

Chez nous

MCH EMPLOYEE NEWSLETTER

Published by Public Relations and Communications | www.thechildren.com

SEPTEMBER 27, 2017

Three siblings, same diagnosis —page 2

Hôpital de Montréal
pour enfants
Centre universitaire
de santé McGill



Montreal Children's
Hospital
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ALSO IN THIS ISSUE:

Dr. Mitchell's letter to the
editor — Page 5

Viagra could help babies
deprived of oxygen— Page 6

PFCC Star of the Month,
Kathy Kehoe — Page 9

Cadence, Ethan and Abigael:

three siblings, same diagnosis

By Sandra Sciangula



► Dr. Roy Dudley shows Kerry and Adam test results while Abigael looks on with interest, and Cadence and Ethan sit patiently on the examination table.

Twins Cadence and Ethan Lenet were about to start pre-K when their mom, Kerry Howard, brought them for a routine eye examination at the optometrist. Kerry was not surprised that Ethan, who had an eye that would look toward his nose when he got tired, was prescribed glasses but was shocked when Cadence was prescribed very thick lenses. “I felt like there was something wrong with her prescription so I sought out a second opinion,” she says.

Kerry went to a trusted family friend, an optometrist who doesn’t usually see children but agreed to examine Cadence and Ethan. Upon examining them, he urged Kerry to go to the Montreal Children’s Hospital (MCH) as soon as pos-

sible. “He put his hands on my shoulders, looked me in the eyes and said, ‘Get Cadie an appointment at the Children’s ophthalmology clinic immediately’,” says Kerry.

AN UNEXPECTED DIAGNOSIS

Dr. Ayesha Khan, a pediatric ophthalmologist, saw Cadence and took a lot of time to examine her. “This made me panic a little,” admits Kerry. Dr. Khan confirmed that Cadence had papilledema which is a sign of intracranial pressure, a diagnosis that surprised Kerry because Cadence never complained of any discomfort. A few weeks after Cadence had an MRI, Kerry was asked to meet with pediatric neurosurgeon Dr. Roy Dudley and the neurosurgery team.

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Chez nous is published by the MCH Public Relations and Communications office

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To submit story ideas or texts to *Chez nous*, contact the Public Relations and Communications office at ext. 24307 or send an email to info@thechildren.com.

Production of *Chez nous* is made possible thanks to funding from the Montreal Children's Hospital Foundation.

Cadence's MRI not only confirmed signs of increased intracranial pressure but also bulging optic discs and a mild chiari malformation which is the descent of the cerebellar tonsils into the spinal canal. Cadence also had somewhat of a long head shape, suggesting craniosynostosis. "The first thing Kerry told us in the subsequent clinic visit was that she herself had had two surgeries for sagittal craniosynostosis in her first year of life. So we sent Cadence for a skull x-ray and a 3D CT scan of her head, both of which confirmed multi-suture craniosynostosis," says Dr. Dudley.

DIFFERENT PRESENTATIONS, UNIQUE CHARACTERISTICS

Cadence was otherwise well, she did not have headaches or vomiting, she was completely neurologically intact and her development was normal. The children's parents, Kerry and Adam, said they would not have been worried about her at all, however, her twin, Ethan, and older sister, Abigael, often complained of headaches.

With this information, Ethan and Abigael also underwent testing. Even though Ethan had a normal head shape, the tests revealed that he had a more mild case of papilledema than Cadence but a more severe chiari malformation. Abigael's tests on the other hand, revealed only mild papilledema but an even more striking multi-suture craniosynostosis than her siblings and no chiari malformation at all.

MANAGEMENT OF CARE

Each child's case was treated in a different manner. Dr. Mirko Gilardino, a pediatric craniofacial surgeon, operated on both Cadence and Ethan with Dr. Dudley. "Cadence had the more conventional approach which is a cranial vault expansion with resorbable hardware. *continued >>*



▶ Dr. Mirko Gilardino examines Ethan several months after his surgery.

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*On the cover: Abigael, Ethan and Cadence Lenet
Cover photo: Owen Egan*

Cadence, Ethan and Abigael... (cont'd)



▶ From l. to r.: Dr. Natascia Anastasio, Abigael, Cadence, Ethan and Kerry

Ethan though, was a perfect candidate for a posterior cranial vault distraction where we place screws in his skull and his parents slowly expand it to generate new bone," says Dr. Gi-lardino. It was agreed that the best approach for Abigael was not to undergo surgery but monitor her as she grows.

HIP HOP TO THE OR

Hip hop dance is a favorite activity of all three children and thanks to the Parental Presence at Induction program at the MCH, which helps children and their parents get ready for surgical procedures, Cadence and Ethan were able to dance along to their favorite song as they made their way into the operating room. Cadence chose Meghan Trainor's *All About That Bass* as her song and Ethan, Justin Timberlake's *Can't Stop the Feeling* as his. "On their way into surgery, I played their songs on my iPad and they danced their way down the hall. Everyone in their path stopped and danced too. It was the coolest thing I have ever seen," says Kerry.

A STRIKING PEDIGREE

A lot of families with craniosynostosis are referred to the genetics clinic to rule out a genetic cause for the condition. The Lenets present a remarkable case because Kerry also underwent surgery for craniosynostosis as a baby and it is not typical for so many members of one family to be affected. Given all her children are affected, it is extremely likely that Kerry carries a change in a gene that causes craniosynostosis, and that this change got passed onto her children.

Dr. Natascia Anastasio is the genetics resident working with the family and so far, no gene has been found to explain the condition in the Lenets. The Genetics team tested approximately 20 different genes associated with craniosynostosis and Kerry did not have changes in any of them. "Moving forward we will be guided by new information that comes up. So, it could be that there is a completely new gene that hasn't been identified yet as being associated with craniosynostosis, and that might be causing the condition in the Lenet family," explains Dr. Anastasio.

As for the Lenet children, they are healthy and happy. Kerry and Adam are grateful for the care their children received and continue to receive. "Everyone who has looked after our children holds a special place in our hearts. Because of the incredible care they have had and will continue to receive, they get to keep dancing," says Kerry. ■



▶ Kerry and Adam are very grateful to Frédéric Lacroix, nurse clinician and coordinator of the Craniofacial and Cleft Surgery Program, who was always available to answer their many questions.



▶ The kids take a play break during their recent visit to the MCH.



Cancer wait times: Letter to the editor

Published in the Montreal Gazette on September 16, 2017

In his article published on September 5, 2017, “Cancer, heart patients waiting longer at MUHC”, Montreal Gazette reporter, Aaron Derfel wrote “cancer patients are waiting considerably longer for surgery at the McGill University Health Centre” and that “the situation is particularly striking at the Montreal Children’s Hospital (MCH)— part of the MUHC — where three patients were waiting at least 57 days”. Presented without context, his article is a gross misrepresentation of the facts and quality of care given at the MCH.

What happens routinely for cancer patients at the MCH is an example of the system working ideally. It is not uncommon for a new patient to have a diagnostic biopsy or tumour removal performed, have all the imaging for tumour staging done, and treatment started within 1-2 weeks of presentation. For a number of patients, their treatments dictate upfront chemotherapy followed by delayed tumour removal at a pre-determined time during the protocol and which is scheduled weeks in advance. This “wait” may confound statistics but the patients are having their tumours removed at the appropriate time in their treatment and last-minute scheduling is avoided. Finally, once a patient has completed their treatment, they may undergo a surgery to remove an implanted catheter through which the treatments were delivered. Waiting for this procedure may be longer than the 57 days mentioned in Mr. Derfel’s article, however this surgery is elective and has no bearing on the outcome of the patient with regards to their cancer. Regarding the three patients mentioned above: one was too sick to have surgery at the planned time and two were having elective procedures that had nothing to do with their cancer treatments.

Fortunately, the relatively low incidence of children and adolescents diagnosed with cancer allows for treatment to be accessed and initiated rapidly. Mr. Derfel’s flippant use of data has created undue anxiety by not providing an accurate and complete portrait of the uncompromising care given to cancer patients and their families at the MCH. The staff at the Children’s recognize the incredible stress caused by the diagnosis of cancer in a child or adolescent and work hard not to add to that burden by providing state-of-the-art, compassionate, and **timely care**.

Dr. David Mitchell

Division of Pediatric Hematology/Oncology

Montreal Children’s Hospital

Viagra could help babies

deprived of oxygen during childbirth

By Julie Robert



► From l. to r.: Antoine, Michel and Aleyda

“We had nothing to lose, but so much to gain,” were the first thoughts of Aleyda Jimenez and Michel Lévesque when they decided to let their son Antoine, then a day old, participate in a new clinical trial led by Dr. Pia Wintermark, a pediatrician and neonatologist at the Montreal Children’s Hospital (MCH). Dr. Wintermark and her team at the MUHC Research Institute are studying how the popular blue pill Viagra seems to repair the brain of newborn babies who have suffered oxygen deprivation at childbirth.

Despite all the precautions taken, there can still be complications around the time of childbirth and everything does not always go as planned. This is what happened when Aleyda stopped feeling her baby move for more than 24 hours. “Everything went very well until this incident. Antoine was

deprived of oxygen at birth and had to be resuscitated, which had serious repercussions on his health, including his heart and lungs,” she explains.

Neonatal asphyxia happens when the baby does not receive enough oxygen at birth. It occurs in four out of 1,000 births. Injuries to the brain can lead to learning and developmental difficulties, cerebral palsy and can sometimes be fatal.

Currently, there is only one treatment for newborns who lack oxygen or blood at birth: hypothermia. It has been a standardized procedure at the MCH since 2008. The newborn’s body temperature is lowered to 33.5°C for 72 hours, which is supposed to allow the brain to recover from oxygen deprivation by preventing too much blood coming back to the

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brain after such a traumatic event. Many studies have already shown that hypothermia reduces the amount of neurological damage to the brain, but, unfortunately, this treatment only works for one in seven babies.

By analyzing the brain of newborns with magnetic resonance imaging (MRI), Dr. Wintermark's team observed that cold does not always prevent the excessive and adverse effects to the increase in blood flow to the brain.

"It was a surprise. It was believed that it was necessary to wait 7 to 10 days after birth to know if the baby had brain damage despite the hypothermia treatment, but from the second day of life, we saw that it is already possible to see brain damage in the babies who were treated," she explains. In a first, the researchers decided to use the hypothermia treatment with sildenafil — the drug marketed under the name Viagra — to children with brain damage as of the second day of life. "It's not the first use we think of when we talk about Viagra, but it's been used by pediatricians for years to treat pulmonary hypertension and other respiratory problems in babies and children. It is also being studied for use in adult patients suffering from stroke," says Dr. Wintermark, who is also a scientist with the Child Health and Human Development Program at the MUHC Research Institute.

"We tested the drug on baby rats that lacked oxygen, and we observed that sildenafil decreased the amount of brain damage and inflammation and increased the number of neurons in the brain of rodents," she says.

The results of the research were so promising that Health Canada has approved a Phase 1 clinical study to be conducted in children with birth asphyxia. The team is currently following three babies, including Antoine, who had brain lesions on the second day of the hypothermia treatment. The three children received Viagra or a placebo on a randomized

protocol for seven days. These babies will be followed up to the age of two years and will undergo a yearly exam for their first two years of life. The team is planning to recruit a total of 30 newborns to complete the first part of the study.

"We will continue to closely study the mechanisms by which Viagra helps repair the brain. We need to do more research to make sure that this treatment does not cause any side effects, then we can expand the study to babies across Canada," says Dr. Wintermark. "Viagra has the advantage of being inexpensive and easy to administer," says the researcher. "If its effectiveness is proven, it could be used throughout the world."

Dr. Wintermark emphasized the courage of the parents who, despite the severity of the situation, agreed to let their newborn participate in this experimental treatment, without having assurances of promising results at this stage of the research.

"My husband and I are scientists, both chemists, and we are aware of the importance of clinical research for the development of future treatments," says Aleyda. "Even though our child was fighting for his life, we decided to have him participate in this clinical trial led by Dr. Wintermark. What we experienced can happen to anyone and if this research can help Antoine or future babies in the same situation, it is worth it."

Dr. Wintermark's research team has also created a website called NeoBrainParents to support and inform parents of babies who are being treated with hypothermia: www.neobrainparents.org ■



Kathy Kehoe: PFCC Star of the Month


By Maureen McCarthy



Kathy Kehoe is this month's PFCC Star, an award given to members of the Children's staff who have been recognized for their commitment to caring for patients and their families. Inga Murawski and William Nahorniak were very pleased to nominate Kathy for the award, a recognition they feel is truly deserved.



To see Eva today, it's hard to believe she spent the first six months of her life in the Children's neonatal intensive care unit (NICU). Now five years old, Eva was born with long-gap esophageal atresia, a condition in which the esophagus, which normally connects the mouth to the stomach, doesn't develop properly.

When Eva's parents, Inga and William, first arrived in the NICU days after she was born, they were quite overwhelmed. "You don't know much about your child's illness, and you have no idea how long you'll be there," says Inga. One of *continued >>*

 **Our PFCC Stars are featured on the Children's Facebook page. Here's what people had to say about our previous award recipient, Marie Antonacci.**

Margaret Ruddy
So well deserved!! Congratulations!

Céline Bélanger
Bravo Marie!

 Like  Comment  Share



▶ Kathy and Eva during Eva's stay in the NICU.

the first people they met was Kathy Kehoe, a nurse who has been in the NICU for most of her career. A few days after Eva was admitted, Kathy approached Inga about being Eva's primary nurse. As the months progressed, they developed a very strong bond, and Inga says Kathy was instrumental in helping them learn about Eva's condition and how they could be part of her care. "Eva's tubes were very complicated and Kathy helped us understand how they work, and how to hold Eva or even bathe her with all her tubes in place," says Inga. Kathy works at night and Inga acknowledges that knowing she was there overnight helped reassure them and ease their stress.

Working at night is not everyone's cup of tea but for Kathy, it was a good fit. "It was a routine that worked really well for me especially when I was raising my children," she says. "I also learned pretty early on that I'm not much of a morning person," she says with a laugh.

The NICU environment always attracted Kathy, and for most of her career at the Children's, she has worked in neonatal care. About 10 years ago, she added another role to her work after completing the course to become a transport nurse. "Sometimes we meet flights transporting babies from up north but our work mostly involves going to nearby hospitals to stabilize a baby then bring them to our NICU," she

says. The nights where Kathy is assigned to transport mean less hands-on care on the unit, but she and her transport colleagues do whatever they can on the unit, while always being ready to go out at a moment's notice.

When it comes to patient- and family-centered care, Kathy believes it's an essential component to ensuring successful outcomes. "Working with a family is the right thing to do, particularly in the NICU where the baby is so vulnerable and there's so much for the parents to learn before their baby can go home," she says. "I've always told parents that they know their baby better than anybody else, so it only makes sense to encourage them and bring them into the process." She adds that for parents, being able to take part in whichever way they can gives them a great sense of pride and accomplishment.

Kathy also believes that making sure parents' needs are being met is an important part of patient- and family-centered care. Working at night, she says it's nice to know that parents trust her and feel comfortable enough to go home for a while. "If the parents are home resting, that's an important part of caring for the family," she says. "I've often said, if they *don't* call you during the night to see how their baby is doing, that's a good thing." ■



▶ From l. to r.: Eva, Inga, Kathy, Miko, and William

Siblings at the Children's receive extra support



► Big brother Raphael builds a train track with Kaitlen Gattuso, one of the care service coordinators.

Any parent who has spent time in the Neonatal Intensive Care Unit (NICU) at the Children's will tell you that they often need extra support to care for their older children while they spend countless hours at the bedside of their sick child. To respond to that need, the Just For Kids Siblings Park opened its doors this summer to welcome siblings of patients being cared for in the NICU.

The Just For Kids (JFK) Foundation, in collaboration with the MCH Volunteer department, launched the pilot project in July. The program is run by two coordinators who organize fun activities in the play room on S1. The service is free of

charge and is currently available to families in the NICU; the goal is to eventually offer it to more families from acute, intensive, and long-term care units across the hospital.

As of October 6, the JFK Sibling Park will be opened **Friday from 4 to 8 pm, Saturday and Sunday, from 9 am to 12 pm and from 1 to 4 pm**. For more information, contact the MCH Volunteer department at ext. 22044. ■



Keeping his promise

P.K. visits the MCH

Before heading back to Nashville after making a stop in Montreal, P.K. Subban dropped into the Children's to visit with new and old friends alike. Patients, family and staff were all smiles as P.K. offered words of encouragement to patients and families and expressed his gratitude to staff. Some of the special moments are captured here.



The Montreal Children's and Shriners Hospitals are hosting the 2017 CAPHC conference

THE NATIONAL CONFERENCE IS BEING HELD IN MONTREAL COINCIDING WITH THE CITY'S 375TH ANNIVERSARY

The annual Canadian Association of Pediatric Health Centres (CAPHC) conference is taking place in Montreal from October 22 to 24. Themed *Engaging Children, Youth, and Families: Are You Ready to Move Beyond Good Intentions?*, healthcare professionals from across Canada will participate in networking activities and have the chance to listen to presentations by The Right Honourable Paul Martin, Dr. Nicolas Steinmetz, Olympic medalist Alexandre Bilodeau and Cindy Blackstone. Single-day attendance and student rates are available, as well as tickets for the dinner on Monday, October 23. For more details, and to register, visit www.caphc.org.

News & Events



MEMORIAL SERVICE

A memorial service will be held on October 3 in the Research Institute auditorium to remember the children who have died recently at the MCH. We will also commemorate children who have died of SIDS. All staff members are warmly invited to attend this service, which will be held on **Tuesday, October 3 at 2:30 p.m. in the Auditorium of the MUHC RI, (ES1. 1129).**



COMPLETE THE *CHEZ NOUS* SURVEY FOR A CHANCE TO WIN!

The Children's Public Relations and Communications office would like your input on *Chez nous*! Answering our short survey helps ensure that *Chez nous* remains a valuable and practical way to communicate important news and information about the MCH. It only takes a few minutes to complete: just visit surveymonkey.com/r/Chez_nous_EN_2017 to answer the questions.

Don't forget to include your name, email and phone number at the end of the survey for a **chance to win a \$50 Amazon gift certificate**. Keep in mind you can also choose to remain anonymous if you prefer.

You can fill out the survey on your smart phone or tablet too! **Deadline is October 12, 2017.**

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