority Projects

Voting Results

1. Which Advocacy & Support projects would you like to see happen? (Multiple Choice) *

7/7 (100%) answered

Monthly Educational Webinars	(7/7) 100%
OFEV Advocacy (Long term strategy, NewMode, GR and PR consultants)	(7/7) 100%

Change to: Educational Webinars (3-5 throughout the year + September)

Change to: Drug Therapy Advocacy (and other high priority patient needs)

Fundraising & Events Work Plan

NO Breakout

Fundraising & Events

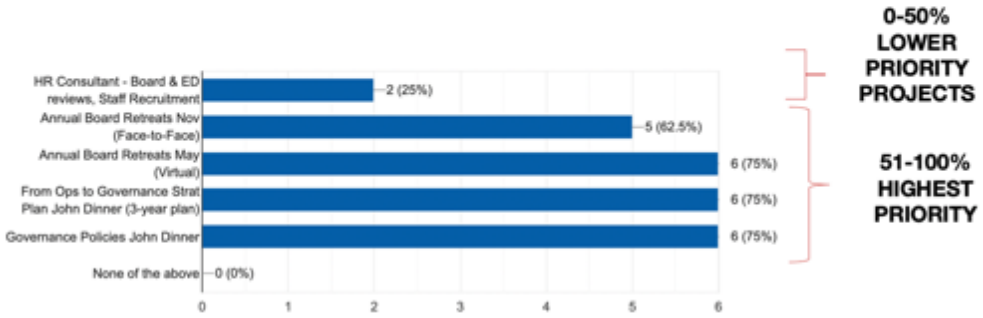
100% of Projects Were Ranked as High Priority!

- ❑ Text to Donate **5 (62.5%)**
- ❑ Rare Disease Campaign **8 (100%)**
- ❑ Scleroderma & PF Campaign **5 (62.5%)**
- ❑ PF Month Events & Fundraising **8 (100%)**
- ❑ Do-it-yourself (DIY) Campaigns **7 (87.5%)**
- ❑ CPFF Innovations Fund **6 (75%)**

Governance and Finance Work Plan

COMMITTEE WORK PLANS – GOVERNANCE & FINANCE

Pre-retreat Voting Results



Canadian Pulmonary Fibrosis Foundation

This project was approved

Governance & Finance Low Priority Projects

Voting Results

1. Which Governance & Finance projects would you like to see happen? (Multiple Choice) *

7/7 (100%) answered

HR Consultant - Board & ED reviews, Staff Recruitment (7/7) 100%

Research, Fellowships & Grants

COMMITTEE WORK PLANS – RESEARCH, FELLOWSHIPS & GRANTS

Pre-retreat Voting Results - BOD Perspective

Q6. Research Work Plan: Do you feel that CPFF should be committed to CPFF Research Grants and Robert Davidson Fellowships even without pharmaceutical funding?

Other

- Dependent on fundraising
- I have not had the opportunity to hear about the research that has been supported so it is challenging to comment. Overall, I support research if it advances the treatment choices for patients
- Do we have the infrastructure in place to raise the amount of dollars required for this commitment. I support the research totally but at what cost?

Canadian Pulmonary Fibrosis Foundation

Breathing should never be hard work

Research Fellowships & Grants

Voting Results

This project was approved

Research Money

Poll ended | 1 question | 7 of 8 (87%) participated

1. Do you agree with the proposed plan for fellowships + 2 research grants every year? ($220,000 Annual Budget) (Single Choice) *

7/7 (100%) answered

Yes	(7/7) 100%
No	(0/7) 0%

2 Fellowships $180k (1x1-year, 1x 2-year)
2 Research projects $20,000 each evaluated annually

10-15% holdback until delivery of report and presentation

Other success metrics to be determined

Pre-retreat Survey Results (as of May 11, 2022)

PART 1 (8 responses)

Revised Strategic Plan FY22-23

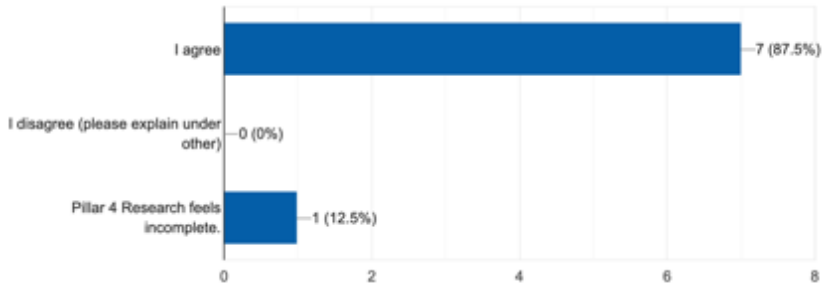
Q1. Are you in agreement with the edit to "CPFF Strategic Pillars"?

Our four pillars of focus guide our strategy. They are:

1. Support: Support those affected by PF;
2. Advocacy: Represent Canadians affected by PF to government, healthcare professionals, the media, and the public.
3. Awareness: Educate and raise awareness about PF among Canadians;
4. Research: Raise funds to finance research and;

The top two priorities are providing more Patients/Caregiver Support and Advocacy. Awareness/Education and Research are also essential and of equal importance.

Edit: Re-ordered pillars and made a statement on ranking of strategic pillars based on learning



OTHER:

Pillar 4 Research feels incomplete

(Note to readers: the pillars were reordered as per agreed upon edit. Research used to be #3 which led into #4 Advocacy "and;" should now be removed.)

Q2. Are you in agreement with the edits to "Key Elements of Our Strategy #1"?

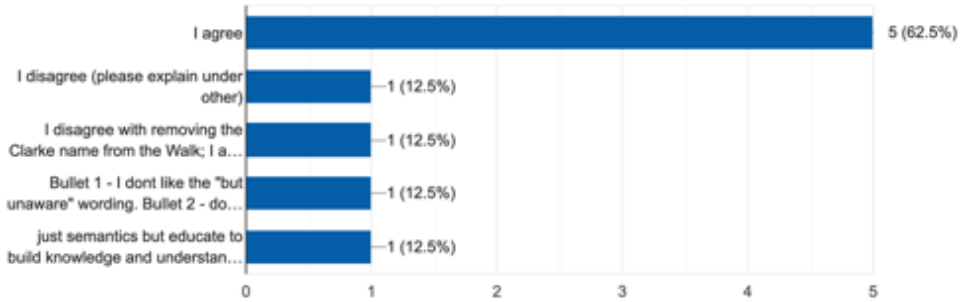
1. **Educate Canadians to increase awareness about both PF and the Canadian Pulmonary Fibrosis Foundation (CPFF)**
   - Utilize state of the art communications (including social media) to most effectively reach our community and communicate our story. Increase efforts to reach audiences beyond the CPFF community including those living with PF but unaware, sponsors, donors, media, and medical professionals.
   - Continue to run a national September campaign annually to recognize PF awareness month. This campaign will include, but is not limited, to the following events:
     - Lighting up of buildings and structures in blue and red
     - Obtaining proclamations from all levels of government
     - Hosting of online and/or in person patient forums
     - Encouraging bubble blowing across the country
     - ~~Clarke~~ Hope Breathes Here Walk for Pulmonary Fibrosis (national event)

- Rollout a community-based CPFF ambassador program that engages and equips the CPFF community to support PF advocacy, awareness, and fundraising.
- Create opportunities for interested parties to become involved in the Foundation.
- Leverage and further develop grassroots relationships.

Edits:

Add in the creation of a community-based CPFF ambassador program that taps into CPFF's engaged community to help educate & build awareness."

Modify copy to expand audiences that CPFF wants to reach beyond the existing CPFF community. Include high-level audience-specific communications tactics you wish to deploy (e.g. People with lung health issues who are unaware that they may have PF, sponsors, donors, media, medical professionals)."



OTHER:

I DISAGREE

I disagree with removing the Clarke name from the Walk; I agree with everything else.

OTHER

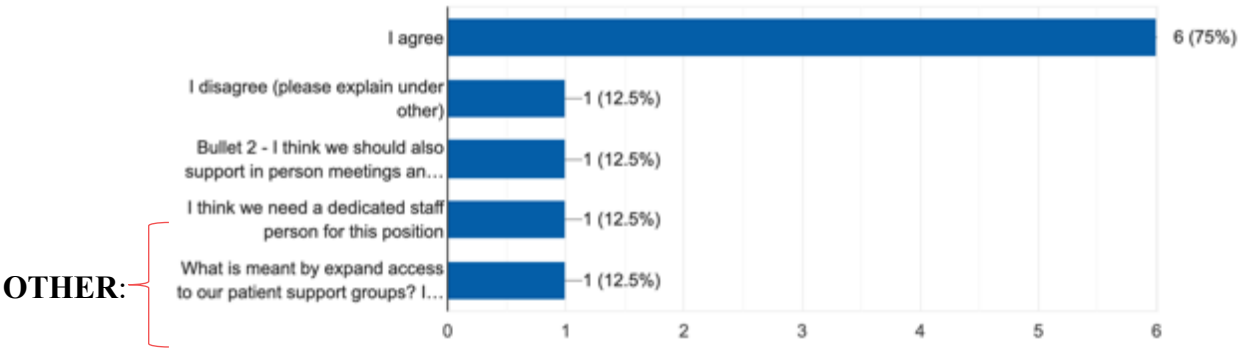
Bullet 1 - I don't like the "but unaware" wording. Bullet 2 – don't think we should call them "patient" forums as they also for others in community. Bullet 2 - Is the bubble blowing effective? Bullet 5 - what do you mean by "grassroots relationships" needs definition and context.

just semantics but educate to build knowledge and understanding and raise awareness - Secondly we go beyond awareness, where is the call to action that ties into building this awareness?

Q3. Are you in agreement with the edits to "Key Elements of Our Strategy #2"?

2. **Strengthen the focus on people affected by PF and strengthen the services we provide to them**
   - Build the numbers of people affiliated with the Foundation, using our network of patient support groups as a platform.
   - Expand access to our patient support groups by both increasing the number of patient support groups and using technology to allow virtual access to support group meetings and events.
   - Continue with our practice of conducting regular surveys of the PF community to identify needs, issues, and priorities.
   - Create practical patient and caregiver support tools that help patients get better access to PF informed healthcare professionals, manage their PF, and find joy in daily living.

   Edit: Expand this statement beyond Foundation growth, expanded support groups, and patient surveys to include specifics around helping people affected by PF get practical tools for better access to care, manage their PF, and find joy in daily living.



I DISAGREE

I disagree (please explain under other);Bullet 2 - I think we should also support in person meetings and helping facilitate. Bullet 2 - I also think instead of just # support groups we should help ppl find existing groups. Bullet 3 - I disagree with surveys unless needs. Waste of time and resource without specific significant change in landscape (new treatments, pandemic, etc). Bullet 4 - I think the update of toold should be a priority.

OTHER

I agree; I think we need a dedicated staff person for this position

What is meant by expand access to our patient support groups? I totally agree with increasing the number of support groups; I also would like to see us create a support group for caregivers.

Q4. Are you in agreement with the edits to "Key Elements of Our Strategy #3"?

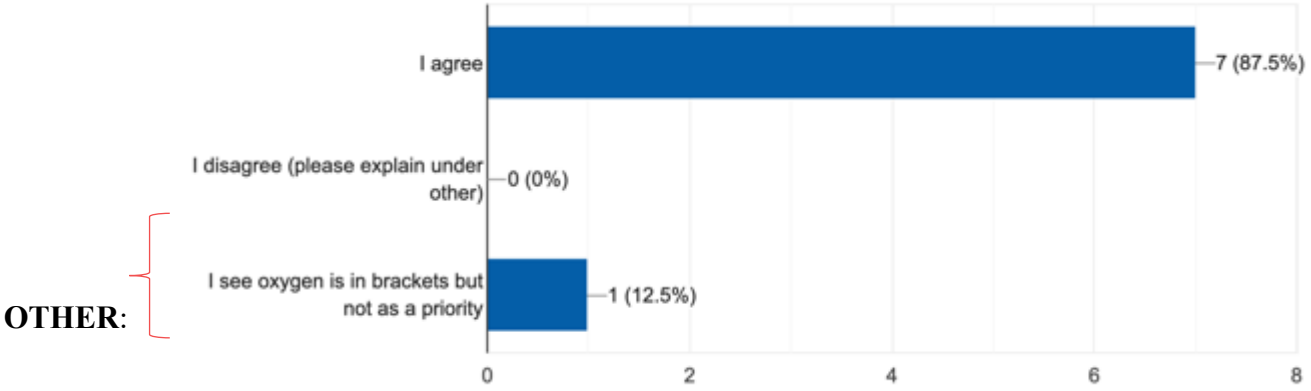
4. Advocate for Canadians living with PF and enhance the services we provide to them

- Maximize our connections with families and individuals living with PF.
- Lead efforts to bring earlier diagnoses, and access to treatment (drugs, oxygen, mental health, and pulmonary rehabilitation support).
- Continue our federal and provincial advocacy efforts to earlier diagnoses and access to treatment (drugs and oxygen) and create a safe environment for people to tell their story.
- Collaborate with other organizations to promote efficiency and communicate a coordinated message.
- Research daily living support needs and advocate with community organizations to facilitate PF awareness and specialized service offerings for people living with PF.
- Build advocacy capacity by empowering patients, caregivers, and other committed stakeholders with tools that help them advocate and influence change.

Edits:

Expand treatment beyond drugs and oxygen to include mental health. Include a goal of advocating for better daily living support.

Include empowering stakeholders to self- advocate/advocate. Build advocacy capacity by empowering patients, caregivers, and other committed stakeholders with tools that help them advocate and influence change.



OTHER

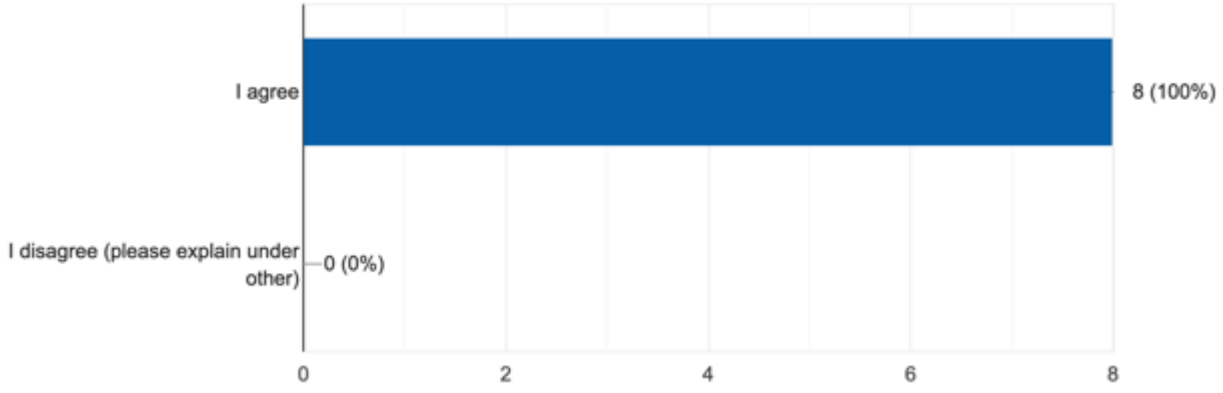
I see oxygen is in brackets but not as a priority

Q5. Are you in agreement with the edits to "Key Elements of Our Strategy #7"?

7. Build the fundraising capacity of the Foundation
   - Maintain strong relationships with existing corporate donors.
   - Develop fundraising plan which will include but not be limited to:
     - Acknowledgement of contributions of current and historical donors and nurturing relationships.
     - Development of donor data base and management plan.
     - Specific plans for individual calendar events (e.g.: Giving Tuesday, Pay it Forward etc.)
     - Strategy for attracting bequests.
     - Nurture new sponsor/major donor relationships with partners that align with CPFF's vision, beyond the pharmaceutical industry for financial and non-monetary support (e.g.: in-kind goods or services, media coverage, promotional partners).
     - Expand efforts to source funding for existing unfunded CPFF assets (e.g. educational webinars, CPFF events etc.) and create new sponsorable assets.

Edits:
Add strategic focus on nurturing new sponsor relationships in industries beyond pharma

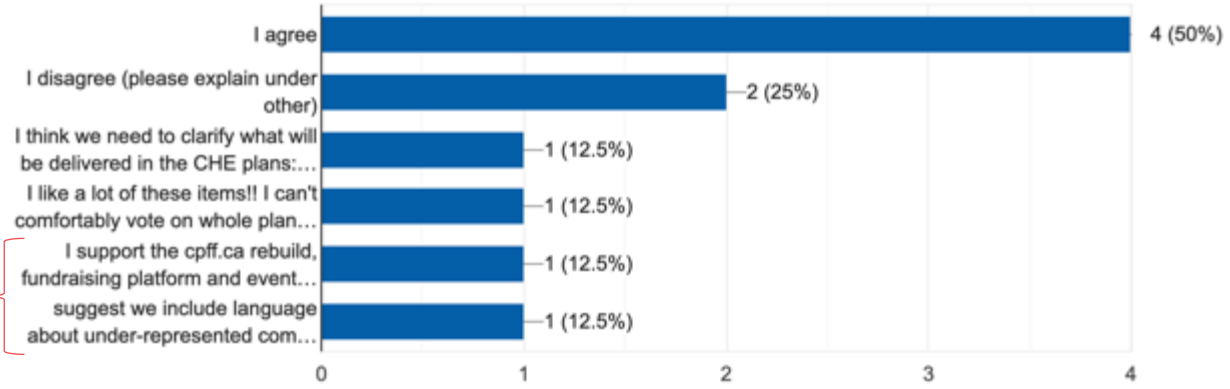
Add the creation of new sponsorable assets that can be funded by sponsors (eg. webinars, patient daily living support program)



PART 2 (8 responses)

CPFF Committee 3-year Work Plans

Q1. Are you in agreement with the focus areas for each year for the overall CPFF 3-Year Work Plan?



OTHER:

I DISAGREE

I disagree (please explain under other);I think we need to clarify what will be delivered in the CHE plans: are we providing the content or are we serving as a directory of resources or are we funding RNs, RTs, etc to get training case by case? Otherwise, agree with the plan

I disagree (please explain under other);I like a lot of these items!! I can't comfortably vote on whole plan as I feel budget is more than I feel comfortable with and feel some items should be removed.

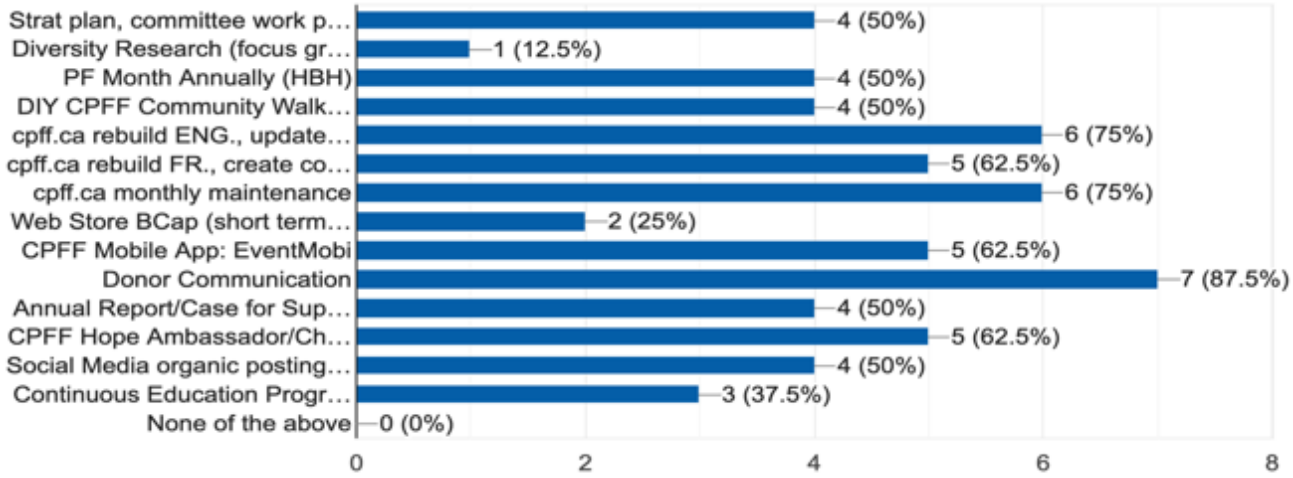
OTHER

I support the cpff.ca rebuild, fundraising platform and event engagement app but I do not agree that these are building the foundation for the foundation. A separate entity is the building of a solid foundation which is the structure - the detailed strategic plan, the mission, the governance and operational plan, the 3-year budget, marketing and communication plan, fundraising, Second point: Do not agree with the title 'Ambassador' program.

suggest we include language about under-represented communities in year 1 or 2; perhaps it's to better understand needs?

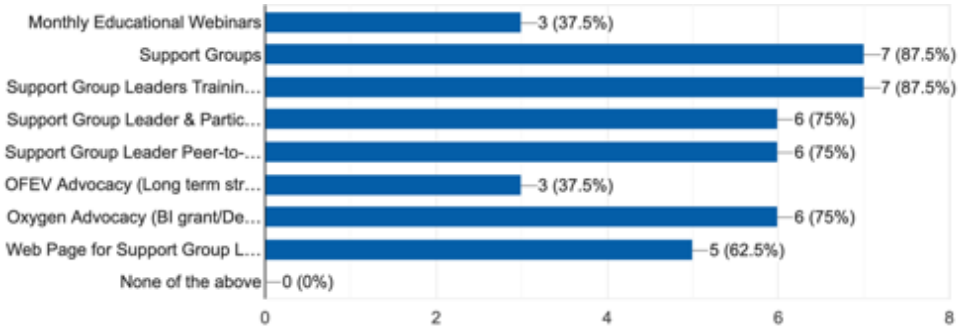
Q2. Communications Work Plan: Which projects do you feel meet the needs of patients and caregivers and support CPFF's Strategic Pillars? (Select all that apply)

Strat, committee, communications plan, community virtual open house;
Diversity Research (focus groups & surveys for under-represented patients)
PF Month Annually (HBH)
DIY CPFF Community Walk Toolbox
cpff.ca rebuild ENG., update & create content
cpff.ca rebuild FR., create content
cpff.ca monthly maintenance
Web Store BCap (short term solution)
CPFF Mobile App: EventMobi
Donor Communication
Annual Report/Case for Support
CPFF Hope Ambassador/Champion Program
Social Media organic posting & paid media ads & traditional ads
Continuous Education Program for Healthcare Pros

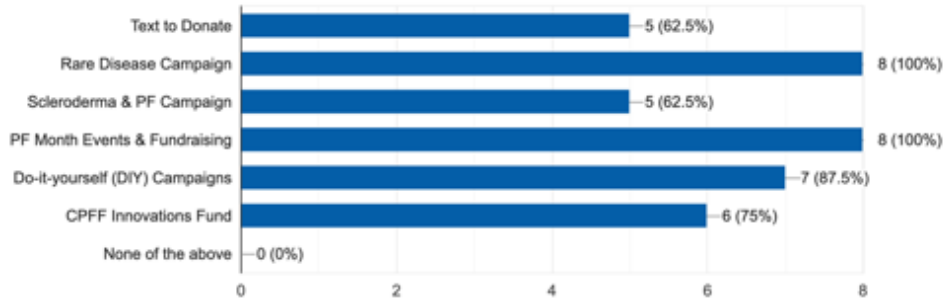


Q3. Advocacy & Support Work Plan: Which projects do you feel meet the needs of patients and caregivers and support CPFF's Strategic Pillars? (Select all that apply)

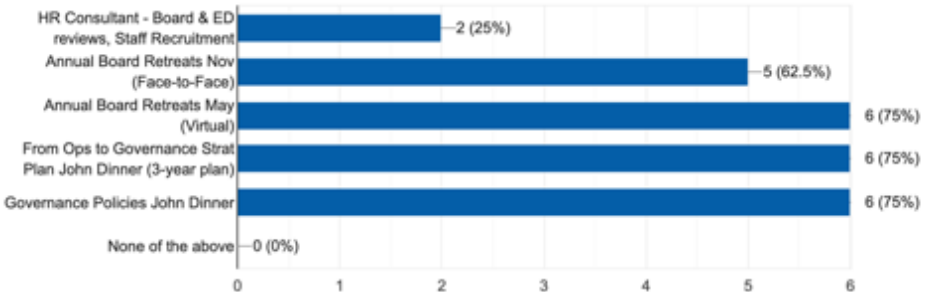
Monthly Educational Webinars
Support Groups
Support Group Leaders Training & Materials
Support Group Leader & Participant Survey
Support Group Leader Peer-to-Peer Meetups
OFEV Advocacy (Long term strategy, New Mode, GR and PR consultants)
Oxygen Advocacy (BI grant/Dec 2021. NewMode, GR, Whitepaper, Patient Videos, PR)
Web Page for Support Group Leaders



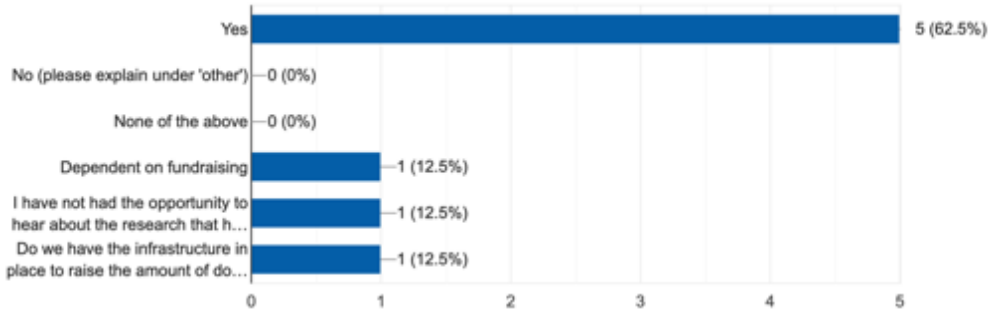
Q4. Fundraising & Events Work Plan: Which projects do you feel meet the needs of patients and caregivers and support CPFF's Strategic Pillars (Select all that apply)



Q5. Governance and Finance Work Plan: Which projects do you feel meet the needs of patients and caregivers and support CPFF's Strategic Pillars (Select all that apply)



Q6. Research Work Plan: Do you feel that CPFF should be committed to CPFF Research Grants and Robert Davidson Fellowships even without pharmaceutical funding?



- Dependent on fundraising
- I have not had the opportunity to hear about the research that has been supported so it is challenging to comment. Overall I support research if it advances the treatment choices for patients
- Do we have the infrastructure in place to raise the amount of dollars required for this commitment. I support the research totally but at what cost?

Q7. Research Work Plan: If you agree that CPFF should be committed to research grants and fellowships even without pharmaceutical funding, how should the budget be distributed between them? Please specify $$ amount for fellowships & $ amount for grants. The total budget is $220,000.

2 X $90K Fellows & 2 x $20K Research Grants
2 fellowships 0f 90 each, rest potential research. If only 1 fellowship rest could go to research if a good project is there.
$90K x 2 annually for RD Fellowships
Division should be decided annually based on quality of applications
Dependent on fundraising.
I need to know more about the criteria for applying for fellowships and or grants.
$150000
2 x $20k plus 2 x $90k seems to work. it would be great if we could fund 2-year fellowships as well.

Canadian Pulmonary Fibrosis Foundation

CPFF Board Village

Canadian Pulmonary Fibrosis Foundation

Get to Know CPFF's Board of Directors

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Mark Ashcroft

I grew up in the country the youngest of 4 boys. We spent all our time outdoors, hiking, fishing, camping, and canoeing. In my teen years, my brothers got me interested in motorcycles something I am still obsessed with today.

After school, I worked as a Paramedic before joining the Fire Service for 32 years.

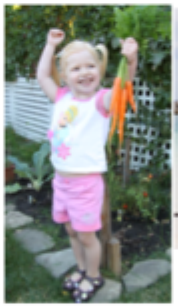
My wife (33 years) and I have 2 children and spent as much time as possible on our Muskoka River Property. When not there we are either watching or attending Blue Jay games.

In 1997, I lost a brother to IPF. My journey began in 2018 with a persistent cough and discovery of scarring on my lungs. Now I am waiting to hear if I am going to be listed for a transplant. Recently another brother has been diagnosed with IPF.

Charlene Fell

- I was born in North Vancouver and grew up in North Van and Honolulu.
- When I was a kid, I wanted to be the next Barbara Walters.
- I learned self-sufficiency and fierce independence from my mum. My dad taught me how to give a proper handshake and engage with people.
- I love to travel and cook and garden and make elaborate Halloween costumes and birthday cakes. My Italian buttercream needs work.
- I'm disappointed if I can't solve Wordle in 3 tries.
- Trees make me happy.
- Getting a dog was one of the best ideas I've ever had. Now I have two. Love them to bits.

- The centre of my world, and my greatest joy, is my daughter Zenovia!



I live for this kid
Zenovia

Todd Georgieff

CPFF Director since 2019

I was born and raised in Toronto and spent my teenage years thinking I would be a musician. After realizing that I probably didn't have the determination for that life, I ended up attending both UofT (Pharmacy) and York U (MBA). My instincts tell me I was right: there are likely fewer struggling pharmacists in the world than starving trombonists!

Despite my changed commitment, I credit those years to my ongoing love of music that ranges from popular (rock, pop, others) to jazz and classical. Since I was in public school, I have also been very interested in cooking. I probably still read way too much about food, wine, cooking and recipes, and I can't say I have a favourite cuisine. My latest deep-dive has been Indian cooking, particularly some of the regional vegetarian dishes.

My wife Nadine and I met in a weekend drawing class. We started dating, got married and then picked up and moved to Montreal – all within a six-month period (!) – twenty-five years ago. We moved to Montreal for my work, and we have loved living here from the start. I had the opportunity to live and work in San Francisco for eight of those 25 years, still keeping one foot in *la belle province*. I joke to my native Montreal friends that I actively chose to live here multiple times, whereas they were only born here.

In my work in pharmaceutical R&D a few of the people on my team were running clinical trials for a new drug for IPF (Esbriet), after the company I worked for acquired the company that had created it. It was my first extensive involvement in IPF, though I was aware of PF before.

My personal connection to PF came through my father-in-law, Donald Pamenter. He had a few health problems including breathlessness, mobility issues, and other issues his doctors originally attributed to angina. He was lucky enough to be referred to the Firestone Clinic in Hamilton. A couple of years later, he was telling me about his new drug, which was quite expensive (luckily it was covered by his insurance) and required him to take 9 capsules a day. Wait – are you talking about Esbriet? That's how I learned of his actual diagnosis of IPF. He passed away in February 2019, after a short time in home-based palliative care. Later that same year, I heard CPFF was looking for board members, getting involved was an obvious choice.

My wife and I still love Montreal, and we've gotten to know our small corner of it quite well, thanks to our fellow dog owners. We are proudly owned by a white standard poodle called Bella.

Sharon Lee

My parents are the most influential people in my life. They both survived WWII, came from large families; 9 on my mother's side and 6 on my dad's side and not everyone survived. They grew up poor but found ways to receive an education. I learned resilience from them in reaching my goals.

I'm an accomplished pianist and violinist.

I chose to graduate with a BA from the University of Toronto rather than a BSc from Computer Science. I have a MA from Saint Mary's University of Minnesota (Non-profit management with emphasis on Philanthropy & Development).

I am a Certified Fund-Raising Executive (CFRE) and recertification is required every 3 years.

I am a graduate of University of Toronto Rotman School of Management – Institute of Corporate Directors (ICD) Non-Profit Governance program for Executive Directors

I've been a Rotarian since 2007. Rotary Club of Etobicoke was charted in 1929, so we are celebrating 93 years of service in our community.

- President of my club for FY 21-22 and re-elected for FY 22-23.
- First woman of Chinese descent to become President
- First woman to serve as President back-to-back
- Fifth woman to serve as President in our 93 years of service
- Second woman to serve twice as President
- Chair of the International & Indigenous Service committee since 2015

The best thing anyone has ever said about me, are from the women who I've mentored throughout my life. They tell me how creative and strategic I am and that whenever they are unsure of what they should do, they ask themselves, "What would Sharon do?"

I am a HUGE Disney fan. I've been to all six Disney parks.

1. Disneyland in Anaheim, California, USA (6 visits)
2. Disney World in Orlando, Florida, USA (22 visits)
3. Disneyland (formerly Euro Disney) Paris, France (3 visits)
4. Hong Kong Disneyland, Hong Kong, China (2017)
5. Shanghai Disneyland in Shanghai, China (2017)
6. Tokyo Disneyland in Tokyo, Japan (2018)

Ranjena Maloni

Selfie of myself and my husband and kids at Christmas. What you cant see is that we are all wearing a matching PJ that I like to do at Christmas and that the 2021 said "We are Family". Describes me well and also why I joined CPFF - because of my family (Grandmother, Uncle).

Taken at a 2018 CPFF board retreat. My husband waiting in the hallway for me to finish meetings so I could nurse 1.5-month-old baby. One of the baby's first outings. Always been so supportive. While my family may not be the ones in the meeting, they are a big force in allowing me to do this.

Where I was born: Lachine, Quebec. Mother Trinidadian Chinese (grew up in Trinidad), Father Indian (grew up in UK).

My family dynamic growing up and how I fit in: Oldest of 3 girls, but also close with my 3 female cousins so really 1 of 6 girls!

The most influential person (s) in my life: My parents. They are also a big reason I volunteer as they strongly believe in service to your community where you can. My number 1 supporter is my husband who allows me to take on all the projects I love to be a part of (picture 2).

What you love to do and who you love to do it with: Love to travel and eat local food and experience different cultures. Love doing that with my husband and now with my kids!

The roots of your commitment to CPFF and your connection to pulmonary fibrosis: As a teen I saw my beloved grandmother battle and pass from PF, 20 years later I saw my Uncle be inflicted with the same disease and thankfully we had a better outcome as a family thanks to OFEV and lung transplant and advancements over the decades.

Moyra Martin

My husband Dick passed away from pulmonary fibrosis in 2018 after a twelve-year battle with this disease. I believe that to affect change, one must be involved. I am honoured to be a Director with the Canadian Pulmonary Fibrosis Foundation and to have opportunities to use my leadership skills to move forward actions that impact patients and all those affected by pulmonary fibrosis. I remain dedicated to supporting the mission of CPFF and I am confident that together we will continue to make a difference. I am an avid reader, theatre-goer and gardener, who loves to travel.

Moyra holds a Masters in Education and Human Resources and has served the Calgary Catholic School District as a teacher and administrator for 25 years. She has served on numerous educational committees at the district and provincial level and served as the Executive Director of the Calgary Catholic Education Foundation. Moyra is a proud Calgarian and an active volunteer with the Calgary Stampede.

Kirk Morrison

I was born in Sarnia, Ontario in 1958. My Dad worked for Imperial Oil During and so we moved a lot! I recall attending 8 different schools from kindergarten to Grade 13, so there was a lot of adapting!

After completing my engineering degree at the University of Waterloo in 1982, I moved to Calgary to work, and with the exception of 1986-88 when Michelle and I went to UBC to do our post graduate degrees, have lived there since then.

Michelle and I have been married since 1983, and we have 2 sons, Robert and Andrew, a great daughter-in-law, Jamie, and two beautiful grandchildren, Jax (8) and Bree (18 months).

The most influential people in my life? Clearly my Mom and Dad made me who I am, and I can also point to Michelle, my kids and their families, a bunch of friends, and co-workers, clients and fellow board members. However, given that we're talking about providing service to the PF Community, I thought it would be appropriate to acknowledge my grandfather, Bob Morrison, who taught me a lot about looking after clients.

My grandfather was a cattle broker - he bought and sold cattle. He was a big, imposing, and gruff man, but he liked taking his grandsons to work with him. On Saturday mornings he would pick me up and we would drive up to his farms around Arthur, Ontario where we would feed cattle, fix fences, eat lunch at the local diner, and do an assortment of other things (he also let me drive his car which was pretty cool for a 10-year-old!). We also always stopped in to visit countless farmers, meat packers, butchers, slaughterhouse operators, you name it. Grandpa had strong personal relationships with all of his clients and their families, and they knew him and his family equally as well. I never realized until after he had passed away, but this was an important part of the trips, as he used them to stay connected to his clients, to understand their needs, and most importantly, to maintain a personal connection. I've used Grandpa's approach throughout my career, and it has never let me down.

I am connected to CPFF through my mother, Barbara, who passed away from IPF in February 2020. Mom gently hinted that I should apply for the CPFF President position. When my mom tells me to do something, I follow through! I've attached a pic of Barb and her kids taken in December 2020.

Finally, something that I'm sure none of you know about me (or will be able to figure out) – I'm into my 5th decade as a Cementhead. I'll let you know what this means at the retreat 😊.

As always, look forward to getting together with you.

Verity Pringle

I was born in Vancouver, BC but moved to Whistler with family shortly after and have loved the mountains ever since. When I was five, my mother was diagnosed with breast cancer that had metastasized to her lymph nodes. Thanks to the research and treatment options being developed at the time, she was able to watch me and my sisters grow up and is still with us today. While I don't have any personal connections to PF, I'm happy to contribute to an organization advocating for the same level of research and treatment for disease since I've seen what an impact it can have.

I did a BSc at UBC focused on botany before doing a diploma in accounting and then my CPA. Currently, I work as an accountant in public practice doing audits and other assurance work with a client base consisting largely of local governments, charities, and not-for-profit organizations. I still like to bore family and friends with long examinations of mosses and other plants while out walking, though. In my spare time, I enjoy cooking, biking, hiking, skiing – both alpine and Nordic, gardening and pretty much anything else outdoors. My inability to sit still led me to start knitting and I usually have at least a pair of socks on the go at any given time.

Raymond Protti

I was born and raised in Edmonton, Alberta and have lived in various cities and provinces across Canada, e.g., Ottawa, Toronto, and Victoria where I have retired to.

My father spent his entire career in the health care sector and developed and implemented the nursing home care program in Alberta. Though my own career went in a different direction, I have long had an abiding interest in health care.

In doing extensive research on the little-known history of the paternal side of my family it has become clear that numerous family members, dating back to the mid 1880s suffered and died from various forms of lung disease.

In 2015, after 3 years of doctor visits and numerous tests, I was diagnosed with IPF. I was prescribed Esbriet and so far my breathing tests have been stable and I am not on oxygen. I have often wondered about a familial link between my condition and the lung insufficiencies suffered by my paternal ancestors.

Since my diagnosis, I have made it my business to research as much as I can on the nature of the disease and what I can do to help manage it successfully.

I am very pleased to be able to contribute to the work of the CPFF.

Dr. Holly Smith

I was born in 1950 Regina, Saskatchewan to an entrepreneurial mother, Ethel Shaw and a disabled father, Gordon Smith. He had lost his hand in the war and was active in war amps all of my childhood.

My parents divorced when I was four and we lived above daycare my mother started in the fifties. All of my family was musical and I love to sing and play the flute. My mother began a downward spiral with prescription drugs. Ultimately becoming addicted to a prescription similar to Ritalin and then benzodiazepines to help her sleep. We lived in the back of cars and as a child it was a challenging existence. Once I went to live with my father there was more stability in my life. But I always saw how the system treated men differently than women and how that contributed to my mother's early death. I was determined to gain an Education and understand gender and it's silent influence on women and minorities. I started off in social work then on to a Ph D in psychology. I am a life-long learner. I also still sing in a choir.

I live on a farm with my spouse, Duffy Fish, and our horses and two . We have two girls and just recently became grandmothers to our new grandson, Declan Dale Shin. I was diagnosed with IPF in 2015 and my partner also has a diagnosis of PF. She has yet to see a specialist. I became involved with CPFF because as a social activist I could see CPFF was making a difference. I wanted to be part of something where I felt that we were doing something to help those with CPFF and where the work I did mattered.

Dr. Gokul Vidyasankar

(1) I was born in St. John's NL and have always consider Newfoundland home.

(2) Youngest, loudest, and naughtiest child

(3) My wife has impacted my life in countless ways. However probably the most important way is that she has brought unpredictability into my life (i like to plan!) and with that, an energy I rarely had on my own.

(4) Favourite movies - Rocky I-V. No question

(5) Connection to IPF - As a Respirologist, we see a varied group of disease on a regular basis. PF to me is fascinating medically, but devastating clinically, and we have a lot of work to do to improve the horizon. To me, it is the area that I feel I can make the greatest impact in.