

LIFE CAN CHANGE IN A HEARTBEAT



Photo credit: Anita McLarry Photography

PRECISION CHILD HEALTH: TRANSFORMING THE FUTURE FOR KIDS WITH HEART DISEASE

April 18, 2008, began like any other school day for Nathan. It changed his family forever. At recess, Nathan was playing basketball with friends. Suddenly he collapsed. His heart had stopped and couldn't be restarted. He was 10 years old.

Four years earlier, Nathan had been diagnosed with a genetic condition of the heart muscle called hypertrophic cardiomyopathy, or HCM. He was being monitored, and there was no sign the diagnosis should restrict him.

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ABBY, NATHAN'S MOM

Cardiomyopathy is the leading cause of heart failure and sudden cardiac death in children and youth. There are no medicines to reverse the disease. It's also notoriously difficult to predict who's most at risk of sudden death — until now.

SickKids has developed the first validated model to predict the risk of sudden death in children with HCM, with over 70 per cent accuracy. The model calculates risk based on a child's age, medical history, and genetic profile. Its predictive power will grow as the new tool is piloted by cardiologists and expands to include environmental and lifestyle data.

It promises to be a game changer: identifying kids who will benefit most from an implantable defibrillator that restarts a stopped heart; and sparing those at low risk from an invasive device they don't need. With this information, families can decide what's best for their child.

The team behind the innovation is led by Dr. Seema Mital, SickKids cardiologist and head of cardiovascular research. She's committed to changing the future for kids with heart disease. Her quest is enabled by a visionary investment of \$130 million that founded the Ted Rogers Centre for Heart Research and the Cardiac Precision Medicine Program, alongside major gifts from the Rogers Foundation, Arthur and Sonia Labatt and their family, and the Heart & Stroke Foundation.

Dr. Mital and her team are pioneers of Precision Child Health, the movement at SickKids that's tailoring health care to a child's biology, life conditions, and environment. They're harnessing new knowledge to transform cardiac care, with precision tools that weren't available to them when Nathan was diagnosed.

“Life can literally change in a heartbeat,” says Nathan's mom, Abby. “This risk predictor gives families hope, and will help children grow safely into adulthood.”