

What's Trending?

Greetings from the Heart Centre Biobank Registry! You are receiving this newsletter because you are a Heart Centre Biobank participant and as always, we are grateful for your contribution to our registry and would like to update you on what your participation has helped us achieve in the past year! Here is an update on what is new and trending in our registry:

Our enrollment is trending up as we continue to recruit new and retain existing participants.

9931↑

Data use is trending up as we have supported over 50 new research studies with the specimens and data that you have donated to the biobank.

Family participation is trending up!
340% increase within this past year



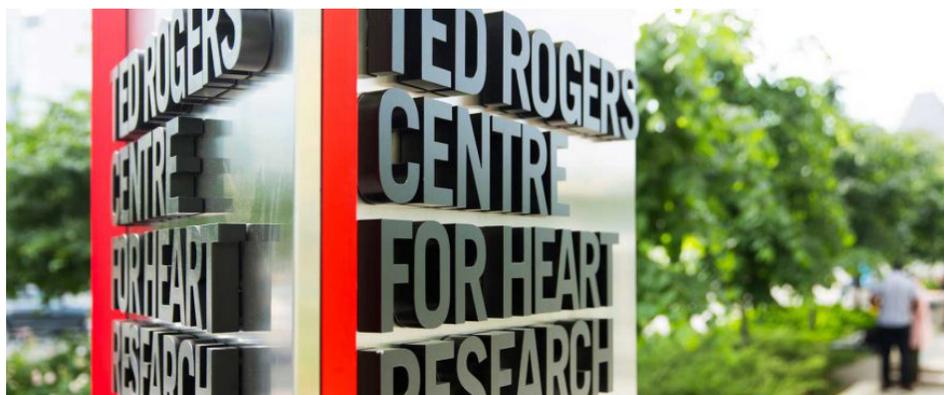
We recognize the importance of studying not just the child with disease but the parents as well to help us determine if the finding is new or passed down. If you are a parent who has not yet participated and would like to, please contact us at heartcentre.biobank@sickkids.ca or 1-866-489-7711. Participation can be coordinated by mail.

COVID19

During this time, we have added the option of virtual consenting to the Heart Centre Biobank. The health and safety of our patients, families, employees, and fellow collaborators has and always will be our top priority. As we continue to work through these uncertain times together, please do not forget to take care of your own physical and mental health and support those around you.

COVID-19 and the heart: resources

To help spread awareness of important information as it unfolds regarding the COVID-19 crisis and how it impacts cardiovascular health and the lives of people with heart disease, the Ted Rogers Centre for Heart Research is constantly updating a list of resources here: <https://tedrogersresearch.ca/2020/03/covid-19-and-the-heart-resources/>



Ted Rogers Centre for Heart Research celebrates fifth anniversary

It marks five years since the Ted Rogers Centre for Heart Research was founded on the promise of bringing together three world-class institutions – SickKids, University Health Network, and the University of Toronto – in the fight against heart failure. After five years, there is much to celebrate; here is a look into some of the work through our Cardiac Precision Medicine program that has made an impact over the last 5 years.

The Heart Centre Biobank and our Precision Medicine Program

The Heart Centre Biobank is now Canada's largest pediatric heart disease biobank and among the world's largest. We are providing generations of researchers and clinicians access to vital genetic samples and data related to heart failure.

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Check out our new website!

We have been working hard this year, to bring a new user-friendly website!

Visit our page, and let us know what you think: www.theheartcentrebiobank.com

For patient and family inquiries, make sure to check out our “For Patients” page.

Let's build a closer working relationship – Our Heart Centre Biobank Participant Engagement Network

Participants and families play an invaluable role in driving research forward. We are always exploring new ways to engage with individuals as partners to drive research forward. Please email us at heartcentre.biobank@sickkids.ca if you are interested in learning more about engagement in biobank supported research. Parents and high school aged children are encouraged to inquire. Volunteer service hours are available for students.

Let's get Social!

Give us a follow and stay updated on all things “Heart Centre Biobank!” @hcbiobank

Would you like to start receiving updates via email? To receive our newsletters? Stay connected with important information and new discoveries? Tell us more on what you want!

Email us at: heartcentre.biobank@sickkids.ca

Searching the Genome

Building on a legacy of expertise in genetics, we have completed whole genome sequencing in cardiomyopathy and congenital heart disease cohorts that has led to exciting new discoveries in what causes heart disease and new targets for drug development. By analyzing and interpreting a patient's vast genome, we are finding clues about the genetic roots of heart failure and returning important results to families that influence their care moving forward. Genetic knowledge empowers families to make decisions about future screening of family members for heart disease so that they can receive timely medical care.

A precision tool to predict and prevent sudden death in hypertrophic cardiomyopathy – PRIMaCY

The first calculator that has been validated for use in a pediatric population

Through an international collaboration involving over 20 centres across Canada, US and Australia,

we developed and validated a risk prediction model that includes factors that are unique to a pediatric population to identify children at high risk for sudden death. “In pediatric heart failure, there is a huge gap in knowledge that has interfered with our ability to prevent these outcomes, resulting in unnecessary use of ICDs,” says Dr. Seema Mital. “Our risk model is the first to be validated in a pediatric population and is driven by factors unique to child patients. It is a much-needed precision strategy to prevent sudden cardiac death and make informed decisions on the use of ICDs.”

<https://www.ahajournals.org/doi/pdf/10.1161/CIRCULATIONAHA.120.047235>



Personalized Genomics for Congenital Heart Disease – PROCEED

Proceeding to find answers

Through an international collaboration with Germany and Amsterdam, we are using whole genome sequencing to explore the human genome in families to find gene defects that cause congenital heart disease, and determine how these gene defects predict severity of heart disease and outcomes. We are working to create a sensitive, accurate pipeline that efficiently detects these tiny gene defects. The team hopes to make these pipelines available to the global scientific community so others can join the effort to uncover unsolved clinical questions about congenital heart disease, so that we can predict outcomes, and guide families as to what they should expect and counsel them about the future risks.

Breaking new ground

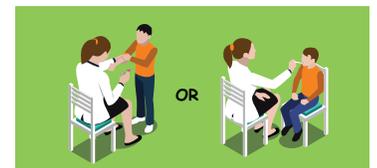
Revolutionizing cardiac care requires vision, innovation, and determination. Read on to see how we continue to work with and bring together experts in cardiac research, in the pursuit of cardiac treatments and breakthroughs.

Blood versus saliva derived DNA

The ability to get a sample non-invasively in participants to use for research and clinical applications

The power of whole genome sequencing is allowing us to discover the genetic causes of disease on an unprecedented scale. But getting a blood sample on a patient can sometimes be difficult. If collected and processed meticulously, we found that a saliva sample can give good quality DNA. Discovering this, enabled us to reach out to patients and family members to provide a sample from home when they were unable to visit the hospital for a blood test, thereby allowing them to participate in genomics research. Our study also provides insights to genomic testing laboratories on the use of saliva samples for whole genome sequencing.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6988365/>



Community Impact

An important and growing effort in our genomic research is returning medically actionable results back to families to guide family screening and help in removing uncertainty for the future.

Clinically significant research findings returned to participants

Genomic research benefits patients, one family at a time

Through a Return of Results Committee, we were among the first to outline the process and experience of returning new research results from exome and genome sequencing to families with heart disease. Of the novel findings returned, all families opted for clinical confirmation of findings, thereby making a measurable difference in their care.

Read the full publication here:

<https://bmcmedgenomics.biomedcentral.com/articles/10.1186/s12920-019-0618-0>

Clinical practice guidelines for cardiomyopathy

Early diagnosis saves lives

Findings from our research have generated critical evidence to inform changes to the clinical and genetic screening recommendations for family members of cardiomyopathy patients.

Read these full publications here: <https://www.ahajournals.org/doi/full/10.1161/CIRCULATIONAHA.119.041021>

<https://academic.oup.com/eurheartj/article/40/45/3672/5512100>

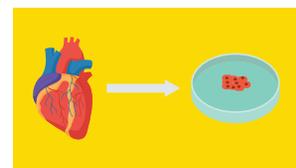
<https://academic.oup.com/eurheartj/article/40/45/3659/5645075>

Breaking new ground cont'd from page 2

Reprogramming technology

The best candidate for drug repurposing, to treat patients with acquired vascular disorders

The deficiency of a protein called elastin can cause serious heart defects. There are no drugs to treat this disorder and many children require many surgical or catheter procedures to relieve the blood vessel narrowing, often starting in early infancy. Our study identified a drug that was able to rescue the disease “in a dish” by using patient skin or blood cells to generate these disease cells and test drugs. The study highlights the important role of patient participants in research. If this drug is able to show benefit in patients in clinical trials, it could improve survival and reduce the need for invasive operations. <https://pubmed.ncbi.nlm.nih.gov/32212852/>



High-quality stem cells enable researchers to better study disease

Scientists across the globe have used induced pluripotent stem cells (iPSCs) to study the mechanisms of disease, and the safety and effectiveness of drugs for patients. For scientists, iPSCs hold enormous potential, including the ability to explore how a disease acts in individual patients. To perform such research and accurately model disease, scientists must compare a patient's iPSC cell line to healthy control cells. A research team from SickKids was able to generate patient and healthy control cells that are now supporting research into heart disease and other conditions in many labs across the world. <https://www.sciencedirect.com/science/article/pii/S2213671119304060>

The Patient Experience

Working together to enhance the experience of our patients, families and caregivers

Patient engagement is critical to ensure that our research is aligned with the values, principles, and conditions that empower our patients and families to be involved in our research. Patient engagement has helped inform the development of many new initiatives, and here is what to look out for from the Heart Centre Biobank this year:

New website: www.theheartcentrebiobank.ca

Educational video (launching soon): Heart Centre Biobank Introductory Video

Information pamphlet (coming soon): Sample Collection & Recruitment - Being part of a Biobank

For the future, we are working towards the inclusion of electronic consenting and use of electronic applications and social media for research updates. We strive to continue to build on our approaches to patient engagement, and hope to collect and share stories, news, events, tools, and tips to enhance the experiences of patients, families and caregivers.

Looking on, for the next five years

The goal of our program is to build on the research discoveries from the first five years to advance them to clinical and knowledge translation. Here's to the first five years, the five after that – and a future where we can continue to transform and improve the future of heart health for children, adults and families across Canada and around the world.

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. Your original contribution through your participation in the Heart Centre Biobank Registry is a gift that keeps on giving as your sample(s) and data can be used to support multiple research studies. The Heart Centre Biobank is thankful to all its participants for their contribution to these discoveries.