HEART CENTRE BIOBANK REGISTRY

PARTICIPANT NEWSLETTER

ISSUE 12 · FEBRUARY 2026

Your Participation

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

Registry Update

The Heart Centre Biobank, led by The Hospital for Sick Children (SickKids), involves 6 hospitals across Ontario. The contribution from participants continues to yield important research discoveries that benefit patients with heart disease and the research community. Newly discovered genetic findings that are medically relevant are returned to consenting participants. This newsletter provides an update on recent registry activities.

10,976
Participants

Turning to Big Data for Answers

Canada's ambitious investment in genomics & precision health:
An opportunity to sequence even more SickKids biobank enrolled participants!

A breakthrough $11.7 million was awarded to SickKids from Genome Canada's Canadian Precision Health Initiative, a new national investment to create a large-scale diverse genomic data asset of 100,000 genomes that reflects Canada's population. As part of this initiative, SickKids will sequence 10,000 genomes in the next 4 years through a project called PCHSeq with an unprecedented opportunity to sequence SickKids Heart Centre Biobank enrolled participants.

This investment in SickKids studies will drive forward innovations that tailor treatments to a child's individual genetics, providing more effective and personalized care. The impact of the Canadian Precision Health Initiative on...

Faster genetic diagnoses
Expanded genome sequencing

Quicker impact on care
Return of new genetic findings to families

Precision treatments
Accelerate discovery of targeted therapies

This initiative is funded by Genome Canada, read more here.

Using Big Data to Improve Life for People with Single Ventricle Hearts

Many people born with a single pumping chamber of the heart undergo the Fontan procedure and now live well into adulthood. However, some develop serious complications later in life, doctors still don't know why this happens to some people and not others.

Led by Dr. Luc Mertens at SickKids, the PHUR4Life study uses big data—one of the largest collections of information from people with a Fontan circulation—to uncover patterns that couldn't be seen before. This approach may help identify early risks and support more personalized care in the future. The study brings together:

- 40+ years of medical data
- 2000 participants
- Advanced imaging
- Genetics & metabolics
- Mental health & societal factors

Funded by the Heart & Stroke Foundation of Canada, read more here.

Heart Centre Biobank

Thank you for participating and for your continued support!

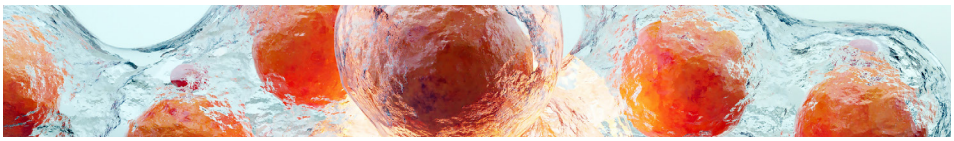
For the most up-to-date news, check us out at www.theheartcentrebiobank.com

Phone: at 416-813-8428 Email: heartcentre.biobank@sickkids.ca

TED ROGERS CENTRE FOR HEART RESEARCH

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.

Precision Cardiac Therapies for Children in the Works



How Fat is Processed in the Heart May Help Us Treat a Hidden Form of Heart Failure in Children

For many children with cardiomyopathy, heart failure doesn't always mean the heart is too weak to pump. Sometimes the heart becomes too stiff to relax properly between beats. This is called diastolic dysfunction, and it can be just as serious — and much harder to detect and treat.

Doctors know that some children develop this stiff heart problem, but until now, they haven't fully understood why it happens or how to predict which children are at risk.

A research team led by Dr. Seema Mital at SickKids set out to solve this mystery. They studied children with different types of cardiomyopathy and looked deep inside their cells using a powerful approach called multi omics, which examines genes, proteins, and fats all at once.

What they discovered was that children with diastolic dysfunction shared the same biological pattern — a problem with how the heart handles fats (lipids).[1]

They found signs that:

- the heart was making and storing too much fat
- the cells struggled to break down fats for energy
- these changes also appeared in the blood, suggesting a possible future blood test

To understand this better, the team programmed beating heart cells in a dish from participant samples that showed fat buildup and energy problems, proving this wasn't just a lab finding — it is happening inside the cells of the heart.

This study is an important step forward. It shows that diastolic dysfunction isn't just a result of heart disease — it may be its own biological condition with a clear cause. And knowing the cause is the first step toward better diagnosis and treatment leading to earlier detection using blood tests and new therapies that address the root cause, not just the symptoms. Further studies are ongoing including those in larger cohorts of individuals, read more below.

This study was funded by the Ted Rogers Centre for Heart Research, read more here.

Publications

1. *Turinsky AL, Hanafi N, Said A, Kinnear C, Lesurf R, López-Guillén JL, Akilen R, Patel S, Meng G, Wei W, Robillard Frayne I, Daneault C, Mertens L, Ellis J, Ruiz M, Mital S. Abnormal Lipid Signaling Characterizes Diastolic Dysfunction in Pediatric Cardiomyopathy. JACC Basic Transl Sci. 2026 Feb 17;11(3):101491.*
2. *Kinnear C, Said A, Meng G, Zhao Y, Wang EY, Rafatian N, Parmar N, Wei W, Billia F, Simmons CA, Radisic M, Ellis J, Mital S. Myosin inhibitor reverses hypertrophic cardiomyopathy in genotypically diverse pediatric iPSC-cardiomyocytes to mirror variant correction. Cell Rep Med. 2024 May 21;5(5):101520.*

The Canadian Cardiomyopathy Collaborative (C3): A Joint Venture to Deliver Precision Therapies for Heart Failure

The Canadian Cardiomyopathy Collaborative (C3) brings together 3 large Canadian registries in Toronto, Montreal and Vancouver to study 800+ participants and apply artificial intelligence techniques for earlier detection of diastolic dysfunction.

What's unique about the study? It's using blood-based multi-omics techniques to detect signatures of diastolic dysfunction by looking at genes (genomics), proteins (proteomics) and lipids (lipidomics) along with patient medical histories. The hope is that we identify a clear pattern identifying patients at risk so that better matched treatments can be developed.

The collaborative is funded by the Canadian Institutes of Health Research - Canadian Heart Function Alliance, read more here.

Clinical Trial for Obstructive Hypertrophic Cardiomyopathy Announces Positive Results!

A new medication targeting the root cause of left ventricular (LV) obstruction in children with hypertrophic cardiomyopathy published positive results from their clinical drug trial! The medication improves patient symptoms by targeting the obstruction itself, an improvement over current medication.

Preclinical studies testing these medicines in a dish were conducted using biobank samples paving the way for these trials.[2]

Read more here.

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.

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