

As I review the stories we're sharing this spring, two themes emerge. The first is how vital the research and data analytics we undertake at SickKids are to achieving the best outcomes for children. The second is the depth of understanding in our major giving community of how vital these sometimes difficult-to-fund initiatives are, illustrated by the generous gift of the Chung family.

I share the conviction of Dr. Mike Salter, SickKids Chief of Research, that what distinguishes SickKids is our ability to translate research into clinical care. As you read about paediatric heart rehabilitation, precision medicine, and cardiac data analytics, you will see how SickKids is, in Dr. Salter's words, "taking fundamental discoveries, putting them out there, and changing the way children are treated."

For your commitment to changing the lives of children and families, thank you.

Sincerely,

Ted Garrard, Chief Executive Officer SickKids Foundation

HEALTHIER HEARTS — FOR LIFE

A PARTNERSHIP TO BRING CARDIAC REHABILITATION TO KIDS



Young heart patient Jane playing with her mom. She's an active toddler, with an active life.

It's a simple, but powerful proposition: exercise is medicine. Canada's first paediatric cardiac rehab program, recently launched at SickKids, puts that idea into practice for patients born with congenital heart disease.

1 in 100 babies are born with some kind of congenital heart defect. Currently, in Ontario, the vast majority - over 85% - come to

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SickKids for surgery. And the vast majority of these patients survive. That's a huge success story.

But what about life after surgery? These children's parents face a dilemma: "Kids should be active. But I'm afraid my kid's heart is too fragile for physical activity." That concern is reinforced by current published guidelines on sports participation for patients with congenital heart disease (CHD), which mainly present restrictions. As a result, young patients who have had surgery, or have ongoing complex heart issues, often lead sedentary lives – which leads to obesity, diabetes, and poor quality of life.

"The opportunity was cardiac rehab for kids."

The opportunity was cardiac rehab for kids - and the Cardiac Health Foundation, Cardiac Kids, and Bike2Play have partnered with SickKids to make it happen. In most provinces, government funding covers adult rehab. For the Cardiac Health Foundation, establishing and funding a paediatric cardiac rehab program fills a significant gap. As Barb Kennedy, Executive Director, Cardiac Health Foundation, and Leo DelZotto, their Board President, put it, "Our mission - 'Prevention, Education & Cardiac Rehabilitation' - has come full circle, from supporting

The impact of this initiative will be to turn a restrictive mindset on its head.

Dr. Terry Kavanagh's pioneer work in establishing cardiac rehab for adults across Canada 50 years ago, to now working with The Hospital for Sick Children to support cardiac rehab for kids and adolescents."

In a brand new Exercise Medicine Room in the Labatt Family Heart Centre, Dr. Barbara Cifra and her team will deliver exercise and lifestyle coaching, based on each child's condition and fitness level. New physiologic assessment techniques will be developed and validated, as will techniques for activity tracking in children. The impact of exercise and lifestyle counselling will be measured. When we know which strategies work best, we'll share our knowledge beyond SickKids, in support of a long-term goal: clinical care that incorporates exercise as standard of care for patients across Canada.

The impact of this initiative will be to turn a restrictive mindset on its head. It will empower kids with CHD to participate in the physical activities they can do, instead of telling them what they can't. Our objective is to make sure patients with CHD are active kids – who turn into lifelong healthy, active adults.

DID YOU KNOW?

Did you know there are many ways you can have a tremendous impact on SickKids? You can make a donation, donate stocks, leave a gift in your will, or donate your life insurance or RRSPs. If you are considering a legacy, or would like more information, please contact your SickKids representative.

Join us. sickkidsfoundation.com/invest

PRECISION MEDICINE. IT'S COMING, FAST

DR. MIKE SALTER CAN'T WAIT

Precision medicine is a medical approach that proposes to prevent and treat disease based upon a person's unique genetic makeup. Genome sequencing, gene editing, and individualized drug development are all part of it. SickKids Chief of Research, Dr. Michael Salter, is more than optimistic about precision medicine's promise at SickKids. "It's the way of the future," he says. "This is something, when I was a medical student, we didn't even think about. But it's not science fiction – we're already in the midst of it." He's also determined that SickKids research will lead the field: "We're in this to win. We want to be the ones making the discoveries."

Thanks to donors, we will. In 2015-16, SickKids Foundation granted over \$58 million of donor dollars to the Research Institute, part of which pays investigators' salaries, which are not funded through healthcare dollars. This means our researchers can concentrate on finding answers.

Dr. Salter believes a key differentiator of SickKids is translating those answers into clinical care. He's proud of our leadership in this area, like a recent application of precision medicine that saved three generations of one family from the burden of daily insulin injections. A very young girl, McKaela, came to SickKids with the symptoms of Type 2 diabetes, like her father's and grandfather's. This is not the type of diabetes expected



Dr. Mike Salter, SickKids Chief of Research, sees better outcomes ahead.

in a two-year-old. Clinicians ordered a complete genetic workup. The underlying genetic issue was identified: McKaela's body was, in fact, making insulin. But her cells were not releasing the insulin into her body. The same was true of her father and grandfather. The answer, for all three, was medication in the form of a pill.

"We'll take a drop of blood, and you'll have your genome sequenced."

Dr. Salter envisions a future where precision medicine is the norm. For every child who comes into SickKids, he says, "We'll take a drop of blood, and you'll have your genome sequenced."



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PATIENT UPDATE

THE POWER OF ANALYTICS TO HEAL THE HEART

A FAMILY'S GRATITUDE GUIDES THEIR GIFT

To win the fight against any disease, we need knowledge. Data, collected and analyzed across the lifespan, allows us to understand how interventions made at SickKids affect patients' lives – both when they're seven, and when they're seventy. Dr. Wilfred Chung, an emergency physician in eastern Ontario, and his wife Carol, understand this. In appreciation of their son Gregory's treatment for a congenital heart defect at SickKids, their gift has established the Dr. William G. Williams Research Directorship in Cardiac Data Analytics.



Gregory Chung, around the time of his surgery.

The Chungs' gift was 20 years in the making. Gregory is now 23, and a recent Queen's University graduate. He was born with a hole in his heart – ventricular septal defect (VSD) – and had surgery at SickKids when he was three. Says his father, "We'd thought about this, but what really started our conversation was Gregory graduating. We looked back on his upbringing, and asked ourselves, "OK, are there any loose ends we should tidy up?"

The Chungs' generous gift is very much more than 'a loose end'. Endowed

in perpetuity, the Williams Research Directorship is their family's way of honouring the contributions of SickKids clinician scientist Dr. William G. Williams, retired Head of the Division of Cardiac Surgery, and Gregory's surgeon. The Chungs had reached out to him for his thoughts on where they could make the most impact. Says Dr. Chung, "His suggestion resonated with me. A lot of people donate money for a certain surgical procedure, or certain diagnostic machinery. Cardiac analytics is something that's not glamorous, but it's very important."

The impact of the directorship will be twofold: in the short term, building on Dr. Williams' legacy of harnessing data (capitalizing on improved technologies like cloud and super-computing) to understand the factors that lead to the best outcomes over time; and, longer-term, reducing preventable deaths, and improving quality of life, over the lifespan, for kids born with congenital heart disease. This is what philanthropy can do – and the Chungs hope their gesture inspires others to follow suit.

OUR TEAM:



SickKids Foundation Major Gifts Team (from left to right):

Back Row: Alicia Leon, Leonard Nolasco

Second Row:

Katie Graham, Colin Hennigar, Denise Higashi, Rebecca Page

Front Row:

Anne-Marie Newton, Ayala Beck, Nancy Horvath, Ashley Smith

Not pictured: Jennifer Ashcroft, Kevin Goldthorp, Angela Murphy

SickKids

For more information, please visit www.sickkidsfoundation.com