the montreal children's hospital foundation

Le Children Newsletter

May 2021

At birth, Isaia had a red bulge between the eyes about the size of three stacked eggs. We knew he would be born with a brain malformation, but we never could have imagined it would be so severe.

His brain was literally jutting out of his tiny skull. Then the diagnosis came: frontonasal encephalocele, a rare malformation that affects one in 10,000 newborns.

The plan was to wait a few weeks to prepare for the surgery and to let Isaia gain some strength. But the surgery became urgent when he was two days old as the liquid that surrounds the brain started to leak. Our baby was at high risk of meningitis, a potentially deadly brain infection.

Our little newborn Isaia would have a portion of his skull removed and his face reconstructed. The surgery took place on a late November afternoon. We knew it was a colossal challenge. He was so small that he needed at least two complete blood transfusions. We were sick with worry, but had a lot of faith in the specialists at the Children’s.

Several experts from neurosurgery, plastic surgery, anesthesia, and nursing worked in succession during the 7-hour surgery that saved our baby’s life.

We’re extremely grateful to the Children’s personnel, notably Dr. Mirko Gilardino and Dr. Roy Dudley, whose steady hands during the highly delicate surgery changed Isaia’s life.

From the bottom of our hearts, we want to thank donors like you. By generously supporting neurosurgery, craniofacial surgery, and plastic surgery, you’ve given Isaia a second chance at life. Today, our baby is developing normally, eats well, is responsive and smiles constantly.

To us, one thing is certain: the Children’s is the best place to be when your child is seriously ill.

— Isaia’s grateful parents

** The baby’s name has been changed to respect the family’s wishes to remain anonymous.*

What you've helped accomplish

Some **1,200** inpatients coped with the anxiety and isolation of being hospitalized through play-based and music therapies organized by our Child Life department

30,000 telehealth medical appointments ensured that the team could continue to care for patients who were at home

100,000 reusable, hospital approved, made in Quebec masks were distributed to patients and their parents upon arrival for a test or treatment

5,000 surgeries made possible thanks to equipment you help purchase for the medical teams

More than **600** families in need were helped through our Tiny Tim Fund

Nearly **1,000** premature and sick newborns benefitted from cutting-edge care in the Neonatal Intensive Care Unit

Evan has had three open heart surgeries.

To read his story, please go to childrenfoundation.com/evan2020

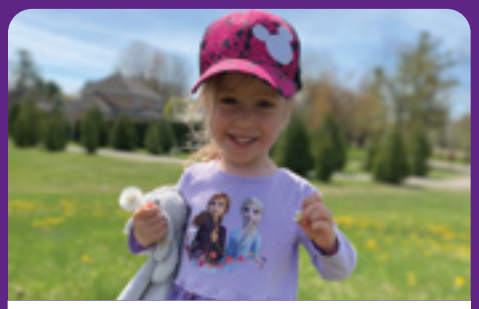
Meet three patients you've helped this year

Léandre, 12

Léandre has been playing the violin since he was 3. After turning 9, he started complaining about headaches when he exercised. When he started throwing up, they headed to the Children's for a scan. Two days after Christmas he was diagnosed with a brain tumour. He had surgery to remove the tumour, then chemotherapy and radiation therapy. Today, Léandre is being followed closely but is doing well.

Logan, 3

Born at 35 weeks, Logan's esophagus was not connected to his stomach meaning he couldn't be fed by mouth. He was rushed to intensive care right after birth and into surgery the next day. While doctors expected him to be in hospital for 6 months, he stayed 16 months! Because he still can't eat, he carries around specialized equipment in a backpack so he can be fed 18 hours a day. There are more surgeries and procedures to come, but Logan's a tough cookie!



Nieve, 4

Nieve had a stroke while in utero but no one knew until months after she was born. That's when she was diagnosed with a dangerous condition in which fluid accumulates in the brain. After two unsuccessful surgeries, plus a serious infection, Nieve came to the Children's. Neurosurgeon Dr. Jean-Pierre Farmer spotted the problem and her third surgery was a success. Today, Nieve is all smiles when she comes to the Children's for follow-ups.

Major Breakthrough in Pediatric Oncology

We can't prevent cancer, but we can now identify which kids stand a greater risk of developing the disease, thanks to a revolutionary mobile app created by a Children's specialist.

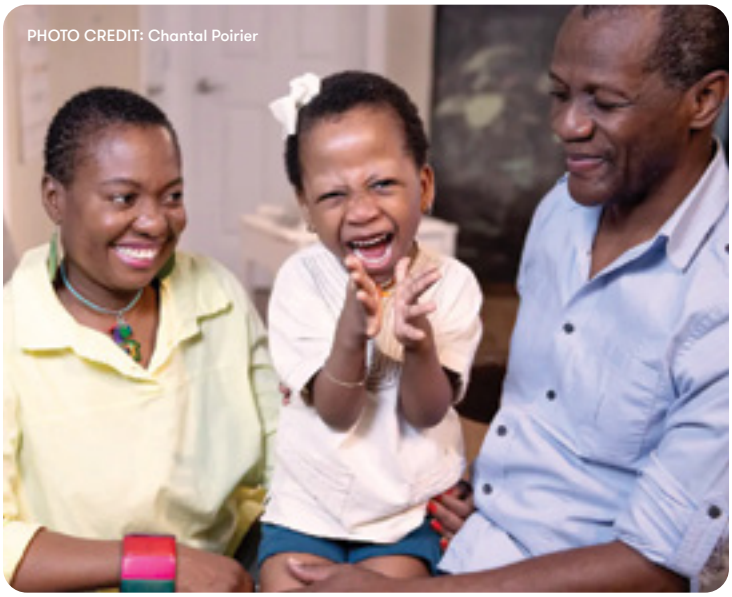
The MIPOGG (McGill Interactive Pediatric OncoGenetic Guidelines) application, developed by the Children's hemato-oncologist Dr. Catherine Goudie and her team, allows doctors to identify patients most at risk of developing a hereditary cancer and which cancer patients require genetic evaluation, which facilitates treatment and improves their chance of recovery. This worldwide first in pediatric oncology offers hope to young patients and their families.

The app identifies cancer predisposition syndromes. By detecting specific syndromes in children with cancer, doctors can tailor their treatment from the start of the disease. MIPOGG will also help identify other family members who may be at risk of cancer.

No less than 10% of children with cancer have a genetic risk of developing one or more other cancers later in life. The project was so relevant and innovative, Dr. Goudie received one of ten $1M grants offered in North America in support of her work as part of the prestigious TD Ready Challenge.

Free and bilingual, the mobile app is already used in nearly 50 countries. The medical breakthrough will soon facilitate universal detection in children and will be used worldwide.

Thanks to your donations, the Children's is creating the Pediatric Centre for Applied Genetics, the first clinic in Canada dedicated to discovering the genetic links that predispose children to cancer. The Children's Foundation is grateful for your support, which allows researchers like Dr. Goudie and her team to help the Children's find Unexpected Ways to Heal.



Rare Disease: A Huge Success Story for Mikaële Laure

It all started when a mass appeared on little Mikaële Laure's right arm a few days after her birth. Soon after, the baby girl was urgently hospitalized for severe respiratory distress.

"We saw the entire Hospital rush to her aid. Everyone was running into her room. That's when we understood it was very serious," says her mother, Rachelle.

Afflicted with a rare disease called myofibroma, which produces benign tumours in her body, Mikaële Laure also required a tracheotomy to help her breathe. After a tracheal surgery to insert a plastic breathing tube, she had to be supervised day and night. Mikaële Laure would only have survived a few seconds if the tube was torn off in her sleep. But the medical team kept a watchful eye on her.

Over their 17-month stay at the Children's, Mikaële Laure and her family could count on unwavering support from the doctors and nurses. "The Hospital's personnel took great care of our daughter, but also of us. We're so grateful to them," remembers Rachelle.

Thanks to you, the Children's can offer kids like Mikaële Laure exceptional care. Your invaluable support gives our teams the resources they need to help families like Mikaële's face serious challenges. As Rachelle says: "If you can give, please do, because it really helps make a lot of families and kids happy."

Now 4 years old, the little girl is making great progress, to the delight of her family, who remains hopeful she'll live a full life. "Despite all the time Mikaële Laure spent in the Hospital, she's developing very well. It's a huge success story for us, and it's also thanks to you," says Rachelle.

P.K. and Loïc: A Friendship That Stands the Test of Time... and Distance!

It's a must! Whenever P.K. is in town, he always makes time to stop by the Children's. Over the years, he has forged strong bonds with some of our patients.

"Loïc was one of the first kids I met at the Children's, and one of the first I built a relationship with. He's an amazing young man. Regardless of his mood or condition, he's bursting with energy. I always look forward to seeing him," says P.K.

Loïc, who suffers from a rare genetic disease that slows his development, is the first kid to successfully complete his schooling from his hospital room, where he has been cared for since 2012. He will even receive Quebec's Medal of the National Assembly. This determined young man also has good things to say about his friend P.K.: "When he comes, we talk and give each other high fives. I like P.K. a lot. He's always smiling. He gives me courage and hope."

There's mutual admiration among the two friends. Their bond is so strong that Loïc, who consistently beats P.K. at video games (but shhh, don't tell anyone), never hesitates to give him hockey advice.

"I'm a Montreal Canadiens fan. Despite that, I've always followed P.K.'s career with interest, even though he was traded and wears a rival team's jersey," he says with a smile.

With his 18th birthday coming up, Loïc's life is about to change too. There are plans for him to leave the Children's to transition to adult care. Nevertheless, these buddies expect to keep in touch. P.K. had these words for him: "As Loïc would say, 'In life, you have to take it one day at a time.' Loïc, buddy, I am so proud of you and all that you have accomplished and overcome. Every year that goes on, I look forward to re-connecting with you and promise to come and visit you in Montreal soon!"

Because of loyal Children's donors like you, Loïc has received exceptional care and can count on a team of medical experts who work like champions every day. Thanks for giving Loïc and other young patients the best quality of life possible. As P.K. says: "Your support helps us change the game."

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