

BCCH BioBank Newsletter

Finding non-invasive methods for detecting kidney transplant rejection

Kidney transplantation is a life-saving treatment for children with end-stage kidney failure. However, a major threat to success is rejection, where the body's immune system attacks and destroys the transplanted kidney. If rejection isn't treated early, it can lead to loss of the transplant and a return to dialysis. Currently we screen patients after transplant with repeated kidney biopsies, which are risky and unpleasant.

Researchers and specialists at BC Children's Hospital have been working to develop new techniques to identify early signs of kidney transplant injury and rejection using simple urine samples. A new Solid Organ Transplant (SOT) research program at BC Children's Hospital is a component of an innovative [TRAnsplantation & CEll Therapy \(TRACE\)](#) program, which was supported by generous donors through BC Children's Hospital Foundation. SOT will partner with the BioBank to look biological markers that might identify when injury or rejection is present.

Children with heart, liver or kidney transplants at BC Children's Hospital are now able to opt in to having samples saved in the BioBank. The BioBank is an essential resource to help us track, collect, and store the most important samples, so that they are available for testing in the future. Working together helps to improve our research, confirm our discoveries and speed up the possibility of having these tests ready and available in the clinic. Having access to biological samples in the BioBank will be invaluable to continuing productive research in this area.

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Dr. Tom Blydt-Hansen

Principal Investigator for the SOT research program

Personal Story: Taking Action to Improve Research Participation

Isabel Jordan is a mother of two children, Zach (15) and Evie (13) and is one of the founders and the Board Chair for the Rare Disease Foundation. Below, Isabel reflects on rare diseases and why biobanking is important to her.

“It wasn't so long ago, that the term “rare disease” didn't have any personal meaning to me. Rare and orphan diseases didn't have any impact on my life, or at least I didn't think they did or ever would. I didn't know that rare diseases in total affect [1 in 12](#) people in their lifetime, I certainly never thought one would affect my son.



The current state of affairs in 2017 for rare diseases is that half of them are diagnosed in childhood, the average time to diagnosis for rare disease patients is about 5 years and for most of these diagnoses there is [no real treatment](#). How do we move forward? For me there is only one answer. We can only move forward together. There is limited funding for research. There is a limited pool of donor resources for non-profits. There is a limited pool of study participants for research studies. There are limits everywhere. What if we could all help each other overcome the limits we have? What if we could amplify each other's efforts by being more efficient with the resources we each have. Now wouldn't that be something? It strikes me, we go further (and faster) together, than we do apart.

Biobanking offers some of these opportunities. The kind of opportunity that has a real, concrete meaning to my family. When my son had to have a rare tumor removed at the age of 6 (nine years ago), we couldn't find anyone researching that kind of tumour. We struggled to find a place to store a tissue sample. We didn't want to waste an opportunity that could help him, or others like him, to find answers. The BC Children's Hospital BioBank provides a space where samples from many different patients including rare diseases can be collected and stored for future research. These samples can be shared with researchers around the world which means that the pool of participants can be increased and the hope for a new outcome is possible.”



WANTED: Parent and Youth Opinions!

Express your opinions on the barriers, risks, and benefits of involvement in biobanking.

WEHN: 20 November 2017 from 5.00-7.30pm.

WHERE: BC Children's Hospital Research Institute

WHO:

Parents of children of who have been involved in research and/or health care

Adolescents aged 14-18 years who have been involved in research and/or health care

Children aged 11-13 years who have been involved in research and/or healthcare

BENEFIT:

- An opportunity to have **YOUR** voice heard about research
- Pizza, salads and snacks
- \$25 gift card
- Reimbursement for parking and babysitting

Email tamsin.tarling@cw.bc.ca to attend.

PARTNERS

