

The Canadian **DONATION** and **TRANSPLANTATION** Research Program

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

ANNUAL REPORT 2021

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EXECUTIVE SUMMARY



The Canadian Donation and Transplantation Research Program (CDTRP) was founded in 2013 with the mission of harnessing the power of research and collaboration to fulfill every donation opportunity and turn transplantation into a cure. CDTRP brought together the distinct solid organ, hematopoietic cell, and donation research communities through funded research projects, and transitioned in 2018 to become a national network of infrastructure to support research.

With its platforms, five inter-related research themes and four cross-cutting priorities—identified through a collaborative process engaging patients, donors, and families—the CDTRP rapidly became the 'go to' platform in Canada for donation and transplantation research. Through the network, CDTRP investigators bring new ideas, find collaborators and partners, and receive resources and infrastructure to strengthen their research and increase their success. The network has grown to include 344 member researchers, trainees, and patient, family and donor partners at 37 sites across Canada, with 70+ partner organizations in Canada and around the world. The research community's ability to produce, synthesize, and mobilize evidence, work together flexibly with partners, and connect people and organizations is forging the path to health, social, and economic benefits. Indeed, connectivity is the most-valued aspect of the CDTRP: connecting researchers to each other, with the network of partner organizations and stakeholders, and with patient, family and donor partners.

In 2021, the CDTRP continued to evolve as a research support network, showing agility in addressing emerging priorities, while consolidating and strengthening support for crucial longstanding initiatives. The CDTRP integrated patient, family and donor engagement even more strongly in its initiatives, forged new partnerships, and continued to develop international connections and impact. The CDTRP management team welcomed new skills, perspectives, and expertise to meet the needs of the research community, and built new systems and ways of working to more effectively sustain research excellence and impact. The community has responded with even stronger engagement and enthusiasm for working together to drive excellence in knowledge generation and benefits across the broad donation and transplantation research and innovation ecosystem. The result can be seen in the many examples of stellar scientific outputs, collaborations, partnerships, and events that are increasingly being recognized internationally.

CDTRP's vision is for a Canada where transplant recipients are confident that their chronic disease or refractory blood cancer is truly cured. Through research, innovation, and knowledge mobilization of the highest quality and rigour, and by collaborating with patients, families, donors and partners every step of the way, this network – this community – can deliver this shared vision.

THE CDTRP TEAM DEEP ROOTS, FRESH FACES

The CDTRP is a network of people. It is the interaction between different groups and individuals that sparks new ideas, supports ongoing collaborations, and helps connect people to sources of new expertise. As the primary infrastructure for supporting the research community, the management team — its evolution and growth — reflects this approach. In 2021, the management team welcomed new faces and roles, diversifying its skills, perspectives, and professional backgrounds. This includes two talented members who are also transplant recipients themselves.



Dr. **Mélanie Dieudé**, PhD Executive Director



Dr. **Patricia Gongal**, PhD Director of Strategic Communications



Dr. **Julie Turgeon**, PhD Program Coordinator



Ms. **Demitra Yotis**, MSc Clinical Data Coordinator



Ms. **Katie Bain**, BSc Research Manager



Mr. **Manuel Escoto**, MPH Manager of Patient, Family and Donor Partnerships & Education



Ms. **Stéphanie Larivière** Communications & Data Manager



Ms. **Diana Tertzakian**, BA Administrative Assistant

The CDTRP Senior Leadership team continues to provide deep connections to the pan-Canadian research community, across donation and transplantation, organ systems and stem cells.



Dr. Lori West Scientific Director University of Alberta



Dr. Marie-Josée Hébert Scientific Co-Director Université de Montréal



Mr. Kristian Stephens, MSc

Knowledge Translation

Coordinator

Dr. Jean-Sébastien Delisle Associate Director (Hematopoietic Stem Cell Transplantation) Université de Montréal



Dr. Sonny Dhanani Associate Director (Donation) - CHEO

RESEARCH SERVICES & DATA INNOVATIONS PLATFORMS

5 RESEARCH THEMES

- Theme 1: Improve a culture of donation
- Theme 2: Inform Universal Practices for Donation
- Theme 3: Engineer and Allocate Better Grafts
- Theme 4: Tailor an Optimal Immune System for Each Patient
- Theme 5: Restore Long-Term Health



- Research Services
- Patient, Family, and Donor Partnership
- Education and Career Development



- Sex and gender
- Pediatric, adolescent and elderly populations
- Indigenous, rural and remote populations
 Policy, commercialization and knowledge transfer

The platforms consolidate new and emerging tools to meet the needs of the CDTRP research community. Research Manager Katie Bain works with investigators, connecting them to the tools and guidance they need to advance their projects. In 2020-2021, by committing **\$202,000 cash and in-kind** in letters of support, CDTRP helped investigators secure **\$5.4 million** in new grant funding – representing >26-fold in leveraging.

CLINICAL TRIAL DESIGN AND SUPPORT

The CDTRP connects investigators to the right experts for advice in designing and running clinical trials, including access to biostatisticians, resources to develop contracts, submissions to institutional research ethics boards and Health Canada regulatory approval, contract research organizations, and it facilitates a monitoring panel for trials. In 2021, 10 ongoing or proposed projects requested this assistance. With the help of Program Coordinator Julie Turgeon, the CDTRP's independent Data Safety Monitoring Board's (DSMB) seven members evaluate study data for participant safety, study conduct and progress, and recommend continuation, modification or termination. In 2021, Dr. Simon Urschel (University of Alberta) and Prof. Tony Panzarella (University of Toronto) joined the DSMB, expanding its expertise to match the requirements of the enrolled studies. Six studies are currently enrolled in the DSMB.

ECONOMIC, ETHICS, LEGAL AND SOCIAL SCIENCES (EELS)

Twelve ongoing or proposed projects requested EELS assistance from the CDTRP in 2021. To expand access to EELS expertise, the CDTRP is trialling a partnership with the Ottawa Methods Centre, whose services include research design methodology, knowledge synthesis, biostatistics, health economics, data management, and big data analytics.



EELS SUPPORT TO ACCELERATE RESEARCH TO MARKET

PROJECT HIGHLIGHT

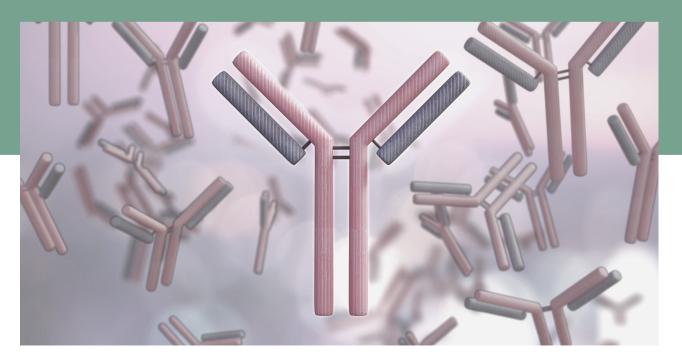


ALLOGENEIC THYMUS-DERIVED TREGS TO PREVENT CHRONIC INFLAMMATION IN TRANSPLANTATION

PI: DR. MEGAN LEVINGS (UBC); CO-PIS: DR. ESME DIJKE (U ALBERTA), DR. LORI WEST (U ALBERTA)

Awarded a 2021 CIHR Team Grant: Preparation to Trial: Inflammation for Chronic Conditions | \$750,000

This project builds on CDTRP work demonstrating that the routinely-discarded human thymus is a unique source of abundant, stable and potently-suppressive therapeutic Tregs. The goal is to provide thymic Tregs to humans as an allogeneic, "off-the-shelf" cell therapy product. The CDTRP is supporting a collaborative market analysis and economic assessment, including a cost assessment for clinical roll-out with the economics research team led by Dr. Kednapa Thavorn at the Ottawa Methods Centre. A trainee from the Thavorn group has enrolled in the CDTRP training program, a step towards increasing Canada's capacity in health economics experts interested in donation and transplantation.



CDTRP NATIONAL SPECIMEN INVENTORY (NANSI)

The CDTRP is working with partners to integrate a national infrastructure linking organ and stem cell donation, solid organ transplant (all organs) and hematopoietic cell transplant data and samples in a secure, searchable and usable interface. The CDTRP National Specimen Inventory (NanSI) portal (<u>https://cdtrp.bcchr.ca/</u>) provides two sections, one for the PREVenT-COVID Study (see page 17), and the other for all other biobanks. Within the PREVenT-COVID arm of NanSI, the portal will contain a Query Builder, a Data Dictionary, and a Dashboard containing only information related to catalogued samples from PREVenT-COVID. Catalogued specimens will provide information on baseline patient demographics as well as sample collection. Within the CDTRP management team, this work is led by Communications and Data Manager Stéphanie Larivière.

MANAGEMENT RESOURCES, SMALL MEETING SUPPORT, AND CONNECTIONS TO EXPERTISE

The CDTRP management team offers logistics assistance, including organizing meetings, building national collaborations, and linking to expertise in areas including biomarkers, immune monitoring, artificial intelligence, and patient-reported outcome measures. In 2021, 37 ongoing or proposed projects requested these types of help.



COMMUNICATION AND KNOWLEDGE TRANSLATION (KT)

The CDTRP Communications Team (Director of Strategic Communications Patricia Gongal, Communications and Data Manager Stéphanie Larivière, and KT Coordinator Kristian Stephens) helps teams plan, develop and disseminate their research outputs. Further, it coordinates the development, translation (French/English), and dissemination of FAST FACTS summaries for the public and experts. Outputs are shared via communication channels, including social media and the CDTRP Patient Portal. In 2021, 39 ongoing or proposed projects requested KT assistance.

KNOWLEDGE TRANSLATION SUPPORT TO DRIVE RESEARCH IMPACT



PROJECT HIGHLIGHT

ADVANCING PUBLIC AWARENESS AND TRUST IN THE DONATION SYSTEM

The pan-Canadian **DePParT study**, led by **Dr. Sonny Dhanani** of the CHEO Research Institute, was published in the *New England Journal of Medicine* (January 28, 2021), one of the most impactful peer-reviewed medical journals. Families who choose organ donation must trust that death has really happened and that it is permanent. Yet, stories persist about people "coming back to life" following a declaration of death, and there was little evidence to inform the medical understanding of dying. DePParT, the largest international deceased donation clinical study in the world, was only made possible by the CDTRP's collaborative framework and the involvement of donor family partner and paper co-author Heather Talbot. The study showed that cardiac activity often stops and re-starts several times during the dying process – and that no patient regained sustained circulation or consciousness – and that the current standard to wait five minutes after the heart stops before declaring death and proceeding to organ donation is appropriate.

Collaborating with the lead institution's communications officer, the CDTRP Communications Team led the preparation of a press kit, organized a media availability for Dr. Dhanani, Dr. West, and Ms. Talbot, developed a press release and pitched the story to media outlets. As a result, 22 mainstream news articles and radio featured this research, including the National Post, The Star, Reuters Health, Vice, and CBC. CDTRP's social media outreach efforts reached an audience of over 6000 within a week. Families and health care teams can trust that when death is determined, it is safe to begin the organ donation process, and through KT support, CDTRP has worked to build public awareness of the research evidence behind this clinical practice.

RESEARCH INNOVATION GRANTS

This program is a peer-reviewed, national competition that provides \$30,000 in seed funding for innovative pilot projects. For the 2021 competition, through **six partnerships** (The Addison Fund/Transplant Research Foundation of British Columbia, The Venture Grants/Transplant Research Foundation of British Columbia, the Kidney Foundation of Canada, Trillium Gift of Life Network - part of Ontario Health, the Université de Montréal and the UHN Multi-Organ Transplant Program), the program invested **\$360,000 in 12 projects** (Appendix X).



GRANT HIGHLIGHT | CDTRP - KIDNEY FOUNDATION OF CANADA RESEARCH INNOVATION GRANT

IDENTIFYING SEX-BASED DISPARITIES IN REFERRAL FOR TRANSPLANT, ACTIVATION ON THE WAITLIST AND KIDNEY TRANSPLANTATION

PI: Amanda Vinson, Dalhousie University (early-career researcher)

This project is creating a series of identical cases of male and female patients with kidney failure, presenting a combination of these cases to kidney specialists across Canada, and asking whether they would place the patient on the transplant waitlist or not. The researchers will then determine if there is a difference in referral rates for men versus women, and if the gender of the responding doctor changes this result. Second, the project will explore rates of kidney transplant in patients from Nova Scotia over 10 years to determine if there is a difference in the likelihood of male and female patients being referred for transplant, accepted and placed on the transplant waitlist, or receiving a transplant once on the waitlist. This study will identify if there is a difference in transplant rates in Canada between men and women, and if so, why. Identifying these differences is the first step towards fixing them.

PATIENT, FAMILY AND DONOR PARTNERSHIP PLATFORM



patient, family, and donor partners are co-leads and co-researchers on active projects



new individuals joined the Platform this year



active CDTRP-supported projects have PFD partner involvement

new projects engaging the PFD platform started up in 2021

6



requests for PFD Platform assistance While researchers are experts on diseases, patients and their families are experts in living with those diseases. In 2021, the CDTRP Patient, Family and Donor (PFD) Partnership Platform welcomed its new Manager, Manuel Escoto. He brings not only multi-sectoral professional experience, a Master's degree in Public Health, but also lived experience as a kidney recipient. Under the leadership of Dr. Marie-Chantal Fortin, the PFD Partnership Platform has continued to integrate PFD voices into all aspects of the research life cycle and CDTRP activities. Some 2021 examples:

- The CDTRP led three workshops to develop the PREVenT-COVID project (see page 17). The Expert Panel Meeting and National Stakeholder Workshop included PFD partners. In April 2021, the CDTRP held a workshop "COVID-19 Vaccination in Transplant Patients: Communication of Research with Patients and Families" to develop the KT strategy (Link: Event Report).
- For the Organ Donation and Transplantation Collaborative strategic ecosystem mapping project supported by CDTRP (see 'Looking Forward'), PFD partners were included in interviews and surveys.
- For the International Legislative and Policy Forum (see page 15), 14 PFDs were involved in the Chapter working groups, and reported feeling that their opinions and perspectives were highly valued in developing the recommendations.

In 2021, PFD Theme Co-leads began attending CDTRP Executive Committee meetings, and various planning committees and working groups (e.g., the Annual Scientific Meeting planning committee) included PFD members. PFD partners are now invited to all Theme calls. However, meaningful engagement required that academic presenters adapt their content to be more easily understandable to those outside the field, and Research Manager Katie Bain works to communicate helpful practices to speakers. For the first time, in 2021, PFDs participated as reviewers in the Innovation Grant peer-review process. The CDTRP management team worked closely with PFD partner Kristi Coldwell from the Transplant Research Foundation of British Columbia to offer training to PFD reviewers, to ensure they felt equipped for the process. Following the peer-review process, debriefing indicated the PFD reviewers had variable perceptions and experiences. We will be using their feedback to enhance the training offered, and to carefully review the preparation and materials for academic reviewers, to strengthen the capacity of both sides of the researcher-PFD partnership to understand each other's perspectives and expertise.

"Our PFD membership has grown substantially and our members are actively engaged within their Theme S projects. I'm personally excited about the work being done in Theme 5, as this year we launched three Hubs. We have a Hub for Exercise, Nutrition and Mental Health. These research areas were high priorities for the PFD members."

-Sandra Holdsworth, PFD partner and Theme 5 co-lead

An exciting development is increasing international engagement and shared learning about effective PFD research partnerships. Other organizations are now regularly seeking the CDTRP's advice on how to involve patients, families and donors in research. In 2021, Executive Director Mélanie Dieudé and PFD Platform Manager Manuel Escoto presented on the CDTRP model of PFD partnership at the American Society for Histocompatibility and Immunogenetics annual meeting and the Cell Therapy Transplant Canada annual meeting, premier research events in their respective fields. As well, the CDTRP's model for including PFDs in research leapt onto the international scene in the recommendations stemming from the International Legislative and Policy Forum. The first research. This focus on the depth of engagement with PFDs will continue in 2022.

EVENT HIGHLIGHT: 2021 PATIENT, FAMILY AND DONOR RESEARCH FORUM

The Forum provided the opportunity to inform and advance collaborations between investigators and patients, family, and donors as active contributors to research projects and knowledge mobilization. Registrants included about 190 people from six countries. Chaired by Linda Powell (caregiver) and Larry Worfolk (transplant recipient), the program included **29 speakers, of whom 14 were PFD partners**. Presentations and discussions focused on issues related to families and caregivers, such as the vast social and economic impacts of caregiving; issues related to transplant patients, such as how to improve engagement and empower patients on their transplant journey; issues related to living organ donation and education, for example, how school children are being taught about organ donation in Alberta and in Ontario; and issues related to engaging PFDs in research, including three Indigenous perspectives on their research journeys and how to build cultural competency.

DOWNLOAD REPORT HERE



EDUCATION AND CAREER DEVELOPMENT PLATFORM

The Education and Career Development Platform has continued to grow under the leadership of Lee Anne Tibbles, Kristina Krmpotic, Francis Migneault and the management of Manuel Escoto. The Platform works with CDTRP trainees through the Academic Program, collaborative learning opportunities such as lab exchanges, and funding for virtual conference registrations (instead of traditional pre-pandemic travel to attend the CDTRP Annual Scientific Meeting). Trainees have also been increasingly integrated into the broader life of the network, including presenting their work at Theme calls, to PFD partners, joining planning committees (such as for the Annual Scientific Meeting), and being welcomed into high-profile, international or national projects and events such as the International Legislative and Policy Forum (see page 14).

Designed by trainees, the 2021 webinar series focused on **"Diversifying your research"** and was funded by Novartis Canada and Aequus Pharmaceuticals (see Appendix page 26). As well, the CDTRP partnered with the University of Toronto's Training Program in Regenerative Medicine to offer the multidisciplinary regenerative medicine graduate course for 2020-2021, providing CDTRP trainees with the chance to connect with some of the best organ transplant, hematopoietic cell transplant, and regenerative medicine researchers in Canada. Over 2020-2021, the CDTRP funded eight trainees to attend the Ontario Indigenous Cultural Safety Program to provide the foundation for positive partnerships with Indigenous peoples over their career.

"I have been a trainee with CDTRP for a little over a year now, and in that short time, CDTRP has made it possible for me to connect with fellow trainees, scientists, and patient partners from across Canada. Thanks to CDTRP, I've had ample opportunities for interdisciplinary collaboration on important and underexplored research topics, and I've forged lasting partnerships that have helped to launch my career. Through CDTRP, I was even able to join an international initiative aiming to develop optimal organ donation and transplantation systems around the world."

- Dr. Nicholas Murphy, postdoctoral fellow



CONNECTING TRAINEES WITH KNOWLEDGE TRANSLATION OPPORTUNITIES

VIRTUAL CONFERENCE: KEY POLICY ISSUES IN ORGAN DONATION AND TRANSPLANTATION, JUNE 17-18, 2021

HOSTED BY THE UNIVERSITY OF OTTAWA AND SPONSORED BY THE CDTRP

Chaired by Prof. Jennifer Chandler, the conference examined the key policy challenges facing the Canadian organ donation and transplantation system. These include shifts in organ donation law, death definition and determination and the 6-month alcohol abstinence rule for liver transplant listing. The CDTRP is collaborating with the organizers and a group of trainees to publish eight FAST FACTS documents to capture key background information and insights from the conference in an easily-digestible and sharable format.

RESEARCH THEMES: THE NODES OF THE CDTRP NETWORK



The CDTRP connects its communities through the Research Themes. CDTRP currently supports 129 projects (see Appendix, page 26 for a complete list). Theme meetings provide a collaborative safe space, bringing together researchers to discuss challenges and test new ideas in their projects. The result in 2021 of aiming for increased diversity in voices, including early career investigators, joint trainee-faculty presentations and PFD presenters, has been stronger engagement and attendance.

THEME 1: IMPROVE A **CULTURE OF DONATION**

- 3 new members
- 5 Theme meetings in 2021
- 1 project awarded external funding in 2021
- 1 letter of support written
- 1 new Innovation Grant awarded

THEME 2: INFORM UNIVERSAL PRACTICES FOR DONATION

- 2 new members
- 4 Theme meetings in 2021
- 3 projects awarded external funding in 2021
- 9 letters of support written

THEME 3: ENGINEER AND ALLOCATE BETTER GRAFTS



- 8 new members
- 6 Theme meetings in 2021
- 1 project awarded external funding in 2021
- 14 letters of support written
- 2 new Innovation Grants awarded

THEME 5: RESTORE LONG-**TERM HEALTH**

- 12 new members
- 12 Theme and Hub meetings in 2021
- 19 letters of support written
- 7 new Innovation Grants awarded

THEME 4: TAILOR AN OPTIMAL IMMUNE SYSTEM FOR EACH PATIENT

- 2 new members
- 7 Theme meetings in 2021
- 3 projects awarded external funding in 2021
- 13 letters of support written
- 2 new Innovation Grants awarded



2021 THEME PROGRESS AND ACCOMPLISHMENTS

INTERNATIONAL DONATION AND TRANSPLANTATION LEGISLATIVE AND POLICY FORUM



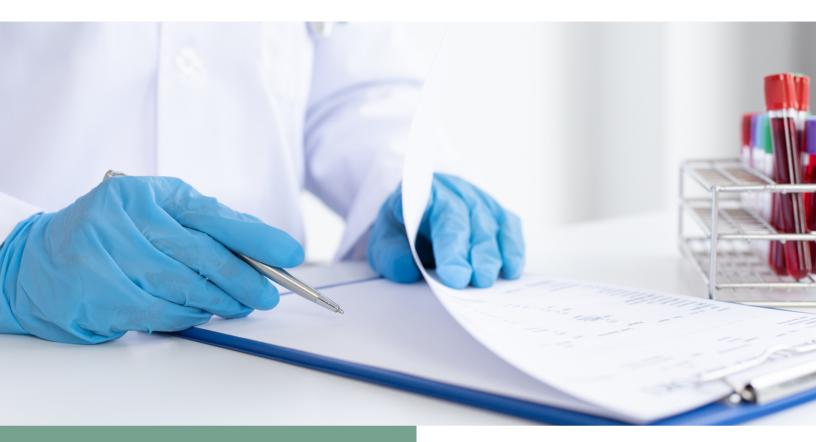
The first International Donation and Transplantation Legislative and Policy Forum was held on October 14-15, 2021, hosted by Transplant Québec and co-hosted by the CDTRP. Over 500 people from 40+ countries registered to participate in person or virtually. Dr. Matthew Weiss, Medical Director – Organ Donation with Transplant Québec and CDTRP Theme 1 Co-lead was the Scientific Director. The Forum provides an international reference for jurisdictions wanting to develop or revise their legal framework on organ and tissue donation and transplantation. The final form of the recommendations will be via academic publication, conferences, workshops, and lay reports.

"It is very exciting to link scientists, researchers, and experts in the international arena to develop knowledge resources that will serve decision makers change donation and transplantation policies, practices, systems, research and innovation. It is only through collaboration across disciplines and sectors that we can make this happen."

- Dr. Marie-Josée Hébert, Scientific Co-Director of the CDTRP

The international Forum was immediately followed by a Forum on the future of organ and tissue donation and transplantation in Québec. At the conclusion, all Québec political parties pledged to initiate a dialogue concerning system reform that includes an open discussion with Québecers.

Visit the Forum website here.



CINERGY: CYCLOSPORINE IN NEUROLOGICALLY-DECEASED DONORS TO DECREASE EARLY LIVER GRAFT DYSFUNCTION -A PILOT RANDOMIZED CONTROLLED TRIAL

LED BY FRÉDÉRICK D'ARAGON, MAUREEN MEADE, AND MARKUS SELZNER

Awarded a CIHR Project Grant

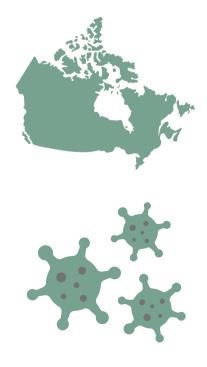
The CINERGY Pilot Trial, in Ontario and Quebec, will assess the feasibility of a national study that tests a drug administered to organ donors to reduce ischemia reperfusion injury (the lack of blood flow that injures a donated organ) in recipients. Arising from Theme 2, the CDTRP has supported CINERGY since its inception. The Patient, Family and Donor Platform is working with 2 PFD partners, who are offering input on study design, ethical issues related to research consent, and important considerations about study outcomes. previous CDTRP А Research Innovation Grant funded qualitative research to enhance understanding of the views of recipients with respect to their roles as participants in clinical research involving organ donors. The CDTRP helped to introduce this work and garner letters of support from almost every organ transplant program in Ontario and Quebec, as well as providing an informed letter of support, leading to recent funding success.

PROSPECTIVE EVALUATION OF COVID-19 VACCINE IN TRANSPLANT RECIPIENTS (PREVENT-COVID): A NATIONAL STRATEGY

The challenges of the pandemic have been particularly acute for transplant recipients. As vaccination programs began rolling out across the country in late 2020, there were many unanswered research questions about COVID-19 vaccination in this population, who were excluded from all the initial clinical trials. In early 2021, CDTRP worked to connect, mobilize, and align our community to identify and address these urgent issues.

On January 6, 2021, CDTRP convened an Expert Panel in the fields of solid organ and hematopoietic cell transplantation, transplant infectious diseases, immunization, public health, and patient partners to identify critical knowledge gaps around vaccination for COVID-19 in transplant recipients. The Panel report formed the backbone for the agenda of a National Stakeholder Workshop held on January 29, 2021. Over 30 stakeholder organizations contributed. These discussions culminated in a large national research proposal (PRospective Evaluation of COVID-19 Vaccine in Transplant Recipients (PREVenT-COVID): A National Strategy) selected by the COVID-19 Immunity Task Force (CITF) for **\$2.7M in funding.**

Research teams in Vancouver, Edmonton, London, Toronto, Montreal, and Quebec City, through a collaboration led by Dr. Deepali Kumar (University Health Network) and supported by the CDTRP network infrastructure, proposed a set of immunogenicity studies and a national safety surveillance study in transplant recipients. The safety surveillance study is being conducted with the Canadian National Vaccine Safety (CANVAS). Through the power of the national collaboration, the immunogenicity studies are being undertaken in pediatric and adult populations, across multiple organs, with monitoring of immunosuppression regimens. With the key early support of FRQS, researchers in Quebec were able to recruit participants prior to their first dose. To help execute this project, CDTRP welcomed two new team members, Demitra Yotis (Clinical Data Coordinator) who is coordinating data sharing and analysis between study sites, and Kristian Stephens (Knowledge Translation Coordinator) to ensure that public health policymakers, transplant centers, and patients and families receive the information they need.



FRESH VOICES IN RESEARCH LEADERSHIP

In 2021, after almost ten years of service, Drs. Megan Levings and Atul Humar transitioned out of their roles as Theme 4 leads, while remaining active CDTRP members. Theme 4 welcomed Drs. Mamatha Bhat and Jonathan Choy as the new Theme 4 leadership. Dr. Bhat is a staff Hepatologist and clinician-scientist at UHN's Ajmera Transplant Program and Assistant Professor at the University of Toronto. Dr. Choy is Associate Professor of Molecular Biology and Biochemistry at Simon Fraser University. I hope to help Theme 4 researchers in their continued success in the research landscape, with the goal of improving the lives of transplant recipients. - Jonathan Choy

CDTRP HUBS AND WORKING GROUPS: DRIVING NEW COLLABORATIONS IN PRIORITY AREAS

Theme 5 Hubs were launched in April 2021. These are targeted groups focusing on collaborative grant development and initiatives to build research capacity across Canada. The hubs began meeting regularly in May; participation is open to the broad CDTRP community. The **Mental Health and Wellness Hub** focuses on mental health and associated conditions related to transplant and donation – an under-researched patient and caregiver priority. The **Exercise Hub** allows for targeted discussion surrounding exercise, prehabilitation, rehabilitation and sarcopenia, and how they relate to the transplant patient pre- and post-surgery. The **Nutrition Hub** is in planning and anticipates a 2022 launch.

ALLIED RESEARCH IN DONATION AND TRANSPLANTATION (ARDOT) WORKING GROUP

Allied health professionals (registered nurses, respiratory therapists, occupational therapists, psychologists, etc.) in donation or transplantation have ideas to contribute to research but lack time and resources. In May 2021, the CDTRP launched the ARDOT Working Group from Theme 1, led by **Dr. Vanessa Silva e Silva**, and co-led by **Dr. Sonny Dhanani.** The group includes CDTRP members in Canada and researchers from Iran, USA, and Brazil. Objectives include promoting inter-professional collaboration and a participatory approach to research addressing the needs of knowledge users at the endpoint of care. ARDOT members will have access to consultations for research question conceptualization, methods development, grant applications, inter-professional international collaboration opportunities, and knowledge translation.

ENGAGEMENT TO STRENGTHEN COLLABORATIONS

The CDTRP has connections with over 100 organizations across many sectors in Canada and around the world. As the network grows and matures, it is deepening relationships with partners and creating authentic collaborations to bring the research community together with all the organizations that influence, fund, deliver, and use research. The CDTRP is increasingly facilitating collaborations with partners from the inception of project planning, rather than considering partners as 'end users' of research. The consequent interdisciplinary and trans-sectoral collaborations are increasing the quality and impact of the research.

"The International Forum was a perfect example of CDTRP's multi-disciplinary potential. The CDTRP team was key in bringing the event together, particularly in identifying PFD partners and ensuring scientific excellence."

- Dr. Matthew Weiss, Scientific Director of the Forum & Medical Director - Organ Donation at Transplant Québec

BUILDING A PROJECT WITH PARTNERS FROM THE GROUND UP: LEADDR

The Legislative Evaluation: Assessment of Deceased Donation Reform (LEADDR) project was launched in 2020 to evaluate the legislative and system changes to donation in Nova Scotia, the first jurisdiction in North America to legislate opt-out consent. The unique partnerbased model of project development, oversight, and direction was highlighted in a 2021 publication in *Transplantation Direct* (Weiss et al., 2021, PMID 33335980). For the development of PREVenT-COVID (see page 17), stakeholders were involved from the outset, with an immense impact on the quality of the project. As an example, Dr. Gaston De Serres, Medical Chief, Immunization Unit, Institut national de santé publique du Québec, led breakout discussions during the January 2021 CDTRP National Stakeholder Workshop, where 40+ stakeholder representatives prioritized key knowledge gaps around vaccination in transplant recipients. Through this collaboration with Dr. De Serres, the Quebec Ministry of Health committed to providing 400 mRNA vaccine doses for transplant recipient immunization independent from the general provincial vaccination program, a commitment made in early spring 2021 with vaccines in short supply. Though the doses were ultimately unnecessary for the study, given the timing of the study roll-out and the public vaccination program, this commitment reflects the deep trust and confidence that CDTRP researchers can deliver.

PARTNERSHIP HIGHLIGHT:

Trillium Gift of Life Network (TGLN) was recently brought within the purview of the Ontario Ministry of Health. At the time of the move, TGLN selected CDTRP as a partner to develop a strategy for the use of **\$397,025** dedicated research funding. A portion of these funds are going towards the Research Innovation Grant program, and planning is underway for a larger-scale funding opportunity.







SUPPORTING THE NATIONAL RESEARCH AND INNOVATION ECOSYSTEM

In 2021, the Organ Donation and Transplantation Collaborative (ODTC), initiated by Health Canada, the provinces and territories, Canadian Blood Services (CBS), together with the ODT community and supported by the CDTRP, launched a national project to develop a report to clarify the roles and interactions of the many diverse stakeholders in ODT R&I. It will help uncover how they participate and contribute to setting priorities for ODT research, conduct and fund research, and enable the movement of knowledge across the ecosystem. This information will help identify new synergies and alignments to continue building a stronger donation and transplantation system for Canadians.

CROSS-CUTTING PRIORITIES

Cross-cutting priorities span all of CDTRP's research, education, and engagement activities:

- Sex and gender;
- Pediatric, adolescent and elderly populations;
- Indigenous, rural and remote populations; and
- Policy, commercialization and knowledge transfer.

Our goal is that when a research project is being planned, researchers instinctively think about these cross-cutting priorities and have the skills or collaborations in place to integrate them. CDTRP staff work with research teams to facilitate connections with the right people to include different populations. This implies long-term relationship-building rather than quick wins. In 2021, the CDTRP focused on involving KT partners in projects from inception (see Engagement section). A particularly important product of these efforts was the International Legislative and Policy Forum (see page 15), whose outputs are already being sought by groups seeking policy or legislative changes in multiple Canadian jurisdictions.

For pediatric research, for a nationally-coordinated approach to implement patient-reported outcome measures, CDTRP supported the 2021 launch of the National Pediatric PROM Implementation Committee, which met several times. The committee includes representation from researchers, patient/family partners, and key partner organizations including Health Canada and CBS.

INCORPORATING SEX AND GENDER IN RESEARCH

"GETTING ON WITH YOUR LIFE WITH A TRANSPLANTED KIDNEY" - GETONTRAK PI: TANIA JANAUDIS-FERREIRA, THEME 5

'GETONTRAK' will develop a web-based, patient-centred self-management intervention to improve quality of life in kidney transplant recipients. The key sections of the website (e.g., quality-of-life appraisal, goal setting, developing action plans) are personalized and take gender into account as patients themselves nominate the areas of life about which they are concerned. When piloting the use of the website, which might include sex-specific topics such as pregnancy, equal numbers of men and women (gender) will be recruited. Focus groups will also include patients, clinicians and researchers with different genders, and the team will examine whether there are gender differences in uptake and user preferences in acceptability evaluation.



FIRST NATIONS AND MÉTIS ORGAN DONATION AND TRANSPLANTATION NETWORK

PARTNERSHIP HIGHLIGHT

CDTRP continues to seek to build respectful and durable relationships with Indigenous communities in appropriate ways. Several years ago, we connected with Dr. Caroline Tait, Research Director of the First Nations and Métis Organ Donation and Transplantation Network, who became a collaborator with the ongoing Neurologic Physiology after Removal of Therapy (NeuPaRT) study. CDTRP Executive Director Mélanie Dieudé is regularly invited to the Network's virtual Think Tanks, and has connected the group to new partners to further its goals. Planning is underway for an international virtual meeting, for which CDTRP has offered planning, logistical, and technical support.



EQUITY, DIVERSITY AND INCLUSION

In 2021, the CDTRP continued efforts to be a more inclusive space for people of all genders, backgrounds, and identities. It continues to play close attention to balance in committee leadership positions, including for example, the PFD Research Forum (see page 11) and the Annual Scientific Meeting which had co-chairs of different genders. It also began monitoring gender balance in the committee roles associated with the Innovation Grant review process. For scientific reviewers and PFD reviewers, There was a strong bias toward women committee members (11 women and 3 men for each type of reviewer).

To standardize EDI monitoring, the CDTRP has developed a set of demographic questions that have been incorporated as part of the Innovation Grant application form for EDI monitoring. It incorporated the same questions into new membership forms (investigators, trainees, and PFDs) and included a field for pronouns to normalize the sharing of pronoun information. In progress towards greater accessibility for CDTRP events, live Zoom events are close-captioned as standard procedure.

In June, Pride Month, the Theme 1 meeting focused on LGBTQ+ issues in donation. The CDTRP was pleased to have member Warren Fingrut speak on his team's work recruiting LGBTQ+ stem cells donors, Jennie Haw sharing CBS' work on the MSM Research Program and MSM Plasma Program, followed by a panel discussion on "How can we build a more inclusive donation and transplantation system in Canada?".

In 2021, CDTRP management team members were again encouraged to take San'yas Anti-Racism Indigenous Cultural Safety Training Program. For September 30, the National Day for Truth and Reconciliation, key resources were shared with the community and non-Indigenous members were encouraged to spend time learning more about the colonial history of Canada, how it shaped health research traditions, and to consider how to respond to calls for action. Furthermore, the management team took time to reflect on how to contribute to reconciliation through the CDTRP's work.





2022 will be an exciting year for the CDTRP as the network continues to evolve to meet the research community's needs. We will host what have become flagship events (e.g., Patient, Family and Donor Research Forum, Annual Scientific Meeting), and progress ongoing projects. Numerous new ideas have emerged to advance the quality and impact of research, which CDTRP will be exploring, including donation and transplantation research literacy in the media, infrastructure for quicker translation of research into policy. research opportunities connected to national ODT data initiatives. and infrastructure that would speed the launch of clinical trials.

The CDTRP is continuing its journey of strategic planning to refine its positioning within the Canadian research and innovation ecosvstem. In 2021 the Evaluation Committee completed an internal, granular evaluation of the themes. platforms, and projects to assess which activities are most successful, which may need recalibration, and what community needs remain unmet. A theme arising from this work was the need for enhanced connectivity across different network activities and enhanced communication of the resources available. In particular, the community placed high value on strengthened support for knowledge translation and economic impact, and stronger integration and tracking of crosscutting priorities.



In parallel, CDTRP supported the first phase of the ODTC-driven project, mapping the national research and innovation ecosystem (see page 20). The report, developed by the arms-length consulting firm Juniper Advisors, will be released in early 2022, and will inform a second phase of national stakeholder consultations and strategic co-creation activities.

"The Collaborative looks forward to the findings of this research project and recognizes the importance and value of these findings and subsequent recommendations for the ODT community. Knowledge on the ODT research landscape will optimize the integration and impact of research and innovation in ODT systems for the benefit of Canadians."

- Cindy Moriarty, Director General, Health Programs and Strategic Initiatives, Health Canada

Informed by the Phase I and Phase II reports, CDTRP will then focus on optimizing its positioning within the ecosystem. Through a series of facilitated discussions with stakeholders key (including patient, family and donor partners, researchers, partner organizations and funders), we will develop a shared vision for enhancing the production and implementation of new knowledge in donation and transplantation for the benefit of Canadians. The outputs of this phase will be actionable an implementation plan.

APPENDIX

2021 WEBINAR SERIES: "DIVERSIFYING YOUR RESEARCH"

- April 19, 2021 **Dr. Rhiannon Reed & Ms. Alexis Carter** | <u>Mixed</u> <u>Methods Study: Let's talk quantitative and qualitative!</u>
- April 26, 2021 **Dr. Charles Weijer** | <u>Virtual Research Ethics: Ethical</u> <u>Issues Conducting Research in the COVID-19 Pandemic</u>
- May 10, 2021 Dr. Olena Hankivsky | Intersectionality in Health Research
- June 28, 2021 **Ms. Cynthia Isenor & Ms. Jade Dirk** | <u>Implementation Knowledge Translation</u>, <u>Dissemination and Update</u>
- November 22, 2021 **Dr. Lisa Mellon** | <u>Interventions for Improving</u> <u>Medication Adherence in Solid Organ Recipients</u>

Supported by





APPENDIX

CDTRP SUPPORTED PROJECTS

DOWNLOAD THE FULL LIST

2021 INNOVATION GRANT AWARDEES

	PI name	Project Name
Pri	mary theme: Theme 1: Create	e a culture of donation
	Charles Weijer	Pilot Study to Explore Ethical Issues and Stakeholder Trust in the Use of Normothermic Regional Perfusion in Organ Donation in Canada
Pri	mary theme: Theme 3: Engineer and allocate better grafts	
	Caigan Du	Evaluation of propyl gallate for limitation of cold ischemic injury in organ preservation
	Corinne Hoesli & Steven Paraskevas	Making every pancreatic islet count – engineering a vascularized transplantation system to treat type 1 diabetes
Pri	nary theme: Theme 4: Tailor an optimal immune system for each patient	
	Ana Konvalinka	Investigating Kidney Tissue Responses to Donor Specific Antibodies in Antibody Mediated Rejection
	David Harriman	Urine Microbiome Profiling in Kidney Transplant Recipients in Health and Disease
Primary theme: Theme 5: Restore long-term health		
	Amine Benmassaoud	Does a 4-week prehabilitation program improve frailty in patients with cirrhosis undergoing liver transplantation? A feasibility trial
	Kirsten Wentlandt	Feasibility of Integrating Patient Reported Outcome Measures and Activity Metrics in a Palliative Care Transplant Programto Improve Function Pre- and Post- Lung Transplant
	Amanda Vinson	Identifying Sex-Based Disparities in Referral for Transplant, Activation on the Waitlist and Kidney Transplantation
	Chantal Bémeur	Optimizing post-liver transplantation outcomes: targeting the muscle.
	Tom Blydt-Hansen	Predictors and Patient Experiences that Enable Access to Care of Post-Traumatic Stress in Pediatric Solid OrganTransplant Recipients
	Michael Khoury	The MedBIKE™: Evaluating a Novel Telemedicine and Video Game-Linked Exercise Platform for Pediatric Heart Transplant Recipients
	Tania Janaudis-Ferreira & Nicholas Bourgeois	Virtual home-based pre-habilitation program in lung transplant candidates' to a Project