



The Canadian **DONATION** and
TRANSPLANTATION Research Program

Programme de recherche en **DON**
et **TRANSPLANTATION** du Canada

PATIENT, FAMILY & DONOR RESEARCH FORUM

3RD EDITION | JUNE 22-23, 2022



POST-EVENT REPORT



SUPPORTED BY

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OVERVIEW

The Canadian Donation and Transplantation Research Program (CDTRP), in cooperation with the Organ Donation and Transplantation Collaborative and the Canadian Society of Transplantation (CST), virtually hosted the 3rd edition of the Patient, Family, and Donor (PFD) Research Forum on June 22-23, 2022.

CDTRP's PFD Research Forum brings investigators, trainees, PFD partners, and stakeholders to advance patient-orientated research and engagement in donation and transplantation. Over the Forum's two days, speakers and panellists presented on PFD research priorities and discussed emerging best practices for patient engagement.



PLANNING COMMITTEE

The 2022 Planning Committee consisted of four CDTRP PFD partners, one CDTRP Trainee, and representatives of the Organ Donation and Transplantation Collaborative and the Canadian Society of Transplantation.



MARY
BEAUCAGE

Co-Chair

Patient Partner



MARIE-CHANTAL
FORTIN

Co-Chair

Investigator



RIENK DE VRIES

Patient Partner



LEONARD HODDER

Patient Partner



LINDSEY KEMP

Family partner



SYLVIA OKONOFUA

CDTRP Trainee



SARAH DOUGLAS

Health Canada
(ODTC)



RUTH SAPIR-PICHHADZE

Canadian Society
of Transplantation



The Committee members with their expertise and experience in donation and transplantation, planned the program over five meetings from April to June 2022.

The CDTRP Management team supported the Planning Committee throughout the process: Dr. Patricia Gongal, CDTRP Executive Director; Manuel Escoto, Patient, Family, and Donor Partnerships & Education Platforms Manager; and Stéphanie Larivière, Communications and Data Manager.

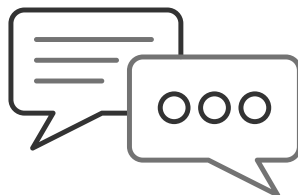


THE PROGRAM

The Committee thoughtfully curated a program reflective of relevant issues, opportunities, and emerging strategies in patient-orientated research and patient engagement. The Forum was divided into four blocks over the two-day event, thematically aligned with research priorities within the donation and transplantation field and moderated by a planning committee member.

1. **Equity, Diversity, and Inclusion in Patient Engagement;**
2. **PFDs in Knowledge Translation;**
3. **Patient Engagement in Research;**
4. **The Evolution of Research with PFDs.**

The Committee invited **24 speakers** to present **12 topics** relevant to the CDTRP community in donation and transplantation research. The speakers included 13 researchers or professionals with expertise in patient engagement and patient-orientated research. The program also had 11 PFD partners from across Canada with a variety of experiences in research. Per CDTRP's Terms of Reference, PFD partners are remunerated for their time preparing and presenting at the Forum.





PATIENT, FAMILY & DONOR RESEARCH FORUM

"The CDTRP Patient, Family and Donor Research Forum is a great opportunity for us to gather and learn about what's going on with patient engagement and research projects that are part of the organ donation and transplantation (ODT) landscape. This year we really wanted to focus on how PFDs can become more involved with research, especially those that have never thought about it before. There's also information for those that want to bring their engagement to the next level. We encourage our researchers to make time to join us too; the topics covered are relevant to everyone."

Mary Beaucage | Forum Co-Chair



"Working in partnership with patients in research and in the clinic opens me to different realities and allows me to anchor my work in issues that are relevant to patients."

Dr. Marie-Chantal Fortin | Forum Co-Chair



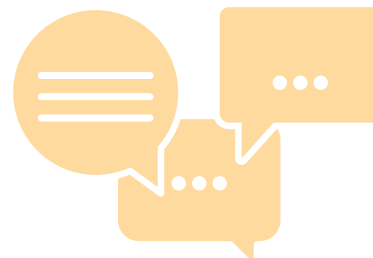
PROGRAM HIGHLIGHTS

DAY I

The morning of **Day 1** centred on discussions related to equity, diversity, and inclusion (EDI) in patient engagement. **Dr. Warren Fingrut** presented on the Stem Cell Club's Diverse Donor Save Lives campaign, outlining the impact of engaging diverse communities and the power of social media to engage harder-to-reach communities. Dr. Fingrut reminded participants that challenges remain, and we must continue developing and implementing donation policies that prioritize equity, patient safety, and address systemic racism in healthcare.

Dr. James Lan and Teresa Atkinson then presented on the Willingness to Cross Program, which improves access to transplants for highly sensitized and difficult-to-match kidney patients. Dr. Lan and Ms. Atkinson told the audience that EDI is fundamental to interprovincial organ sharing. There is a need to ensure patients from diverse backgrounds are recruited and that materials are understandable and appropriate.

The EDI block ended with a thought-provoking presentation and open discussion led by **Dr. Murdoch Leeies**, who focused on the 2SLGBTQIA+ community. To address existing inequalities, Dr. Leeies outlined his research, which is now at the patient engagement stage and will include the 2SLGBTQIA+ ally advisory team of patient partners. This advisory group will provide support throughout the research lifecycle, including setting research priorities, research design, knowledge mobilization, and future direction.



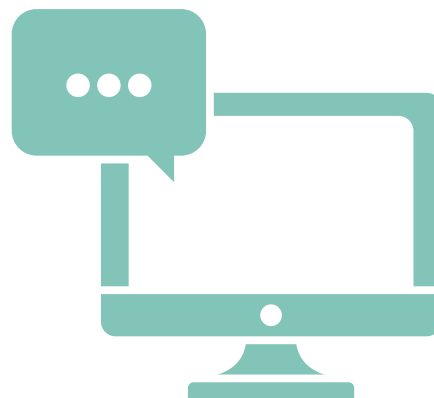


PATIENT, FAMILY & DONOR RESEARCH FORUM

The afternoon of the Forum's first day focused on PFDs in knowledge translation. **Dr. Davina Banner and patient partner Marc Bains** presented on the role of PFD partners in knowledge creation and translation. They discussed the value of integrated knowledge translation and the need for a collaborative research model based on the value of co-production, with partners engaged across the research process, and a recognition that PFDs are knowledge users.

The Forum's participants then heard from **Carrie Thibodeau and Kristi Coldwell**, who presented on a multi-year research project to improve engagement and empower patients on their transplant journey. As noted by the presenters, "Embracing the power of lived experience to guide and inform a truly patient-driven project where research priorities are defined by patients, families and donors." With PFD partners involved at every step, the project developed three recommendations to improve the transplant journey.

Our final presenters were **Alicia Murdoch and Linnea Franson from the Can-SOLVE CKD Network**, who presented how Can-SOLVE has embedded patient engagement throughout the Network. As a patient-oriented research Network, Can-SOLVE has incorporated patient partners throughout its projects, leadership, and governance activities. To be successful, they remind us of the need to (1) develop an onboarding process to understand what patients need to participate fully; (2) maintain clear and open communications; (3) honour what PFD partners bring regarding their experiential knowledge; and (4) to understand that relationships take time.





DAY 2

On **Day 2**, its morning concentrated on patient engagement in research. The first speakers were **Dr. Samantha Anthony** and **patient partner Joanna Mitchell** who presented on a mindfulness retreat intervention for mothers of pediatric transplant recipients. The presenters acknowledged the critical need to align research with patient and family needs. The presenters outlined that this project's success was because it was patient-informed. Key to the patient engagement strategy was developing inclusive mechanisms, maintaining respectful communication and collaboration, developing multi-way capacity building, recognizing the value of experiential knowledge as evidence, and creating a shared purpose.

Next, **Dr. Holly Mansell, Nicola Rosaasen, Paraag Trivedi, and Terry Steeves-Gurnsey**, spoke on their co-development of a video series to improve transplant education. With an overarching goal of improving transplant education, the presenters shared how patients and families shaped the project and research process. The mini-video series can be found on [CDTRP's Patient Portal](#). A key lesson shared by the presenters is that people are unique. One patient partner is not enough for the lifecycle of a project, and it is impossible for one person's lived experiences to fully represent the donation and transplantation community's diversity.

The morning's session closed with a stimulating **PFD partner panel featuring Sherrie Logan, Sylvain Bédard, Heather Badenoch, and moderated by Mary Beaucage**. Participants learned what inspired them to get involved in donation and transplantation and what they have learned from interacting with investigators and PFD partners. Key learnings from the discussion are the need to create a collaborative space where PFD partners are heard, and their experiential knowledge is recognized. One way to acknowledge this value is by compensating partners for their time and expertise.





PATIENT, FAMILY & DONOR RESEARCH FORUM

For the afternoon of Day 2, its theme focused on the evolution of research with PFDs. The Committee was pleased to welcome back **Dr. Lynne Feehan from the BC Support Unit**, along with her co-presenters Dr. Larry Mróz and patient partners Kristi Coldwell and Aggie Black. With the increase of PFD partners in grant reviewer roles, they shared results on building capacity for PFD partners to succeed in these roles. Recommendations include training on patient-oriented research, having a single organizational contact person, and providing clear and understandable materials and explanations on grant objectives, timelines, commitments, and rights & responsibilities as PFD reviewers. Formal training and ongoing mentorship for PFDs are also recommended.

The program welcomed **Dr. Maria Santana**, who presented on the Patient and Community Engagement Research (PaCER) program. With the goal of creating research by patients, for patients, and with patients, PaCER trains individuals with lived experience on how to conduct research. PaCER graduates have assumed roles in research, health systems, and patient engagement.

The Forum then concluded with research in action as two CDTRP PFDs facilitated a **workshop focused on COVID-19 and mental health**. Led by Sherrie Logan and Rienk de Vries, they wanted to understand the PFD perspectives on the impacts COVID-19 has had on mental health and the support required to improve their journey. This research aims to identify the support needed as the world transitions to a new normal, build resiliency, and improve support, and equitable access.



SUPPORT



The CDTRP counted on the support of **17 organizations** (16 national and one international) to help promote the Forum to their networks via social media, their organization's website, and newsletters. We also wish to thank Astellas Pharma, Inc. for their financial support.



PATIENT, FAMILY & DONOR RESEARCH FORUM

Each supporter received an English and French **Communications Kit**, which contained an overview of the event, prepared articles for their newsletters, post-ready social media posts, and graphics.

The CDTRP team is grateful for the ongoing support of:

- BC SUPPORT Unit
- BC Transplant
- Canadian Blood Services
- Canadian Liver Foundation
- Canadian Transplant Association
- Can-Restore
- Can-SOLVE CKD Network
- Canadian Society of Transplantation
- Kidney Foundation of Canada
- Newfoundland and Labrador SPOR SUPPORT Unit
- Saskatchewan Centre for Patient-Oriented Research (SCPOR)
- Stem Cell Club
- Swab the World
- Transplant Families
- Transplant Research Foundation of British Columbia
- Trillium Gift of Life Network (Ontario Health)
- World Transplant Games Federation

The **Twitter** event hashtag (**#PFDForum**) reached 67,300 individuals. Twitter posts with **#PFDForum** received 84 interactions and 69 likes, and were shared 15 times. CDTRP was also mentioned 44 times.

On **Facebook**, the Forum related content was liked 557 times and reached 7,281 individuals.





ATTENDEES

The Forum was attended by **157 participants from 68 cities across Canada and globally**. Our global participants came from Cameroon, Peru, India, Uganda, the United Kingdom, and the United States. Participants self-identified as researchers, health professionals, transplant patients or recipients, living donors, family/caregivers, or partner organization supporters.



POST-EVENT

The CDTRP prepared a post-event survey and shared it with all participants throughout the event, and in a [Thank You post to the CDTRP's weekly newsletter](#). The recordings are posted and will remain available on the CDTRP's website and on our YouTube channel.

VIEW THE RECORDINGS

Stay tuned for updates regarding CDTRP's 4th Annual Patient, Family, and Donor Research Forum scheduled for June 2023!

Participants who want to be updated for the 2023 Forum or other PFD opportunities are encouraged to subscribe to [CDTRP's weekly newsletter here](#).

Participants interested in joining CDTRP's PFD Partnership Platform are encouraged to complete our online application below.

BECOME A PFD PARTNER



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Programme de recherche en **DON**
et **TRANSPLANTATION** du Canada

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THANK YOU!

THANK YOU for helping make the
CDTRP's 3rd Annual Patient, Family and
Donor Research Forum a success!

If you have ideas for new sessions, email us
at info@cdtrp.ca.

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