



Hôpitaux Shriners
pour enfants
Shriners Hospitals
for Children™

Canada
Pediatric Specialty Care

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THE ORTOPEDIK



Helping Kids Defy the Odds



■ Benjamin, 8 years old [page 3]

First Shriners Hospitals for Children Satellite Clinic Opens in Winnipeg, Canada

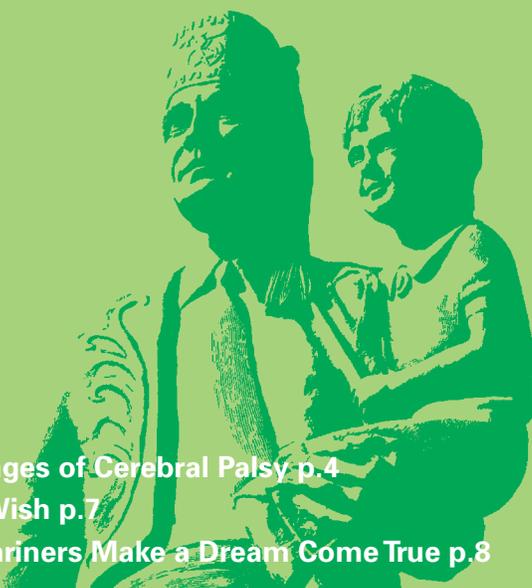
[**Emmanuelle Rondeau**] On January 30, 2009 Shriners Hospitals for Children (SHC) – Canada, the Rehabilitation Centre for Children of Winnipeg, the Winnipeg Regional Health Authority (WRHA) and the Khartum Shriners announced the official opening of the first Shriners Hospitals Satellite Orthopaedic Clinic. The purpose of the Clinic is to evaluate children referred from Manitoba, Saskatchewan, Nunavut, or Northwestern Ontario, to Shriners Hospitals for Children in order to determine whether they can be treated in Winnipeg or whether they need to be at SHC-Canada in Montreal for specialized orthopaedic care. The new Shriners clinic is one of 14 clinics available at the Winnipeg Rehabilitation Centre for Children to children with special needs.

In the first year, the Clinic will function as a pilot project operating a half day per month approximately 10 times per year. The Clinic will operate under the auspices of SHC but will be staffed by orthopaedic surgeons who are credentialed in both the Shriners and the Winnipeg Regional Health Authority's systems.

According to Dr. Susan Thompson, "The primary purpose of the Clinic will be assessment and diagnosis." If children assessed at the Clinic require further treatment that can be managed locally (i.e., surgery, orthotics, physiotherapy, etc.) they will be referred from the Clinic back into the Winnipeg health care system. If a child requires transfer to Montreal for orthopaedic surgery, this will be arranged and administered through the Clinic, in coordination with SHC – Canada. After a child has had surgery in Montreal, the Clinic will provide physician follow-up such as post surgery evaluation, cast removal and arranging care and rehabilitation with any local resources required. [continued on page 2]

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From left to right: Khartum Potentate Don Thomson, Cheryl Susinski, Executive Director of the RCC, Céline Doray, Administrator of SHC – Canada, patient Brandon and his mother Michelle, Dr. Brian Postl, President and CEO of the WRHA, Dr. John McPherson and Dr. Susan Thompson, orthopaedic surgeons and Noble Craig Houston, Khartum Shrine Hospital Chairman.

[continued from page 1] All costs related to the Clinic will be covered by SHC-Canada. Physicians will bill Manitoba Health on a fee for service basis for services rendered.

Khartum Shriners of Winnipeg will provide support for this Clinic in the form of fundraising, volunteers and publicity. Referrals to the Clinic will originate through the usual Shriners Hospitals' process. |

"This Satellite Clinic represents transportation cost savings for the Shriners Centres. More importantly, we will be able to help more patients from this area, as well as reduce stress, travel and time away from home, school and work for these families," explained Céline Doray, Administrator at SHC-Canada.

Administrator's Message

SHC – Canada reaches out to the communities it serves thanks to the advancement of technology, innovative care models and our partnerships with different health care systems and Shrine centers in the communities we serve. Our optimal goals remain to provide the best quality of care to children and to facilitate care for the families we serve.

In 1996, the Hospital held its first Outreach Clinic in Sudbury (Ontario). There are now clinics in Gander (Newfoundland), Bathurst (New Brunswick) and Halifax (Nova Scotia) and of course Sudbury. During these clinics a nurse and a physician from Montreal travel to a partnering institution

to assess new patients and those requiring follow-ups. In 2004, the Hospital implemented Telemedicine which allows our professionals to work with other care givers in remote areas through a real time two way video link. More recently, the Hospital opened the first Satellite Clinic of the Shriners Hospitals system in Winnipeg (Manitoba). This Clinic will be lead by Dr. Susan Thompson of Winnipeg who studied at McGill and has been credentialed by SHC. Patients who need to will travel to Montreal for care and obtain the evaluation and follow-up they need at the Satellite Clinic.

Many of the children referred to SHC – Canada have chronic conditions and

can benefit from these different health care delivery models. Such is the case for children who live with cerebral palsy. At SHC – Canada, we are one of the leading Hospitals in Canada to offer the full range of treatment options from an interdisciplinary care team to improve the quality of life of children with this complex condition. I invite you to find out more about this increasingly common condition.

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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Learning to Walk is Not Always as Easy as 1, 2, 3

[**Emmanuelle Rondeau**] Benjamin was born prematurely and fought to survive for the first two months of his life in the care of the neonatal intensive care unit of the Jewish General Hospital. Unfortunately, his twin did not survive.

At 9 months, Benjamin was diagnosed with cerebral palsy. Benjamin immediately started physiotherapy twice a week and occupational therapy once a week. Luisa and Carl, Benjamin's parents, faced the challenge of dealing with what seemed like an endless series of tests and follow-ups. As well, 17 months after his birth Benjamin's baby sister Jemma came into the world.



Benjamin with his family.

"We were first time parents and as a baby, you could miss that he was not hitting some milestones, but as a toddler it was quite apparent. As he got older, we could see that things were not right" remembers Luisa, Benjamin's mom. Benjamin could only drag himself on the floor like a snake. With the help of physiotherapy he eventually managed to crawl on his elbows and knees when he should have been walking.

Their pediatrician referred them to Dr. Jean-Pierre Farmer and SHC's multi-disciplinary spasticity clinic to evaluate whether he was a candidate for a selective dorsal rhizotomy surgery (the dorsal nerves that cause the improper movements are identified and severed). After another battery of tests, the team confirmed that Benjamin could benefit from this surgery, performed at the Montreal Children's Hospital by neurosurgeon Dr. Jean-Pierre Farmer and his team.

Prior to the rhizotomy surgery Benjamin was not able to walk or stand without a walker. He had trouble controlling

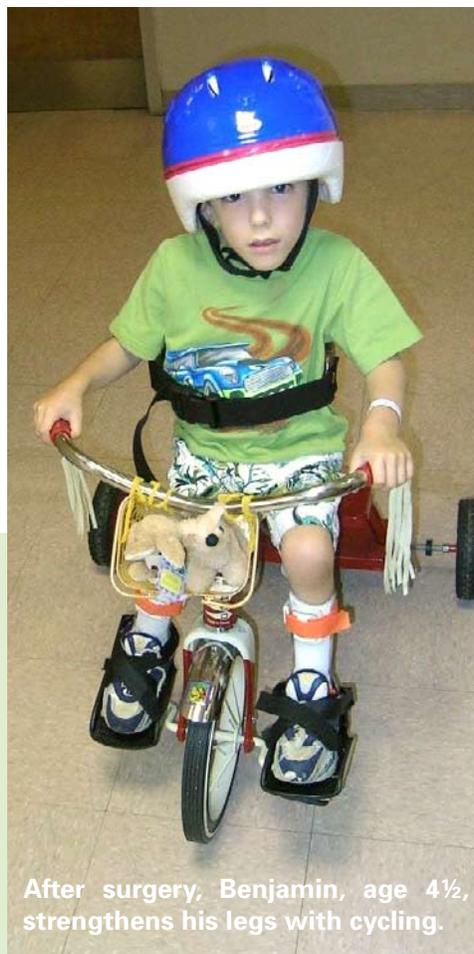
his movements and his legs would buckle underneath him causing him to collapse.

After the rhizotomy surgery Benjamin began intensive physiotherapy for two months at the Shriners Hospital and then three times a week as an outpatient. "After six months, he took his first few steps on his own and this opened up a whole new world for him and for us!" recalls Luisa.

"During physiotherapy and occupational therapy Benjamin had to learn so many things that we take for granted ... how to hold a pencil and what to do if he lost his balance. Dr. Farmer was always good about warning us of the challenges ahead so that we would not get discouraged, and he was always right on the mark" says Luisa.

Benjamin has continued to improve dramatically over the last two years. Supplementary Botox and casting treatments helped to release some of the remaining stiffness in his right leg. Today Benjamin walks and runs without assistance and is able to follow his friends on the playground.

Benjamin is a lively boy who loves school. His favorite subject is recess. He has a great sense of humor, and adores cars, building things and the outdoors. I



After surgery, Benjamin, age 4½, strengthens his legs with cycling.

"The surprising thing about being at the Shriners for two months is that Benjamin never asked to go home and he never complained about physiotherapy. The therapists made it like a game for him. Throughout, the support from the Shriners Hospital has been amazing and a blessing," state Luisa and Carl.

Multidisciplinary Care is the Answer to a Complex Condition

[**Jean-Pierre Farmer, MD**] Cerebral palsy is a group of chronic but non-progressive disorders that affect body movements and muscle coordination, caused by lesions during brain development of the fetus or newborn.

The degree of cerebral palsy varies from minimal to extremely severe incapacity. The many manifestations of cerebral palsy can be categorized in five main types: spasticity, athetosis, ataxia, rigidity and dystonia. Spasticity affects 50 to 60% of children diagnosed with cerebral palsy, causes jerky movements and may lead to posture and coordination problems.

Adapted treatments

Over the past twenty years, different treatments have been developed for different degrees of impairment and allow children and their families to have a better quality of life and more motricity. These treatment modes can be complementary.

- **Therapies:** Occupational therapy, physiotherapy and speech therapy help children to learn how to use their limbs and to develop motor skills.

- **Orthopedic surgery:** Orthopedists Dr. Thierry Benaroch, Dr. Marie-Andrée Cantin and Dr. Chantal Janelle perform corrective surgery on the bones and tendons to allow better use of a limb, reduce its rigidity and reduce the pain associated with spasticity.

- **Botox:** The botox injections administered by Dr. Thierry Benaroch, Dr. Marie-Andrée Cantin and Dr. Chantal Janelle are used for children with a shallow impairment located in one or two muscles, because the quantity of the drug used for each treatment is limited. Botox treatment must be repeated regularly and is usually combined with physiotherapy to stretch the affected muscles and tendons.



Nicholas, 11 years old, was born prematurely at 24 weeks. His right hand and his right leg are affected by spasticity. For the first few years he wore orthoses, but when he was 4 years old he was referred to the Shriners for botox treatments. With the first treatments, his parents saw a great improvement in his walking and the use of his hand. He repeats his botox treatments every six months and does daily physiotherapy at school. Today he participates in karate and swimming.

- **Selective rhizotomy:** Since 1991, Dr. Jean-Pierre Farmer, neurosurgeon, has completed more than 225 selective dorsal rhizotomies. Children who have the potential to walk are those who can benefit from this surgery. This treatment involves all the muscles of the lower limbs, however, improvements are often felt in the upper limbs. During surgery, nerves are stimulated; response is recorded and monitored by pediatric neurologist Dr. Chantal Poulin and her team in order to allow selective elimination of spastic movements. Once the spasticity is eliminated, the muscles can be strengthened and the child can support himself and walk. The radiclectomy is followed by intensive physiotherapy and occupational therapy at the Hospital.



Supported by his physiotherapist Corinne, Benjamin learns to walk after his selective dorsal rhizotomy.



SHC's multidisciplinary spasticity team with Benjamin.

Specialized care provided by a multi-disciplinary team

Since cerebral palsy affects children at various levels, at SHC-Canada, the child and the family are supported by a multidisciplinary team, in addition to the orthopedists and the medical and surgical teams.

Nursing: coordination of care

Nurses Sarah Mondoux and Christina Oesterreich help families manage appointments, obtain prescriptions and prepare for surgery. They also act as resource people when the families need additional medical assistance.

Physiotherapy: working towards rehabilitation

According to Joanne Ruck, Head of the Physiotherapy Department at SHC- Canada, the role of physiotherapists is to teach the child to move without the constraints of spasticity. We want to help the child progress from one functional level to a higher level: for example, if he gets around by crawling prior to surgery, we will work with him to use a walker.

Occupational therapy: learning activities of daily living

Occupational therapist Marie-Élaine Lafrance helps children become independent in activities of daily living, refine their fine motor skills and adapt to the special needs and challenges of using adaptations, splints and wheelchairs when needed.

Social work: support in the community

Social worker Catherine Dubé helps children and families deal with the impact of cerebral palsy on the emotional, relationship and financial levels and on family and social dynamics. She helps families find local and community resources and build a support network, if applicable.

Child Life: play therapy and support in school

Educators in the Child Life and School Services play an important role for children who are hospitalized for surgery. They normalize the hospital experience through play and help the child avoid falling behind in school, thus easing the return home. |

• **Baclofen pump:** Before 1999, there weren't many solutions to relieve children affected by spasticity too wide spread for botox and whose muscle tone was too weak for radicellectomy. These children are often confined to a wheelchair and usually suffer from secondary conditions, such as hip dislocations and scolioses, because of their great spasticity. A pump diffusing

a medication called baclofen is installed under the skin with a long tube along the spinal column. The baclofen is diffused continuously, allowing overall of spasticity, a decrease in discomfort, improvement of the child's quality of life and facilitation of the child's hygiene. The children also seem to show gains in speech and the use of their upper body.

Research plays a major role in the evaluation and development of treatments

According to Kathleen Montpetit, Coordinator of the Clinical Outcomes Research Program at with SHC – Canada, there are currently four clinical research projects aimed at improving care for children living with cerebral palsy.

- Selective dorsal rhizotomy: ten year follow-up
- Vibration platform: to improve functional mobility in children with limited walking ability
- The "CAT" Computer Adaptive Testing Platform: using artificial intelligence to measure changes after treatments
- Hand function in children with hemiplegia (one side of the body affected): comparing surgery, botox and therapy.

More on these research projects in the next issue of the newsletter.

What is ethics?

Ethics considers questions relating to values, proper conduct, and moral judgment. To do so, different approaches to ethics emphasize virtues, duties, intentions, and consequences. Jonsen, Siegler and Winslade define clinical ethics as a practical discipline that provides a structured approach for identifying, analyzing and resolving ethical issues in health care and clinical medicine.

[Matthew Hunt] The clinical ethics service is an important resource to support the provision of excellent patient care at SHC – Canada. The clinical ethics service consists of a Clinical Ethics Committee (CEC) and an on-call clinical ethics consultant.

The clinical ethics service has a threefold mandate:

- 1) provide consultation regarding ethically complex situations in patient care;
- 2) develop educational activities related to ethics;
- 3) review or develop hospital policies from an ethics perspective. Research protocols are reviewed by a university-based Research Ethics Board.

The goal of the clinical ethics service is to support, promote and contribute to the provision of compassionate, fair and respectful care for all patients.



Matthew Hunt, Clinical ethics consultant.

Examples of How the Mandate Areas are Addressed

Consultation:

The ethics consultant and CEC are available to be consulted by patients, families, hospital staff, volunteers or students in relation to ethically complex clinical situations. Examples of the types of issues considered include consent to care, capacity to make decisions, and confidentiality. Key aims of a clinical ethics consultation are to help identify and clarify ethical aspects of the situation, draw attention to contextual features and the role of values and beliefs, and assist in seeking to resolve the situation. The role of the clinical ethics consultant and CEC are consultative only. Treatment decisions are ultimately the responsibility of the treatment team, patient and/or the patient's substitute decision-maker(s).

Educational Activities:

A number of educational activities have been organized to promote discussion of ethics topics. Most recently, the CEC hosted a seminar entitled, "The role of hope in our practice: Accompanying families and patients living with chronic disability." Other ethics education sessions have addressed confidentiality of personal information, and the processes of ethics deliberation in interdisciplinary teams. Another forum for discussing ethical aspects of clinical care is the monthly Psychosocial Rounds organized by the Social Services department and the psychologist.

Policies:

The third mandate area relates to the review and development of policies. The CEC may be given the task of developing a particular policy that has an important ethics dimension. A recent example was the development of a Confidentiality Agreement Form for hospital volunteers.

As we provide ethics training for staff, participate in reviewing and developing hospital policies, and remain available for clinical consultation, the clinical ethics service seeks to promote engagement with the ethics of our practice, and support activities to foster optimal care for patients. |

Donors in Action



Khadidja with the Child Life team. From left to right (standing): Dominic Gendron, Child Life Specialist, Maria Caruso, Teacher, Marie Donato, Teacher (sitting) Angie Gugliotti, Child Life Specialist and Khadidja Chougui.

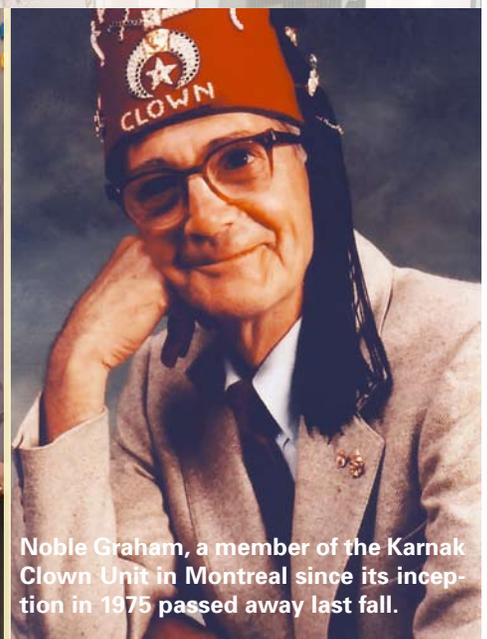
A Donation for 2009

[**Guylaine Ouellet**] Khadidja Chougui is a grade 12 student at a school on Montreal's South Shore. As part of the International Education Program, Khadidja had to complete a personal project. She chose to produce a calendar of drawings by patients from Shriners Hospital for Children. The funds raised from the sale of the calendar were donated to the Hospital. After several months of work to collect the drawings and necessary permissions as well as sponsorships to help cover the costs of the project, she reached her objective and raised \$1120 for Shriners Hospital for Children. The Hospital has a special place in her heart because she has been a patient since the age of three. Khadidja has osteogenesis imperfecta, better known as brittle bone disease. In choosing this project, she hoped to help other children with this genetic condition benefit from the best care possible. |

Honouring a Clown's Wishes

[**Stephen Roberts**] Members of the Karnak Clown Unit presented a donation in memory of one of their brother's, Noble Hugh Graham, to Hospital Administrator Céline Doray, thereby fulfilling his wishes. Noble Hugh's clown activities date back to the days when the circus was at held in the Montreal Forum.

He was a very active clown until his health would no longer let him pursue his passion. He bequeathed the sum of \$10,000 to be donated by his Unit on his behalf to the Shriners Hospital Research Department. |



Noble Graham, a member of the Karnak Clown Unit in Montreal since its inception in 1975 passed away last fall.



Good news for the Shriners in Western Canada – Khartum Shrine

[Craig Houston] The Nobles and Ladies of Khartum Shriners, whose jurisdiction covers the entire province of Manitoba and a part of Northwest Ontario from the Manitoba border to a point 140 miles east of Thunder Bay, Ontario, are extremely pleased that the Satellite Clinic in Winnipeg has now opened. I am sure that WAWA Shriners in Saskatchewan feel the same way, as this clinic will assist in the reduction of transportation costs to both our Shrine Centres as well as time spent away from home by the various families.

The role of Khartum will be to ensure that all patients attending the clinic are contacted and arrangements are made for transportation, accommodation and



Photo: CP

Ill. Sir Don Thomson, Potentate and Noble Craig Houston, Hospital Chairman both from Khartum Shrine during the Press Conference on January 30th 2009.

meals. Khartum Nobles and Ladies will meet and greet patients and families while attending the clinic, making their visit as comfortable and stressless as possible.

This Satellite Clinic has been in the works as far back as 1996, and only through the sustained efforts of Dr. François Fassier, Chief of Staff, Gary Morrison, Chairman of the Board of Governors, SHC- Canada, and the writer, especially over the past two years, has it materialized. Nevertheless, there is still a lot to be accomplished. People kept telling us that the Satellite Clinic would never fly - well it has - and as Winston Churchill said "Give us the tools and we'll finish the job". We are still interested in extending this type of Satellite clinic to other Shriners Hospitals for Children that our patients use, and we will be pursuing this as well. I look upon this as a Shriners Hospitals Clinic and the more we can do universally for the children who need our help, the better. |

Who Are Those Guys with the Curly Toed Shoes? – Rameses Shrine

[Les Vass] My interest was piqued at a very early age as I was watching the annual Santa Claus parades with my dad. Who are those guys with the colourful costumes and those curly toed shoes, and what is that awful sound I hear? I was later informed and corrected that was the sweet sound of the musette.

My dad explained to me that those men were Shriners and that they help children. From that moment on something took hold in my mind and continued to grow because I knew that one day I wanted to be among those men. The opportunity presented itself in my early twenties to join the

Shrine, specifically Rameses Temple in Toronto, Ontario. After doing so, I immediately joined the Shrine Club nearest to me which was the Shriners' Club of Hamilton. I have now been a Shriner for 23 years and am a member of our Klown Unit. The fun we have is unbelievable. Some of the events we participate in are parades, parties, hospital visits and circuses. We have also initiated our own fundraisers such as the annual trike-a-thon, car rally, Robbie Burns dinner and the Kans 4 Kids program.

It is truly a privilege to be a member of the world's greatest phil-

anthropy and an honour to be able to help our children. I have been blessed with many "pay days" since becoming an active member of our Klown Unit. The warm hugs, silly laughs, wide smiles and the sparkle in their big bright eyes is more rewarding than anything money can buy. For those of you who have not taken the opportunity to visit one of our truly remarkable hospitals, I truly encourage you to do so. I can only tell you that you have no idea what you are missing. |



Les "Flat Foot" Vass

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