



# BREAKTHROUGH

Spring 2016 Newsletter | Issue 2

As we kick off 2016, we look forward to the year ahead as an opportunity to pursue new goals. At SickKids, we are approaching this year with a vision of enhancing the patient experience across a seamless continuum of care. As a member of our community of donors, we will look to you to help realize this vision for improved child health. Through philanthropic investments we can build upon our past successes to elevate what we can accomplish in the future.

Collaboration is quickly becoming the hallmark of leading-edge hospitals, with integrated professional teams helping to raise the bar of patient care. In recognition of heart month, you will read about incredible collaborations and innovations that are taking place at SickKids to help make young hearts stronger. Innovations like Dr. Mike Seed's work to combine new cardiac and brain imaging techniques to improve outcomes for at-risk pregnancies, and how donor support can offer hope to many families.

We are so grateful to you, the leaders in our giving community, as we work together to create a brighter future for children around the world.

Sincerely,



Ted Garrard,  
President and CEO  
SickKids Foundation

## CONGENITAL HEART DISEASE: FROM SURVIVING TO THRIVING.

**Oxygen in babies' moms to create better outcomes for babies' brains.**

*Dr. Seed, Clinician Investigator and Staff Cardiologist / Cardiac Radiologist*



Dr. Mike Seed and Dr. Steven Miller have seen the effect that spectacular advances in surgery for babies with congenital heart disease have made.

The surgery works. More babies survive. It's their mission to see that babies do more than survive. They want to see them thrive.

Dr. Miller is SickKids' Neurology Head, and Dr. Seed is Clinician Investigator and Staff Cardiologist/Cardiac Radiologist. They lead the new Cardiac Neurodevelopment Program, a SickKids initiative based on the premise that optimal development requires attention from before the baby is born, through their hospital stay, and beyond.

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As Dr. Miller says, “The care of infants with congenital heart disease has seen incredible advances in the last decades. We can now focus on ensuring that children undergoing surgery for CHD thrive in their development.”

It had long been noted that children treated surgically for congenital heart disease had poor neurodevelopmental outcomes. Dr. Seed and Dr. Miller have demonstrated that, in Dr. Seed’s words, “Surgery isn’t the problem. Heart disease is the problem.” The period before repair is critical for brain development, and one of the keys to this is oxygen.

**“I feel strongly that those of us who can support this good work should do so. It’s important we ensure that the doctors and staff at SickKids have the equipment and tools necessary to carry into practice the advances their research produces”**

Which is why Dr. Seed is piloting a trial based on an elegantly simple idea: putting mothers of babies identified with high-risk CHD on oxygen, as soon as the fetus is diagnosed, to prevent developmental delays due to oxygen deficit. Donations are critical to make the Cardiac Neurodevelopment Program, and trials like this, sustainable. Currently, the program does well for a very limited number of the highest risk patients. But funding is needed to extend the program’s success to all patients.

Says donor Anthony Camisso, “I feel strongly that those of us who can support this good work should do so. It’s important we ensure that the doctors and staff at SickKids have the equipment and tools necessary to carry into practice the advances their research produces.”

Dr. Seed speaks with conviction (from the heart, you might say) about working to “identify modifiable risk factors for developmental outcomes.” Anthony Camisso also speaks from the heart. “I will be forever grateful to SickKids for ensuring that my grandson will have a normal, healthful life.”



A patient in the Cardiac Neurodevelopment Program

## MEET CLAIRE WATT, NURSE PRACTITIONER, CARDIAC CRITICAL CARE UNIT



*“I can build relationships because I’m consistently there. You’re the person the family will remember. You walk with them.”*

Claire Watt will be a sixteen year veteran of SickKids in May. She has two roles. As a Nurse Practitioner in the Cardiac Critical Care Unit, she describes herself as the “collaborative link” between all the members of the team and the family. Her greatest satisfaction is working with an amazing team to deliver the best cardiac care. Or, as she puts it, “making things happen.” Her other role is as a member of the Neurodevelopmental Follow-Up Program which monitors, evaluates, and supports high-risk patients who’ve had heart surgery. “We fix their hearts. We want to make sure their brains are OK, too.”

# MARNIE'S STUDIO

## Donations build a new healing space for kids.

It says 'Hospital' on the outside, but inside, SickKids has always been a place where childhood is cared for as much as the child. Marnie's Lounge is our oasis of play and fun. Now, thanks to the Kimelman and Reznick families, a companion space is underway: Marnie's Studio. Here, the emphasis is on the healing power of the creative arts: art, music, dance, movement – even yoga. It will have a performance stage with state-of-the-art lighting and sound, and a multimedia tv production studio. For kids who can't come to Marnie's Studio, this means that story time or a therapeutic clown can come to them, through one of the hospital's more than 420 closed-circuit tvs. New, too, is a multi-sensory room: a stimulating wonderland of light, colour and scent for kids experiencing pain, kids who have special needs, or who are palliative.

Linda Kimelman says, "We know that Marnie would have loved to see the children laugh and play. Our family is committed to ensuring that patients and families have a space where they can be creative as part of the healing process."

Marnie's Studio is underway.



## DID YOU KNOW?

### TRUE

CRISPR is a new genome editing tool. Think of a pair of genetic scissors, with which precise snippets of DNA – those that code for disease – can be replaced



SickKids is researching the use of CRISPR against diseases like Duchenne Muscular Dystrophy and Cystic fibrosis

### CRISPR-cas9

"CRISPR is the most important technology that I have encountered in my scientific career thus far. I'm often in a position where I can provide a diagnosis, and perhaps supportive care, but no treatment. CRISPR could change that. It could revolutionize the way we care for patients with currently untreatable genetic conditions."

–Dr. Ronald Cohn, SickKids Chief of Clinical and Metabolic Genetics and Co-director of the Centre for Genetic Medicine

### FALSE



CRISPR is a man-made technology created in the lab.

**FALSE!**

It's a naturally-occurring defence mechanism derived from bacteria

'Designer Babies' are on the way.

**FALSE!**

Ethical research is focussed on CRISPR's therapeutic uses



## PATIENT UPDATE

# JAKE: A HEART FOR HOCKEY

**Jake Lipkus is alive today because of SickKids.**

Jake's mom, Sandra, says what he likes to do most is grab a stick – and his brother, Ryan – to go play ball hockey. Today, he's an energized two-and-a-half-year-old. At 4 months, it was a different story.

The Lipkus family; Jake on the left



Jake was in SickKids, diagnosed with dilated cardiomyopathy. The echocardiogram showed his heart was at least twice normal size. The SickKids team knew he might require a transplant. With medication, Jake was able to go home. For Jake and his family, the wait was on.

SickKids expertise was always available. Sandra speaks in glowing terms of the advice and support the family received from Heart Function Team Nurse Practitioners Judith Wilson and Kristen George: "If I emailed them Friday night, they emailed back. They felt like family."

By November, 2013, Jake was listed for transplant. In March, 2014, just before he was to be admitted for end-stage heart failure, his family got the call: a heart was available. Even with a virus and a fever, it was 'go' time for Jake.

Handing him over to the surgical team was tough. "I was a basket case," says Andrew, "but we knew something had to change. This child was dying."

Eight days after Dr. Ed Hickey performed the transplant, Jake was home. His parents know having today's 'normal, happy kid' wasn't just the doing of his surgeons. It was everybody – the donor family, and, at SickKids: Occupational, Speech, and Physical Therapy; kidney function and infectious disease specialists; Social Work; and the Paediatric Advanced Care Team (PACT).

Every weekend they're at the cottage with Jake (and that's every weekend they possibly can), Sandra and Andrew throw Jake into everything, along with their other kids. Thinking, with gratitude, about what his SickKids doctors told them: "We gave him a heart. Now go live."

## WAYS TO GIVE

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.



SickKids Foundation Major Gifts Team (from left to right): Colin Hennigar, Alicia Leon, Katie Graham, Rebecca Page, Anne-Marie Newton, Ayala Beck, Nancy Horvath, Beth Weintrop, Jennifer Ashcroft (not pictured: Denise Higashi)

# SickKids®

For more information, please visit  
[www.sickkidsfoundation.com](http://www.sickkidsfoundation.com).