

Your Participation

You are receiving this newsletter because you consented to be a participant of the Transplant Biobank Registry. We thank all of our participants who took the time to learn about this initiative and donated samples and their medical histories to create this rich resource for researchers working at improving outcomes after organ transplant. Your contribution has fueled and continues to fuel important practice-changing research.

Registry Update

The Transplant Biobank Registry, led by The Hospital for Sick Children (SickKids), involves 7 pediatric transplant hospitals across Canada. The registry played a pivotal role in representing pediatric transplant recipients as part of the [Canadian Donation and Transplantation Research Program \(CDTRP\)](#). The contribution from participants continues to yield important research discoveries that benefit transplant patients and the research community. This newsletter provides an update on recent registry activities.



1,525
PARTICIPANTS
(INCLUDING TRANSPLANT
DONORS AND RECIPIENTS)



17
PROJECTS
SUPPORTED



80%
PARTICIPANT
SAMPLES STUDIED

Samples and data from biobank participants have helped develop personalized transplant medicine approaches, understand mechanisms of immune tolerance, unravel pathogenesis of organ failure, and helped with many other exciting discoveries!



New Discoveries



Improving Medication Adherence - Pediatric Outcomes in Transplant: Personalising Immunosuppression To Improve Efficacy (POSITIVE Adherence Study)

Immunosuppression management in children is challenging due to changes in developmental maturation and behaviour particularly during adolescence and transition to young adulthood. In a study led by Dr. Bethany Foster, McGill University Health Centre, a comparison of medication adherence between male and female transplant recipients found better adherence in females than males, but greater variability in tacrolimus levels in females than males. While high variability in tacrolimus levels has been suggested to reflect poor medication adherence, this observation suggests that biological factors, such as sex hormones, may play a role in the variability in tacrolimus metabolism.¹ The study also aimed to identify care processes and structures that support better medication adherence and found that more frequent scheduled testing of drug levels and more nurse time were associated with better medication adherence.² These findings are helping inform strategies for improving medication adherence in the young transplant population.

Thank you for participating and for your continued support!

For the most up-to-date news, check us out at www.transplantbiobank.ca



New Discoveries cont'd

Heart in a Box – Expanding the Donor Pool to Keep Hearts Alive

A third of infants on the waitlist for a donor heart succumb to worsening heart-failure while they wait. This is driven by a shortage of donors and a lack of suitable mechanical pumps for support at such a young age.

Dr. Osami Honjo, a SickKids cardiothoracic surgeon, has developed a first of its kind, pediatric ex-vivo (outside the body) cardiac perfusion system to combat this challenge. This perfusion system is used to resuscitate and repair hearts from marginal donors as well donors after circulatory death (DCD) to ensure they are healthy before they are transplanted. This has the potential to significantly increase the numbers of available donor hearts in Canada. The prototype has been successful in animal studies, with a pilot trial using human donor hearts now underway.³ This work is supported through the Ted Rogers Centre for Heart Research.

Read more about this work here:

<https://tedrogersresearch.ca/2019/07/2019-innovation-fund-awardees/>

Listen to the podcast of this story here:

<https://www.sickkidsfoundation.com/podcast/brokenhearts>

Human Liver Atlas – Working Towards a Treatment for a Rare Liver Disease

An effort led by University Health Network Researchers, in collaboration with SickKids, and through the study of liver tissues from Transplant Biobank Registry participants, has produced the first snapshot of primary sclerosing cholangitis (PSC), a rare autoimmune liver disease for which there is no cure.

The study, using a multi-omic approach with single cell, single nuclear and spatial atlasing, has uncovered insights into the diverse immune cell populations of healthy and PSC livers that drive disease progression. This work provides a framework for the future development of new precision medicine therapies for PSC.⁴

Read more about this work here: https://www.uhn.ca/corporate/news/pages/Pioneering_patient_guided_study_helps_map_rare_liver_disease.asp

References

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2. Dabirzadeh A, et al. [Care Processes and Structures Associated with Higher Medication Adherence in Adolescent and Young Adult Transplant Recipients](#). *Pediatric Transplantation* 2021 Aug 2:e14106
3. Kobayashi J, et al. [Flow-targeted pediatric ex vivo heart perfusion in donation after circulatory death: A porcine model](#). *J Heart Lung Transplant*. 2020 Mar;39(3):267-277.
4. Andrews TS, et al. [Single-cell and spatial transcriptomics characterisation of the immunological landscape in the healthy and PSC human liver](#). *J Hepatol*. 2024 Jan 4:S0168-8278(24)00003-5.

Transplant Biobank Registry Team & Contacts

Transplant Biobank Principal Investigators:
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