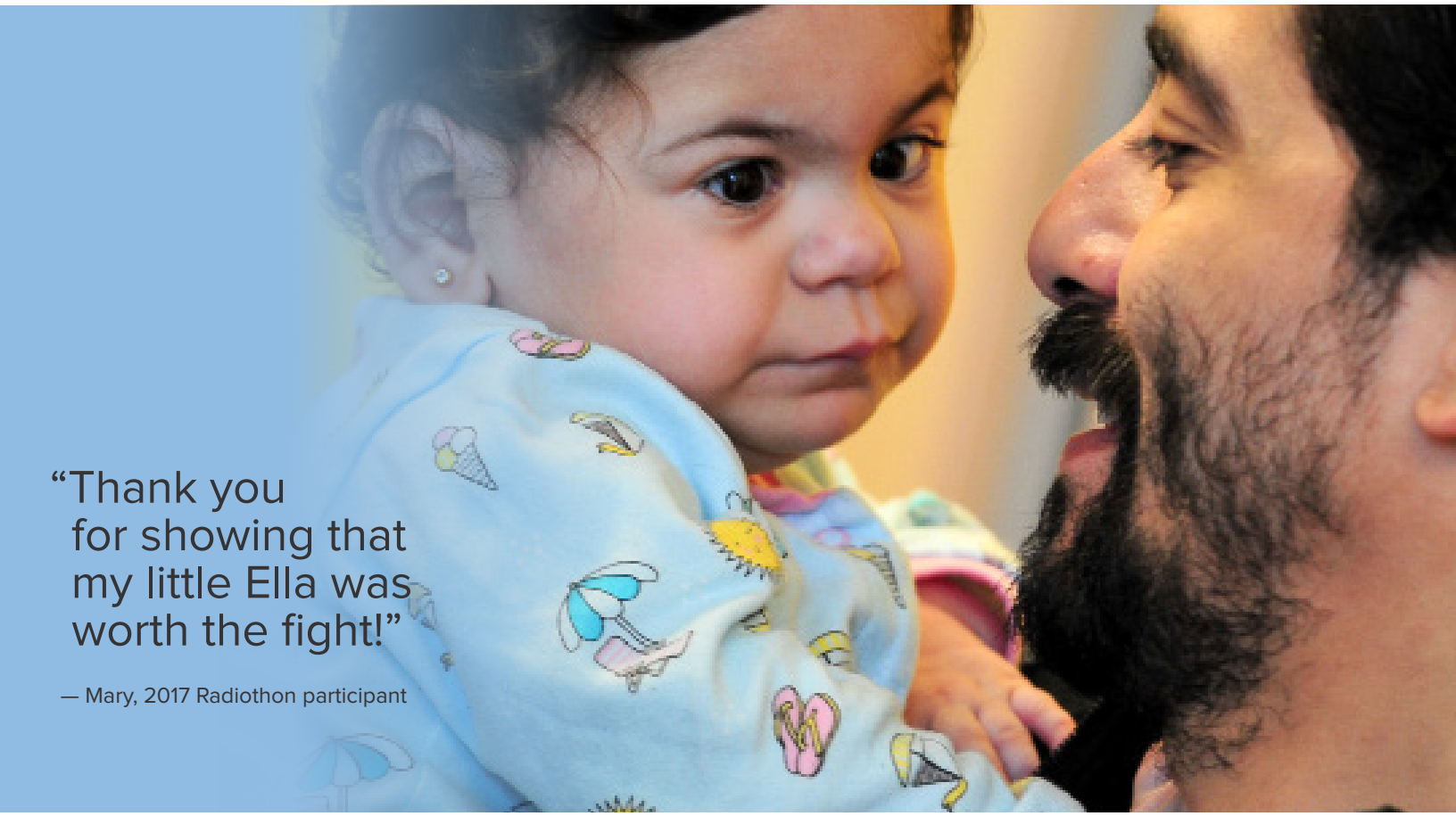
# LE CHILDREN NEWSLETTER

MAY 2018



"Thank you for showing that my little Ella was worth the fight!"

— Mary, 2017 Radiothon participant

## I DON'T KNOW ABOUT YOU, BUT PUBLIC SPEAKING ISN'T MY FORTE. LAST YEAR, I SWALLOWED MY FEAR AND TOLD MY STORY ON THE RADIO DURING RADIOTHON.

I did it because it was vital to me to thank donors like you, anyway I could, for being by our side in what has been the most challenging experience of our lives. If you go up to the NICU and ask the nurses about Ella, they'll tell you she is 'a miracle baby.' She was born prematurely at 27 weeks, weighing only slightly more than a package of butter, at 1.2 pounds.

At birth, Ella was put on a donor funded jet ventilator to help her tiny lungs breath and then on conventional ventilation. In all, she was on life-saving equipment, much of it paid for by people like you, for 7 months. We had many ups and downs. At one point, her abdomen became swollen with fluid.

When they tried to drain it, her blood pressure dropped and she crashed. Ella was crashing and coding all the time.

It became so serious that my husband and I discussed palliative care. Put yourself in our shoes: we didn't want her to suffer. We gave ourselves one month. Then miraculously, she got better in two weeks!

But other challenges lay ahead. Ella developed a clot in her heart. While the solution - a stent - was risky for such a small baby, doing nothing meant she would die. The doctors were willing to try everything to keep Ella alive. Thank goodness the 8-hour surgery was successful!

It was worth the fight! Now, although Ella is still fed with a feeding tube, she is developing into a healthy kid.

The list of what Ella has gone through in her year-long stay is astonishing.

> Thankfully, you gave my baby the strength to fight for her life, and you showed us that she was worth the fight. With Radiothon right around the corner, please be generous and help support families like mine. Let's get Radiothon off to a great start!

– Mary
Ella's mom

# WHAT YOU HELPED ACCOMPLISH

Below are two examples of the amazing work your support makes possible.

## ALLEVIATING CHRONIC PAIN

Imagine being born with a rare genetic condition that makes your body develop blisters instantaneously? Evan doesn't have to imagine. He suffers from epidermolysis bullosa. On any given day, the eight-year-old will have a minimum of 10 blisters on his body, all painful. At home, it hurts so much to walk on his blistered feet that 75% of the time, Evan must move around on his knees.

Thanks to your support, Dr. Pablo Ingelmo created the Chronic Pain Service, a special interdisciplinary team of physiotherapists, psychologists, social workers and nurses, to find innovative therapies that can provide relief for kids like Evan.

Because of their work, Evan is now the first child in the world to use nitrous oxide (laughing gas) at home to help relieve the pain associated with his condition. His parents say he's less fearful of things because he knows that there's some comfort and relief at the end of the day if he needs it. You help free children like Evan from having to take powerful painkillers and decrease the impact of chronic pain on their life. Thank you!

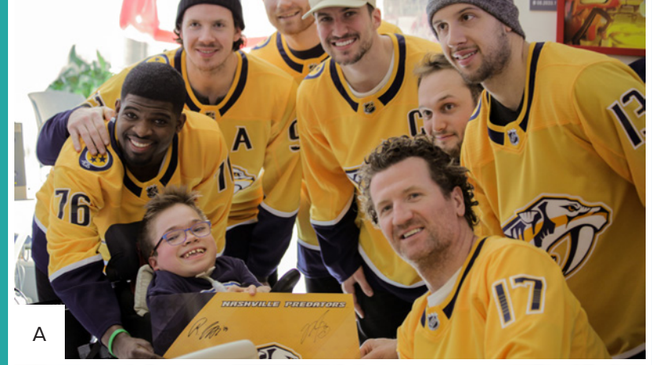
## ULTRASOUND PROBE

Did you know that at a week old, a baby has a heart the size of a walnut? Jaxon was born with Transposition of the Great Arteries – a condition where the main arteries of the heart get mixed up. He was just 7 days old when he had open heart surgery!

This is the reality some families have to live through, and a challenge our doctors are more than ready to meet. Your support helped purchase a new ultrasound probe used for more accurate readings for heart catheterizations, as well as to perform ultrasound scans on patients treated in urology and general surgery.

For kids, ultrasound is the machine of choice. It's a technology that is less invasive than an MRI, and it allows kids to avoid sedation or accumulating dangerous radiation in their bodies.

Thanks to you, 2000 ultrasounds will be performed yearly.



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B

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## A BEHIND-THE-SCENE LOOK

*P.K. Subban came to visit last February with some of his Nashville Predators teammates, away from the media.*

**A.** The nurses had decided to keep the visit a secret from one patient: Loïc, a severely disabled teen whom P.K. greatly admires. Words couldn't express how happy Loïc was to see a crowd of players in their yellow jerseys enter his room.

**B.** As people bustled around the hospital corridors, Élyse was trying to keep her cool in a nearby hallway. The teenager is a hockey fanatic, and P.K. is her favourite player. "Meeting P.K. is my dream," she said.

**C.** "I've been in the hospital with my 18-month-old son for 6 weeks now," said Samantha who was overcome with emotion when meeting the players. "He's under medication. He can't move or expend energy. Having access to free Wi-Fi and TV is a huge help for us. Thank you, P.K."

# RESEARCH: THE RELENTLESS SEARCH FOR A CURE

*Imagine your house gradually filling with waste, waste that piles up each day, and there is nothing you can do to stop it.*

That's what the 4-year-old Félix-Antoine has to live with. When Félix-Antoine was 2, he was referred to a pediatrician at the Children's because his head was larger than normal. They found out his liver and spleen were abnormally large. His parents, Jean-François and Edith, never could have anticipated that these signs pointed to a frightening and cruel diagnosis: a rare degenerative disease that, to this day, spares no one. It's called Hunter syndrome.

Waste is slowly accumulating throughout Félix-Antoine's body, causing progressive damage to every organ system, including his eyes, ears, lungs, heart and bones. Two thirds of boys with the disease also suffer from an accumulation in the brain which causes a gradual loss of development milestones. Results indicate Félix-Antoine could be one of them.

Pediatric endocrinologist Dr. John Mitchell is working tirelessly with his research team to find ways to understand how the cellular waste causes damage to the brain.

> "Understanding this process is the first step in developing new therapies to prevent the accumulation in that organ. To do this, we need research funding." The truth is plain to Dr. Mitchell: "Every bit of money counts in the search for a cure."

For now, Félix-Antoine benefits from the Children's expertise. He receives intravenous enzyme replacement therapy to slow the disease's progression and alleviate symptoms.

In the meantime, his parents try not to think about the future. It's too painful. "We prefer to stay focused on the present moment," says Jean-François. They hang on to hope that a cure may be found for their son. "It's not too late."

# CARE: HELPING THEM GROW UP AT HOME

*When Amanda was born, she had Trisomy 18 – which means she has one extra chromosome – and a heart defect.*

At one week old, she was sent to Complex Care at the Children's. She was "a real fighter," says her mom Esmirna "and we wanted to fight with her".

Fighting, they have been doing for the past 10 years. Thankfully, donors have been there to support programs that help them through all the challenges they've faced.

When Amanda turned 5, she got pneumonia which robbed her of her ability to eat normally. Their daughter would need to eat through a feeding tube, which had to be installed surgically. Esmirna remembers the first time she returned home with her daughter, with instructions on how to test for leaks, the tube being kept inside the belly thanks to a balloon filled with water. "I had a syringe with a needle. I was nervous and I deflated the balloon, so the feeding tube came out," she recalls. Panic swept over her as she sent her daughter by ambulance to the Children's.

It's for families like Amanda's that the Children's Complex Care Service rallied the province's other pediatric hospitals around an innovative project: a website providing a wide range of information and support to all families of Quebec children with complex health needs.

Now, with just a few clicks, parents of children who require special devices such as gastrostomy tubes, tracheostomies, central venous lines or other technologies can follow step-by-step procedures to administer care to their child.

> "Each piece of information is evidence-based and there is an agreement from all of our healthcare partners in Quebec," says the physician who spearheaded this program, Dr. Hema Patel, Complex Care Service Director.

"We used the input of many families to select the format and content and our biggest wish is for the information to be helpful to the families of children who have complex medical needs."

Thanks to our donors, children like Amanda now have a better chance of growing up at home instead of prolonged stays in a hospital setting.

# CHICKEN MAYO MAC'N NUTS AND VEGGIES

**HERE'S A KETOGENIC MEAL IDEA, SHARED BY A MOM WHOSE DAUGHTER IS TREATED AT THE CHILDREN'S FOR EPILEPSY.**

*Did you know the keto diet was originally created in the 1920s to treat children with epilepsy? A diet low in carbohydrates can control seizures. This diet as a treatment for epilepsy is done under medical supervision only to avoid serious complications, such as nutritional deficiencies and osteoporosis.*

*Try it. It's yummy!*

**Ingredients**

| | |
|---|---|
| 15g | Broccoli |
| 25g | Chicken breast raw (no skin) |
| 10g | Nuts, Macadamia dry roasted with salt |
| 7g | Butter |
| 20g | Hellmann's Mayonnaise |
| 4g | Olive oil |

**Instructions:**

Cook your chicken with the Hellman's mayonnaise. Add the Macadamia nuts and the butter on top of the chicken and grill. Add the oil on the cooked broccoli.

*Enjoy!*

# Could this be a *concussion*?

*Have you ever had a blow to the head?*

You'll often hear people downplay a concussion. But a concussion is a brain injury. And children like adults can develop complications if they don't take symptoms seriously enough, and return to their activities too quickly.

The Montreal Children's Hospital is a provincially designated trauma centre and neurotrauma centre of excellence. Each year, the Hospital sees over 3,500 children and adolescents with head injuries, ranging from minor to severe. As the summer approaches, here are a few tips on how to recognize a concussion, and how to care for it.

## RECOGNIZING THE SIGNS

### COMMON SYMPTOMS INCLUDE:

**HEADACHES DIZINESS**

**DIFFICULTY SLEEPING & FATIGUE**

**NAUSEA**

### OTHER SYMPTONS INCLUDE:

Changes in behavior; irritability, anxiety and stress

Difficulty with memory, concentration and attention

Sensitivity to light, sound and motion

### RECOMMENDATIONS DURING RECOVERY PERIOD

- Do not let your child attend school for the first 2 days. On day 3 return to school for 1 or 2 half-days. Continue progression to full days as tolerated.
- Inform daycare, school, teachers, and coaches of the concussion sustained and the restrictions and recommendations in place.
- Avoid sports or gym activities or attending sport practices, games, music, drama, or dance classes. The student should not be in the same room during these activities.
- No screens (even texting!) for the first 2 days.
- Avoid driving, energy drinks, alcohol or drugs.
- Short leisurely walks of 10-20 minutes are permitted.
- Adequate rest and breaks are encouraged.

**If you don't see any improvement within 10 days, consult with the Concussion Clinic at 514-412-4400 x 23310. Please note: A referral from a doctor will be required.**