



Hôpitaux Shriners
pour enfants
Shriners Hospitals
for Children™

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Pediatric Specialty Care

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THE **ORT** **OPEDIK**

Helping Kids Defy the Odds

Making Medical History in Canada... Twice

[Emmanuelle Rondeau] When Dr. Lucie Lessard speaks about her patient Chantell, she glows with pride for many reasons. Perhaps it is because they have realized two important medical firsts. But, beyond that, it is because of the very special trust they share.

Last spring Chantell graduated from high school with Honors after having spent six weeks away from home to undergo her latest major surgery. This fall she is beginning a Bachelors degree with a double major in Arts and Social Work.

This is an account of two incredible journeys as they intersect.

Chantell first came to Dr. Lessard with her mother, Darlene, at the age of two. A Shriner in their home community of Halifax, Nova Scotia, referred Darlene to Shriners Hospitals for Children (SHC) in Montreal. On their first meeting, Dr. Lessard put together a plan that left no doubt in Darlene's mind that she was in the right place.

"I remember Dr. Lessard taking me in her arms before procedures in the operating room. I've always felt safe in her hands"

Chantell was born with a severe form of Treacher Collins syndrome (also known as Franceschetti-Zwahlen-Klein syndrome), which affects 1 in 10,000 babies. It is a rare genetic disorder, an anomaly on chromosome 5, characterized by head, skull and face deformities, including abnormal facial bones, which result in cheek bones with a sunken appearance, abnormal eyelids with missing eyelashes, a prominent nose and a very small retruded jaw and chin. Patients generally have absent, small, or unusually formed ears and, in some cases, defects in the middle ear causing hearing loss and the absence of ear canals. Chantell also had dentition problems and could not eat or chew properly because of her abnormal jaws.

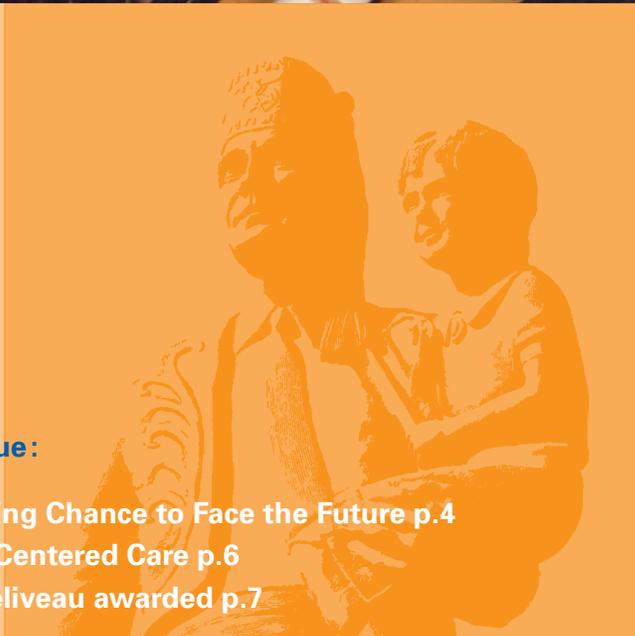
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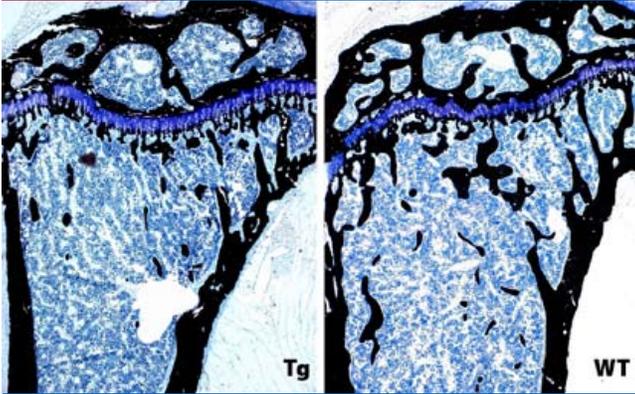
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■ Chantell, 17 years old, on Graduation Day





The images show bones stained using the von Kossa technique, which colors solid bone in black. The reduced amount of black stain in the left panel shows the reduced bone mass in the FIAT transgenic mice that express an increased amount of FIAT. (WT, wild-type; Tg, transgenic).

Significant Advance in Research to Help Bone Formation

[René St-Arnaud Ph.D.] Researchers at SHC-Canada have recently identified a protein that blocks the expression of genes in bone cells (osteoblasts) to regulate their activity. They have named this molecule FIAT, for Factor Inhibiting ATF4-mediated Transcription.

“Using various techniques, we have shown that more FIAT blocks osteoblast activity, while less FIAT increases it. FIAT may thus represent an interesting drug development target since even a small reduction in its activity would presumably significantly increase bone formation”, explains Dr. St-Arnaud.

SHC-Canada has protected the FIAT intellectual property and holds the patent. The FIAT technology now needs to be translated into drug development. The development of a screening test is a key step in this process. We will use three parallel strategies to develop a medium- to high-throughput test to screen for small molecule compounds that could modulate the activity of FIAT. Since less FIAT leads to increased activity of bone-forming osteoblasts, the identification of a small molecule that could block FIAT could be beneficial as a drug for the treatment of fractures or osteoporosis, for example. |

Administrator’s Message

Improving the health and quality of life of children treated at the Shriners Hospital for Children is our priority. Innovation is one of our basic values, the ultimate objective being to help young patients overcome the impossible. We know that innovation plays a major role in increasing knowledge and improving care. There are a number of different definitions of innovation, but they all share a common point: innovation in health requires an investment in basic and clinical research and collaboration among researchers and specialists everywhere.

This issue features the incredible story of Chantell and Dr. Lucie Lessard. This report highlights Canadian firsts in medi-

cine, the cooperation of different specialists within the Shriners Hospital for Children network and a moving account of complicity and trust between patient and doctor. Also, Dr. René St-Arnaud tells us about a new patent, showing that at SHC-Canada, basic research is a major source of innovation.

Of course, innovation takes place within a very human framework, where the well-being of children and their families is what’s most important. Steeve Désaulniers, a volunteer at the Shriners Hospital for Children since February 2008, agreed to share his story with us, one that began almost 30 years ago.

In closing, Rick Hansen, president of the Man in Motion Foundation, chose the title “The Promise of Innovation: Better Health and Quality Life” as the title for an article published in 2006 at InnovationCanada.ca, a title that reflects our values and commitment to offering children the best care available.

Enjoy your reading.


Céline Doray

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We want to hear from you! If you would like to ask us a question or suggest a topic for an article in an upcoming edition of the Orthopedik, please contact us at gfouellet@shrinenet.org or 514-282-6990.

The Orthopedik can also be downloaded from www.shrinershospitals.org/Hospitals/Canada.

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The Shriners Hospital: the Experience of a Lifetime

Steeve referees a tight game



[**Steeve Désaulniers**] My name is Steeve Désaulniers, and I am 32 years old. I have been a volunteer at Montreal's Shriners Hospital for Children since February 2008, and I am also a former patient. People volunteer to give of themselves and help others. But I don't believe that people are volunteers out of a sense of altruism. I am firmly convinced that volunteers have deep motivations that push them to donate their time. For my part, I wanted to use my interpersonal skills and give back a little of what I received when I was a patient.

My story with the Shriners Hospital begins in 1979. I was two and a half, and my parents had just learned that I had cerebral palsy. At the time, there were very few places that offered care for people with disabilities. My father heard about the Shriners Hospital through a friend, and he convinced my mother to present my case to an orthopaedist at the Shriners. At my first appointment, I was diagnosed with two

I grew up with the Shriners, both physically and as a person. I owe my understanding of the physical and psychological pain of parents and patients to the Shriners. I owe the fact that I am bilingual today to the Shriners. And I owe the fact that I can walk to the Shriners.

What I remember above all is that the Shriners Hospital was not like a regular hospital. The walls weren't green, the nurses didn't wear uniforms and there were recreational activities, even outings. I was even able to catch up on my school year without too much trouble because teachers and volunteers allowed me to continue my curriculum.

dislocated hips. It was to be the beginning of a series of six operations that went on until 1993. Throughout the years, my family and I were supported by the hospital staff. I remember wrenching separations when my parents returned home to Shawinigan, while I had to stay at the hospital. I also remember the pain I endured during the operations. Every time, there was a nurse there to ease my pain and comfort me.

In short, everything possible was done so that my stays at the hospital would be as pleasant as possible. I also made a few friends during those years, among volunteers, staff and patients. I would like to salute and thank Joe, who was my teacher during my last operation, and also Yvonne Rock, who was one of the first nurses who took care of me through all the years I was a patient.

Today, I've come back to the Shriners as a volunteer. I remember the years when I was a patient, and I try to pass on the Shriners spirit to the children I meet. I share my joie de vivre with them, and I listen to them in moments of joy and pain. I also talk a great deal with the parents of patients. I like to find out how they heard about the Shriners and how their child's situation has improved since they came to the hospital. It's a very enriching experience.

Thank you Shriners. |



Steeve, 9 years old.

There is no cure, only treatment options

[Emmanuelle Rondeau] “Treacher Collins is not degenerative; however it causes major facial malformations which involve functional and social integration problems. When there are breathing issues or hearing loss, they must be dealt with early on so that the child can develop and integrate normally”, comments Dr. Lessard, Chief of Plastic Surgery at the McGill University Health Centre and the main Plastic Surgeon at SHC – Canada.

Rebuilding Chantell’s face

According to Dr. Lessard, the surgical plan for Treacher Collins syndrome must be tailored to the patient’s specific deformities, taking into account facial growth and psychosocial impact. The surgical correction can be separated into procedures for the upper face and those for the jaws and lower face.

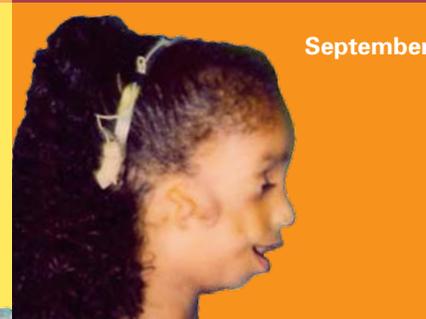
At first the cheeks

For the upper face, surgery is recommended as early as the age of 5 or 6 years old. This was the case for Chantell who underwent craniofacial surgery when she was 6 years old. In order to perform the reconstruction and correction of the orbits and eyelids, Dr. Lessard used bone from Chantell’s own skull as grafting her own bone gave her the best chance of success. After harvesting the bone with the neurosurgery team, Dr. Lessard prepared the access to the orbit and the cheeks from under the scalp to avoid visible scars on Chantell’s face. The 6-hour surgery was performed at The Montreal Children’s Hospital because of the availability of neurosurgery and pediatric intensive care expertise. This type of craniofacial reconstruction requires all of the surgeons’ skills, intellect and knowledge. Dr. Lessard was laying the groundwork for the surgeries to come. “When she came out of surgery I was shocked. She had 75 staples in her head,” remembers Darlene, “but when the swelling went down, we were both so happy with the results!”

Then the ears

Chantell was born without ears or ear canals and more importantly, without the ability to hear. In 1996, when Chantell was 7 years old, Dr. Lessard proposed to give Chantell a Bone Anchored Hearing Aid (BAHA). This technology conducts sound through the bone of the skull to the inner ear and the cochlea. It can give patients nearly normal hearing. The surgery is conducted in two steps. First the anchor is inserted in the skull and under the skin. Then, when the skin around the anchor heals, the device is can be installed and used.

Chantell was Dr. Lessard’s first patient to receive a BAHA and the first child of that age in eastern Canada and the US to receive a BAHA at that time. Since then, with the support of the Shriners and the Daughters of the Nile, Dr. Lessard has been able to complete 70 more BAHAs.



September



June



April



April



March

"When Dr. Lessard first installed the BAHA and I could hear clearly, they asked me what I wanted to do. I called my grandfather on the phone back home!" recalls Chantell.

"I discuss things with Dr. Lessard, I can tell her what I think and how I feel, and if I don't want something, she respects that. What's amazing though, is that we are usually on the same wavelength," says Chantell.

Over the years, Chantell has also had the option of having her ears redone. She looked at the best possible prosthetic ears on the market and the option of Dr. Lessard building ears from rib bones, but Chantell did not want more surgery.

Then the smile

Due to the malformation of her jaws, Chantell's teeth could barely touch. Working diligently with Dr. Paul Bourque, her orthodontist at home in Halifax, she has had braces to straighten her teeth for nine years.

And finally the lower jaw

When it came to finding the best option to improve Chantell's jaw-bones, give her the ability to chew more normally and to sleep without apnea, Dr. Lessard turned to a trusted colleague and mentor. Dr. Leonard Kaban is Chief of Service at the Department of Oral and Maxillofacial Surgery, Massachusetts General Hospital (MGH) and Professor at Harvard University.

Dr. Kaban's plan was to use the technique called distraction osteogenesis to lengthen and grow new bone but with a new unique curvilinear device. SHC Canada has longstanding expertise in this technique for long bones such as leg bones, but for facial bones, the movement is complex due to the presence of teeth and the shape of the jaw. The curvilinear distraction device and the software program to calculate the location of the device on the jaw and the path of distraction were developed by Dr. Kaban's team at MGH. Having obtained the CT-Scan material he needed from Dr. Lessard, Dr. Kaban's team in Boston planned the surgery and built 3D models of what Chantell's face would look like once the procedure would be completed.

With the support of the Philae Shriners combined with Montreal and Boston Shriners Hospitals, Chantell went to SHC- Boston to see Dr. Kaban for this major surgery last February. Dr. Lessard went as well to observe the new technique.

Dr. Kaban's team has been using this surgical device for selected patients during the past 6 years and Chantell was Dr. Kaban's first Canadian patient to receive it. Once implanted on her lower jaw and under her skin, Chantell had to turn the external part of the device 1mm each day. A few months later, when her jaw reached 33 mm, the turnings were then completed. However, the device could only be removed later to allow proper consolidation of the bone.

Chantell's journey in life is just beginning. She has not been alone. She has had the strong and unwavering support of her family and friends. But along the way, she has found a guide and most fervent supporter in Dr. Lucie Lessard. |

1993

1995

2002

2005

2008



X-ray taken in February 2008

Family-Centered Care Makes a Difference



The selection of books and other information resources available in our Family Resource Library and from clinicians reflects our conviction that care includes addressing the needs of the patient's entire family and goes beyond looking at just the illness or treatment to consider how these impact family life.

One of the objectives of our interdisciplinary staff is to help patients find independence as they reach adulthood by sharing our expertise and providing guidance and support. Our Transition program was developed for this purpose. Starting at the age of 14, patients begin to take on increased health related responsibilities and learn important life skills such as financial management, job searching and finding transportation.

Ensuring that We Provide Care that Fits

At SHC-Canada, it is essential for us to monitor how we are doing and to ensure that patients and families' voices are heard. In order to do so, all families are asked to comment on their experiences by completing a satisfaction survey. Their feedback is an important source of information in our program planning and evaluation.

These are just a few examples of how patients and their families participate actively in their care. We are always on the lookout for new ways to involve patients and families in order to provide care that truly fits their needs. To us, family-centered care is what makes the difference, and is the only way to go. |

Samuel, 6 years old, and his mother Jennifer, meet with the interdisciplinary team during an osteogenesis imperfecta conference. Left to right: Francis Glorieux, M.D., Ph.D, Kathleen Montpetit, Occupational Therapist, Frank Rauch, M.D., Ph.D., Aileen Coronel, Nurse, Trudy Wong, Social Worker, Marie Lalonde, Dietitian-Nutritionist, Joanne Ruck Physiotherapist, Jennifer Milner, mother and François Fassier, M.D.

[Susan Takahashi] At "Family-centered care" is a concept that is grounded in the idea that families play a central role in the health and well-being of individuals of all ages. To provide optimal care, it is then essential to put the needs of patients and families first and to help empower them to take charge of their own health. The main principles that guide family-centered care are:

- Respect for patients and families, including their beliefs, values and choices.
- Sharing of complete, accurate information in a useful and ongoing manner.
- Collaboration between health care providers and families with the recognition that families are the experts in the needs of their children.
- Providing or facilitating emotional, social, and developmental support as needed.
- Encouraging active participation of family members in the health care team.

What This Means to Patients and Families

In clinical nutrition, family-centered care means that the meal experience for each child is adapted to provide healthy food choices while taking into account the age of the child, his likes and dislikes, familiar foods, and personalized nutrition counseling when needed.

In nursing, with each intervention family-centered care is applied in unique and creative ways by each nurse. It means assessing for unmet family needs, providing individualized care, and facilitating access to health care resources.

Another example of family-centered care is the interdisciplinary approach of team conferences that are held regularly for patients with complex care needs, such as osteogenesis imperfecta or spina bifida. These meetings bring together the team of health care providers with the family to discuss priorities and goals and to establish a plan.

Hurray for the Montreal Canadiens Children's Foundation!



[Guylaine Ouellet] Mr. Jean Béliveau, Patron of the Montreal Canadiens Children's Foundation was at Shriners Hospitals for Children (SHC) - Canada on June 19th to unveil a new ultrasound machine. This new piece of equipment was purchased thanks to a donation from the Canadiens Children's Foundation.

Mr. Béliveau had the opportunity to try out the equipment as he performed an ultrasound of his wrist with medical imaging technologist Pina Napoletano. The new piece of equipment replaces an outdated ultrasound and provides clearer and more precise images vital to proper diagnosis, even with young patients who

have complex health problems. Shriners Hospitals for Children also publicly recognized the outstanding generosity of the Canadiens Children's Foundation. The Benefactor Award was presented to Mr. Jean Béliveau in recognition of the continued support of the Canadiens Children's Foundation. |



From left to right: Ill. Sir Norton Paish P.P. - Chairman 2008 Montreal Shrine Bowl, Céline Doray - Hospital Administrator, Noble Robert Sheppard, Constantine Anagnostaras - Fund Raising Event Chairman, James Bruce Thornton (seated) - Artist, John Patrick Dore - Executive Member of the Fund Raising Event Committee, Noble Gregory Williams and Noble Steve Gallant.

Raffle Raises \$10,000

[Guylaine Ouellet] Following the donation of a painting by artist James Bruce Thornton, Restaurant Poulet Doré owner Constantine Anagnostaras in conjunction with many friends and local Karnak Shriners organized a raffle to raise funds for the SHC-Canada. In just six weeks, more than 5000 raffle tickets were sold at the restaurant in Deux Montagnes and shopping malls in the surrounding area, raising more than \$10,000 for the Hospital. |



Send in the Clowns

[Guylaine Ouellet] For three days in July 2008, members of the North East Shrine Clowns Association (NESCA) took a special road trip to the three Shriners hospitals in the northeast region: Springfield, Boston and Montreal. This year, NESCA made special donations in support of

their Shrine Clowns. They arrived in each Hospital with a pediatric utility transporter. This is a versatile wheelchair that allows for pediatric patients to be transported from place to place while enjoying safety and comfort. The maker of the transporter, Steelcraft Inc., donated a pediatric IV stand with each transporter. |

Nobles David Newcomb and Ernest Pearlstein, a.k.a. Do-No and Rollo, performed in the universal language of magic, laughter and smiles for the patients at SHC-Canada. Here they posed with Administrator Céline Doray.



Shriners Leadership

[Emmanuelle Rondeau] The 191 Shrine Temples are governed by the Imperial Council, which is composed of Representatives. The Representatives include all past and present Imperial Officers, Emeritus Representatives (who have served 15 years or more), and Representatives elected from each Temple. These representatives meet once a year to make policy decisions and enact legislation regarding both the fraternity and the Hospitals. The Representatives also elect the Imperial Divan which consists of 13 officers plus an Imperial Chaplain. The Chief Executive Officer

of the Shrine of North America is the Imperial Potentate, who is elected for one year.

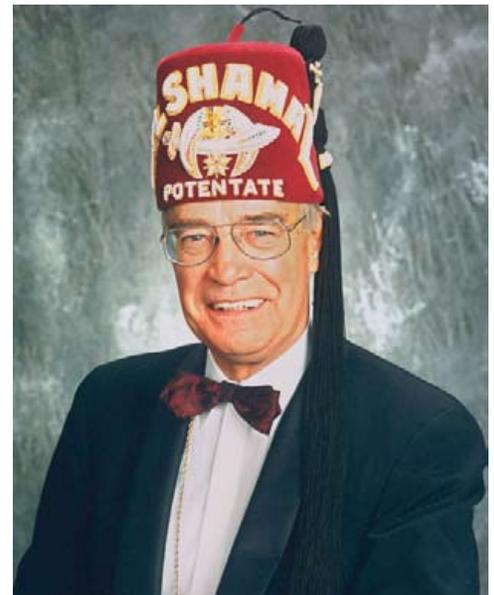
The 134th Imperial Council Session was held in St. Louis June 29-July 3. During the 2008 Imperial Council Session, Douglas E. Maxwell of Chesterfield, Mo., was elected Imperial Potentate of Shriners International. He is serving his eleventh term as a member of the Board of Directors for the Shriners fraternity, as well as Chairman of the Board of Directors for Shriners Hospitals.

Three nobles were recognized for their exceptional lifetime achievements during the Imperial Council Session. The Imperial Potentate's Award of Merit, created in 1997, can be given to as many as five deserving Shriners each year. There is no greater honor in the Shriners fraternity. This year nobles Robert "Bob" Burr, Pete Goltra and Bruce Hogle were recognized. |

Special Congratulations to Bruce Hogle

Illustrious Sir Bruce Hogle was in the first class of Edmonton's Highlands Masonic Lodge and received 50-year pins, jewels and certificates in 2003 from both the Grand Lodges of Alberta and British Columbia. He served as public relations director when Al Shamal Shriners was chartered in 1986 and has served on the Imperial Public Relations Committee.

Hogle helped to usher in 55 new members while serving as Potentate in 1994. He also established Operation Red Coat/Red Fez, a program that partnered Shriners with Alberta's Royal Canadian Mounted Police to promote the services of Shriners Hospitals in rural, isolated areas of the province. |



From left: Ellis Lindsay, Potentate; Noble Grant Whittaker, President Brockville District Shrine Club (making the donation); Noble Michael Pierson; Richard Abrams, Past Potentate/ Hospital Board Member (acknowledged the gift on behalf of the SHC -Canada)

Tunis Shriners

[Richard Abrams] Tunis Shriners from Brockville District Shrine Club, Ontario, present a donation for the amount of \$82,500 to Potentate Ellis Lindsay at the Spring Ceremonial. This sizeable gift will provide new state of the art sterilization equipment in the Operating Room at the Canadian Hospital in Montreal. |

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