



Hôpitaux Shriners
pour enfants
Shriners Hospitals
for Children™

Canada
Pediatric Specialty Care

Volume 4, number 3 | **AUTUMN 2009**

THE **ORTHOPEDIK**

Helping Kids Defy the Odds



■ Taylor, 18 months old [page 3]

Women across Canada raise \$1 million for Shriners Hospitals for Children – Canada

[Emmanuelle Rondeau] On Saturday July 18, Shriners Hospitals for Children (SHC) - Canada received a cumulative \$1 million donation from the Daughters of the Nile (DON). The donation was presented by Mrs. Vesta Marshall on behalf of the 2900 members from the 12 Canadian Temples of the Daughters of the Nile (DON). These funds were raised over the last 7 years through a variety of community based events across the country.

“This donation represents many hours of devoted time and talents on the part of the Canadian Daughters of the Nile to raise this amount of money. These ladies are passionate about our work and show much love for our Order and I thank them for their continued devotion”, said Mrs. Marshall during the official ceremony held at SHC-Canada. During the Supreme Session in London, Ontario, on June 11th, 2009 the Daughters of the Nile had crowned Vesta Marshall as Supreme Queen for the North American Daughters of the Nile charitable organization. She is the 8th Canadian to receive this honor.

This is the 3rd million raised and presented to SHC-Canada by the DON, a first in the Shriners Hospitals system. The Canadian membership of the Daughters of the Nile has made such an exceptional contribution twice before. Past Supreme Queen Rhona Kerr of Oronto Temple No. 69 in Toronto (Ontario) presented the first million in 1995 and Nancelyn Ross of Sphinx Temple No.116 in Winnipeg (Manitoba) the second million in 2002. [continued on page 6]

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Dr. Francis Glorieux Receives Significant Appointment



Francis Glorieux, OC, M.D., Ph.D., Director of Research and Head of the Genetics Unit at Shriners Hospitals for Children (SHC) - Canada has been appointed to a three-year term as chairman of the Medical Advisory Council of the Osteogenesis Imperfecta (OI) Foundation (USA). As chairman, he is also a member of the foundation's board of directors.

Dr. Glorieux's work in research related to OI is known worldwide. He pioneered the use of bisphosphonates to treat severe forms of the disease. Treatments based on the research conducted at SHC - Canada are now used to help children everywhere. Dr. Glorieux's development

of these new, more effective treatments for OI brought worldwide attention to the research efforts of Shriners Hospitals for Children. In addition, his team continues to work towards a better understanding of the genetic and metabolic causes of OI, to further improve the treatment of this complex condition. Dr. Glorieux also contributed to the development of a treatment of several forms of rickets.

His pioneering work brought him countless awards and accolades such as the Frederic C. Bartter Award from the American Society for Bone and Mineral Research (ASBMR), the IBMS Elsevier Award in recognition of a distinguished career as scholar, educator and leader in the field of bone and mineral research and the Jonas Salk Award from The Ontario March of Dimes for outstanding achievement in developing an effective treatment for osteogenesis imperfecta. He has received a Queen Elizabeth II Scientist Award from the Medical Research Council of Canada, and in 2004 was made an Officer of the Order of Canada, the country's highest honor for lifetime achievement. In 2005, Dr. Glorieux he received an Award of Excellence from then-Imperial Potentate Raoul Frelve in special recognition of invaluable service to the patients at the Canadian Shriners Hospital. |

Administrator's Message

Excellence and innovation go hand in hand at Shriners Hospitals for Children (SHC). Our mission is three fold: provide the highest quality of care to children, provide for the education of physicians and other health care professionals and conduct research to discover new knowledge that improves the quality of care and quality of life of children.

In 1973, after completing his post-doctoral studies at McGill University, Dr. Glorieux a pediatrician with a Ph.D. (Magna cum Laude) in Human Genetics was recruited as the first Director of research at SHC-Canada. As a physician

and a scientist, Dr. Glorieux fostered the bench to bedside approach where clinicians and basic scientists work side by side, constantly linking research effort to the care and well being of our patients. Recently, Dr. Glorieux was appointed to the prestigious Osteogenesis Imperfecta Foundation, a well deserved recognition.

At SHC-Canada, we recognize that excellence and innovation translate to the bedside thanks to the support of Shriners and the generosity of affiliated groups such as the Daughters of the Nile. In this issue, you will meet two of our grown up

patients, Taylor and Katie. As well, we provide the answer to one of the most frequently asked questions - how do children get referred to Shriners Hospitals for Children - Canada?

Thank you for supporting the best possible care.

Céline Doray

The Orthopedik is a quarterly publication of the **Shriners Hospitals for Children – Canada**
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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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Playing a Leading Role

[Taylor Long] I was born missing my fibula bone in both legs which meant my feet did not develop properly. At home in Halifax, my mom was told that I would probably never walk. Shortly after my birth, a friend of the family and Shriner Bryce Gibson, recommended Shriners Hospital in Montreal and helped my mother with the application.

My first trip was when I just a month old. My mother tells me that the moment she stepped foot in the hospital she felt relief. She had a hard time deciding how to go about handling my birth defect. There were two options, amputate both feet, or try to save one of the feet. The hospital team encouraged my mom to speak to other families that had gone through both operations. A family whose child's feet were saved had been faced with a series of painful surgeries. Another family, whose young child had had the amputation, recommended the solution; their child was running around and playing completely unaware of his amputation. This justified my mother's decision to have both of my feet amputated.

The experiences I can best remember are my last two surgeries to correct the growth of my right leg. Five

Taylor, 18 months old.



years ago, I was scheduled to have a surgery and I can safely say that this was the first time that all of the information exchanged during my clinic exam actually sunk in. What calmed me down was the openness of the doctors about the operation. I was interested in learning about what they were going to do, why, and with what results; and all of this was provided to me.

The second surgery was about three years later. I remember just walking into the operating room and sitting down, feeling completely calm. I respect the work of the doctors because I know their level of professionalism and experience and I can only trust them. They have done extremely wonderful work for me, I can walk, I can skate, I can swim and most importantly I can live a normal life.

There's one great story that's a wonderful example of all of the work that local Shriners do behind the scenes. When I got my first pair of artificial limbs, after both amputations, it was difficult to walk. The one thing that would really help me was the kid sized grocery carts that were available at the grocery store. My mom mentioned this to our Shriner in Halifax and, within a few hours, a kid sized grocery cart from IGA arrived at the house. My mom used to fill it with cans of food and I would run around the house pushing it. That's how I learned how to walk and balance properly on my prostheses.

Now, at the age of eighteen, I'm beginning to look back at everything that has made me who I am today. Shriners Hospital truly played a principal role in helping to raise me. This fall I am starting a Bachelor of Music at Dalhousie University, studying voice. This takes an extreme amount of confidence in terms of performing. The team helped me develop confidence and helped to support me in any way we needed. I can't imagine how different my life would have been without the impact of each staff member who helped me overcome my disability. Your work is incredible. |



Taylor performing on stage in May 2009.

How Do Children Get Referred to Shriners Hospitals for Children – Canada?

One of the most frequently asked questions the staff gets at SHC-Canada is how do children get referred or accepted for care at the Hospital. It is actually a relatively simple procedure, and the decision is mainly based on the child's medical needs and the Hospital's capacity to offer care that the child requires.

About the Hospital

Located in Montreal, SHC-Canada is a bilingual, short term, acute care centre providing elective **pediatric orthopaedic** health care. The role of the Shriners Hospitals is to promote health and to provide care and rehabilitation to children with orthopedic and neuromuscular problems in a family-centered environment without financial obligation to patients or families. Based on the needs of the child, the hospital will provide specialized equipment -prosthesis-orthosis that would not be covered by the Medicare system in Canada.

Eligibility

Children up to age 18 are eligible for **care** at Shriners Hospitals for Children if, in the opinion of our physicians, there is a reasonable possibility they can benefit from the specialized services available. Acceptance is based mainly on a child's medical needs.

Second opinions

Families can also apply to obtain a second opinion at SHC-Canada. It is an opportunity to get an objective opinion on a condition and care option from specialized professionals. Most often, when the care plan suggested by the referring physician is appropriate, our physician will reassure

the family and encourage them to continue care with this physician. There may be different treatment options for the same condition and if our physician believes that the hospital can offer more complete or different care than what the child may be able to obtain close to home, then the referring

physician and the family may determine that continued care at the SHC in Montreal is appropriate. It is highly recommended that the child's home physician be involved in the second opinion for better flow of information.

Exposing a few myths:

- Does a **child** have to be related to a Shriner to receive care?
- Does the Hospital have an emergency room or walk in clinic?
- Is the Shriners Hospital private and therefore do parents pay for treatment?

The answer to all of the above questions is no. Let's look in greater detail at the eligibility criteria and application process.



Application for orthopaedic care

A child can be referred by a physician, a **Shriner** or apply for care directly. For a child living in the province of Quebec, a referral from a physician is preferred. For those who reside in the rest of Canada or abroad, the process always begins with the application form.

To obtain an application form, a family can simply download it in English or French by visiting www.shrinershospitals.org.

Forms can also be obtained from any **Shriner** or Shrine Club; by writing

to Shriners Hospitals for Children, P.O. Box 31356, Tampa, FL 33631; or by calling the Shriners Hospitals (800) 237-5055. (In Canada, call (800) 361-7256 or (514) 842-4464.)

All sections of the application forms must be completed clearly. Simple items such as a valid second phone number are essential. It is also important that the referring Shriner or Shrine Temple or Club information be included. Once completed, the form should be sent to SHC-Canada.

All forms should be accompanied by applicable medical **records** or a medical summary prepared by the referring physician. This helps the hospital to determine if we are able to treat the child's condition and which specialist should see the child.

If uncertain if the Hospital can help a child, please call prior to filling out the form. The diagnosis is important. Children are seen at the hospital by appointment, surgery is elective and scheduled ahead of time.

Application process

Once an **application** or physician referral (Quebec residents) is received, a **nurse** care coordinator reviews the request and contacts the family for details of the condition and obtains any missing information and details to complete the file. At this stage, if the diagnosis is not one that falls within the orthopedics mandate of the hospital, the nurse will inform the family.

The role of the **nurse** is also to **triage** the applications to establish an appropriate wait time for the application process and ensuing wait time for a clinic appointment. From January to August 31st 2009, the hospital has received an average of 242 new patients' referrals per month. Some conditions must be treated rapidly (such as a new born with club feet) in order to avoid deterioration and therefore require that the child be seen sooner.

Applications from outside of Quebec and complex referrals are brought to the chief of staff for medical review. If

it is deemed on purely medical criteria (the child is receiving appropriate care at home or there is no orthopaedic component to the condition) that the hospital cannot help the child, a letter stating the reason for the refusal is sent to the referring physician (Quebec patients) or to the family and if applicable to the Shrine Temple for out of provinces applications.

If the child can be helped, then it will be determined whether the child should be seen in a clinic in Montreal or at one of the our Outreach **Clinics** for assessment such as Bathurst (New Brunswick), Sudbury (Ontario), Gander (Newfoundland and Labrador) and Halifax (Nova Scotia), or in our **Satellite Clinic** in Winnipeg (Manitoba) or by Telemedicine. For out of province applications, the family and referring Shriner will receive an approval letter which confirms the appointment location, date and time with the name of the physician.

For international cases, the chief of staff will bring the file to the Board of Governors for approval. As well, children coming from abroad must have a host family and have the ability or support required to pay for their travel to Montreal, including travel insurance and lodging expenses once here. Only the expenses related to the orthopaedic care approved in the application are covered by the hospital, for example, clinic visits, admission and treatment costs in the SHC hospital therefore appendicitis or other medical emergency situation are not covered by the hospital. A special meeting with the host family to outline these responsibilities takes place prior to final acceptance of an application.

Once an **application** for treatment is received, the hospital keeps detailed records of the application process. Therefore families or the referring Shriner can contact the hospital to track the application's progress.

Daughters of the Nile Philanthropy Recognized

[Continued from p1] The ceremony involved Shriners Headquarters Leadership officially recognizing the outstanding contribution and achievement of the DON with an official plaque presentation. “The Daughters of the Nile are a model of will and perseverance to ensure the health and well being of children today and tomorrow” declared Deputy Imperial Potentate George A. Mitchell. “This contribution is as tremendous as the size of their collective hearts”, added Past Imperial Potentate Ralph W. Semb. The donation was recognized through the Shriners Hospitals for Children Philanthropic Society which honors major living donors and deceased benefactors who give contributions and/or bequests in excess of \$250,000. The Daughters of the Nile were honored with the placement of their third Gold Plaque for gifts of \$1 million or more located in the philanthropic centre wall near the entrance of the hospital.



Quebec singing sensation and Shriners patient Jérémie Gabriel gave a touching testimonial and then performed two songs for the more than 200 representatives present. He is able to hear and sing thanks to bone anchored hearing aids.

“Thanks to this generous donation, young patients treated at Shriners Hospital and their families will benefit from a variety of much needed services” declared Jacques Chagnon, Member of the National Assembly for Westmount-Saint-Louis.

“I am extremely pleased by this tremendous gesture of generosity offered to the Montreal Shriners Hospital, whose presence in our city has always been a source of pride,” said Jocelyn Ann Campbell, Associate Councilor for families and social and community development at the City of Montreal.

Daughters of the Nile funding has allowed, among other projects, the implementation of innovative programs such as the Bone Anchored Hearing Aid (BAHA) program led by Dr. Lucie Lessard.



Imperial Sirs George A. Mitchell and Ralph W. Semb present the philanthropic society plaque to Supreme Queen Vesta Marshall)

Thanks to this technology and her expertise, since 1995 more than 70 profoundly deaf children have gained in their capacity to hear. The DON also provides vital funding for the purchase of hundreds of prostheses and orthoses annually.

“In addition to this extraordinary donation, the DON contribute to improve the quality of care and quality of life of the children and their families by providing arts and crafts material and games for our Child Life Department” explained Gary Morrison, Chairman of the Board of Governors, SHC-Canada. |



As part of Chairman Gary Morrison's congratulatory remarks, patients and parents each carried the digits that compose \$1 000 000. Queen Vesta, Hospital Administrator Céline Doray along with Chief of staff Dr. François Fassier and Westmount-St-Louis MNA Jacques Chagnon joined in for the photo.

When the Caterpillar Takes Flight

[Kathryn Cashin] My name is Kathryn Cashin, though my friends and family call me Katie. I am 21 years old and I have a physical disability that has been my blessing from birth. To this day my disability is mystery to physicians and scientists alike. Despite that fact, Shriners Hospital in Montreal took me under their wing when I was only 7 months old and have taken care of me ever since. Sadly my turn is now coming to an end.

Even though I did not want this day to ever come, it has, and I too have to leave. Forever this place has been my HOME, forever this place was my safe place; forever no more. Now I am becoming an adult, I will no longer be able to call this place home...

And though I have been dreading the arrival of this day for so long, I chose to make something positive of it. Therefore, I decided that instead of gifts, I wanted money (and lots of it) for my 21st birthday, and that all of my money would go to the Shriners as a token of my gratitude for everything that they have done for me, my family, and all the other families. I was successful in raising \$2,000 and donated \$1,000 to the Occupational Therapy Department and \$1,000 to the Mazol Temple in St. John's (Newfoundland) for their Travel Assistance Fund. As well I collected pennies and loose coin for the Shriner's wives Penny Sneaker Fund. I am very happy with the amounts I raised this year, though next year will be bigger and better! I am hoping to do something similar for my birthday each year - it's the least I can do for everything that Shriners have done for me!

My life is just one example of what is possible with the help of the Shriners; they have done tremendous work with regards to helping



Katie, 8 years old, with David Connelly, a former patient.

"How does one become a [flutterby]?" she asked pensively. "You must want to fly so much that you are willing to give up being a caterpillar." – Trina Paulus

me with transition into what I know will be a beautiful life.

I still have a few years left of school (I'm studying Social Work), but one day, I would like to work with children and youth who have disabilities, as well perhaps open some sort of youth centre / community centre. Just because I have a disability does not mean that I don't get to live a fulfilling life.

I want to take this opportunity to THANK Shriners Hospital in Montreal for who I am today. The staff and Shriners have changed my life forever. If it weren't for their enduring support I wouldn't be here today! |



From left to right: Joanne Ruck Head of Physiotherapy and Kathleen Montpetit, Head of Occupational Therapy at SHC-Canada accept Katie's donation.



Increasing Service and Savings! – Karnak Shriners

[Bill Pitts] Karnak Shriners are dedicated to raising funds for the Canadian hospital and are also very involved in the transportation of patients who come to this facility.

For many years the Motor Corps of Karnak provided transportation services but as the patient load increased, drivers became more difficult to find. In 1981, the Greeters unit took over picking up patients and families from the airport and dropping them off at the hospital.



Volunteer driver Leo Sculnik awaits the arrival of his next patient transport.

In 1996, Karnak Temple's Transportation Fund was being stretched beyond its means because of the great number of taxi's and transportation costs. It was then decided to form the Patient Transportation Service (P.T.S.). This group was made up of many Shriners using their own vehicles and paying their own expenses. But this was still not enough to

answer all the calls. Therefore with the help of Luxor (Saint John, New Brunswick), Mazol (St. John's, Newfoundland), Mt. Sinai Shriners (Montpelier, Vermont), Philae (Halifax, Nova Scotia) and Tunis (Ottawa, Ontario) Shriners, Karnak leased a van and has been operating it since 1996. There is a volunteer driver every day from Monday to Friday and several alternate volunteer drivers as needed. Approximately 2 years ago, the P.T.S. and Greeters units were combined. Overall, thanks to the volunteer hours put in by our drivers and greeters, we are saving a considerable amount for all the Temples who send patients to Montreal. In fact, for the year 2008 alone, we have now saved the Temples \$47,742. Since 1996, total savings to the Shrine Temples is approximately \$750,000.00. |

Oriental Shriners – Troy (New York)



Earlier this year, 30 ladies from the New York - Ontario Association held a quilting bee over a weekend to benefit Shriners Hospitals for Children. During the Hospital Seminar held May 22, Lady Kathleen (on the left) and Oriental Shrine Potentate William Fink Jr. presented some quilts to hospital Administrator Céline Doray and Board of Governors Secretary, Frederick Clarke.

Shriners Hospitals for Children – Canada Safety Tips

[Kathryn Fournier] Safety Tips is a new feature following the article *An ounce of prevention is worth a pound of cure* published in the summer 2009 edition of the Orthopedik. The Tips stem from SHC-Canada staff and are brought to you by the 17 Temples that support the hospital.

Backpacks

Help your child avoid lower back pain and injury this school year – follow these simple tips. The backpack should:

- weigh less than 15 % of the child's body weight
- have two wide, padded straps that go over the shoulders (make sure your child uses both straps at all times)
- have a padded waist or chest belt
- not be wider than your child's body

Heavier items should be placed to the back of the backpack, next to the body. To pick up the backpack properly, your child should bend at the knees and grab the pack with both hands to lift it to his shoulders.

School Grounds – Jacket and Sweatshirt Drawstrings

Drawstrings may look trendy, but they can easily get caught on surrounding objects. Remove drawstrings on hoods or around the neck of clothing. If drawstrings at the waist or bottom of an article of clothing are looking a tad long, trim them down to no longer than 3 inches. |

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