

Chez nous

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New aortopathy clinic
**Personalized
care for unique
patients** — page 2

Hôpital de Montréal
pour enfants
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Montreal Children's
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The Montreal Children's Hospital Aortopathy Clinic

A unique service for patients with specific needs

By Christine Bouthillier

Patients suffering from aortopathy live with a perpetual sword of Damocles hanging over their heads. At risk of a rupture of the aorta, which can lead to death, they must be monitored closely and regularly. To meet their specific needs, Dr. Tiscar Cavallé Garrido and Dr. Bettina Mucha-Le Ny opened the Montreal Children's Hospital (MCH) Aortopathy Clinic in March 2021.

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► On the left: Dr. Tiscar Cavallé Garrido, pediatric cardiologist, and Dr. Bettina Mucha-Le Ny, medical geneticist.

The clinic diagnoses and treats patients who suffer from inherited diseases of the connective tissue, which supports or binds different tissues or organs in the body. These diseases are usually caused by Marfan syndrome, Loeys-Dietz syndrome or vascular Ehlers-Danlos syndrome. They can lead to aortopathy, which is a progressive widening and weakening of the aorta, but also to orthopedic, pulmonary and ophthalmologic problems.

Patients at the clinic are evaluated in Cardiology and Genetics and undergo several tests to monitor the evolution of their disease: echocardiography, electrocardiogram, etc. Potentially affected family members are also evaluated. Depending on their symptoms, patients may be referred to other departments.

STRONGER TOGETHER

“Given the rarity of these disorders, the variability of symptoms and the current “silo” model of healthcare provision, patients endure multiple investigations by different specialists over long periods of time before a correct diagnosis is made,” says Dr. Cavallé Garrido, a pediatric cardiologist at the MCH.

“I followed many of these patients in my cardiology clinic over the years. I realized the complexity of their care and how they struggled in the medical system until they finally received a unifying diagnosis, and a proper care plan was implemented. I felt the need to consolidate expertise to provide the best care and advocate for these patients.”

A delay in diagnosis sets back the start of treatment and lifestyle changes

that could prevent aortic aneurysms. Ultimately, this wait time is partly responsible for the short life expectancy of this population. Together with Dr. Mucha-Le Ny, a medical geneticist at the MCH, Dr. Cavallé Garrido established the multidisciplinary clinic.

The clinic is held four times a year, and about a dozen patients are seen each time (three in genetics evaluation). With the waiting list gradually growing, the goal is to increase the number of clinics held annually.

Dr. Cavallé Garrido also hopes to coordinate the clinic with visits from other specialists to foster multidisciplinary, add a genetic counselor/clinic coordinator and a psychologist to the team, and conduct community education and research initiatives. ❄

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Translation: Geneviève Cocke, Joanne Lavallée

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On the cover:
Candy Gonçalves and
Eduardo Lucca Soares

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It all started with an asthma attack

In December 2019, Eduardo Lucca Soares went to CHU Sainte-Justine for an asthma attack. During the consultation, Dr. Jade Hindié noticed that he also had a slight scoliosis and long fingers.

These small details were enough to make Dr. Hindié suspect that Eduardo had Marfan syndrome. Genetic testing later revealed that the teenager, now 16, had a similar disorder, Loeys-Dietz syndrome.

In June 2020, he was evaluated at Shriners Hospital for Children (Shriners). Within six months, his scoliosis had gotten much worse: his spine had rotated 65 degrees. Eduardo required surgery.

The surgery took place in February 2021, and to say the least, it didn't go as planned. The teenager went into cardiac arrest twice and ended up in the Pediatric Intensive Care Unit at the MCH.

Eduardo was born with a pectus excavatum, which means that his breastbone goes inside his chest. When his spine was straightened, his heart got stuck and would wander from left to right, causing his heart to stop. The teenager had to undergo another surgery, this time at the MCH, to insert rods that opened his chest to make room for his heart.

"I was obviously stressed, but we were well taken care of. I don't have words to

say how grateful I am for the services offered at the MCH," says his mother, Candy Gonçalves.

CAREFUL MONITORING

Eduardo is followed in the Aortopathy Clinic, as well as in Ophthalmology and Respiratory Medicine. The divisions try to coordinate appointments, notes Candy.

"When I come to the aortopathy clinic, they look at my heart and lungs to make sure everything is okay and avoid emergency surgery. So far, it's stable," the teen explains.

However, he has to avoid impact when playing sports and stop when he is out of breath. He also has to take medication to keep his blood pressure down to prevent a rupture of the aorta.

He had a pneumothorax in October 2021 and still has bubbles in his lungs. This means that he cannot do any activities at altitude or in deep water, such as diving or travelling in a helicopter. He may need surgery if another attack occurs.

"When I was diagnosed, I was sad. I still feel like I am alienated from the other kids. Fortunately, I've had follow-up at the hospital, including from a social worker. My needs are well taken care of," says Eduardo, who would like to thank all the hospital staff for their support. ❁

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► Candy Gonçalves and son Eduardo Lucca Soares.

The importance of research

Noah Seto Pereira, 14, has been followed at the MCH for over two years. He was diagnosed with Marfan syndrome after the tragic death of his father, who unknowingly had the same disease.

Genetic testing showed that Noah and his sister also have Marfan syndrome.

The teenager has aortopathy, while his sister has eye and orthopedic problems.

Noah goes to the Aortopathy Clinic every six months to monitor the evolution of his disease, while his sister is followed at the MCH and the Shriners.

Their mother appreciates this concentration of services.

“There are not many clinics in Quebec that specialize in treating children with this syndrome. So far, we have been very well served. Dr. Cavallé Garrido has been patient and answered my many questions,” says Joanne Seto, Noah’s mother.

BUILDING KNOWLEDGE

Joanne emphasizes the importance of research into this genetic syndrome.

“When you have this disease, you have it your whole life. It’s important to do research and advance treatments. The Aortopathy Clinic provides an opportunity to share knowledge and learn about new developments in the field,” she says.

Predicting what will happen as an adult is also crucial.

“If Noah wants to have children, it has to be planned. For example, you can detect the problem in the embryo,” she adds.

That is why it’s important to take a long-term, multidisciplinary approach like the one offered at the Aortopathy Clinic. ❁



► Joanne Seto.



Cooling treatment

Research to the rescue of sick newborns

By Sandrine Pelletier

Medical research can become a major beacon of hope for families who suddenly face a critical situation. Parents of babies born with oxygen or blood deficiencies can now rely on an innovative treatment to help prevent brain damage in their child, thanks to the research of Dr. Pia Wintermark, a pediatrician and neonatologist at the Montreal Children's Hospital (MCH).

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► Above: Mathis during hypothermia treatment in the Neonatal Intensive Care Unit at the MCH.

Dr. Wintermark's professional trajectory stands out. Originally from Switzerland, she studied pediatric medicine and practised until the age of 30, then immigrated to the United States to further her research knowledge. Dr. Wintermark has since spent the majority of her time studying cases of neonatal encephalopathy, a rare condition that affects the brains of babies who suffer oxygen or blood deficiencies at birth.

"Several things can cause babies to experience a lack of oxygen or blood at birth, such as a uterine rupture, placental abruption, or an umbilical cord around the baby's neck," explains Dr. Wintermark.

"Some of the damages most frequently associated with this condition are significant developmental delays, partial or complete cerebral palsy, as well as vision loss," she adds.

AN INNOVATIVE TREATMENT

Each time a baby is admitted to the Neonatal Intensive Care Unit (NICU) with neonatal encephalopathy, the race is on to start treatment as rapidly as possible.

This involves artificially lowering the baby's internal temperature by a few degrees for a period of 72 hours. "The purpose of hypothermia is to slow down the activity of the brain and facilitate recovery, therefore lessening the risk of significant damage developing," explains Dr. Wintermark.

Treating babies with hypothermia presents some limitations in very advanced cases of asphyxia, however. "Some babies will regrettably develop brain

damage even with the cooling treatment," the neonatologist points out.

Presently heading a clinical study that shows promising results, Dr. Wintermark and her team are providing a breath of new hope for parents whose baby is in a precarious situation.

Research has found that through magnetic resonance imaging, it is possible to observe during the treatment whether brain damage is developing

despite controlled hypothermia. When this is the case, Dr. Wintermark's team approaches the parents to inform them of the clinical study, which consists in adding a medication to the cooling treatment.

The medication in question is called sildenafil. Widely known by the public for treating erectile dysfunction and pulmonary hypertension, and notably branded as Viagra, sildenafil may also

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► Pediatrician and neonatologist Pia Wintermark in her laboratory at the Research Institute of the McGill University Health Centre.

play a protective and restorative role within the central nervous system of sick babies.

“We have successfully demonstrated that sildenafil decreases inflammation in the brain, regenerates neurons and expands the protective layer around the brain’s nerve cells, known as myelin,” explains Dr. Wintermark.

These findings have been achieved through her dedicating many years of laboratory work to investigate the effects of sildenafil on the brain.

IN THE NICU

Neonatal encephalopathy cases usually mobilize a large portion of the staff when they arrive in the NICU. A variety of instruments is used to fulfill multiple monitoring functions: electroencephalogram electrodes are attached to the baby’s head to check brain activity, a probe to monitor body temperature, a pulse oxidizer to measure blood oxygenation, a blood pressure monitor, small intravenous catheters, and, in rare cases, a machine to help the baby breathe.

All this impressive equipment will closely monitor the baby’s vital signs while it rests in a hypothermic state for the next three days.

One of the monitors, the electroencephalogram, measures the electricity produced between the neurons in the brain. “When the current is very weak, it usually indicates significant damage,” says Lisa Carruthers, a nurse and technical



► Nurse Lisa Carruthers shows the electricity in neurons on the electroencephalogram.

coordinator for simulations in the NICU at the MCH. “It basically means there is very little activity in the neurons. The monitor also helps us to foresee any risks of seizures, which can be worrying in the first few hours after birth.” It is typically in such cases that Dr. Wintermark’s team steps in to try to minimize brain damage.

BORN UNDER A LUCKY STAR

Émilie Retailleau and Jérémy Goimard, parents of a little boy named Mathis,

are very familiar with Dr. Wintermark’s team and the NICU staff. On January 22, 2019, their baby boy was born with non-functioning lungs, another likely consequence of oxygen or blood insufficiency at birth.

“We were told at the hospital that Mathis was unlikely to survive due to being without oxygen for too long,” Émilie recalls over the phone. “But then, within a few hours, his vital functions improved because of the cooling treatment.”

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Against all odds, Mathis' heart and lungs had resumed functioning the next morning. He had however suffered significant brain damage as a result of his birth asphyxia. "As soon as Mathis was admitted to the NICU, hypothermia treatment began," recalls Jérémy. "Dr. Wintermark's team later approached us to say that Mathis was a good candidate for their study."

"At the time, we were rather overwhelmed by the news," says Émilie. "It took us a while to process everything."

Mathis' parents finally agreed to have their boy participate in the study. "Little by little, his vital functions recovered; his lungs, his heart, his liver..." she says. After spending almost two weeks at the MCH to receive the sildenafil treatment,

Mathis and his parents were finally able to return home.

Today, Mathis presents no residual effects from his neonatal encephalopathy. His parents believe their boy was born under a lucky star. "We even gave him the middle name of Orion, after the constellation," adds his mother. ❁



► Today, Mathis is three years old and has no apparent after-effects following his asphyxiation at birth.

A perfect fit!

MCH staff talk about the sports that get them moving and keep them going

By Maureen McCarthy

We put out the call earlier this summer to ask the Montreal Children's Hospital (MCH) staff what they do to stay fit, and the response was great! The stories we received are really inspiring and surprisingly diverse. Read on to find out how different sports and activities are helping staff stay healthy and provide that important work-life balance.



Rita Barrafato

Administrative Technician, Respiratory Medicine/Therapy

Rita Barrafato proves that it's always a good time to try something new. "I started weight training eight years ago at the age of 49," she says. "My husband was the one who first got me interested but it quickly became my passion, training four to five days per week and also doing fitness classes."

Last fall, Rita trained and prepped six days a week to get ready for her first photoshoot, and was recently featured in a fitness magazine.

Rita currently trains regularly three to four days per week and is as passionate about weight training now as she was when she first discovered it. "I absolutely love it! I can honestly say I'm in better shape now than in my 30s!" ❄️

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Marisa Leone

Respiratory Therapist, Respiratory Assistant Manager (Pediatrics)

Marisa Leone's fitness passion is karate, specifically the Shinkyokushinkai style. "As a respiratory therapist, where my vocation is to help others, I never thought I would want to practice a sport where we hit people," she says. "That was before I actually started karate with my youngest daughter. She was four, I was 32."

At the time, Marisa's husband was a karate teacher and her eldest daughter was already practicing, so they decided to practice together as a family. "What I learned was that karate is so much more than a sport. It is about mental fortitude, partnership, and pushing through the pain together."

Over the past 21 years, Marisa has competed in many competitions, tested her mental and physical limits in both winter and summer training camps, and done numerous wood breaking challenges. She achieved her third level black belt

(sensei), and both her daughters also received their black belts. "Practicing karate as a family has been a priceless experience."

Marisa and her husband own a karate school, Dojo Tansei Arts Martiaux (www.karate-tansei.com), where they teach traditional Shinkyokushin karate to people ages four to 70. They also have an international competitive team that they coach and have competed locally, regionally and internationally in Japan, Belgium, Switzerland and the US.

"At 53 years old, I lead by example and work out just as intensely as my karate students do," says Marisa. "We overcome our limits to push further every time we step into the class. The running joke I tell them is, if I can do push-ups at 53, you have no excuse not to do them at a third of my age!" ❄️

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Shahanaz Bhuiyan

Respiratory Therapist, Critical Care

Shahanaz Bhuiyan has been a respiratory therapist at the MUHC for 20 years, first at the Royal Victoria Hospital, and now at the MCH. She says that work stress can often take a toll on her but happily, she's found something that helps ease that pressure. "On my days off, my escape is my workout, which I enjoy immensely," she says.

Since February 2020, Shahanaz has been a member at 30 Minute Hit, doing circuit training which encompasses boxing, kickboxing, general self-defence, and core stability training. And for Shahanaz, it's both physical and mental fitness. "What I love about this institution, it takes 30 minutes of my day, and I get a full body workout. It teaches me how to self-defend through a series of many techniques of kickboxing.

"After my workout, I am energized and I am feeling overall positive. The workout shifts the negativity away to focus on my well-being." She also adds with a laugh: "I am grateful to my trainers for always challenging my workout when I "make things look easy"." ❁

Dr. Caroline Ouellet

Emergency Department

Dr. Caroline Ouellet takes part in a number of different sports including river canoeing, downhill skiing, running, and mountain biking. The way she sees it, all these sports help her stay in shape, look after her mental health and unwind after demanding shifts in the emergency room.

"I believe that physical exercise, even though it requires effort and motivation, is the BEST remedy for lots of problems: anxiety, sleep disorders, mood disorders, diabetes, cardiovascular issues, etc." Her enthusiasm for her outdoor pursuits is plain to see. "I'm happy to share my passions because I am passionate about all these sports!" ❁



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Maryse Dagenais

Nurse Manager, Pediatric Intensive Care Unit (PICU)

Maryse Dagenais has done every kind of race you can think of. An avid runner for much of her life, she did her first triathlon in 1983. "I've always enjoyed sports, and with my friends I used to do bicycle touring and swimming," she says. In 2010, she got back to serious running and logs about 1,000 km a year.

During the pandemic, she completed seven half-marathons but only one was an official event: the other six she did solo. "I do it to challenge myself, to stay fit and to relieve stress," she says. "Exercise is my way to unwind from busy days. I focus on the next km to run and enjoy the scenery. I love to stop and take pictures, and focus on the beauty around me." ❁

Alexandra Lachance

Nurse, PICU

Alexandra Lachance works in the PICU at the MCH and is currently on a northern work assignment in Nunavik. "I'm an avid runner so that's how I stay in shape," she says. "I believe that physical activity is essential to maintaining a balanced life."

Alexandra also tries to get her fitness in when she's commuting. "I especially like to come and go to work by active transportation either by biking or running!" ❁



Dr. Joe Nemeth

Emergency Department

Dr. Joe Nemeth has always been involved in physical activities, and played team sports all his life including being on the McGill Redmen football team when they won the national championship in 1987. But after getting into medical school and then starting a family, he had to rethink how to keep fit.

"Doing team sports was not ideal from a time management point of view," he says. "That's when I started triathlon and marathon training. I can do it on my own time, at my own pace."

Dr. Nemeth has done three full marathons and three half-ironman distance triathlons. "It serves as a big-time stress reliever and great way to keep the pounds off since I love eating and am married to a wonderful Sicilian chef."

❁

