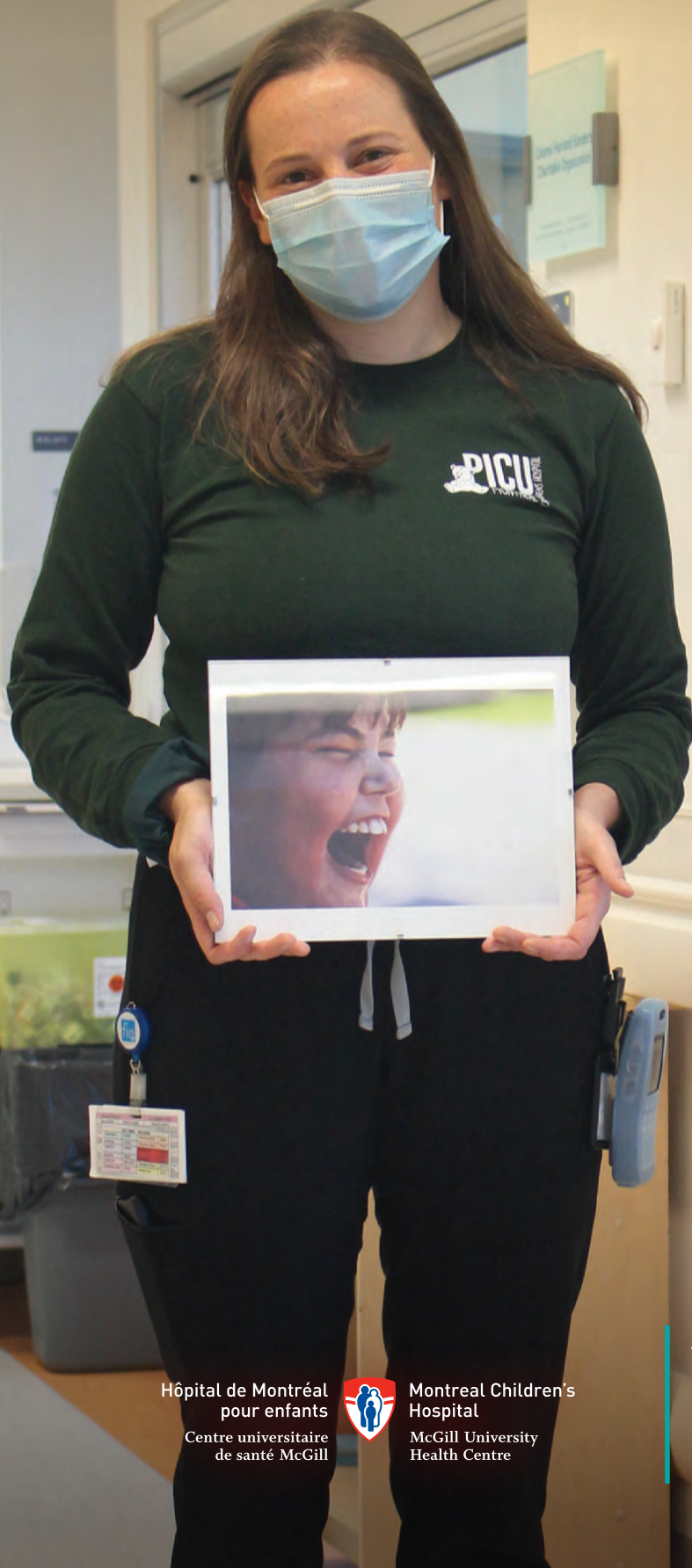


Chez nous

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FALL 2021



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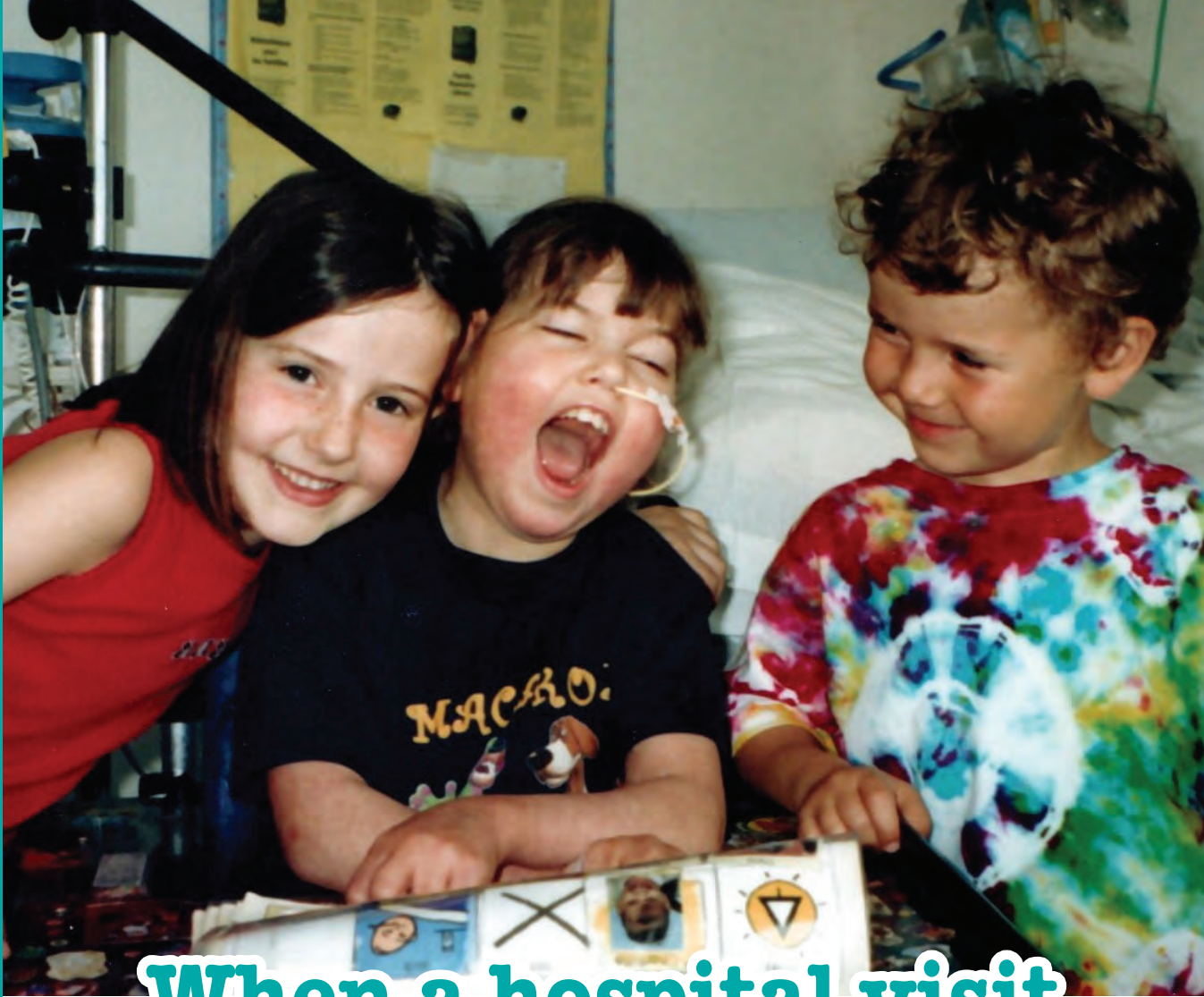
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When a hospital visit leads to a career change

By Christine Bouthillier

Some relatives of patients at the Montreal Children's Hospital (MCH) were so affected by the time they spent here that they decided they wanted to work with us. The compassion of the staff and their own desire to give back were among the reasons they chose to turn their hospital experience into a career.

► Above: Nurse Claire Duschenes-Best with her sister Charlotte and cousin Olivier during one of Charlotte's hospitalizations at the Montreal Children's Hospital.

Claire Duschenes-Best

It's safe to say that nurse Claire Duschenes-Best's life has been greatly influenced by her older sister Charlotte's medical journey. Suffering from Moya Moya disease, Charlotte was first hospitalized at the MCH at six weeks of age following a series of strokes that left her with numerous physical and intellectual disabilities.

"Chouchou," as Claire likes to call her, had been hospitalized on and off throughout her life, including to undergo a kidney transplant at age 10. By 21, she had begun a gradual transition to the Royal Victoria Hospital. Unfortunately, Charlotte developed post-transplant lymphoma, and, after a third occurrence, she finally succumbed to the disease at age 25 in 2017.

"My older sister guided my choices. I worked at Camp Massawippi, where she went in the summer, and I volunteered at her old school, Lethbridge-Layton-Mackay Rehabilitation Centre as well as at The Lighthouse pediatric palliative care centre, where she stayed for respite care. I always knew I wanted to work in healthcare because of Charlotte," says Claire, who has been a member of the MCH Pediatric Intensive Care Unit team for a year.

A STRONG IMPRESSION

Claire often accompanied her sister on hospital visits.

"In high school, I wavered between becoming a doctor or a nurse. I realized



► Claire Duschenes-Best.

that the people I remembered most were the nurses. [...] When Chouchou passed away, their presence by our side had a profound effect on me, as did their empathy. It motivated me to want to be there for our patients in those moments," she explains.

Claire has a strong sense of belonging to the MCH and has wanted to be a member of the team since childhood.

"The care that my sister received went beyond anything we could have expected. [...] Being able to give back, when

you've been treated with such kindness and attention, to be part of that process is very important," she adds.

When Claire arrived at the MCH as an employee, many staff members recognized her. They were gratified and touched to see that she was bringing her experience to bear for the patients.

"My sister was always excited to come to the MCH. Here were all her favourite people. I thought there was a special bond there that I wanted to continue," she says. * [continued >](#)

Alison Jung

Alison Jung's first contact with the Montreal Children's Hospital was stressful, to say the least. In 2016, her son John, then 11 months old, swallowed a button cell battery, which is a highly toxic and corrosive object. Ingestion can cause severe throat burns and organ damage, even leading to organ failure.

John had swelling near his aortic valve. His esophagus was completely blackened. He had to have surgery as soon as he arrived at the hospital.

"Dr. Ana Sant'Anna saved his life," says Alison, full of gratitude for the MCH pediatric gastroenterologist.

John spent a few days in intensive care and then a month on the ninth floor. He had no idea how serious the situation was.

"The doctors would play with him; the nurses were so kind. People were very compassionate and helped the whole family. I also noticed their multidisciplinary and holistic approach. Everyone worked as a team," says Alison.

She was on maternity leave at the time from a private company where she worked as a director of human resources. Alison remembered thinking how rewarding it must be to evolve in an environment like the MCH, dedicated to helping others.

John underwent further procedures. Most notably in 2017 when he was again hospitalized at the MCH to treat his blood disorder, immune thrombocytopenia.



► Alison Jung and her son John O'Neill, age 5.

A PROFESSIONAL RECKONING

Back at work, Alison began to feel the pain of being separated from her family. She had to work evenings and often left town on business trips. In 2019, when she saw that a temporary position in human resources had opened up at the McGill University Health Centre (MUHC), she jumped at the chance.

"You know when you go to an interview, and you already know you're going to like the job? That's what happened," she explains.

Alison's first assignment was at the MCH, where she was involved in a development project to support staff recruitment and retention.

"It gave a sense of purpose and meaning to my career. If I can improve the working conditions of the staff, even just a little bit, it also affects the patients. As a parent of a former patient, I know how hard the staff works," emphasizes Alison.

She has since become a management consultant, business partner, at the MUHC. Alison was particularly impressed with the way the staff handled the pandemic, reinventing processes overnight. But the MCH continues to hold a special place in her heart.

"The people who work there are angels on Earth. The culture is one of compassion. Changing jobs was the best decision of my career," she says. ❁

continued >

Eva Sokol

Eva Sokol always knew she wanted to work with children. And when her daughter was hospitalized at the MCH, she discovered where she wanted to do it.

Pregnant with twins Jodi and Jesse, Eva learned that her daughter had a congenital heart condition: ventricular septal defect. As soon as she was born, Jodi was admitted to the Neonatal Intensive Care Unit. She was operated on at five weeks of age by Dr. Christo Tchervenkov.

Unfortunately, a portion of her heart ran out of oxygen during surgery, and her life hung in the balance. Eva had to make a painful decision: leave her daughter on extracorporeal membrane oxygenation (ECMO) to see if she recovered, while risking potential brain damage, or remove the ECMO and hope for the best.

Eva finally chose the second option.

“Jodi lived for an hour, then two, then a week—and now she’s five!”

Little Jodi has undergone several other procedures: surgery to enlarge an aorta and removal of a rejected sternal cerclage—both at age one—and open-heart surgery in November 2020 to remove excess scar tissue. She continues to have bi-annual cardiology follow-ups and has her pacemaker checked at the same frequency.

A TRUE VOCATION

Before becoming a mother, Eva had completed a university degree in child

studies. Her experience with Jodi confirmed her desire to work with children, especially within the welcoming walls of the MCH.

She returned to her studies to complete the courses she needed to become a Child Life specialist. In the meantime, Eva volunteered in Child Life services, joined the Family Advisory Forum, and currently participates in the Research Ethics Board, all at the MCH.

She is also taking part in an initiative in the Pediatric Intensive Care Unit that helps children heal more quickly through careful monitoring of their pain, mental health, and other indicators, while involving their parents.

“After Jodi’s first surgery, I asked how I could help. [...] The hospital had done so

much for us, I wanted to give back. I fell in love with this place!” she exclaims.

Eva also encourages her own kids to get involved. For example, Jodi has helped distribute coffee and hot chocolate in the waiting room of the Division of Cardiology through the auspices of the En Coeur foundation.

Eva was looking to do an internship at the MCH to complete her training when COVID-19 happened, putting her plans on hold. But she would like to be hired.

“My heart is here. [...] We have received so much good care; I can’t imagine having such impeccable service anywhere else. I have grown attached to the hospital; I know it very well. Everyone I’ve met here is incredible. They are people with great souls,” she concludes. ❁



► Eva Sokol with her children Jesse and Jodi Krieble.



Fighting Pediatric Cancers Together

By Maude Samson

September is Childhood Cancer Awareness Month—a month to celebrate medical advances, remember children who have died, and raise awareness about an unfair disease that still claims too many victims. Jasmine and Noah are among those who have survived the ordeal. Their stories are a testament to the Herculean strength that children and their families display in the face of serious illness.

Jasmine's story

At the tender age of seven, Jasmine was a spirited and dynamic soccer player. As she finished her school year at home, she began to experience increasingly frequent headaches. Then came the vomiting. Previously full of energy, Jasmine was now constantly exhausted.

On August 11, 2020, her parents knew for sure that something was wrong; their daughter, displaying uncharacteristic lethargy, refused to go to soccer practice.

A battery of tests was performed to no avail. An MRI scan finally revealed a medulloblastoma, a malignant tumor located in the little girl's cerebellum.

[continued >](#)

► Above: Thanks to a GoFundMe campaign initiated by their relatives, the family got the chance to focus on Jasmine's happiness during her treatments. From left to right: Jay Pothier, Julie Turcotte, Jade and Jasmine.

“Within minutes of starting the MRI, five physicians were standing around the screen,” says Jasmine’s mother, Julie Turcotte. “That’s when they realized there was an abnormality.”

On August 17, Dr. Jean-Pierre Farmer, Surgeon-in-Chief and Director, Neurosurgery division, at the Montreal Children’s Hospital, removed the tumour in a procedure that kept Jasmine on the operating table for almost 13 hours.

“Thanks to significant technological advances, we were able to perform a delicate operation that would have been less successful 10 or 15 years ago,” says Dr. Farmer. “For example, with the intra-operative resonance room, we have an image of the brain before, during, and after surgery. This increased precision allows us to see the boundaries of the tumour and the eloquent areas around it more clearly, and it avoids having to operate again if the tumour has not been completely removed. So, after this lengthy surgery, we were able to let Jasmine wake up peacefully and go home to await further advances in adjuvant therapy, including proton therapy.”

A GLIMMER OF HOPE

Following surgery, Jasmine began proton therapy, a state-of-the-art targeted treatment that treats the affected area without damaging the surrounding cells. Because this innovative treatment is not yet available in Canada, the family was referred to Boston Children’s Hospital. The little girl spent two months there.

“So as not to worry Jasmine, we lived day-to-day,” say her parents Julie and Jay. We visited a lot of beaches, New Hampshire, Cape Cod, and spent time

as a family. The two sisters became very close.”

Despite the difficult times they went through, the family returned home more united, ready to face the next steps.

A CHALLENGING SIX MONTHS

It was during chemotherapy that things took an even more difficult turn for Jasmine: the treatment cycles wreaked havoc on her body.

“The longer it went on, the less she could eat. The foods she used

to love now tasted metallic, and a second operation was needed to install a G-tube,” recalls her father. In all, she lost 17 percent of her body mass.”

In addition to Jasmine’s nausea, frequent fevers, and sleep disturbances, her morale was also affected by the pandemic. To comply with safety measures, Jasmine’s parents took turns at her bedside. Furthermore, her sister was not allowed to visit her. Despite the support of the hospital staff, the family says they felt very isolated during this time. **continued >**



► Now in remission, Jasmine is back on the soccer field!

BACK TO NORMAL

After six difficult months, Jasmine began to recover. Her treatments officially ended on June 15, 2021, and her entire family was able to start breathing again. The speed with which she has regained her energy and the progress she has made impress both her parents and her healthcare team; Jasmine is quietly returning to her former life. ✨

Noah's story

"Noah's story proves that you can be diagnosed with stage 4 cancer and still make it through," says the teen's mother, Mary Quinn, after the most difficult year of their lives.

Like Jasmine, 15-year-old Noah felt tired for several months before he realized something was wrong. His world came crashing down when he confided to his brother that he had found a lump on his shoulder.

Noah's pediatrician acted quickly.

"He wrote three words on his prescription pad and handed it to me saying, 'Mary, you need to go to the Montreal Children's Hospital right away. I have to warn you: they're going to check Noah for cancer,'" Mary recalls with visible emotion.

Things went from bad to worse. From triage, Noah was immediately hospitalized for chest x-rays and blood work. He met with Dr. Catherine Vézina, a pediatric hematologist-oncologist, that same day.

After a nightmarish week, the diagnosis came down: stage 4 Hodgkin's lymphoma. The biopsy also revealed dramatic news: Noah had not one but four tumours. Aggressive chemotherapy treatments had to start as soon as possible.

"Given the advanced stage of his disease, Noah received five cycles of

chemotherapy, one more than many children with the same diagnosis," explains Dr. Vézina. "You could feel his anxiety, but he was the one consoling his mother after the diagnosis."

Filled with anguish, the family prepared to make room for the reality of cancer [continued >](#)



► "During these very difficult moments at the hospital, the doctors and nurses that I met all took good care of me, remembers Noah. Thank you for giving me back my health."

under their roof. The pantry was filled with medical supplies and Mary, an elementary school teacher, was now changing her youngest's catheters. What the family didn't know was that the toughest part lay ahead.

A TRAUMATIC EPISODE

On April 9, 2021, Noah and Mary walked into the infusion room for the first of five cycles of chemotherapy. As soon as the powerful anti-cancer treatment was injected, Noah reported an abnormal sensation in his throat. A few minutes later, a Code Blue was called, as the young man, his complexion now purple, struggled to breathe and convulsed. The teenager was one of the few to experience an allergic reaction to the drug.

"The PICU team arrived right away. There must have been 20 people working together to give him oxygen, intubate him, and administer intravenous medications," recalls Mary. "They saved my son."

Time was of the essence, however, so treatment resumed the next day in the ICU under constant supervision. As the months progressed, Noah continued to encounter obstacles at every visit. Against all odds, he never gave up.

"He remained quiet, positive and extremely resilient. At these appointments, he was the one asking the nurses and doctors how they were doing. That's my son," Mary says proudly.

When Noah was finally able to come home, he made up for lost time with his



► For this close-knit family, being separated from Noah during his hospitalizations was very difficult. Thankfully, they are reunited now! From left to right: Noah, Frank Ierfino, Mary Quinn and Jacob.

father Frank and his brother Jacob, from whom separation had been particularly difficult during his treatments. They share a passion for music that provided the teenager with a well-deserved respite from the hospital.

THE LONG-AWAITED NEWS

Noah received his last chemotherapy treatment on July 17, 2021. He then waited 10 long days before learning

that radiation treatments would not be necessary. After an arduous year, the family considers this the biggest victory of their life.

It was a happy ending for Jasmine and Noah; both are now in remission but still being followed at the MCH. As time goes by, their visits will become less frequent until this year of illness becomes a distant memory. ❀



Easing the Pain One Heartbeat at a Time

By Christine Bouthillier

Losing a child is the worst ordeal a parent can face. To help relieve that pain, the music therapy team at the Montreal Children's Hospital (MCH) offers parents a precious memory: a song set to the rhythm of their child's heartbeat.

“A heartbeat is a gentle, comforting sound that immediately puts us in touch with the person in a very intimate way,” says Christelle Jacquet, music therapist at the MCH.

The child's heartbeat is recorded before their death by means of an electronic stethoscope. Then, using a software program, it is superim-

posed on a melody chosen by the family. The music therapists play the piece themselves, adapting it to the child's heartbeat.

“In music therapy, rhythm is really the basis of life. Sharing your heart is a powerful image,” adds Pascal Comeau, music therapist at the MCH.

continued >

► Above: Christelle Jacquet and Pascal Comeau, music therapists at the Montreal Children's Hospital.

BENEFITS FOR FAMILY AND STAFF

The musical tribute is a reflection of each family's wishes. Some want only a recording of their child's heartbeat; others opt for an instrumental piece; still others, a song with vocals. The range of pieces produced by the team is very broad: from lullabies to rock music, depending on the preferences and culture of the families.

"Each recording is personalized, not only with respect to the child, but also to the family, making it a touching and unique tribute," says Christelle.

Siblings can also help choose the melody, a contribution that eases some of their own sadness. Moreover, the song can serve to introduce the child to extended family members who perhaps did not know them; it's a way to bring them into their world.

Hospital staff may also benefit. When faced with a patient at the end of life, they sometimes feel helpless. Since the health care team is involved in recording the heartbeat, it offers the family a memory they can cherish forever.

"As a nurse, my role is to accompany families when a child dies. I sincerely believe that it is possible to make these difficult moments beautiful and memorable for them. [...] I really appreciate being able to provide this gift," says Emilie Moline, a nurse in the Neonatal Intensive Care Unit.

A HEARTBEAT CATCHES ON

The popular service has led to new initiatives. As a result of a collaboration

between the Royal Victoria Hospital's Department of Obstetrics and Gynecology and the MCH Neonatal Intensive Care Unit, Joanie Ayotte, a palliative care music therapist, has begun offering the service to certain adult patients.

"I once recorded the heartbeat of a woman in oncology, who was going to die after giving birth, so that her baby could find comfort in it in her absence," explains Christelle.

She says that the mother was able to find some solace in knowing that a part of her would continue to exist for her child. Weeks later, the father confided in her that the recording helped him to grieve and was a precious memory that he liked to share with his daughter.

DEFINING MOMENTS

"To accompany parents in these circumstances is very moving, and we

feel privileged to be able to make a difference in this specific way," says Christelle.

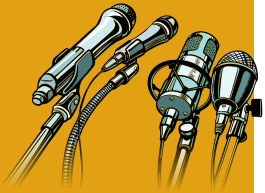
She remembers one occasion in particular where a child's death was imminent. Called to record his heartbeat, she eventually stayed in the room with the family and played music until the end. The relatives told her that this accompaniment helped them to let go of their child.

"The ability to listen to our son James's heart whenever we felt the need to do so soothed our broken hearts, and we knew it would help us heal," attests Kristen Roberts, a mum who has also benefited from the service.

The heartbeat music program was made possible by generous donors to the Montreal Children's Hospital Foundation, including Sarah's Fund for Cedars, Andy Collins for Kids, and Stelpro. ❁



► The electronic stethoscope.



Thank you 1,321,603 times!

By the Montreal Children's Hospital Foundation

The Montreal Children's Hospital Foundation and **CJAD 800, 95.9 Virgin Radio, CHOM 97.7** and **TSN Radio 690** are proud to announce that the **2021 Caring for Kids Radiothon**, held on August 26, raised **\$1,321,603** for young patients. Contributing to the success of this year's edition were the 21 families who shared their stories, the hospital staff who participated in the Children's Champions interviews, and the scores of generous listeners who donated.

Since 2004, more than \$26 million has been raised for the Healthy Kids Fund to meet the most urgent needs of the hospital, which include medical and surgical equipment and funding for innovative projects.

The Foundation thanks the **Bell Media** radio stations as well as our phone bank partner **Dormez-vous** and our Miracle Hour Sponsors: **Larente Baksh & Associates at TD Wealth, Otsuka, Revolution Textiles & Home Décor, Rio Tinto, SNC-Lavalin, The Tenaquip Foundation** and **Traffic Tech.**



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On the cover: Claire Duschenes-Best, holding a photograph of her sister Charlotte. Cover photo: Christine Bouthillier

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