



**foundation  
of stars**  
the magic of research

# ANNUAL REPORT

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## 2017 - 2018





**WHEN SUPPORTING OUR TINY HEROES**

**IN THEIR DAILY COMBAT**

**EVERY GESTURE COUNTS!**

# Table of Contents

4	MISSION, VISION AND VALUES
5	DID YOU KNOW THAT...
6	MESSAGE FROM THE CHAIRMAN OF THE BOARD OF DIRECTORS AND THE CHIEF EXECUTIVE OFFICER
7	MESSAGE FROM OUR SPOKESPERSON
8	CHILD STARS
11	FUNDRAISING CAMPAIGNS
12	SOCIAL NETWORKS
13	CORPORATE EVENTS
16	PUBLIC EVENTS AND CHALLENGES
19	RESEARCH PROJECTS FUNDED
24	FINANCIAL HIGHLIGHTS
25	BOARD OF DIRECTORS, FOUNDATION OF STARS TEAM AND GOVERNORS
26	AMBASSADORS AND MASTERS OF CEREMONIES
27	CORPORATE PARTNERS

# Mission, vision and values

## AN ESSENTIAL ROLE

From the moment it was founded, the Foundation of Stars has focused its efforts on the health of our children, primarily by contributing to pediatric research. This dedication has made it possible for the Foundation to remit a total of nearly \$70 million to fund innovative research projects involving children's diseases.

Acknowledged as one of the main sources of non-governmental funding for research, the Foundation has become a true driving force for the next generation of researchers.

Many medical breakthroughs have been achieved to date. The hope that inspires us is clearly that each children's disease will one day have its cure. To bring us closer to this goal, we continue to funnel each dollar raised into research.

## OUR MISSION

The Foundation of Stars has a singular mission: funding pediatric research as a means of protecting, promoting and improving the health and well-being of children and adolescents

## OUR VISION

The Foundation of Stars' efforts are designed to propel pediatric research and thereby up the odds of finding cures for the diseases impacting the health of our children.

## OUR VALUES

Everything we do, we do openly and with integrity.

**INTEGRITY**

Our every action ultimately seeks to bring hope for our children's health and education.

**LEADERSHIP**

We channel our passion for the good of our children, the work of researchers and society as a whole.

**COMMITMENT**

# Did you know that...

## Did you know that each dollar invested can ultimately equate 5 to 10 times that in research funds?

The bursaries we provide to research scientists and the amounts we dedicate to help fund research projects ultimately attract additional funding for the works involved. The Foundation's support has the effect of reassuring other potential funders of the importance and quality of the work underway, which can prove a key factor in their decision to invest.

## PROGRESS IN PEDIATRIC RESEARCH SINCE THE FOUNDATION'S EARLY DAYS

- ★ In 2017, the **survival rate for children aged 1 to 4** with a cancer diagnosis was extremely high (82% for boys and 85% for girls), particularly compared to the rate of 71% in 1980.
- ★ Progress in perinatal research **has generated a significant improvement in the survival rate of extremely premature babies**, which is now at 80% for children born before the seventh month of pregnancy.
- ★ **The survival rate for children 14 years old or younger who suffer from acute lymphoblastic leukemia** is 91% after 5 years and is continuing to rise.
- ★ Thanks to numerous awareness-raising campaigns and the identification of risk factors, **the number of cases of sudden infant death syndrome in Canada continues to drop** from one year to the next, and was at 0.3 per 1,000 births in 2009.
- ★ Significant improvements in the process for evaluating and treating children suffering from **viral bronchiolitis** have led to fewer risks of complications.
- ★ The **progress made in the area of organ transplants** is also impressive. Case in point: in 2018, surgeons at CHU de Sainte-Justine removed 25% of the left lobe of a mother's liver and transplanted it into her son. This is the fourth living donor operation since the transplant program's founding in 1983, and the only one in Québec where the organ recipient is a child.

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## EXAMPLES OF PROGRESS MADE POSSIBLE THROUGH OUR SUPPORT

- ★ The research conducted by Dr. Nada Jabado, MD, Ph.D., pediatric hemato-oncologist at the Montreal Children's Hospital, culminated in the creation of a targeted treatment able to decrease the size of brain tumours in children, which are the primary cause of cancer-related deaths in patients under 20 years of age. After one year of therapy, our star Karl's tumour had decreased by 88%. This innovative treatment is currently being studied by a panCanadian team comprised of over 30 pediatric research centres and not for profit organizations.
- ★ A team of researchers conducting a project at CHU de Québec, Université Laval on the genetic causes of rare children's diseases was, through exome sequencing, able to identify a genetic alteration with a high probability of causing diseases.
- ★ The NeoBrainLab, comprised of a team of researchers from CHU de Sainte-Justine, discovered that asphyxia at birth causes changes in the structure of the cerebella, a part of the brain with a role in coordination, balance, vision, cognition, learning and language. The data gathered will support a better understanding of the brain damage caused by asphyxia at the time of birth.



# Message from the Chairman of the Board of Directors and the Chief Executive Officer



Mr. Jacques Dubuc,  
Chairman of the Board of Directors

*"I'm extremely proud to have had the opportunity to work hand in hand with the Foundation. And while I am stepping down from my position as Chairman of the Foundation's Board of Directors today, I will personally continue to support pediatric research in the years to come, by notably staying on as a Board member, to fight alongside the entire Foundation of Stars' team to bring smiles to the faces of sick children."* Jacques Dubuc

## The time has come to bring this 40<sup>th</sup> year to a close!

From the time it was established - in 1977 -, the Foundation of Stars has seen the future with a bright eye and played a role in breaching the frontier of research, time and time again. A philanthropic pioneer, the Foundation this year spearheaded numerous initiatives aimed at bringing concrete improvements to sick children. 2017-2018, in fact, saw nearly \$2 million dedicated to research into children's diseases. Novel areas of focus were addressed in Québec's 4 pediatric research centres: 1) reproductive health, at CHU de Sherbrooke, 2) inflammation and infections at the Montréal Children's Hospital, 3) rare diseases at CHU de Québec, and 4) mental health and neurodevelopment at CHU de Sainte-Justine. We also simultaneously supported a project concerning brain cancer being carried out by the dedicated Dr. Nada Jabado, MD, Ph.D., pediatric hemato-oncologist at the Montréal Children's Hospital, and Dr. Sébastien Perreault, MD, M.Sc., PRPCPC, assistant clinical professor, Université de Montréal and pediatric neuro-oncologist at CHU de Sainte-Justine.

This past year, the Foundation of Stars also opened Québec's first *Centre d'excellence Fondation des étoiles en obésité infantile*, an entity dedicated to fighting the obesity epidemic among today's children and adolescents. A first in Québec! And lastly, through our partnership with the FRQS (Fonds de recherche Québec-Santé), we are continuing to support promising research projects by students and young research scientists.

We would also like to underscore the hard work and talent of these renowned researchers. Their dedication to innovation continues to grow and plant seeds of hope in the hearts of the families of sick children. We thank them, and are proud to play a small role in the success of their endeavours.

This year, we are also proud to welcome a newcomer to our Board of Directors, the talented Dr. Anne Monique Nuyt, head of neonatology at CHU de Sainte-Justine and full professor at the Université de Montréal Faculty of Medicine. We also find ourselves thanking Carl Vien for his seven years of committed service as a Board member. Another Board of Directors member who dedicated both time and energy to our cause, Cimon Plante, is leaving us this year. Lastly, we would like to thank Dr. Guy Rouleau for having sat on the Board since 2016; he will serve as a special consultant moving forward.



Ms. Josée Saint-Pierre,  
President and CEO

And more specifically, our thoughts kept returning to those who are at the heart of our battle: the children. Their strength, courage and determination push us to give more of ourselves every day. Unveiling their warm smiles amidst the stars is always one of our proudest moments.

I would like to personally thank our partners and donors for their steadfast support over so many years. You are the reason we can continue to help and fund so many important research projects.

I would also like to recognize our wonderful spokesperson Maripier Morin, whose unflagging energy and sincere dedication over the past year have been major assets to the Foundation.

Also, our sincere thanks to the dedicated volunteers who help make each one of our events a resounding success and who generously give of their time in support of our cause. By moving forward in this manner, side by side and as a cohesive unit, we will be able to reach the stars!

*"I want to thank Jacques Dubuc for his involvement with our cause. His support and dedication over the last six years were invaluable, and I wish him all the best in his future endeavours. I am also thrilled at his decision to stay on as a member of our Board of Directors."*  
Josée Saint-Pierre

## Message from our spokesperson

My first year as spokesperson for the Foundation of Stars was nothing short of astounding. During every activity, I was able to work alongside other Foundation supporters and see firsthand the impact of our efforts in support of pediatric research.

I was privileged to meet the research scientists who received financial support from the Foundation of Stars, notably during the campaign "Reach for the stars with Maripier!". Our challenge was to raise \$20,000 in 20 days, a target we easily met!

In addition to the funds we raised, what truly touched me was the exchanges I had with the people who work to improve the health of our children. We had the opportunity of clearly showing our donors where their money was being spent and in essence, why it was so critical that everyone keep giving.

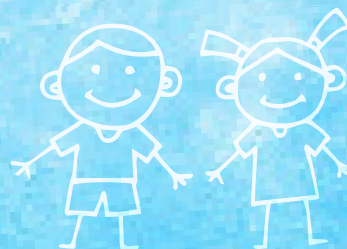
This year also allowed me to meet and spend time with the families of sick children; observing how they manage to remain resolutely courageous in spite of immense pain is a deeply moving experience. The resilience of these young warriors has become the driving force behind my commitment.

I am extremely pleased to toss my hat into this particular ring and help raise funds for research. I urge all of you to remember that we are the origin of all that impacts our children's health. Without funding from organizations such as the Foundation of Stars, research centres could not continue identifying and refining various treatments and cures. Giving to research is an investment in our children's future.



Maripier Morin,  
spokesperson

*As you continue reading this report, you will get to meet very brave sick children and learn more about their stories. I am confident that everyone of them will touch you as did me.*



## Our star Karl

Karl's journey began with a simple fall. While playing - at the tender age of 7 - the young boy awkwardly fell against a swing. He complained of pain in his arm, but the boy's parents were not immediately concerned, certain the discomfort was simply a result of Karl's minor accident. Karl's pain, however, did not diminish, and his arm became increasingly numb. Within a mere few days, the boy was unable to use his right hand and his shoulder was slumping.

Karl underwent an MRI (magnetic resonance imaging), which revealed the presence of a ganglioglioma, a benign brain tumour. The boy's parents were understandably in shock, as nothing could have led them to anticipate such a terrible turn of events.

The tumour, located along the brainstem and touching seven cervical vertebrae, was in a truly delicate position. While surgery was a possibility, it was also risky, requiring an extremely long incision that might destabilize the young boy's cervical spine. There were also numerous potential side effects.

This was when Karl and his parents met Dr. Nada Jabado, MD, Ph.D., a pediatric hemato-oncologist at the Montreal Children's Hospital awarded numerous Foundation of Stars bursaries. Dr. Jabado outlined a highly promising option with few side effects, i.e., a new targeted therapy that could shrink the tumour. And shrink it did: after only three weeks of treatment, Karl's tumour had decreased by 50% and the boy was able to resume using his right hand. What more, after a year of therapy, the tumour had shrunk by 88%!

With this medication, young Karl enjoyed a speedier recovery and was able to return to school sooner than might have been expected. The treatment, consisting of only two pills per day (taken at home), requires no drips (infusions) or trips to the hospital, ensuring the boy a better quality of life.

Brain tumours are at present the primary cause of cancer-related deaths among children. The survival rate for certain other tumours is higher, and brain tumours also carry a higher risk of severe sequela (this because of where they are located and the treatment required to slow their growth).

*"When we were given the diagnosis, I would have sold my soul to the devil to change places with him. It was all I could think of." Marc, Karl's father*





## Our stars Élodie and Béatrice



The Roy family's war against galactosemia began in 2012, following the birth of their first daughter. Complications soon surfaced, among them feeding problems: the baby refused to drink, was projectile vomiting and began to lose weight. A few days later, Élodie stopped breathing on five separate occasions.

She was then transferred to CHU de Sherbrooke, where a team of doctors, nurses, respiratory therapists and paramedics quickly took over caring for the child. Tests were carried out, blood was drawn and the child was given blood transfusions. Elodie was also subjected to a spinal tap, phototherapy and the intravenous administration of antibiotics. Specialists at the CHU de Sherbrooke quickly identified Élodie's problem, in a rapid diagnosis that ensured she would at least not suffer from any further or more serious effects.

In Élodie's case, the liver and kidneys were fully afflicted, and the disease would have then moved on to the brain. Due to her young age, the sequela associated with Élodie's disease were reversible. After spending a few days in the ICU and pediatric ward, Élodie was able to go home, where she was closely monitored. Audrey and her husband Patrick underwent DNA testing, which confirmed that they were both carriers of the disease and that any children they had would have a 1-in-4 change of being afflicted with galactosemia. Their second child, a daughter, was born on June 18, 2014, and diagnosed as a carrier. Their third daughter, Béatrice, also has galactosemia, but will not have to take the tortuous road her older sister Élodie did years before. She will, instead, be monitored by DNA specialists and ophthalmology experts at CHU de Sherbrooke to ensure that she stays healthy.

*"She nearly died when she was only 8 days old, and we thank God for having decided it was not her time. Today, we have a beautiful 5-year old girl who's full of life and nothing less than a ray of sunshine." Audrey, Elodie and Béatrice's mother*

## Our star Lionel



Lionel's parents, shortly after the 2016 Christmas holidays, were staggered to learn, following the ultrasound performed at 20 weeks, that their unborn son had a serious cardiac defect. But Éliane and Maxime did not let their initial shock get them down.

Doctors quickly reassured them that Lionel, the miracle created thanks to an egg cell donation that they had been looking forward to for a very long time, showed no signs of any of the other problems associated with the cardiac malformation he suffered from, the tetralogy of Fallot.

They were also reassured by Dr. Frédéric Dallaire, a pediatric cardiologist at CHU de Sherbrooke who has received numerous Foundation of Stars' bursaries: yes, the defect was serious, but a known entity, "the kind of problem that's documented in the annals of medicine." Lionel was born in April 2017, following a period marked by difficulties and worries. When they left the hospital, Éliane

and Maxime already knew that their baby boy would have to undergo open heart surgery at some point during the first 6 months of his life. In Lionel's case, there was a large hole in the wall separating the ventricles in the boy's heart, which allowed oxygen-rich blood to mix with blood with a low oxygen count. Until Lionel's surgery last summer, the parents lived with the fear that they would see their son "run out" of oxygen and turn blue.

The diagnosis prior to Lionel's birth allowed all of the professionals involved to better prepare for his "arrival" as well as the surgical procedure that he would need to undergo within a few months of being born. In this case, and like many other defects of its kind, a diagnosis during the pregnancy allows for avoiding emergency procedures or unexpected and often catastrophic interventions. Thanks to progress in the field of pediatric research, most malformations are now detected prior to a child's birth. In Lionel's case, his parents' implication and the dedication of hospital personnel allowed the boy to enjoy an excellent recovery from his open heart surgery.

*"All of these huge machines to keep such a small little body alive, it's both incredibly amazing and heartwarming." Éliane, Lionel's mother*

## Our star Théo

"Hello. My name is Théo and I'm 11 years old.

I suffer from a disease that many people have a hard time identifying as such: obesity. And yet, it's such a real part of my everyday life. Before my condition worsened, I didn't move much and I guess you could say I \*really\* enjoyed video games! My diet was far from healthy, to the point that I couldn't get around like I would have liked to.

My parents decided to have me see a professional at Clinique 180. And what a relief it was! Eventually, after being seen by numerous doctors, I was able to regain some of my self-esteem and the tension at home diminished a bit.

It's not always easy, but I'm doing my best to improve. Thanks to the help of my parents and everyone at Clinique 180, I am getting better grades in school and my relationship with food is slowly becoming healthier."

Théo is not an isolated case. Obesity, the primary cause of the spike in cardiovascular diseases and type 2 diabetes observed recently, now impacts 15% of young Quebecers. The World Health Organization considers this disease as nothing less than an overlooked and ignored epidemic.

The obesity epidemic brings with it other problems, among them depression, poor self-esteem and disabilities, as well as generating immense prejudice among the general population. The children afflicted deserve to have access to appropriate and effective healthcare, adapted to their reality and which will allow them to develop in better mental and physical health. This will in turn enable them to achieve their full potential without being hindered by societal stigmatisation. It had become critical to bring together the best researchers and professionals from all of the sectors related to childhood obesity in Québec. The *Centre d'excellence Fondation des étoiles en obésité infantile* is dedicated to fighting the obesity epidemic among today's children and adolescents.



*"Although Théo is the one afflicted by the disease, our entire family fights alongside of and for him on a daily basis." Marie, Théo's mother*

# Fundraising campaigns

Each year, be it by means of a letter or e-mail, during a telephone conversation or since a certain time, via the Web, you have demonstrated interest, awareness, curiosity and commitment to our cause. There will never be enough words to thank you for your loyalty and incredible generosity in support of research into children's diseases. Each donation, regardless of its size, is a precious gift with the possibility of changing the lives of sick children. Children who have but one dream: to be cured.

## IMPRESSIVE FACTS ABOUT OUR FUNDRAISING CAMPAIGNS

- ★ **Over 3,000 donors** contribute a total amount of \$32,900 each month (\$395,000 for the year)
- ★ **Close to \$445,000** gathered through 6 different fundraising campaigns, namely:
  - ★ **The June 2017 paper newsletter**, providing news of the Foundation's activities and a look at the progress made by the researchers we support;
  - ★ **A telephone initiative, carried out in** summer 2017, to find new partners in support of pediatric research;
  - ★ The highly coveted **calendar** released in the fall of 2017;
  - ★ **The Reach for the stars with Maripier! Web campaign**, held in October of 2017 and aiming to raise \$20,000 in 20 days.
  - ★ Our Christmas 2017 initiative, whereby we shared our star **Lionel's touching story** by e-mail and through a telephone blitz.
  - ★ **A novel spring fundraising campaign, with matching of funds** by Mr. Rémi Gilbert (Investors Group), which had the effect of doubling the amount raised in early 2018.

## A first Web-based campaign

REACH FOR THE STARS WITH MARIPIER MORIN!

Amount raised - \$20,209

Last October, the Foundation of Stars launched its first-ever fundraising campaign through social media, inviting Quebecers to support our stars alongside Foundation spokesperson Maripier Morin.

This new and original campaign ran for 20 days and sought to raise \$20,000. Three video clips were produced to shine a bright light on our experienced researchers as well as up-and-coming young scientists.

We are extremely grateful for your commitment, dedication and support throughout this important campaign. Thanks to you, we were easily able to reach the goal that had been set.



## Testamentary donations

Mr. Pierre G. Bouchard - \$50,000 ★

Ms. Agathe Fortin - \$15,950 ★

Ms. Madeleine St-Laurent - \$8,539 ★

Ms. Thérèse Lacroix - \$37,500 ★



**f**  
 +19% « likes »,  
 and a community of  
 1976 followers

**i**  
 +30% members,  
 a community  
 comprised of  
 542 followers

**t**  
 A community  
 comprised of  
 813 followers

**y**  
 16 new videos

**in**  
 208 group  
 members,  
 +32% over  
 the year

## Social networks

# Corporate events

## 34<sup>TH</sup> GREAT EVENING OF STARS

On March 21, the 34<sup>th</sup> Great Evening of Stars was held at the St-James Theatre, to the unrelenting beat of Saturday Night Fever! Cochaired by Jessica Harnois and Danièle Henkel, two women whose generosity knows no bounds, and hosted by Foundation spokesperson Maripier Morin and the amicable Étienne Boulay, the evening featured breathtaking performances by the likes of Kim Richardson and the professional dance troupe directed by Connie Rotella and Émilie Josset.

The event was also marked by the deeply moving story of our star Karl, a young boy with a brain tumour, who attended the evening along with his parents and pediatric hemato-oncologist Dr. Nada Jabado.

Our heartfelt thanks to all those who were present: partners, artists, hosts and Québec stars!



Marco Riccardo Rusconi, Consul General of Italy; Josée Saint-Pierre, Foundation of Stars; host and spokesperson Maripier Morin; Jessica Harnois, Vins au féminin; Gaëtan Barrette, Québec Minister of Health and Social Services; Danièle Henkel, Entreprises Danièle Henkel Inc.; host Étienne Boulay; and Jacques Dubuc, Stokes.

Since its creation: **\$8,247,095**

## 12<sup>TH</sup> ENCAN DES VINS DE MONTRÉAL

On May 1, 2017, renowned sommelier Véronique Rivest hosted the 12<sup>th</sup> edition of the Encan des vins de Montréal, event chaired by Alain B. Auclair, UBS and Alain Giasson, Alfa Capital inc., which raised over \$260,000.

Guests were privileged to taste the Carlos Ferreira wines from Portugal along with those from the Domaine Faiveley vineyard in the Bourgogne region. Karl, a Foundation's star who suffers from a brain tumour, generously accepted to share his touching story, accompanied by his parents and Dr. Nada Jabado, MD, Ph.D., a pediatric hemato-oncologist at the Montreal Children's Hospital.



Sandra Ferreira, Carlos Ferreira vineyard; Jacques Dubuc, Stokes; Carlos Ferreira, Carlos Ferreira vineyard; Marc Bérubé, Coaching Financier Trek; Eve Faiveley, Domaine Faiveley; Alain Giasson, Alfa Capital inc.; Stephen Kelly, Norton Rose Fulbright; Anne Saint-Pierre, translator; Benoit Crowe, Novexco inc.; Alain B. Auclair, UBS Securities Canada Inc.; Josée Saint-Pierre, Foundation of Stars; Francois Pintal, National Bank Financial; and, Véronique Rivest, sommelier, SOIF Bar à vin.

### *A special thank you to our loyal partner Groupe Antonopoulos*

The prestigious group, overseen by the Antonopoulos family, owns and operates several upper-end establishments in Old Montréal that have greatly contributed to the city's tourism offering. Groupe Antonopoulos is one of the Foundation of Stars' most valuable partners. For the past 12 years, it has graciously allowed us the use of its establishments for the Encan des vins de Montréal and provided a gourmet meal for all those present.



2017-2018: **\$259,375** | Since its creation: **\$1,844,307**



## 12<sup>TH</sup> ENCAN DU CLUB DES VINGT

Last February 8, the 12<sup>th</sup> Encan du Club des VINGt was held in the salle de la Commune at Marché Bonsecours. The special evening, hosted by Mosé Persico and chaired by Stéphan Bourbonnais, TD Wealth Management, was replete with everything Italy, as guests mingled and got to taste a selection of wines from Domaine Domodimonti. Again this year, the Consul General of Italy Marco Riccardo Rusconi graced us with his presence.

Young Théo and his family spoke to us about their experience and battle against childhood obesity, alongside Dr. Julie St-Pierre, pediatrician, president of the Cardiovascular Health Network and director of the *Centre d'excellence Fondation des étoiles en obésité infantile*.



2017-2018: \$141,687 | Since its creation: \$1,498,702



Stéphen Bouchard, Labelink Inc.; Bruno Anania, Desjardins Securities Inc.; David Zarea, Melmat Sales & Distribution Inc.; Jean Tremblay, SAIL Plein Air inc.; Mosé Persico, host, CTV; Sylviane Chatel, Foundation of Stars; Benoit Roberge, Dunton Rainville, attorneys-at-law; Théo; Julie St-Pierre, Centre d'excellence Fondation des étoiles en obésité infantile; Stéphan Bourbonnais, TD Wealth Management; Valérie Leduc, LEDUCconseils; Bruno Moreau, Centre d'Affaires Micro-Info inc.; Jacques Carrier, Gestion Carrier-Sauvé Inc.; and, Nathalie Deslauriers, Foundation of Stars.



Marc-André Rousseau, BMW Sherbrooke; Louis Martineau, N.V. Cloutier Sherbrooke; Raphaël Forcier, F4 pilot; Renaud Fortier, Hyundai Sherbrooke; Jean-Luc Mongrain, reporter and TV host; Christiane Auray-Blais, CHUS; Jennifer Saint-Laurent, CHUS; Danielle Rousseau, Sherbrooke Toyota; Nicole Poisson, Lions Club; Jean-Paul Praud, CHUS; Ronald Thibault, Thibault GM; Janick Dallaire, Audi Sherbrooke and Volkswagen de l'Estrie; and, Josée Saint-Pierre, Foundation of Stars.

## 5<sup>TH</sup> ENCAN DES VINS DE SHERBROOKE

To celebrate its 5<sup>th</sup> edition, the Encan des vins de Sherbrooke was thrilled to welcome its first vineyard representative, Mr. Pierre Gaillard from Les Vins de Vienne.

Thanks to the 220 guests who attended, including our guest of honour, Jean-Luc Mongrain, the event raised a grand total of \$132,000. Those present were deeply moved by the Roy family, as they shared, alongside Dr. Bruno Maranda, geneticist at CHU de Sherbrooke, the emotional journey of their two daughters, Élodie and Béatrice. All of the money collected at this year's event will once again be offered to CHU de Sherbrooke's mother-child unit. Below are the research scientists - and their areas of study - funded with the monies raised in 2016:

- ★ PAFI project: trajectory for children having received services from the CIUSSS de l'Estrie-CHUS' neonatal monitoring clinic – Dr. Chantal Camden
- ★ Standardization of echocardiograph measurements among obese children – Dr. Frédéric Dallaire
- ★ Effect on kidneys of a mother and her 5-year old son related to a pregnancy complicated by gestational diabetes, premature delivery or low weight at birth - Dr. Anne-Marie Côté
- ★ Evaluation of healthcare personnel training on sustaining motivation with regard to vaccination – Dr. Arnaud Gagneur
- ★ Development of an animal model to trigger the activity whereby intestinal microbiota are modified to better understand the factors impacting premature deliveries – Dr. Pasquier

2017-2018: \$132,849 | Since its creation: \$557,224



## 2<sup>ND</sup> ÉTOILES CÉLESTES

The 2<sup>nd</sup> edition of Étoiles Célestes heralded two successful events, one in Montréal and the other in Québec City! Held in the majestic rooms of the Port de Québec terminal and the panoramic hall at the Montréal Science Centre, these activities once again constituted an opportunity for supporting research into children's diseases in a most original manner.

19 wine producers from around the globe accepted our invitation to participate in a wine-tasting experience on May 15 and 16, 2017, as part of two star-studded evenings dedicated to raising funds for research into children's diseases.



2017-2018: \$67,427 | Since its creation: \$130,452



Charles Goyer, La Céleste Levure; Maripier Morin, spokesperson and host; Sylvie Cardin, La Céleste Levure; and, representatives of the vineyards present at the event.



Marie-Julie Allard, CUSM, and, Cimon Plante, National Bank.

## STAR BOUTIQUE

Guests were invited to shop in a highly unique and spellbinding boutique where they could peruse singular products offered by Québec stars and designers. The evening included a festive cocktail party at Place Ville-Marie's 360 Observatory, thereby offering guests a one-of-a-kind view of the city.

The event was well-attended, and guests had the opportunity to mingle with stars such as our own spokesperson Maripier Morin, actor and radio host Sophie Prigent, businesswoman and diplomat Isabelle Hudon, and beloved actress Anne Dorval.

2017-2018: \$26,623



# Public events and challenges

## 3<sup>RD</sup> EDITION OF CHANTAL LACROIX'S CHALLENGE "DÉFI MOI POUR TOI"

The 3<sup>rd</sup> edition of Chantal Lacroix's Défi Moi pour Toi, held on September 16-17, 2017, brought together 175 runners who took part in a 250-km relay race between Montréal and Québec City. This year, the event's organization benefited from the unflinching support of television host and reporter Karine Champagne.

Participants truly outdid themselves, running the course under a grueling sun... after having raised the impressive amount of just over \$105,000.

They were encouraged along the way by friends, family members and spectators who gathered along the roadway to offer words of encouragement and a extra little boost to keep them going. The participants were also warmly greeted at the finish line, by a large crowd with smiling faces and eyes glistening with tears of satisfaction.



2017-2018: \$106,148 | Since its creation: \$329,048



## 5<sup>TH</sup> EDITION OF THE ULTIMATE POLICE TRAINING CHALLENGE



On December 7-8, 2017, secondary 4 students from Collège Laval gathered at the Adrenaline Performance Center for the ULTIMATE challenge, namely training like RCMP officers. The 200 young participants were urged on by actor Eric Hoziel and Formula 4 pilot Raphaël Forcier.

These youngsters, due to their perseverance and determination, gathered over \$20,000, an amount greater than that raised in any of the other years!



2017-2018: \$20,267 | Since its creation: \$70,033

## SCOTIABANK CHARITY CHALLENGE

In its 4th year participating in the Scotiabank Charity Challenge (April 22-23, 2017), the Foundation of Stars formed a team of 28 members, walkers and runners, in the following categories: 5K with stroller, 5K and 10K.

All of the participants were extremely excited and despite the grey skies, boasted wide smiles as they crossed the finish line, proud of a job well done! .. And for a good cause! Overall, the group raised over \$5,400.



2017-2018: \$5,405 | Since its creation: \$16,014





## ST-VIAEUR BAGEL

Happiness and joy were on hand on May 21, 2017, as Montréal's iconic St-Viateur Bagel shop celebrated its 60th anniversary! It was a party, with animated characters to amuse the children, music for the older crowd and enough traditional bagels to go around.

The event was nothing short of a resounding success, raising over \$61,000.

Montréal can be proud of St-Viateur Bagel, which makes the best bagels, hands down, and is the result of the hard work of a family equally devoted to fighting children's diseases.



2017-2018: **\$61,107** | Since its creation: **\$332,445**



## RECYCLAGE DE TEXTILE CANADA SOMODIF INC.

Somodif, a proud partner of Foundation of Stars since 2000, runs a clothing recycling program with drop-off boxes. While these boxes have traditionally been strategically placed in the Greater Montréal area, they have now begun to pop up in Toronto. By the simple act of dropping off a bag of clothing they no longer wear, people can help support research into children's diseases.

2017-2018: **\$34,400** | Since its creation: **\$364,400**



## TOUR BY GHISLAIN LEBLANC

This past May, Foundation of Stars underscored Mr. Ghislain Leblanc's 30 years of involvement, support and dedication to our organization. To date, the activities organized have gathered over \$1.2 million for research, in what can only be considered a spectacular contribution to supporting the fight against children's diseases. Thank you!



2017-2018: **\$23,471** | Since its creation: **\$1,291,193**



## 34<sup>TH</sup> EDITION OF THE RCMP SPAGHETTI LUNCH

The 34<sup>th</sup> edition of the RCMP spaghetti lunch held on September 11, 2017 at the Hôtel Omni Mont-Royal was a smashing success, as illustrated by the gleeful expression on the boy's face! What more, the event raised over \$15,000! Our warmest thanks to the RCMP as well as to all of the sponsors and volunteers who made this event happen.

2017-2018: **\$15 053** | Since its creation: **\$478,824**



## RESEARCH PLACEMATS

You have no doubt already noticed, upon sitting down in a restaurant at some point, a placemat harbouring a photo of the Foundation of Stars, surrounded by various local business ads. This initiative is spearheaded by Mr. André Bernier, who began travelling throughout Québec in 2005 to raise awareness of the importance of pediatric research among regional companies and elected officials.

2017-2018: \$14,280 | Since its creation: \$179,280



Josée Saint-Pierre, Fondation of Stars; P/M Lochie Bisailon and D/M Sylvain L'Heureux, RCMP; and, Sylviane Chatel, Fondation of Stars.

## ROBBIE BURNS EVENING

On February 3, 2018, the RCMP pipes and drums band held its first edition of the Robbie Burns evening in support of the Foundation of Stars. The event raised \$2,000.

2017-2018: \$2,000

### Other public events





- Manon Bédard concert, Saint-Roch-de-l'Achigan (April 13, 2017) Camille Pelletier
- Kahnawake country evening (April 29, 2017) Gilles Pelchat and Ghislain Leblanc
- Sale of promotional items at the Québec Lions convention (May 2017)
- Subaru family day (May 22, 2017) Robert Scott
- Fundraising activity by the Brit & Chips restaurant (entire month of June 2017)
- Bowl-a-thon at École Jean-Baptiste Meilleur in Repentigny (October 14, 2017) Mégan Peticlerc
- Darts tournament Legion 120 Mascouche (October 24, 2017) Marcel Rolland
- Beer hall Lévis Lions club (October 20, 2017) Colombe Roger Côté
- Sale of promotional items, Québec City hospitals (2017) Colombe Roger Côté
- Acadian day Académie John Caboto Montréal (December 7, 2017)
- Expeditions to the stars – Famille Randonneuse (2017 – 2020)

### Our faithful partners

- Air Canada** which provides our lucky winners with tickets to fly just about anywhere in the world.
- Ballons Granger Balloons Inc.** which has for numerous years been supplying us with balloons - free of charge - that bring smiles to the faces of young and old alike!
- Légaré Location** which has for another year provided us a rental vehicle to transport equipment to various events.
- Subaru Montréal**, a new partner, which generously allowed us the use of two vehicles during the entire Défi Moi pour Toi week-end.
- Trudeau Maison** and **Vins & Passion** which have, for countless years now, been providing us with gifts for the guests at our events.
- Zendatamarketing** which helps us keep our donors apprised of our activities through newsletters sent out several times a year.

# Research projects funded

From the moment children begin to grow in the womb until they become adults, their formative years are sprinkled with potential hazards and challenges. For some youngsters, however, what are mere bumps in the road for most soon grow into mountains. The mission of the Foundation of Stars is to help these children scale these mountains despite their illnesses, by funding worthy research projects that address every step of their lives .

 In the womb	 At the time of birth	 Children	 Adolescents
CHUS Perinatal	CHUQ Rare diseases	CUSM MUHC Montreal Children's Hospital Inflammations/infections	CHU Sainte-Justine Neurodevelopment/ Mental health

OVER \$1,000,000 FOR THE 4 PEDIATRIC RESEARCH CENTRES  
\*\$251,355 from the Foundation of Stars

Funding for the new generation of researchers (master's, doctoral and post-doctoral students),  
in conjunction with the Fonds de recherche du Québec-Santé (FRQS)

OVER \$500,000 FOR YOUNG RESEARCHERS

Canada-wide experimental project on brain tumours,  
spearheaded by Dr. Nada Jabado and Dr. Sébastien Perreault

OVER \$200,000 FOR BRAIN CANCER

Foundation of Stars Centre of excellence on childhood  
obesity (a first in Canada)

OVER \$370,000 FOR CHILDHOOD OBESITY  
\*over a 3-year period



Jacques Dubuc, Stokes; Dr. Noha Gerges, CUSM; Dr. Ekaterina Kritikou, CHU de Sainte-Justine; Dr. Yves Tremblay, CHU de Sherbrooke; Dr. Jean-Paul Praud, CHU de Sherbrooke; and, Josée Saint-Pierre, Foundation of Stars.

## CHU SAINTE-JUSTINE RESEARCH CENTRE

### On the road to treating intellectual disabilities: development of electrophysiological biomarkers

*Project directors: Dr. Graziella Di Cristo, Dr. Sarah Lippé, Dr. Lionel Carmant, Dr. Elsa Rossignol, Dr. Jacques L. Michaud, Dr. Bénédicte Amilhon, Dr. Philippe Campeau, Dr. Sébastien Jacquemont, Dr. Sébastien Perreault and Dr. Philippe Major / Collaborators: Dr. François Corbin, CHU Sherbrooke and Dr. Myriam Srour, CUSM*

This project's primary goal is the identification of brain activity patterns specifically associated with genetic forms of intellectual disability, and this in both children and mouse models. By relying on the study of these electrophysiological models - or biomarkers - we are striving to develop simple tests that can be quickly administered to assess the impact of pharmacological therapies. Biomarker identification significantly decreases the time usually required to move from preclinical discoveries to clinical trials to treatments with a major impact on children afflicted with a given disease.

Over the past year, we have made significant progress in both areas. We have evaluated electrophysiological patterns associated with the sensory responses and learning processes of children presenting with various genetic forms of intellectual disability. Preliminary data show that not only are our electrophysiological protocols sensitive to the severity of intellectual disabilities, but that intellectual disability syndrome has a specific pattern. We will pursue our research with patients presenting with other forms of intellectual disability over the coming months. At the same time, we developed a platform for recording cerebral responses to sensory stimuli in awake and alert mice at various stages of cognitive development. This new platform will enable a direct comparison of the cerebral responses of patients to those of animal models, as well as a rapid transfer of our findings to the clinical setting.

## MCGILL UNIVERSITY HEALTH CENTRE - MONTREAL CHILDREN'S HOSPITAL

### Role of maternal inflammation on the genesis of autism

*Project director: Dr. Guillaume Sébire, CUSM / Collaborators: Prof. Maxime Descoteaux, CHU Sherbrooke and Marie-Julie Allard, Ph.D. student at the CUSM*

Marie-Julie Allard used a preclinical animal model to illustrate how a placenta infection triggered by certain strep B subtypes impacted the genesis of disorders along the autism spectre in males, but not in females. She discovered the inflammatory buffers induced during the process and illustrated the much stronger placental inflammatory response in males, compared to females. The next research phase will involve blocking the inflammatory buffer while also administering antibiotics, in an attempt to protect the growing brain from inflammatory attacks generated by an infected placenta.

### The microglia and neurophiles active in asphyxiated newborns

*Project director: Dr. Pia Wintermark, CUSM / Collaborators: Dr. Sophie Tremblay, CHU Sainte-Justine and Prof. Giamal Luheshi, Douglas Institute*

The NeoBrainLab, comprised of a team of researchers from CHU Sainte-Justine, discovered that asphyxia at birth causes changes in the structure of the cerebellum, a part of the brain that plays a role in coordination, balance, vision, cognition, learning and language. The data gathered will support a better understanding of the brain damage caused by asphyxia at the time of birth.

### Key factors in liver scarring among children with a vesicoureteral (VU) reflux

*Project director: Dr. Indra Gupta, CUSM / Collaborators: Dr. Sophie Turpin and Véronique Phan, CHU Sainte-Justine*

Vesicoureteral reflux is a urine flow problem, common in children, that impacts the emptying of the bladder. Urine, instead of flowing out of the bladder, is pushed back - in the other direction - by the kidneys, which can lead to a bacterial infection of the latter. Afflicted children may develop frequent infections that will eventually cause irreversible kidney damage and renal failure. We are gathering DNA samples from children who are afflicted as well as some who are not, our goal being to determine whether the genes of children in the latter group (not afflicted) responsible for coding proteins critical to the immune system and making it possible to rid the body of bacteria and thereby fight infection are different from those in the other group. The project seeks to identify those children with a risk of renal injury, so that they can receive appropriate treatment.



## CHU SHERBROOKE RESEARCH CENTRE

### Québec cohort of newborns with a cardiac defect

*Project director: Dr. Frédéric Dallaire, CHU Sherbrooke / Collaborators: Dr. Marie-Eve Roy, CHU Sherbrooke, Dr. Laurence Vaujois and Dr. Christian Drolet, CHU Québec, Dr. Nagib Dahdah, CHU Sainte-Justine and Dr. Andrian Dancea, CUSM.*

Cardiac defects are the most frequently observed malformation at birth. Despite significant advancements in the treatment of cardiac malformation over the past few years, some children will live with the ensuing sequelae and complications their entire lives. Thanks to a bursary from the Foundation of Stars and the close cooperation of all four pediatric cardiology centres in Québec, we are in the process of creating a provincial register of cardiac defects. The data testing phase will begin in the fall of 2018. This databank, once completed, will be of great help to those examining various treatments; it will also help us to better understand how cardiac problems develop as children grow.

### Pro-Omega-3: reduced inflammation and premature modulation

*Project director: Prof. Éric Rousseau, CHU Sherbrooke / Collaborators: Dr. Jean-Charles Pasquier, Dr. Sheela Ramanathan, CHU Sherbrooke and Dr. Emmanuel Bujold, CHU Québec.*

The basic premise of this project is simple: seek to reduce inflammation among pregnant patients with a premature rupture of the membranes, with the goal of delaying the onset of labour that would lead to a premature birth. We thus sought to measure the average time that elapsed between the onset of labour and childbirth in both groups, i.e., the one being treated with MAG-DHA (an Omega-3 derivative and the precursor to resolvins) and the group receiving a placebo (made of sunflower oil). We have thus far submitted applications and received all of the scientific and ethical approvals necessary to begin the project. We are in the process of obtaining a go-ahead from Health Canada for the clinical testing phase.

## CHU QUÉBEC-UNIVERSITÉ LAVAL RESEARCH CENTRE

### PRISMES (rare diseases research and innovation program)

#### Improving our understanding of the molecular problems associated with certain rare diseases

*Project director: Dr. Serge Rivest, CHU Québec / Collaborators: Prof. Bartha Maria Knoppers, CUSM, Dr. Nicolas Chrestian, Dr. Marc-André Dugas, Dr. Baiba Lace, Dr. Rachel Laframboise, Dr. Arnaud Droit and Prof. Jacques Simard, CHU Québec.*

As part of the PRISMES project on the identification of the genetic causes of rare children's diseases, nearly 50 families were accepted for testing since the onset of recruitment at CHUQ-UL in March of 2017. What more, an additional 30 families were selected and will be recruited over the coming months. The rare diseases examined include several types of neurodegenerative, neuromuscular and metabolic diseases, as well as body dysmorphic disorder.

Exome sequencing made it possible to identify the presence of a genetic alteration with a high probability of causing some of the diseases in several families. We consider these findings encouraging, particularly when we consider that all of the patients recruited obtained negative results from genetic testing.

## CENTRE D'EXCELLENCE FONDATION DES ÉTOILES EN OBÉSITÉ INFANTILE

On September 14, 2017, the *Centre d'excellence Fondation des étoiles en obésité infantile* celebrated its official opening at Montréal's Clinique 180, where it also has its offices. This Centre, led by pediatrician and lipidologist Dr. Julie St-Pierre and the first initiative of its kind in Québec, was created to support innovative and collaborative research for identifying sustainable solutions to the childhood obesity epidemic.

Since the opening of the Centre, the team can proudly boast of having:

- ★ Implemented an efficient organizational structure;
- ★ Developed a strategic plan and identified the areas of focus for research into childhood obesity in Québec (this phase will be finalized based on forum conclusions/findings);
- ★ Created partnerships with childhood obesity research scientists;
- ★ Planned and prepared for the first scientific forum on obesity among children and youth (May 31, 2018).

## RESEARCH PROJET CARRIED OUT BY DR. NADA JABADO (CUSM) AND DR. SÉBASTIEN PERREAULT (CHU SAINTE-JUSTINE)

**Clinical test using a targeted treatment (Mekinist/Trametinib) for plexiform tumours and low-grade glioma in children suffering from neurofibromatosis 1 as well as children not afflicted.**

Low-grade glioma account for 25% of the brain cancers in children. The work of several groups around the world, including ours, has illustrated that these tumours are the result of a signalling pathway that acts as a "fertilizer", i.e., which generates cell multiplication while favouring tumour growth. When located in areas that are difficult to access through conventional surgery, these tumours can have severe effects, including loss of vision or other functionalities, depending on the exact site of the tumour. Children in U.S. studies treated with target inhibitors that stop this pathway from functioning properly have shown improvements, as have Québec patients treated as part of a compassionate approach.

The Foundation, with its \$200,000 in funding over a two-year period, is playing a key role in this research. The amount granted has allowed for initiating this important study concerning children who require targeted treatments as well as encouraging cooperation among various pediatric research centres in Québec and Canada. By offering targeted therapeutic options, this study will improve quality of life and make it easier to manage chronic and hard-to-treat tumours. In fact, this study's direct implication with Novartis has led to the undertaking of various high-grade tumour studies in Québec.



# Upcoming projects from the next generation of researchers

The Foundation of Stars has been collaborating with the FRQS (Fonds de recherche du Québec - Santé) to support research projects from the next generation of researchers. To date, over \$1.7 million has been jointly awarded to support the efforts of thirty-seven students.

## 2017-2018 FUNDING RECIPIENTS

**Toriba Bahar** – McGill University Health Centre (MUHC)

The role of B lymphocyte regulator cells in patients allergic to cow's milk and undergoing oral immunotherapy

**Claire Lefebvre** – McGill University Health Centre (MUHC)

Prescribing nephrotoxic medication to children suffering from severe chronic kidney failure

**Sophie Regueiro** – Université de Montréal

The neurodevelopment of babies presenting with macrocephaly

**Marshall Carley** – McGill University Health Centre (MUHC)

Prenatal and postnatal maternal depression and the onset of anxiety problems in children: role of complex genes vs. environmental factors

**Valérie Gagné Ouellet** – CHU Sherbrooke

A study of genetic and epigenetic factors associated with childhood obesity

**Éliane Danis** – Université du Québec à Montréal

Linear thinking among children with an autism spectre disorder: cerebral development and mechanisms

**Marie-Ève Bolduc** – McGill University Health Centre (MUHC)

Brain development and function during the early years in children suffering from a congenital cardiac defect

**David Ogez** – Université de Montréal

Development and pilot test of the Reprendre le contrôle ensemble (Joining forces to regain control) initiative designed to support the parents of children with cancer

**Lara Eid** – Université de Montréal

Changes to the migration of GABAergic interneurons in provocative encephalopathies

# Financial highlights

The previous pages were dedicated to outlining what was in every way a wonderful year. You have thus read about the events, fundraising campaigns and collaborators, partners and others who have helped us support pediatric research. Over the course of the year, a total of \$1,649,538 was remitted to various worthy projects! We can only hope that next year will be even more exciting and provide us with yet more opportunities to support the fight against children's diseases.

## ALLOCATION OF FUNDS EARMARKED FOR PEDIATRIC RESEARCH

Partners	2017-2018	2016-2017	2015-2016	Cumulative at March 31, 2015
Montreal Children's Hospital (MUHC) Pediatric Research Institute	\$392,500			\$28,907,639
CHU Sainte-Justine Pediatric Research Institute	\$392,500			\$28,907,639
Centre hospitalier universitaire de Québec (CHUQ) Pediatric Research Institute <sup>(1)</sup>	\$126,500			\$6,761,856
Centre hospitalier universitaire de Sherbrooke (CHUS) Pediatric Research Institute <sup>(2)</sup>	\$88,500 \$91,172 <sup>(3)</sup>	\$83,256 <sup>(4)</sup>		\$3,075,921
Bursaries for the next generation of researchers (FRQS)	\$251,366	\$221,320	\$178,986	\$58,358
Special projet (brain cancer)	\$200,000			
Child and Youth				\$100,000
Mother-child research, provincial award	\$3,000			
<i>Centre d'excellence Fondation des étoiles en obésité infantile</i>	\$104,000			
<b>TOTAL</b>	<b>\$1,649,538</b>	<b>\$304,576</b>	<b>\$178,986</b>	<b>\$67,811,413</b>

<sup>(1)</sup> Since 1985

<sup>(2)</sup> Since 1999

<sup>(3)</sup> Funds remitted during the 5<sup>th</sup> Encan des vins de Sherbrooke

<sup>(4)</sup> Funds remitted during the 4<sup>th</sup> Encan des vins de Sherbrooke

The fiscal year ended at March 31, 2018 and the Foundation of Stars' financial statements were audited by the firm Gosselin et associés. They are available for consultation upon request.



# Board of Directors, Foundation of Stars team and Governors

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**Sylviane Chatel**  
Development director

**Nathalie Deslauriers**  
Administrative assistant, Corporate events

**Alicia Gradziel**  
Project manager, Communications and events

**Carole Lalande**  
Executive assistant

**Carole McDermott**  
Coordinator, Data management and donor services

**Mireille Vaillant**  
Chief accountant and head of internal audits

# Ambassadors and Masters of ceremonies



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*Étienne Boulay*  
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*Jessica Harnois*  
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(Ambassador and Master of ceremonies)



*Véronique Rivest*  
(Master of ceremonies)



*Mario Tessier*  
(Ambassador)

The unflagging support of each and every one of our volunteers, regional directors, governors, ambassadors and committee members has made it possible for the Foundation to achieve stellar results while shining a bright light on the importance of research.

Thank you to everyone for your time, your efforts and your support. We deeply appreciate it!

# Corporate partners

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## \$35,000 TO \$50,000

Fondation Air Canada

## \$60,000

St-Viateur Bagel



**foundation  
of stars**  
the magic of research

To make a donation, join our group of precious volunteers or receive an English copy of this report, please contact us at:

Pour faire un don, pour joindre les rangs de nos précieux bénévoles ou pour obtenir des exemplaires de ce rapport, prière de communiquer avec nous à :

#### **FOUNDATION OF STARS**


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Montréal, QC H3J 1S6  
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Telephone: 1-800-665-2358  
For Montréal: 514-595-5730  
Fax: 514-595-5745  
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