

PATIENT, FAMILY AND DONOR RESEARCH FORUM

November 4-5, 2021

Post-Event Report



The Canadian **DONATION** and
TRANSPLANTATION Research Program

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

01 Overview

The Canadian Donation and Transplantation Research Program, in cooperation with the Organ Donation and Transplantation Collaborative and the Canadian Society of Transplantation, hosted the 2nd annual Patient, Family, and Donor Research Forum on November 4 – 5, 2021.

The Forum built on the success of CDTRP's first virtual Forum in 2020 and was proudly supported by twelve national and international supporters.

This event was dedicated to Canadian organ donation and transplantation research and how patient, family, and donor – or PFD – research partners have helped or are helping the success of that research, policy, and best practices.

"The CDTRP is a progressive program bringing meaningful and actionable research to transplant communities. They do this in a partnership where recipients, donors, families and researchers work together for the betterment of those communities."

-Co-chair Larry Worfolk



Planning Committee

02

The 2021 Planning Committee consisted of four CDTRP Patient, Family, and Donor partners and representatives of the Organ Donation and Transplantation Collaborative and the Canadian Society of Transplantation. **Larry Worfolk**, co-chair and lung transplant recipient; **Linda Powell**, co-chair and caregiver to a liver patient; **Joanna Mitchell**, caregiver to a pediatric heart transplant recipient; **Sarah Middleton**, a non-directed living donor; **Sarah Douglas**, Organ Donation and Transplantation Collaborative Secretariat; and **Dr. Rahul Mainra**, nephrologist and Canadian Society of Transplantation representative devoted their time through over ten planning meetings from June to November, bringing their expertise and experience to craft a relevant, impactful, and thought-provoking program for Forum participants.

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



Linda Powell
Co-Chair

Caregiver to a liver
patient



Larry Worfolk
Co-Chair

Lung transplant
recipient



Sarah Middleton
Non-directed living donor



Joanna Mitchell
Caregiver to a pediatric heart
transplant recipient



Rahul Mainra
Canadian Society of Transplantation



Sarah Douglas
ODTC – Health Canada

03 The Program

The Forum was divided into four blocks over the two-day event, thematically aligned with CDTRP's PFD partner profiles. Each was moderated by a member of the Planning Committee: 1. Caregivers and Family; 2. Transplant Recipients; 3. Living Donors & Education; and 4. Engaging PFDs in Research.

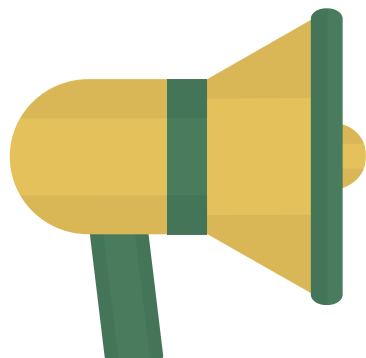
The Planning Committee invited **29 speakers** to present on 20 topics relevant to the PFD community. The speakers included **10 researchers and 14 patient, family and donor partners**.

The overarching goals of the Forum were two-fold. First, to empower participants to learn about the importance of PFD partnership in organ donation and transplantation research. Second, to provide practical examples of effective collaboration and patient from clinicians, researchers, trainees, and PFD partners.

"The CDTRP Patient Family Donor Research Forum is a dynamic example of the partnership and engagement of the patient, family and donor community in organ donation and transplantation research [It is an opportunity to] learn, engage, participate and be involved! Ultimately, we all seek the best care for all."

-Co-chair Linda Powell

PFD speakers were provided with a stipend for their time to prepare and present at the Forum. All speakers who were not patient, family and donor representatives were professionals who have worked with patient, family and donor partners in research and could attest to the power of PFD involvement in research.



29 SPEAKERS
10 RESEARCHERS
14 PFD PARTNERS

Program Highlights

04

The morning of the Forum's **first day** centred on discussions related to families and caregivers. Some mentioned the benefits that can occur with patient engagement in research projects:

- Improves patient and health system outcomes
- Improves quality of care
- Improves the quality and relevance of research
- Provides new ideas not previously considered
- Facilitates the recruitment and dissemination of results
- Promotes the transfer of knowledge and the translation of research results into practice
- Empowers patients, families, and donors

Afterwards, participants learned about the vast social and economic impacts of caregiving, an overview of resources available to support them, and a discussion of current knowledge gaps in caregiving policy and research.

The afternoon of the Forum's first day focused on transplant patients, first, how organs can be better utilized in Canada, followed by how PFDs can be engaged at the World Transplant Games. Next, discussions examined how to improve engagement and empower patients on their transplant journey and how PFDs are being engaged in the development of recommendations to improve the organ donation and transplantation system in Canada through the work of the Organ Donation and Transplantation Collaborative.

On **Day 2**, the morning concentrated on living organ donation and education. After hearing a moving living organ donation story telling us what living donation means for the recipient, their family, and the donor, participants then heard about how school children are being taught about organ donation in Alberta and in Ontario.

For the afternoon of Day 2, the theme was engaging PFDs in research. The patient-focused website www.mykidneysmyhealth.com was presented, which was created for kidney patients by kidney patients. Lastly, participants heard from three Indigenous perspectives on their patient-oriented research journeys and how researchers can build their cultural competency.

05 Support

The CDTRP counted on the support of **12 organizations** (11 national and 1 international) to help promote the Forum to their networks via social media, their organization's website, and newsletters.

The CDTRP team is grateful for the ongoing support of:

- Can-Restore
- Can-Solve CKD Network
- Canadian Blood Services
- Canadian Society of Transplantation
- Canadian Transplant Association
- Cystic Fibrosis Canada
- Kidney Foundation of Canada
- Organ Donation and Transplantation Collaborative
- Stem Cell Club
- Swab the World
- Transplant Research Foundation of British
- World Transplant Games Federation

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 event hashtag (#PFDForum) reached 132,100 individuals, was used 98 times, was shared 160 times, and received 233 likes.



#PFDForum

Attendees

06

The Forum was attended by **189 participants from 89 different cities** across Canada and globally. Our global participants came from France, India, Ireland, Senegal, the United Kingdom, and the United States.

Participants self-identified as researchers, health professionals, transplant patients or recipients, living donors, family/caregiver, or partner organization supporters. They came from **75 organizations**, including health authorities, transplant centres, universities, research networks, patient partnership networks, industry, and the not-for-profit sector.

Participants remained very engaged throughout the presentations, panel discussions, questions & answers, and poll questions and contributed to active discussions with speakers and other participants.

"THE PERSONAL STORIES ARE ENERGIZING - IT MAKES ME WANT TO BECOME MORE INVOLVED."

"EXCEPTIONAL VARIETY OF SPEAKERS, WELL ORGANIZED, EXCELLENT ENGAGEMENT AND REPRESENTATION FROM ALL LIVED EXPERIENCE SPEAKERS."

"HEARING FROM A DIVERSE GROUP OF PEOPLE WITH DIFFERENT EXPERIENCES AND HAVING THE OPPORTUNITY TO ASK QUESTIONS."

"I ENJOYED IT ALL!"



07

Post-Event

The CDTRP prepared a post-event survey and shared it with all participants throughout the event, as well as in a Thank You post to the CDTRP's weekly newsletter. The recordings are posted and will remain available on the CDTRP website.

[VIEW RECORDINGS](#)

CDTRP will announce the date for the 3rd Annual Patient, Family, and Donor Research Forum in early 2022.

Participants who would like to be kept up to date for the 2022 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 email mescoto@cdtrp.ca.

"Research is not something that is widely discussed among typical transplant forums and this is an area I am interested in. I like to be able to share new findings/advances through my organization's social media, as I think there are others who might like to know as well. Also, our provinces have very different regulations and programs and we tend to stay within our own provinces with information sharing. So it was great to learn more about what other provinces are accomplishing."

- PFD FORUM PARTICIPANT

THANK YOU for helping make the CDTRP's 2021 Patient, Family and Donor Research Forum a huge success!