TRANSPLANT BIOBANK | Participant **Newsletter**

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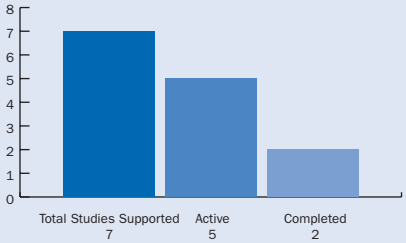
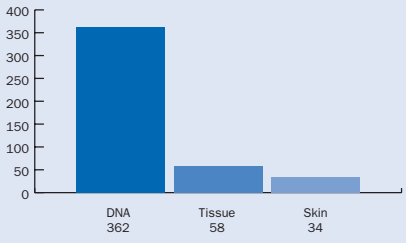
Your Participation

Welcome to all participants. Through this annual newsletter, we are pleased to provide you with updates about the research program and to thank you for your continued support and participation in the Transplant Centre Biobank Registry. We now have 410 individuals enrolled in the Transplant Centre Biobank Registry. The samples and information that you have donated have already supported seven research studies. Your contribution continues to assist researchers in understanding the genetics of transplantation and related disorders, and how best to improve the outcomes of children after transplant.

Studies Supported



Banked Samples



The Honourable Leona Aglukkaq, Minister of Health announces the launch of the Canadian National Transplant Research Program alongside participating investigators from across the country.

Expanding Across Canada and Disciplines

The Transplant Centre Biobank Registry was initiated at the Hospital for Sick Children in June 2010. Since then, the program has expanded to five other centres across Canada making the Transplant Biobank Registry the largest pediatric transplant biorepository in Canada. Participating Canadian centres include The Hospital for Sick Children (Toronto, Ontario), Stollery Children's Hospital (Edmonton, Alberta), Alberta Children's Hospital (Calgary, Alberta), Winnipeg Children's Hospital (Winnipeg, Manitoba), CHU Sainte Justine's (Montreal, Quebec) and McGill University Hospital (Montreal, Quebec). The Transplant Biobank Registry and research network is now a part of the Canadian National Transplant Research Program (CNTRP), funded by the Canadian Institutes of Health Research (2013-18) with overall goals of increasing the number, quality and efficacy of transplants in Canada. SickKids is leading the pediatric aim of this program through a project titled "Paediatric Outcomes in Transplant: PersOnaliSing Immunosuppression To ImproVe Efficacy" (POSITIVE Study). The purpose of this project is to study how immunosuppression after transplant can be personalized to the unique needs of pediatric patients as they mature with age to make it safer and more effective while reducing infectious and drug-related complications after transplant. The outcomes from this study will lead to improved outcomes and quality of life in children after transplant.

Thank you for participating and for your continued support!

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

Theme: Personalized Medicine

Personalized medicine is an approach which uses the genetic information from a patient to tailor therapies specifically for that patient. Information about a patient's genetic profile can be used to select the safest and most effective medicine and drug dosing for each patient. Additionally, such methods can be used to assess risk for a number of conditions and tailor management strategies. This section will give you an idea of ongoing research in the Transplant Centre Biobank with particular focus on personalized medicine.

Pharmacogenetics refers to the individual genetic differences between us and how it affects our responses to medicines.

Phamacogenetics of Tacrolimus Dosing After Pediatric Transplantation

The purpose of the study is to personalize the dose of tacrolimus for each patient to make it safer and more effective. Tacrolimus levels are measured in blood after giving a dose and need to be in a narrow range since high levels cause side-effects and low levels increase the chance of rejection. Pharmacogenetics refers to the individual genetic differences between us and how it affects our responses to medicines. CYP3A5 is a gene responsible for clearing tacrolimus from the body. Children with a fully functioning gene need higher doses of the drug and those with the non-functioning gene need lower doses. Currently, tacrolimus dose is not adjusted by genotype. DNA samples from the Transplant Centre Biobank Registry were used to look at the CYP3A5 gene and gain a greater understanding of its role in tacrolimus metabolism in transplant patients. The information learnt from this analysis supported the initiation of a clinical trial to assess if adjusting tacrolimus dose by genotype will help children reach desired blood levels of tacrolimus sooner and reduce the risk of rejection or drug side-effects.

Gijsen V, Mital S, van Schaik RH, Soldin OP, Soldin SJ, van der Heiden IP, Nulman I, Koren G, de Wildt SN. Age and CYP3A5 genotype affect tacrolimus dosing requirements after transplant in pediatric heart recipients. J Heart Lung Transplant. 2011 Dec;30(12):1352-9

Epstein-Barr Virus (EBV) Infection in the Immunosuppressed Setting of Organ Transplantation

Ongoing across Canada, this study is investigating children and young adults with primary Epstein-Barr virus (EBV) infection after their immune systems have been weakened following organ transplantation. EBV can cause a wide range of problems in individuals who get infected. The virus often infects white blood cells, causing the cells to multiply out of control in a condition known as post-transplant lymphoproliferative disorder (PTLD). Doctors are in need of more information to help them better understand the reasons why some individuals do well with EBV infection, while others do not. This will help them to design the best treatments, particularly for those with weakened immune systems. This study will use DNA samples collected through the Transplant Centre Biobank Registry to find out if the certain genes explain why some children get mild infection while others get more severe infections post transplant and use this knowledge to guide management of infections and complications of related to EBV and PTLD.

Transplant Centre Biobank Registry Team

Research Coordinators: Tanya Daljevic, Mina Safi, Steven Habbous, Alan Fung

Biobank Working Group: Dr. Seema Mital (Chair), Dr. Rulan Parekh, Dr. Binita Kamath, Dr. David Grant, Dr.Hartmut Grasemann, Dr. Upton Allen, Dr. Simon Urschel, Dr. Patricia Birk, Dr. Veronique Phan, Dr. Lorraine Bell, Dr. Lorraine Hamiwka

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