

Chez nous

MCH EMPLOYEE NEWSLETTER

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Finding the light after a loss

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Photo: Owen Egan





Finding the light

How one family found strength after the death of their daughter

— By *Stephanie Tsirgiotis*

Some stories are very hard to put into words. They are hard to write about and even harder to speak about. But they still need to be told. Ophélie Fournier was 16 months old when she passed away peacefully while lying in bed next to her mother. Before falling asleep, her parents, Stéphanie and David, spent hours holding her, kissing her and saying goodbye. They knew she was going to die soon. Her body could no longer support her.

Stéphanie was six months pregnant when she lost her daughter. At the time her eldest son, Jacob, was only three. She explained to him that Ophélie was now a star in the sky and he rushed to

the window to try to find her. The days that followed felt empty. All she wanted to do was hold her daughter again, feel her warm cheek against hers. Nobody knew what to say. Some friends stopped talking to her and David, while others went on as if nothing happened - as if their lives weren't completely changed forever. "Losing a child is like losing a part of yourself. Eventually you will learn how to live, but it'll never be the same," says Stéphanie.

Ophélie was barely two months old when she started suffering from epileptic seizures. Each episode ended with a trip to the Emergency Department at the Montreal Children's Hospital.



(l. to r.) Stéphanie sits with her sons Jacob and Adam, while David and her go through a book she had printed to prepare Jacob for Ophélie's death. She printed three different versions for him. She gave the first and second books to him before and after Ophélie passed away, and printed a third one when he turned four years old and started to ask more questions about her death.



Stéphanie and her sons look through a wooden chest full of Ophélie's keepsakes.

She was eventually hospitalized and underwent a number of tests. Then on October 6, 2010, her parents received the worst possible news. Their daughter was going to die and there was nothing they could do. "The images from the MRI spoke for themselves. We were told that Ophélie's brain was too small and it could not support her growing body," explains Stéphanie. "There was no treatment or cure. No miracles."

After receiving such devastating news, the Fournier family decided to go back home, surround themselves with family and friends and make the most of Ophélie's short life. They had no control over this horrible situation, but they did have the choice to wake up every day and make the most of it. "We really wanted to give her a life of absolute happiness," says Stéphanie. Working with the MCH's Pediatric Palliative Care Program, Stéphanie and David looked at all the options and services available to them and their daughter. Day by day, they began to adapt to her needs.

Ophélie slept a lot. She had a severe developmental delay and suffered from stiffness in her legs and arms. But her parents chose not to focus on the things she couldn't do and instead focused on making her life as peaceful and happy as possible. She didn't react to sound, but she did react to touch, so her parents held her as much as they could. They would caress her cheeks and snuggle with her in their bed. She



"It's very important for us to keep her legacy alive," says Stéphanie.

Continued >>>

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Finding the light (cont'd)

also loved being in water, so her parents would draw her baths where she would sit calmly for hours.

Stéphanie also started writing a blog about her family's experience. It helped her sort through all her thoughts and emotions and she began to connect with other families going through the same thing. It was also another way to make sure Ophélie's legacy would stay alive, even after she was gone. She tried to end every blog post on a positive note, but after Ophélie passed away it became harder and harder to do. "While Ophélie was alive we tried to take advantage of every moment. We truly celebrated her life, but after she was gone things just felt very heavy," she says. "The void was large."

Another thought eating away at Stéphanie and David was Ophélie's official diagnosis. There was none. Geneticists had found a genetic mutation on one of her mitochondrial DNA, but they had never seen anything like it. They couldn't tell if the mutation was responsible for her disease or whether Jacob and their newborn son Adam were at risk. They also didn't know if the mutation started in Ophélie or was passed on by Stéphanie and David. Then on October 16, 2014, almost four years to the day after finding out that their daughter was going to die, they got the news they were waiting for.

Ophélie died from a neurodegenerative disease called Pyruvate Dehydrogenase Complex Deficiency. A mutation had occurred inside her mitochondrial DNA code, which meant the mitochondria, also known as "the powerhouse of the cell," couldn't supply enough energy to her cells. "When Ophélie's brain asked for an extra dose of energy from the cells that helped create it... well the pool was empty and the cells were not able to charge their batteries," writes Stéphanie in her last blog post. "This explains why her brain was so small." The diagnosis also answered a few other concerns the family had. The genetic counselor confirmed that the disease started in Ophélie's body after conception and was not passed on by Stéphanie and David. There was also no risk to Jacob and Adam. The family now felt like they could turn the page.



Ophélie Fournier

"Ophélie was born this way. She was who she was and she will forever be in our hearts. She taught us how to live life and that is her legacy. We now live one minute at a time, one tear at a time and one smile at a time," says Stéphanie. "Our story is one of life, love and resilience and that is all thanks to her." •

The MCH Pediatric Palliative Care Program provides comprehensive care for children with life-limiting and terminal illnesses at home and in the hospital. The team addresses clinical issues including pain and symptom management, communication on end-of-life care issues, sibling support, advance care planning, location of care preferences and options, psychological and spiritual assessment, quality of life treatment options, and bereavement support. "Our goal is to maximize the good times and minimize the bad," says Marie-Claude Proulx, clinical nurse specialist with the MCH Pediatric Palliative Care Program. "We talk with the family about their main goal when it comes to caring for their child and then we help them find treatments that align with that goal. We give them different options to think about and help guide them through the process." The team works closely with community partners and offers their services 24/7.



Spotlight on our pharmacists:

March is Pharmacist Awareness Month

Pharmacists are our allies in delivering safe care and finding optimal treatments for our young patients. Did you know that at the Children's we have 15 pharmacists on staff, working in various departments and units throughout the hospital? As part of Pharmacist Awareness Month, we're introducing you to a few of their friendly faces.

Catherine Sicard

*Pediatric pharmacist at the
Montreal Children's Hospital
Hired: 2010*

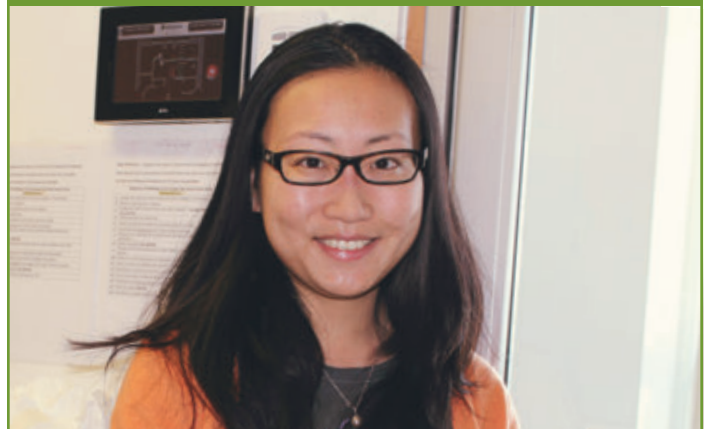


"I found that being a pharmacist was a way to interact more with people—to help them and take care of them," says Catherine Sicard, pediatric pharmacist. Catherine says she decided to focus on pediatrics because she's drawn to the incredible strength of her patients even when they're sick. "Children respond much quicker and get better faster, which is something I find very gratifying," she says.

Catherine views hospital stays as a good opportunity to review the medications that a patient is taking at home. Part of Catherine's job is to explain and reassure parents about the medications prescribed to their children, especially when it comes time to discharge them. Children do not react to drugs the same way as adults do, and they may also refuse to swallow medications—all things that Catherine needs to consider when writing a prescription.

Nora Ruo

*Pediatric intensive care pharmacist
at the Montreal Children's Hospital
Hired: 2011*



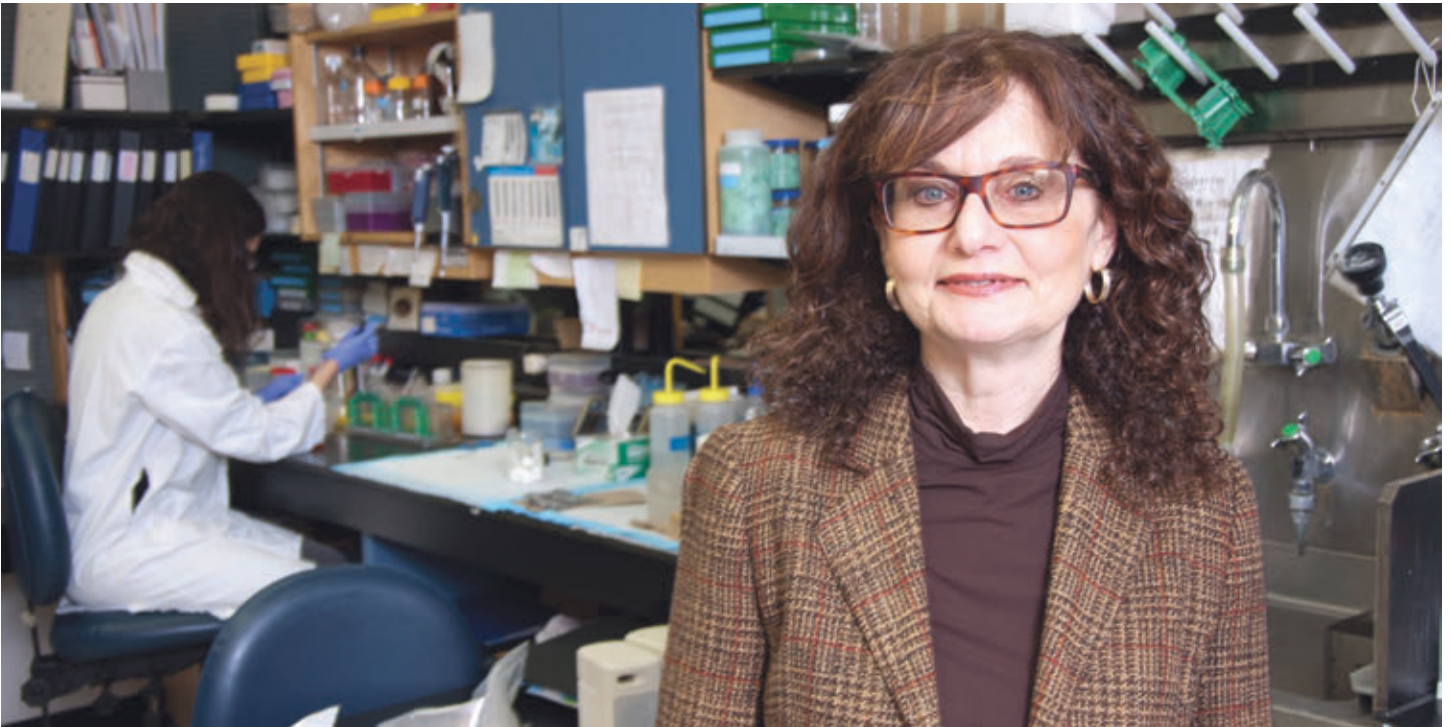
"Children are always happy. Even when they're sick, you'll never hear them complain. They just want to play—they're so positive and optimistic. That's what gets me out of bed every morning; that, and their smiling faces," says Nora Ruo, pediatric intensive care pharmacist.

While at university, Nora did several internships in hospital pharmacy departments, leading her to a position at the Children's after she graduated. "I love that my job is challenging, no two days are ever the same. In fact, I learn something new every day," says Nora.



A face-to-face with one of our research leaders

— By Gilda Salomone



Dr. Rima Rozen

Dr. Rima Rozen's research focuses on genetic and nutritional deficiencies in folic acid and their impact on various diseases. Over the course of her 30-year career, Dr. Rozen has produced over 200 publications and made significant discoveries in her field. She has recently identified biomarkers, or genetic changes, that could lead to early diagnosis of colorectal cancer.

What is so fascinating about Genetics that you've decided to devote your career to it?

R.R.: Genetics has exploded in the last few decades and I've been part of that evolution. When I first trained, it was all about biochemistry and metabolites. Then we moved on to chromosomes, cellular studies and the cloning of genes. Now we're able to look at the entire genome. It's been an exciting and challenging adventure.

For the last 25 years, you've been investigating folic acid. Why?

R.R.: I'm particularly interested in the interactions between genes and metabolism. Folic acid is a very important vitamin involved in many disorders, the most important being neural tube defects, but it is also important in prevention of cancer, some forms of heart disease and possibly some neuropsychiatric conditions. In 1995, my lab identified the first genetic variant that was a risk factor for neural tube defects. Individuals with this change in their genes, which represent 10 to 20 per cent of the population, need even more folate in their diets than the average person. These individuals may also be at greater risk for the other disorders mentioned above.

Continued >>>

Nowadays our food supply is fortified with folate and women are told to take folate-containing supplements even before they find out they're pregnant to prevent these types of birth problems. In the last couple of years, we have identified some negative consequences related to too much folate, including heart defects and liver damage in animal models. So now we're looking at both ends of the spectrum of folate intake.

In 1985, you created the first accredited Molecular Genetics Diagnosis Service in Quebec, at the Montreal Children's Hospital. How did that happen?

R.R.: I had been involved in DNA testing during my training and that type of service was just developing. The diagnostics activity had nothing to do with my own research, but I loved it. When you do research you may not see the fruits of your labour for 10, 20 years. But my work as a director of that service for 17 years was instant gratification! The fact that some of the things you do in the lab may actually benefit people is very rewarding.

How do you see this important transformation at the MUHC, with the move to the Glen?

R.R.: I'm optimistic. At the Children's we're a relatively small group of researchers, so the opportunity to be with our adult colleagues is very exciting. In my experience, most collaborations start through direct interactions, either in congresses or, simply, at the cafeteria! At the Glen it will be easier; there will be people with different talents at the end of the hall. It's also fabulous that we'll have our core facilities in one building.

How are you preparing for the big day?

R.R.: I have accumulated 30 years' worth of papers, binders, etc.! Not only my own, but those left behind by my graduate students. When we did our initial count, we had over 300 binders in the lab. I must have gone through 200 of them thus far! •

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MCH social workers: key members of our healthcare teams

March is National Social Work Month and to mark the event, we asked MCH social workers to tell us about their work and why they chose pediatrics. Here's what they had to say.

Matthew Park

Social worker in the Pediatric Intensive Care Unit (PICU) of the Montreal Children's Hospital



Matthew Park makes his mark as a social worker in the Pediatric Intensive Care Unit (PICU) of the Montreal Children's Hospital, helping patients and their families cope with a child's severe illness. "Things change minute by minute in the PICU, we're there to help care not just for the child, but for the parents as well," he says.

"Life continues on outside the hospital, but time stands still for those families that are going through what is probably the most devastating, vulnerable time in their life," he explains. "Being able to work with families who are in crisis and feel that you are having an impact by empowering them... it feels like you're making a difference."

Patricia Gauthier

Professional Coordinator of the Social Services department at the Montreal Children's Hospital



"Children have this incredible ability to manage things that we as adults sometimes couldn't even fathom taking on. They're so flexible and adaptable, and can always find something to strive towards," says Patricia Gauthier, Professional Coordinator of the Social Services department at the Montreal Children's Hospital.

Having worked in a number of departments and clinics throughout the hospital prior to taking on her newest role, she believes social workers have a big part to play in medical teams by dedicating themselves to offer the best care to patients and their families. A big thanks to Patricia for the amazing support she provides to her team, and to patients and families, day in and day out!



Getting ready for our little ones

Neonatal Intensive Care Unit begins simulation training at the Glen site

— By Stephanie Tsirgiotis

Change is never easy, especially when you have to change how you work and where you work. Since November 2013, Dr. Richard Gosselin and a team of nurses, physicians and respiratory therapists from both the Royal Victoria Hospital and the Montreal Children’s Hospital Neonatal Intensive Care Units (NICU) have been meeting on a monthly basis to develop an action plan for how to best prepare their staff for the Glen site. “We decided that the best way to test our new work environment and subsequently train and orient staff would be to simulate a normal workday,” explains Dr. Richard Gosselin, a neonatologist at the Children’s.

the results, the team summarized the main concerns emerging from the various professional groups and developed a blueprint of themes to explore in simulation. One major concern was communication. Namely, in the case of an emergency, how would a staff member call for help? How will the work be divided in such a large space? In covering 52 single-patient rooms, how will staff members communicate with the team at large?

Dr. Gosselin and his group then brainstormed on how to use simulation to tackle the main concerns identified in the survey,

Planning a simulation needs expertise

To help develop this plan, the team worked closely with Dr. Jesse Bender, Assistant Director of Neonatal Simulation at the Rhode Island Hospital Medical Simulation Center. “Dr. Bender has written extensively on simulations after his own experience moving a neonatal intensive care unit and helped guide us in creating our own test pilot for simulation,” says Dr. Gosselin. “Members of the team also had the chance to visit his hospital and see how the staff worked in single-patient rooms.”

The planning group then surveyed staff and asked what their biggest concern was about moving to the new NICU at the Glen site. After analyzing



(l. to r.) Nurse Lorraine Dubeau works with Dr. Richard Gosselin on a mannequin during one of the simulations.

Continued >>>

Getting ready (cont'd)

all while testing out their new work environment, including their workflow. They decided to develop nine different real-life scenarios and test them on NICU early activators during the first phase of their simulation training. Together they could then determine what worked or didn't work in their new space. It would also give them the opportunity to identify and find solutions to potential problems or hazards before patients and families arrive.

Launching simulations: a two-phase approach

For eight days straight, two one-hour simulation sessions were held a day at the Glen site. Each half-day started with a 30-minute huddle, during which team members received an orientation on the process of simulation and received a "sign-out" on the simulated patients. Each member was assigned a role (corresponding to their usual professional role) and was instructed to act out the scene alongside their colleagues, while one or two members acted as narrators by guiding team members through the various simultaneous scenarios.

During one afternoon session, Andréane Pharand, the MUHC NICU nursing coordinator, was moderating the simulation and occasionally threw curveballs to see how the team would react. "A very emotional mother is on her way and wants to know



(l. to r.) Assistant head nurse Sophie Fournier looks over test results with neonatal nurse practitioner Margarida Ribeiro-DaSilva. They were caring for a set of "twins" during the simulation.



(l. to r.) Nurse Émilie Brisebois-Tremblay and respiratory therapist Natasha Daniel take part in the first simulation of the day.

why her son is getting a PICC line," she would say, or, "Your multi-disciplinary committee has just arrived. They don't know where the conference room is." Team members were instructed to take note of issues that arose during the simulation. Each simulation was followed by a two-hour debrief period where team members' observations were brought forward for discussion. Following each simulation session, solutions to these issues were also discussed at length.

From April to May, the second simulation phase will begin and will be tied into orientation and unit-specific training for the rest of the NICU staff. Over a five week period, 200 NICU employees from the RVH and MCH will be trained in their new environment. "Each person will receive a full day of training. The morning will be devoted to orientation and in the afternoon we will continue to train staff by simulating different scenarios," says Dr. Gosselin.

NICU early activators will also be on-site following the two subsequent NICU moves (the RVH NICU is moving on April 26 and the MCH NICU is moving on May 24) to offer support to staff members who might feel overwhelmed or confused by the new space or workflow. "To date the feedback has been very positive. We are happy that we have chosen to test our environment prior to moving. Our staff is feeling better prepared," says Dr. Gosselin. "We're getting there!" •

You asked, we answered!

Answers to frequently asked questions about the Glen

I'VE HEARD A FEW STORIES ABOUT THE LACK OF CELL PHONE COVERAGE AT THE GLEN. WHAT DOES THIS MEAN FOR STAFF?

The existing cell network does not yet provide full coverage at the Glen site, however Information Services has implemented temporary solutions until permanent measures can be fully deployed. The problem is due to the fact that cellphone signals cannot penetrate the special film that has been placed over all the windows, a material used for the hospital's LEED Silver Certification for energy and environmentally-conscious design.

The Glen site has many complementary communication systems in place, allowing you to become fully operational in your new environment and stay connected with your colleagues. As soon as you move to the Glen site, you have access to a vast WiFi network and multiple telephony options: 5,500 new IP desktop phones, over 600 WiFi phones (to replace the SpectraLink) and 200 green emergency phones in critical locations. In addition, 500 all-in-one printers are in place and additional antennas have been installed to boost pager signals.

Implementation plans for a Distributed Antenna System (DAS) are being finalized. Another 700 antennas will gradually be installed starting this spring to provide cell signals (voice and SMS) throughout the site. Until then, the V-Sign, BBM and iPhone iMessage apps are fully operational over the wireless network, and pagers will be provided to employees needing the locating functionality or peer-to-peer communication. Cell signals will continue to improve week after week as the DAS is gradually implemented.



I'M A NURSE ON THE WARDS AND I WAS WONDERING HOW AND WHEN WE SHOULD START COMMUNICATING WITH INPATIENTS ABOUT THE PATIENT MOVE. IS THIS MY RESPONSIBILITY?

All inpatients and their families will receive printed and verbal communication regarding their move to the new hospital. Child Life and Social Services will distribute printed, bilingual pamphlets to all long-term inpatients a month prior to the move. The pamphlets will explain:

- The date of the move;
- When patients should pack their belongings;
- What steps or changes a patient may expect leading up to move day;
- Who can answer their questions/concerns about the move;
- How will they be taken to the new hospital;
- What patients can expect on moving day with respect to their routine and meals;
- The parents' role on moving day;
- Where parents can wait for their children when arriving at the new hospital;
- Parking and shuttle details between hospitals;
- How a family will find out their child's new room number.

A week before the move, all inpatients and new admissions will receive the same printed, bilingual pamphlet. Volunteers will hand out these pamphlets on the wards and will be trained on how to answer questions from parents. Social Services and Child Life will focus on the critical areas, NICU and PICU, because parents will likely have more questions and concerns.

Volunteer Services, Social Services, and Child Life will meet on a daily basis to go over the list of admitted patients and will determine which families need more support. They will also double-check to make sure all inpatients/families, especially newly admitted ones, have received the pamphlet. •

Ring in the new!

To highlight some of the exciting and smartly designed spaces at the new Montreal Children’s Hospital and what our patients and staff can look forward to, we’re featuring a “Before and After” series in upcoming issues of *Chez nous*. The “old and

new” photos are also being posted to the Children’s Facebook page so that the public can see how the new spaces will enhance patient care and the family’s experience. Here’s a look at three key areas:



NEONATAL INTENSIVE CARE UNIT (NICU)

Tiny patients, brand new big spaces! With 52 single-patient rooms, the layout of the NICU at the new Montreal Children’s Hospital will be bigger and extremely patient-focused. With a key location next to the Birthing Centre and Post-partum Unit, newborns requiring critical care will be much closer to their parents, helping to reduce stress and promote healing. Special rooms have also been designed to accommodate multiple births, providing parents of twins and triplets a private room for their children requiring critical care.

Continued >>>



OPERATING ROOMS (ORs)

Careful thought was put into nearly every aspect of the design of our new Operating Rooms (ORs) at the Glen site, from their central location and adjacencies to key departments, as well as logistics. Perioperative services for pediatric patients at the Glen site will include access to six operating rooms (three to be named for the “Just for Kids” Foundation), five procedure rooms (including the MRI suite and the cardiac catheterization lab), as well as four treatment rooms, all of which will be filled with cutting-edge equipment.

Continued >>>



SLEEP LAB

Respiratory Therapists in the Montreal Children's Hospital's Sleep lab make the most of their small space on the 5th floor of the hospital's C-wing, but the space is tight. So with patients' comfort level top-of-mind, the new Sleep lab at the Glen site will not only be bigger, but floors in the sleep rooms will be cushioned, the rooms will be sound-proofed and each room will have independent climate control.

Making the move!

Our researchers were some of the first to make the move from Place Toulon, located just down the street from the Children's, to their new research facilities at the Glen site. The Centre for Translational Biology of the Research Institute of the MUHC has 105 lab modules in a five-storey building — all within close proximity to hospital facilities giving our researchers direct access to clinicians and patients while encouraging collaboration. ●



The team marked the big move with this giant cookie – how delicious!

A memorial service...

is being organized to remember the children who have died recently at the MCH. We shall also be commemorating children who have died of SIDS. All staff members are warmly invited to attend this service, which will be held on **Tuesday April 14th at 2:00 p.m. in the Amphitheatre (D-182).**