Mighty Max: overcoming congenital lung disease

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“I get so emotional thinking about it, but if it weren’t for the doctors, nurses and everyone who took care of us, he may not have made it,” says Robyn Schwartz about her third and youngest son Maxwell who is now 15 months old. At 20 weeks into her pregnancy, Robyn underwent a routine ultrasound that revealed her baby had a cystic malformation of the lung.

Congenital lung disease does not usually require fetal intervention but it is followed closely. Throughout her pregnancy, Robyn and her husband Martin got to know their care team well, a group made up of professionals from various adult and pediatric specialties. Before Maxwell was born, Dr. Thérèse Perreault, head of the Neonatal Intensive Care Unit (NICU) at the Montreal Children’s Hospital (MCH), gave the couple a tour of the unit to familiarize them with the environment. “Parents expecting a baby with fetal anomaly tend to be very anxious, so giving them a tour of the NICU gives them a better idea of what to expect once their child is born and can help temper some of the anxiety,” explains Dr. Perreault.

Maxwell was born in March 2016 in the OR at the Royal Victoria Hospital (RVH) where about half of all babies treated in the MCH NICU are born. “We work hard with the RVH to provide the best care to mothers and babies,” says Dr. Perreault. Maxwell was immediately transferred down the hall from the RVH birthing unit to the MCH NICU. “Dr. Perreault was ready for us,” adds Robyn, “and she was also there during the delivery.”

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Although Maxwell was a seemingly healthy nine pound baby, an examination showed otherwise. “We imaged him the day after he was born,” explains Dr. Sherif Emil, Chief of Pediatric General and Thoracic Surgery at the MCH. “His x-ray was worrisome, and we were faced with a dilemma in terms of what to do.” In 80 to 90 percent of congenital cystic lung disease cases, the mass can be removed electively six to 12 months after the baby is born by thoracoscopic lung resection, a technique Dr. Emil introduced to the MCH in 2008. This technique allows these anomalies to be removed through small incisions instead of open chest surgery. However, Maxwell’s malformation was so large that it was pushing his trachea and heart to one side, meaning more urgent surgery had to be considered.

Dr. Emil was filling in for his colleague, Dr. Jean-Martin Laberge, a pediatric surgeon with extensive experience in congenital lung anomalies, who was away during Maxwell’s surgery.

▶ Robyn considers herself lucky to have had the support of her family throughout Maxwell’s hospital stay. They took care of Maxwell’s brothers so that Robyn and Martin could be by Maxwell’s side at all times. continued >>>
at the time of Maxwell’s birth. “I had never met Dr. Emil before but after he came to speak to us while I was recovering at the RVH we were reassured that Maxwell would be in good hands,” says Robyn. Dr. Emil had an open conversation with Robyn and Martin about their options: operate on Maxwell within a few days, or wait and risk his lung expanding and causing severe respiratory depression. To give the family greater peace of mind, Dr. Emil consulted with Dr. Laberge by email, who agreed that surgery sooner rather than later was the better option.

With the NICU team members, Dr. Laberge, Robyn and Martin all in agreement, Dr. Emil performed a lobectomy on Maxwell on his fifth day of life, removing half of the lung on the left side. Although the surgery went well, Maxwell had some complications including an infection and a collapsed lung. He spent the first month of his life in the NICU which was a trying one for Robyn. “I couldn’t breastfeed him and I could only hold him sporadically because he was under observation,” she says. “It was very hard.” She built a trusting bond with Marilyn, a night nurse in the NICU who encouraged Robyn to go home for a few hours to rest and promised to text or call if anything came up. “Feeling confident about leaving Maxwell at the hospital overnight meant a lot to me and I am so, so grateful to her.”

Human lungs continue not only to grow, but also develop new functional units in the first several years of life and Maxwell, who is still followed by Dr. Emil, is doing great. “He is big and healthy, and he has hit all of his milestones: he stands on his own and crawls on his tummy,” says Robyn about Maxwell, whose strength and resilience has earned him the nickname “Mighty Max”.
More than words:
Interpreter maintains strong ties to her community

By Maureen McCarthy

Eva Saganash (3rd from r) is an interpreter who works for the Cree Health Board. She is seen here with Davey (3rd from l), a patient in the hospital’s Spina Bifida clinic who lives in Chisasibi, and (l. to r) Dr. June Ortenberg, Dr. Mohamed El-Sherbiny, Lina Di Re, and Dr. Alice Yu.

June 21 is National Aboriginal Day, a day for all Canadians to recognize and celebrate the unique heritage, diverse cultures and outstanding contributions of First Nations, Inuit and Métis peoples. The Montreal Children’s Hospital Northern and Native Health Program has provided care and services to Quebec’s First Nations communities for more than two decades. For many families who come to Montreal — and to the Children’s — their hospital visits are made easier with support from people like Eva Saganash, an interpreter who works for the Cree Health Board, which provides health and social services to communities of the Cree Territory of James Bay.

Eva is originally from Waswanipi, and has lived and worked in Montreal since she was in her 20s. She came to work for the Cree Health Board later in her career. “I had worked for a large company before that, but when my job was eliminated, I thought it was time to think about working with my Cree people,” she says. “Eventually, a friend suggested I apply to the Cree Health Board.” She began working in the offices but within several years was asked if she’d like to work as an interpreter. “My first thought was ‘that would be completely different’, and then I thought, why not try it?” she says.

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Learning by doing

“With interpreting, you learn by doing, and Daisy Benjamin, who recently retired, trained me when I first came to the Children’s,” says Eva. In recent years, Eva has worked primarily with Cree patients at the Royal Victoria Hospital, but she still occasionally works with families at the Children’s. “The older people need interpreters for their medical appointments because they generally don’t speak English or French,” she says. And although most young families speak English or French, Eva’s help is sometimes very welcome. “There was one woman I met who spoke English, and after giving her some basic information about tests and paperwork, I got up to leave,” says Eva. “But she asked me to stay because she was nervous and wanted to make sure she really understood everything the doctor said. So sometimes our role involves figuring out what the patients are thinking and feeling, not just what they’re saying.”

When asked if she likes her work, Eva answers, “I love it.” A few years back, she had a short-lived retirement, but didn’t hesitate a moment when asked if she’d like to return to work. “I don’t want to be sitting at home just staring at the walls or watching TV,” she says. “My work lets me meet new people all the time. I’ve even met people who I went to high school with but haven’t seen since. They’ll say, ‘I heard you were in Montreal but I didn’t know you’re doing this!’ It’s always nice when that happens.”
A grateful teen:
MCH Trauma team helps patient get back on his bike

By Sandra Sciangula

Nicolas is grateful for the care he received at the MCH. “If it takes a village to raise a child, it takes a village to heal one,” says Karen.

Karen got to the scene of the accident in time to ride in the ambulance with her son as they made their way to the Montreal Children’s Hospital (MCH) Emergency Department (ED) which is a provincially designated Trauma Centre. The Trauma team was notified that a category 10/10 trauma was on its way and to get ready. “A 10/10 is the highest level of activation for the most severe traumas,” explains Debbie Friedman, Director of the Trauma Department at the MCH. “It involves as many as 20 people, and sometimes more, all with different expertise in the medical, surgical, nursing, psychosocial and rehabilitation care of the trauma patient and their family. The Trauma team is like an orchestra, everything must be perfectly timed and work in harmony,” she adds.

Upon their arrival to the MCH ED, two moments stuck with Karen: the first was being told by Social Worker, Kevin Brady, that he would walk her through the entire process, and the second was to expect a lot of people to immediately surround her son. “I appreciate that I wasn’t shoved to the side,” says Karen. “I was allowed into the room, I could see what was going on and I could answer any questions the team might have about Nick.”

Nicolas suffered multiple lacerations to his face, as well as a few loose teeth and a concussion. Dr. Brett Burstein, emergency physician, was the trauma team

Nicolas’s lacerations were still healing a few weeks after his accident, but looking much better, according to his mother, Karen.

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leader (TTL) the evening Nicolas was rushed to the ED. Dr. Burstein volunteers to be a TTL because it’s a program he believes in. “This is a model program for interdisciplinary team work. It is a well-organized approach to caring for some of the sickest patients. These patients rarely get to go home right away.”

Nicolas was no different, he spent one night in hospital, where he was offered a book to read, some pet therapy and the support from a member of the Spiritual Care team, services both Nicolas and Karen appreciated. But the care he received did not end there. “We take care of the patient and the family even after they are discharged,” says Diane Richard, Trauma Coordinator. She ensures the orchestra continues to play even outside the ED by scheduling follow-up appointments, which for Nicolas meant seeing specialists in the Concussion, Dental and Plastic Surgery clinics. The team also takes phone calls from parents who might have questions about their child’s recovery.

Nicolas does not remember the accident but says he is very happy he was wearing a helmet knowing he may have suffered significantly more severe head trauma had he not been wearing one. He gradually returned to school and couldn’t cycle for a few weeks while his bicycle was in for repairs but when the time came, he had no reservations about getting back on his bike—with a helmet on, of course.
Matthew Park, our PFCC Star in May, nominated Marie Antonacci for this month’s award. “Marie embodies the concept of patient- and family-centered care and she’s an example for all the PICU staff,” says Matthew. “She takes a collaborative approach to working and partnering with families, and she ensures that respect, dignity and participation of the most vulnerable patients always remains at the heart of our PICU mission.”

Marie is one of three assistant nurse managers in the Children’s pediatric intensive care unit (PICU), a role she has held for more than two decades. Even before she came to the PICU, Marie was aware of the importance of patient- and family-centered care. “It’s one of the things that attracted me to pediatrics when I was a student nurse, the idea that working with the child means working with the family too,” she says.

Marie says the evolution of care and technological advancements in critical care have meant significantly better outcomes, but one thing hasn’t changed: many families still experience enormous stress and strain when their child is in the PICU. “The parental role is limited in the context of a PICU admission so it’s up to us to see how we can partner with families to be involved in their child’s care.” Part of helping families in the PICU is providing psychological and social support. Marie is at the centre of this. “I coordinate the

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Our PFCC Stars are featured on the Children’s Facebook page. Here’s what people had to say about last month’s star, Matthew.

Genevieve Turcotte
Thanks for all the help you gave us, Matthew! 😊

Monica Gallagher
Well deserved Matthew... you were always there... Monica

Maria Bonfitto
Congratulations Matthew, well deserved.
core psychosocial group in the PICU which includes Lise Gagnon, Judith Legallais, Jennifer Bourque, and Matthew Park from the hospital’s Child Life, Psychology, Spiritual Care and Social Work services respectively. They are an amazing group.” The team meets daily to discuss the type of support that can be offered to each family on the unit. They focus on making the family’s experience as positive as possible, and accompanying them through their child’s illness. “The PICU has always been very open to including families in care,” she says, “and it’s essential as health care professionals to partner with families and determine the best way to support them and to ensure they feel they are being heard.”

Parents as partners
In the past couple of years, the PICU has invited several parents to join their committees. “We had a transition group leading up to the hospital’s move to the Glen site in 2015, but once we were here, there were still a number of projects to work on so the group evolved into what is now our PFCC committee,” says Marie. “The parents on our committees are really motivated to make changes and it’s important for them to see that we also want to make changes to make family life better in the ICU. Sharing their past experience in the PICU and giving us feedback is very special. It’s a gift for us.”

Being part of a movement

Dr. Janusz Rak, Senior Scientist at RI-MUHC in the Child Health and Human Development Program, tells us about his research.

The movement
Dr. Janusz Rak believes that cancers in children do not act as independent collections of cancer cells but as ‘societies of cells’. One language that cancer cells use to communicate consists of tiny membrane bubbles called exosomes or extracellular vesicles.

“There is an intense interest to understand what exosomes do and what their roles in brain tumours are. It is an area that has been of great interest for the last decade, and we are part of this movement.

We want to know what happens within each and every cancer cell in terms of the molecular machinery. That is, what’s wrong with these cells? Why do they keep dividing? We are interested in these questions and would like to further them by asking how the tumour cells interact with each other.”

The goal
“We are trying to understand the mechanisms and approaches to disrupt or alter tumour cell communication. There are very few examples of anti-cancer agents that have been designed to disrupt tumour cell communication and we are very interested in this concept, because I think this is a completely unexplored area of therapeutic intervention.

How can we modulate or cure or treat the cancer by disrupting the exosomes? For instance, since exosomes interact with certain cancer cells, can we load them up with anticancer drugs to deliver them to those cells? We don’t know how deep this goes, but this is one of the mechanisms that exists, and there’s no drug out there yet that can disrupt exosomes.”

The timeline
Dr. Rak says that in a short time the principles of exosome biology have already resulted in diagnostic tests in cancer and exosome based therapeutics that are in advanced stages of preclinical development, with some clinical trials already ongoing.

“Any biological discovery breeds new opportunities. Exosomes in cancer have not really been explored, it is a field that is just emerging meaning there are so many opportunities…”

The support
Dr. Rak’s work is supported by a number of donors, notably the Cole Foundation, the Dara Meaghan Korne Fund and the Edward and Phyllis Pascal Foundation.

FCC Star of the Month... (cont’d)
Radiothon

► This year marked the 14th edition of the Caring for Kids Radiothon, raising a remarkable $1,208,000. A special thanks to all the patients and families who were courageous enough to share their stories and to everyone who called in to make a donation.

The Fondation Jovia and its beloved Clown doctors celebrate their 15th anniversary.

► The 15-year journey started here at the Children’s and has since taken Fondation Jovia and its clown doctors to institutions right across the province. To celebrate, patients and families were invited to partake in a live reading of Les aventures de Dr. Sanguine by Dr. Pédalo and Dr. Sanguine herself. Congratulations to everyone at Fondation Jovia, wishing you a happy 15th and many more!

Pit Stop at the Children’s

► Montreal’s very own Lance Stroll visited the MCH for the first time a week before the city’s Grand Prix weekend. The Williams Martini F1 driver played foosball and air hockey with patients and visited others in the clinics who couldn’t make it to the teen lounge. Lance was all smiles as were the patients, family and staff who met him. A big thanks to Lance!
Awards: Dr. Caroline Erdos

MCH Speech-Language Pathologist, Dr. Caroline Erdos was awarded the Prix Germain Huot 2017 from l’Ordre des orthophonistes et audiologistes du Québec. In her 20-year career, Dr. Erdos has been a pioneer in the study of bilingualism and multilingualism in children. She has made remarkable advancements in the understanding of bilingual and multilingual children with learning disabilities and has affected changes on clinical, academic and social levels. Congratulations to Dr. Erdos on receiving this award.

Children in Peru get some special gifts from MCH nurse

▶ In her free time, MCH OR nurse Julia Harding knits and sews. For the second consecutive year, she worked on a special project to make dozens of puppets for her fellow OR nurse Karina Olivo who volunteers with Operation Smile. Last year, Karina brought them with her to China and they were so popular that she brought them again, this year, to Peru. The puppets are included in a care package that is given to each of the young patients while they recover in post-op.

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