



SUMMER ■ 2011
ROGER'S HOUSE

Chronicles

5TH ANNIVERSARY

Upcoming Events

- ◆ August 30, 6:30-8:30 PM: Volunteer Info Session. Please register with Lise Beauchemin, Coordinator of Volunteer Services at (613) 523-6300, Ex. 605.
- ◆ October 4-November 15, 6:00-9:00 PM: Volunteer & Staff Palliative Care Training Sessions.

Admission Notices

The Nursing staff at Roger's House have a few requests of families using respite services

(See Admission Notices P.4)

A MESSAGE FROM NEW BOARD CHAIR - ERIN CROWE

It is hard to believe that Roger's House has just celebrated its fifth birthday. We have seen so many changes since the house opened, but throughout this time there has been a steadfast focus on ensuring quality and compassionate care for the children, youth and families who have been guests of Roger's House.

Roger's House would not be where it is today without the unwavering support of the Sens Foundation, the Province of Ontario's Ministry of Health and Ministry of Child and Youth Services, and of course CHEO.

Over the past year, there have been many accomplishments made by the Roger's House team, including new funding from the Sens Foundation to serve Quebec patients, a second bereavement group program, renovations to the nursing work stations, a positive licensing review from MCYS, and continued profile for the successes achieved by Roger's House at national and international conferences through presentations by RH staff and in peer reviewed journals. Thank you to the staff & physicians for all your hard work!

I feel honoured to be the Chair of the Board of such an incredible establishment. Rest assured that the children, youth and families of Roger's House will continue to be our focus and we are committed to providing them with the care and support they require. Thank you to all our children, youth and families for making Roger's House such a special place and for giving us the confidence to care for you and your children.

Mike Fisher - Roger's House door is always open for you!

In a special reception at Roger's House on July 13, Mike Fisher officially said good-bye to his five-year role as the Honorary Chair of Roger's House. Senators forward Chris Neil and his wife, Caitlin, were named as the new Honorary Chairs of the hospice.

"There are lots of people to thank here. I would like first to thank Roger's House staff members, those wonderful people who always smile whenever I came... ' Mike said in an emotional speech to the crowd. Mike also thanked community donors for their support to Roger's House and the Ottawa Senators for giving him the opportunity to work with Roger's House.

On behalf of Roger's House staff members, Executive Director Lloyd Cowin expressed his sincere thanks to Mike for his dedication and support for Roger's House kids and their families in his role as Roger's House Ambassador over the past 5 years. This was the first time Mike returned to Ottawa since February. To Mike, it was special to be back at Roger's House, a place he has been closely attached to over the years. Even though Mike is no longer the honorary chair, he will always support Roger's House from his new home in Nashville.

As the new co-honorary chairs, Chris and Caitlin Neil will help promote awareness and fundraising for the hospice. "We're honoured to be associated with Rogers House. This facility is such an important part of our community. Caitlin and I are excited to help out in any way we can" said Neil.

As part of the ceremony, Mike was presented with several farewell gifts, including a book of pictures of Mike on the ice and of his work in the community, including - of course - Roger's House. The children of Roger's House gave Mike a framed, hand-decorated tie, which Mike said he would proudly put up on the wall at home.



Max Keeping:

"Don't make me look like the most important, I am just a member of the team!"



In this edition, we are honoured to introduce the profile of Max Keeping - the ex-CTV news anchor widely known to Ottawa residents for his active role in many charitable drives. Together with 3 other Roger's House Honorary Board Members - Dave Ready, Roy Mlakar and Garry Cardiff - Max Keeping has significantly advanced and supported Roger's House from its inception.

Max's connection to Roger's House has come from two main sources. From a business standpoint, Max is the Chair of the Ottawa Senators Foundation so Max's support came as a result of the support from the Sens Foundation. Beyond the business part, there was also a special reason. Four years ago, one of Max's young friends, a 16 year old hockey player, was diagnosed with cancer. As his health deteriorated rapidly, he went to Roger's House. That was when Max saw for himself how Roger's House worked, especially during his friend's last 2 weeks. Roger's House provided a beloved environment for Max's friend and his family. Max saw the dignity with which his friend died and the wonderful way that the family was given support at Roger's House.

It might not be a coincidence that Roger's House philosophy of 'Living life to the fullest' is how Max has lived his life. Max always says to people he knows: 'Live well today' - a sentence he borrows from Jean Vanier, known in the world as the 'male' Mother Teresa. To Max, Roger's House is more than palliative care. It's holistic palliative care. Looking back, Max is happy and proud of what Roger's House has done over the past 5 years. Roger's House provides such a wonderful break for parents of kids who have enormous need for care and support. While Roger's House founders had to look at Canuck Place at the very beginning to borrow the idea, now other cities are looking at Roger's House to duplicate its model. To Max, there are good reasons to say that Roger's House is now 'a key component' of the hospital campus. And in the capital city where children's care is the first priority, children's palliative care deserves even more attention. That is the reason why, to Max, we need to tell a better story about Roger's House.

Since his retirement from CTV, Max has been acting as the station's Community Ambassador. "I retired from the news, but I don't retire from the community. I am much busier now, but I don't have stress. I am having great fun with what I am doing", Max said. Everything Max is currently doing is community-related. By the end of this December, Max will have made 600 public appearances on behalf of various organizations and charities. "I've never felt better and happier than I do now. I am getting to my 25th birthday next year (laugh). I never tell people that I am 70. My body may look like I'm 170 years old but my mind is just 25."

8th Annual Scotiabank Walk, Roll & Run Raised \$192,000

The Sens Foundation, on June 19th, raised \$192,000 for Roger's House at the eighth annual Walk, Roll & Run presented by the Ottawa Citizen. The event, which took place at Scotiabank Place, saw more than 800 participants.

This year's event featured Roger's Dream Team, an innovative fundraising campaign that encouraged local businesses to sponsor one of 10 courageous children currently receiving care from Roger's House, and Roger's All-Stars, a group of families who have come together to support fundraising efforts and celebrate the lives of their deceased children. Both campaigns were a success. Once again, title sponsor Scotiabank encouraged its staff to participate and collect pledges for the event. The bank raised more than \$62,000 from more than 10 branches across the region.

In tribute to Roger Neilson, this year's event asked children to draw a colourful tie for the event T-shirt. The contest was a huge success with more than 100 submissions. The winning design belonged to Madeleine Visser, 10-year old Kanata resident. Congratulations Madeleine!!!

Walk, Roll & Run is the signature fundraising event for Roger's House - the Sens Foundation's charity of choice. The event honours the memory of Roger Neilson, a former Senators assistant coach who died in 2003 after a lengthy battle with cancer.

On May 15th Roger's House hosted a family party to celebrate the 5th anniversary of Roger's House's opening and the launch of the Walk, Roll and Run Dream Team members. The Dream Team children and youth were proudly introduced and raised the roof with their cheers for Roger's House. We also heard heartfelt words from Jim Hoyt, a bereaved parent from the Roger's House All-Star Team.



Past and present families spent time reconnecting with each other. The children all enjoyed doing spring crafts and everyone used their amazing creative abilities to make delicious ice cream sundaes. A highlight was an interactive and highly spirited sing along with Roger's House volunteer and amazing entertainer, Paddy Stewart. Siblings enjoy being part of the special events and see the house as a welcoming place to be.

Parents often speak of the opportunity to chat with each other and share their stories and insights in a relaxed setting as one of the benefits of attending family parties. Our next family party will be at Halloween when we hope to see many families again.

A Message from Executive Director — Lloyd Cowin



I would first like to thank Ian Hendry, our outgoing Board Chair. Ian has been on the board since our inception and has been Chair of our Governance Committee, Vice Chair of the Board and has just completed his term as Chair. Thankfully, we will retain Ian's leadership and influence as he will remain on the Board as Past Chair this coming year.

It is my pleasure to welcome Erin Crowe as our new Board Chair. Erin has also been on the Board since we began in 2006. She has been Chair of our Finance and Audit Committee and Vice Chair of the Board, so she is very familiar with the needs and goals of Roger's House.

I would also like to thank the Ontario Ministry of Health and Long Term Care, the Ontario Ministry of Children and Youth Services and the Sens Foundation for their ongoing financial support. Their partnership and support are vital to our ongoing pursuit of excellence in service provision, education, research and advocacy in pediatric palliative care.

The Ontario government provides 70% of the operating costs for Roger's House. These funds are designated for nursing and personal support. The Sens Foundation contributes annual operating funds equaling 30% of the Roger's House budget, a capital budget for house repairs, improvements, major equipment, etc, and funding for an endowment fund to address the long-term needs for Roger's House. Without our funding partners, Roger's House would not exist.

On behalf of the children and families we serve, we thank our funding partners for their ongoing support!

Volunteers - 5 years of selfless contributions to Roger's House

- Lise Beauchemin, Coordinator of Volunteer Services-

Recently, I attended a conference for Managers of Volunteer Services. At my Round-table, I was asked: "What do volunteers do in a pediatric palliative care hospice?" Without hesitation I responded: "What don't they do?" Let me count the ways they contribute:

All the quilts and children's patterned pillowcases on the beds - sewn with love by volunteers. The knitted slippers, cardigans, mitts and toques - knitted by volunteers. Bereavement cards and memory boxes - artistically created by volunteers. The household seasonal-themed decor and gardening - volunteers!

Changing light bulbs and repairing broken furniture - maintenance volunteers extraordinaire. Home-baked cookies and casseroles - prepared by volunteers. Precious family moments captured on film - volunteer photographers.

Parties, celebrations and fundraising events - the helping hands of special events volunteers. Public speakers and tour facilitators - the speaker's bureau volunteers. Friendly and warm greetings for every visitor and delivery person - reception volunteers. Assisting the nurses in the provision of care and supervision of the children and youth - volunteers!

Guiding the mission and vision of Roger's House, and helping us stay on track - the Volunteer Members of the Board of Directors. Also, family members who access the Roger's House services donate their time to the Family Advisory committee. Volunteers are integral members of our care team, sharing their strengths, talents, skills, human warmth and caring.

To all these valuable individuals, we are very grateful!!!



Liberal MPPs visit Roger's House

On April 8th, we were honoured to welcome four Liberal Members of Provincial Parliament for a tour of Roger's House.

The MPPs also met with some families that use our services. Bob Chiarelli from the Ottawa West-Nepean riding, Madeleine Meilleur from the Ottawa-Vanier riding, Phil McNeely from the Ottawa-Orleans riding and Yasir Naqvi from the Ottawa Centre riding were all touched to hear the families' stories. They were deeply moved by the care that Roger's House provides to our families.

We are proud and fortunate parents of Osayd Abdali who was with us for a very short life of six and half years. Osayd, our little angel, made his way to heaven on January 8th, 2011 at Roger's House. We miss him so much but are relieved that he is free from all his sufferings. Fortunately, due to Roger's House we were able to spend the most difficult time of Osayd's journey in peace surrounded by eyes that were crying with us, hands which were ready to wipe our tears and words that gave us strength in the most excruciating painful moment of any parent's life.

A couple of months after Osayd's death, we joined the Bereavement Group at Roger's House. We were not sure how we were going to cope after losing Osayd. Visiting Roger's House, meeting with the social worker and other staff and joining Bereavement Group provided us peace and also helped us in grieving. Even though grieving the loss of a child is a never-ending process, the group provided us a safe environment where we could share our feelings, thoughts and emotions. It gave us comfort and helped finding our 'new normal' by listening and sharing with other similar parents.

Roger's House means the world to us. Where else on this earth, will we find a place where nurses not only take care of your child but also are always ready to prepare tea and coffee for you? We are glad there is and will always be a home for Osayd called Roger's House. As Osayd's parents, we will never be able to find the words to thank enough everyone involved with Roger's House. If Osayd could speak, he would have said to Roger's House:

*A day might come when you've freed me all of the pain
and I am running all around carrying the ideals of love to espouse,
but at present for all the pampering I got here,
let me thank you for bringing me to Roger's House.*

*This place is like a heaven on the earth
Love spread all around here has no limits, no magnitude,
Apart from my crying and smiling.
Please accept this as a token of gratitude.*

Spotlight on a Volunteer - Josée Robillard

Josée has volunteered at Roger's House for over a year and brings a wealth of life experience, talent and creativity to the House. She began as a Family Support Volunteer, responsible for caring for the children and visiting families.



However, once Josée's creativity and artistic abilities came to light, her role expanded to include facilitating Mandala Workshops for both the parents in the Palliative Care Family Support Group and the Bereavement Support Group.

The word 'mandala' means 'sacred circle' in Sanskrit, the ancient language of India. Creating a mandala is a therapeutic and symbolic journey through self-expression and does not require any artistic skill or experience. The workshop invites individuals to access their own inner wisdom and explore thoughts and feelings in a constructive, non-threatening manner.

Josée also visited the Bereavement Group as a guest speaker, where she was able to draw on her own journey through grief to support other bereaved parents with their healing journey. We are grateful for Josée's generous spirit, warmth and caring with the children and families and her many talents and ideas. She is a valued member of the Roger's House team.

*Thank you to Isabelle Piché, our Volunteer
Translator for translating the Newsletter from English to French!*

1. If your child is diapered, please bring an adequate supply of diapers and disposable wipes. Roger's House does not have access to a commercial laundry like other institutions.
 2. Please bring an adequate supply of clothing for your child's stay so laundering is not necessary. Due to workload, nursing & PSW staff are not always able to do laundry for each of the children.
 3. Please label all toiletry items (shampoos, soaps, creams) with your child's name or initials. Staff will place toiletry items in a box labeled with your child's name but single items can easily be misplaced.
- Thank you in advance for your cooperation!*

Have you heard about a safe place where you can seek quick help and support from palliative care specialists on issues related to death and dying? The Canadian Virtual Hospice is just the one. This website provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators. It also includes space for palliative care communities to share information and network as well as to disseminate the latest advances in palliative care. For more information, please visit the Canadian Virtual Hospice at: www.virtualhospice.ca

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