

# HEART CENTRE BIOBANK REGISTRY PARTICIPANT NEWSLETTER

ISSUE 09 · DECEMBER 2022

## \$90-million gift to Ted Rogers Centre for Heart Research



10,490  
Enrolled



Sustain family  
enrollment



2,350  
Genomes  
sequenced



Scale up  
sequencing



Novel gene  
identification



Increase genetic  
diagnosis



New  
personalized  
therapies



Deliver  
to clinical  
practice

The gift will also see  
new investments in:

Building our capacity for artificial  
intelligence in medicine

New clinical space as part of  
the planned new hospital  
through Project Horizon

## Delivering Precision Medicine to Children

Since 2007, over 10,490 individuals have consented to donate their samples to the Heart Centre Biobank, a research registry at SickKids aimed at studying the genetic and environmental causes of heart disorders through the study of DNA, tissue and other samples. Our vision is to support research that can help deliver precision medicine, a form of medicine that uses information about an individual's own genes or proteins to prevent, diagnose and treat disease.

This past year, we've been excited to receive two large investments in precision medicine research of which the biobank is an integral part.

### \$90-million gift to Ted Rogers Centre for Heart Research

In October 2022, the Rogers Foundation announced a second landmark gift of \$90 million, building on the \$130 million original gift to create the Centre in 2014. This second gift will build on the promise of precision cardiac health. The Centre is a partnership between three institutions: The Hospital for Sick Children (SickKids), University Health Network (UHN) and the University of Toronto (UofT), each having their unique but complementary nodes of research. The renewed gift at SickKids will continue to build on the program achievements and sustain its future activities. Read more at <https://tedrogersresearch.ca/2022/10/90-million-gift-to-ted-rogers-centre-for-heart-research-marks-new-era-in-cardiac-health/>.



### SickKids to lead the pediatric arm of the newly funded Canadian Heart Function Alliance

The Ministry of Health and the Canadian Institutes of Health Research (CIHR) in May 2022 announced the launch of the Canadian Heart Function Alliance (CHFA), a network spanning eight provinces and one territory with 23 connected research projects targeting heart failure. SickKids, as part of this network will lead PRIORITY, precision medicine for heart failure in the young, a program with 3 studies focused on detecting and preventing heart failure using **artificial intelligence**, reducing hospital admissions through **remote patient monitoring**, and improving the adolescent **peer support** system to help with transition to adult care. The access to biological and clinical data from our biobank patient participants was key to our ability to find novel markers for heart failure in children and to expand our study into a pan-Canadian study that will include patients across all ages.

If you would like to partner with us on this Alliance, please email us at [heartcentre.biobank@sickkids.ca](mailto:heartcentre.biobank@sickkids.ca)

Read more at <https://tedrogersresearch.ca/2022/05/canadian-heart-function-alliance-launches-today/>.



Canadian  
Heart Function  
Alliance

*Linked by the heart*



**Thank you for participating and for your continued support!**

For the most up-to-date news, check us out at [www.theheartcentrebiobank.com](http://www.theheartcentrebiobank.com)

Phone: at 416-813-8428 Email: [heartcentre.biobank@sickkids.ca](mailto:heartcentre.biobank@sickkids.ca)



If you are a parent that isn't already participating or you have parents that would like to, please call or email the Biobank team for information.

## Personalized Genomics for Congenital Heart Disease (PROCEED) – Researcher-Patient Symposium Highlights



As part of our transnational PROCEED Study, we hosted a virtual symposium in Spring 2022 geared to both researchers and patients. A patient-researcher forum concluded the event providing an opportunity for patients and families to ask questions and have a conversation with a diverse panel that included those with shared lived experiences and experts in cardiac genetics, surgery, cardiac neurodevelopment, and heart function. Two educational talks kicked off the session providing attendees an overview of how genetic testing is used in practice and how findings can impact patient care. With new genetic discoveries, we also learnt how these new discoveries can inform new therapies. A recording of the event is available upon request by emailing [heartcentre.biobank@sickkids.ca](mailto:heartcentre.biobank@sickkids.ca)

Interested in learning more about this study? Check out our video on YouTube! <https://www.youtube.com/watch?v=oagkoYyZGYA&t=15s>

## Whole genome sequencing doubles the diagnostic yield over conventional testing



Cardiomyopathy is a genetic disorder that is often inherited from one generation to another. Cardiomyopathy causes the heart to lose its ability to pump blood effectively; it is the most common cause of heart failure and sudden cardiac death in children and adults. In one of the largest studies in this population, we used whole genome sequencing to search remote areas of the genome to find small hidden gene defects that identified the genetic cause of cardiomyopathy in nearly half of patients in whom the cause had not been found after clinical genetic testing.

Knowing the disease-causing gene brings us closer to developing precision therapies targeting the root cause of disease. It also provides better screening tools for early detection of family members at risk for developing cardiomyopathy. This work highlighted that genome sequencing may be useful in clinical practice as it becomes more widely available. Read more at <https://tedrogersresearch.ca/2022/03/new-study-shows-whole-genome-sequencing-can-identify-hidden-genetic-changes-patients-with-cardiomyopathy/> and read the full publication at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8921194/>.

## Discovery to Practice – Expediting Translation to Clinical Patient Care

Whole genome sequencing can provide one-stop shopping when looking for a genetic cause of disease. We calculated the costs of doing genome sequencing with a view to supporting more routine use of whole genome sequencing for clinical testing. Our work will help inform healthcare funders on resource requirements for offering this test to families. Read more details in our published study at [https://www.gimjournal.org/article/S1098-3600\(22\)00036-3/fulltext](https://www.gimjournal.org/article/S1098-3600(22)00036-3/fulltext).

*Jegathisawaran J, et al. Trio genome trio sequencing for developmental delay and pediatric heart conditions: A comparative microcost analysis. Genetics in Medicine 2022; 24(5): 1027-36*

## A Message from the Heart Centre Biobank

The discoveries made through the research highlighted in this newsletter would not have been possible without your participation in the Heart Centre Biobank Registry. Your contribution is a gift that keeps on giving as your samples and data are used to support research in all types of childhood onset heart disease. The Heart Centre Biobank is thankful to you for your contribution to these discoveries.