

# PATIENT, FAMILY AND DONOR RESEARCH FORUM

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## POST-EVENT REPORT

OCTOBER 15-16, 2020



**2020**  
EDITION



# OVERVIEW

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The Canadian Donation and Transplantation Research Program, in cooperation with the Organ Donation and Transplantation Collaborative, Canadian Society of Transplantation and fourteen national and international supporters, was pleased to host the first virtual **Patient Family and Donor Research Forum** on October 15-16, 2020. The event was a substitute for the one-day in-person conference typically held prior to the CDTRP Annual Scientific Meeting.

The Forum was divided into four distinct blocks and themes: 1. Caregivers and Family; 2. Transplant Recipients; 3. Living Donors and 4. Future avenues for research.

Each block was hosted by a patient, family and donor research partner who was a member of the Planning Committee. Content was planned around current, upcoming and concluded projects that were transformed by including a patient, family and donor research partner in the project planning. Timely topics were also included, such as COVID-19 and its effects on the lives of transplant recipients and racial-based and sex-based disparities in transplantation and donation.

To whet participants' appetites and support them to better understand research, a month before the event, we recorded and posted two presentations, on how the immune system works and how to read a scientific publication. The topics and presentations were prepared by CDTRP Trainees, graduate students Laura Westhaver from Halifax and Alissa Rutman from Montreal.

A large teal speech bubble containing the text "189 registrants From 86 cities across Canada and globally". Below the bubble are three stylized hands in shades of orange and yellow, with blue cuffs, appearing to hold the bubble.

**189 registrants**  
From **86 cities** across  
Canada and globally

## Support of 14 organizations



# PLANNING COMMITTEE AND PROGRAM

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The Planning Committee was composed of Heather Badenoch, a non-directed living donor; Sylvain Bédard, a two-time heart recipient; Kristi Coldwell, a heart recipient, and Hans Vorster, a kidney recipient. It was supported by Dr. Rahul Mainra, representative of the Canadian Society of Transplantation, Dr. Mélanie Dieudé, CDTRP Executive Director, Patricia Gongal, CDTRP Director of Strategic Communications, Stéphanie Larivière-Beaudoin, CDTRP Data Manager, and Chelsea Patriquin, CDTRP Research Manager. Observers included Elizabeth Dunning and Marie-Hélène Gérome from Health Canada.

Through over five one-hour meetings from July to October, the Planning Committee prepared 21 topics for the program and arranged for **52 speakers**, of which 21 were patients, family, or donors. Patients, family and donors invited to speak were provided a stipend for two hours; one for preparation and one for speaking. Other speaker profiles included clinicians, research coordinators, nurses, and trainees involved in critical care, infectious diseases, nephrology, physical therapy, hepatology, hematology, cell, xenotransplantation, psychology and transplantation. All speakers that were not patient, family and donor representatives were professionals who have worked with patient, family and donor partners in research and could attest to their importance.

Speakers hailed from **seven provinces**: Alberta, British Columbia, Manitoba, Nova Scotia, Ontario, Saskatchewan, Quebec and one international representative from Switzerland.

**52 speakers**  
**From seven provinces**



# SUPPORT AND COMMUNICATIONS

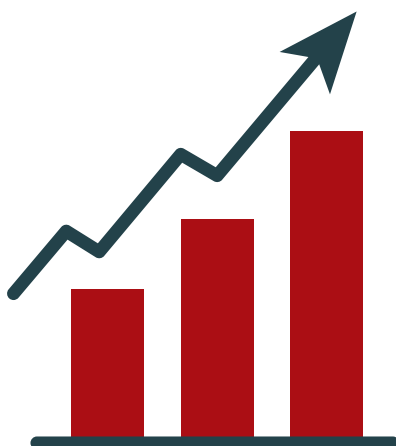


The CDTRP counted on the support of **14 organizations** (13 national and 1 international) to help with promotion for the event on social media platforms and via their networks:

- Astellas Pharma Canada, Inc
- Can-Restore
- Canadian Blood Services
- Canadian Liver Foundation
- Canadian Society of Transplantation
- Canadian Transplant Association
- Centre of Excellence for Partnership with Patients and the Public
- Cystic Fibrosis Canada
- Kidney Foundation of Canada
- Organ Donation and Transplantation Collaborative
- Stem Cell Club
- Swab the World
- Transplant Research Foundation of British Columbia
- 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 pictures.

The event hashtag (**#PFDRF**) reached **9,331 individuals** and had **22,194 impressions on Twitter, Instagram and Facebook**. In the month leading up to the event, the webpage for the Forum had 909 visits to the main page and **849 visits** to the program page. The pre-symposia videos were accessed 170 times.



**#PFDRF REACH**  
9,331 individuals  
22,194 impressions on socials  
849 visits on website

# ATTENDEES

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The Forum attracted **189 registrants** from **86 cities across Canada and globally** (including Bordeaux, Toulouse, Dublin, Budapest, Moscow, Cape Town, and Panama City). Representing an average attendance rate relative to registrations for an online event, there were approximately 50-70 participants in each of the sessions. Overall, attendees were highly engaged: they answered 22 polls throughout the event at a 50-75% participation rate and participated in a lively discussion on the open chat with speakers and other participants with 375 messages exchanged.

# POST-EVENT

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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 will be posted and will remain available on the [cdtrp.ca](http://cdtrp.ca) website.

# COMMENTS FROM ATTENDEES

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"It was a beautiful thing to see an event *for* patients, families and donors come together – where we aren't an afterthought, but where two days of sessions were actually **FOR** us."

"All comes down to **KNOWING** I am **NOT** alone and am valued in research."

"I have to admit not being a Canadian. British Transplant recipient, It has been a privilege to join you for these 2 days I have learnt a lot and it has been a pleasure to listen to all the presentations."

"As a trainee new to the field of transplantation, this was an amazing introduction to the people at the heart of it... Even though this was a virtual forum, I found it one of the most engaging conferences I have ever attended."

"I am very interested in getting involved in research with our own hospital and found a few ideas on how to approach them."

