



WINTER ■ 2011

ROGER'S HOUSE

Chronicles



Wishing you the miracle of hope, the joy of sharing, the comfort of friendship, and the blessing of peace during the holiday season. And throughout the year.

From the Board of Directors, Staff & Volunteers of Roger's House



Message from the Board

The mission for our team at Roger's House is to provide the best respite and end of life care to children and youth facing life limiting illness. We are continuously working to improve our care through research and continuing education by and for our dedicated group of professionals and volunteers at Roger's House.

Recently the staff of Roger's House played a key role in the 2010 Canadian Hospice Palliative Conference held in Ottawa. Lloyd Cowin, our Executive Director, chaired a session workshop on effective governance. Marion Rattray, our Manager, led a team presenting a paper on an interdisciplinary approach to palliative care. She was able to clearly show how the Roger's House team approach improves the quality of care. Other papers presented by Roger's House authors highlighted perinatal hospice, feeding and hydration at end of life, measuring nursing workload, volunteer satisfaction, and the value of a family support group. Board member, Ruth Hartanto, led a workshop concerning the importance that families play in establishing a good plan of care. As you can see our staff and board members are actively engaged in promoting education and research not only in Ottawa but at National and International Conferences. In doing so, we will continue to offer the best possible level of care.

Roger's House continues to be an active and vibrant home. My continued thanks to all of our supporters, our staff, the Ontario government and the Ottawa Senators Foundation for their role in making it all happen.



Ian Hendry,
Chair, Roger's House



Children's Wish Foundation & Roger's House Working Together!



Jane Pendang is a 3-year-old who arrived in Canada in May of 2009. Jane had previously been a healthy, happy toddler, living with her Mom, big sister and maternal grandparents in the Philippines when she became very sick, resulting in severe brain damage and a tracheotomy. A decision was made for the family to immigrate to Canada, where Jane's father, Carlo, was already settled and working to support his family.

The family says that the move to Canada was crucial to ensure Jane received the best care possible. They were connected to CHEO, Roger's House and CCAC nursing support, which made a significant difference to the quality of Jane's life. However, an ongoing sadness remained, because they were so far from Jane's grandparents in the Philippines. Jane's parents could see how fragile their daughter's health was and worried her grandparents would never get to see her before she died.

The family was introduced to the Children's Wish Foundation. Although Jane could not verbally communicate her wishes, the foundation asked for the family and physician caring for the child to verify their belief that this wish would benefit Jane. The wheels were set in motion and this past summer, Jane's grandparents arrived in Ottawa for an incredible holiday with their family, fully paid for by the Wish Foundation. Jane's grandparents have been able to spend time with Jane, take in tourist sights such as the Thousand Islands, and provide emotional support to Jane's parents and sister. The family would like to thank the Children's Wish Foundation for their incredible generosity and making a dream come true for all of them. It would not have been possible without the Wish Foundation.

Other children who are visitors to Roger's House have also received wishes, such as trips to Disney World, Snoezelen Rooms or entertainment centers for the child at home. The Wish Foundation is open to ideas and creative suggestions from families, so don't hesitate to reach out to them or a member of the Roger's House team for more information!

If you would like more information, please contact:

Joanne Doucette, Social Worker at Roger's House (613) 523-6300, Ex. (622)

Nora Ulyot, Child Life Specialist at Roger's House (613) 523-6300, Ex. (9474)

Emily Angel or Mara Berzins, Children's Wish Foundation

(613) 221-WISH (9474)



Message from the Executive Director

Our priority is, and always will be, the care we provide our children and families.

However, there is more to Roger's House than the care we provide. Given that pediatric palliative care is a relatively new field of health care, I would like to focus on some of the sharing of information we are doing through education and research.

I am particularly proud of the number of presentations the CHEO Palliative Care Team and Roger's House staff and board were involved in at the recent Canadian Hospice Palliative Care Association conference. We

led five workshops and an oral presentation, moderated the pediatric panel presentation and presented three posters. We also assisted in planning the conference.

Earlier in the year, at the Ontario provincial One Vision: One Voice hospice palliative care conference we presented a workshop and two posters, winning the award for Best Poster of the Conference. We also presented two posters at the International Pediatric Palliative Care Conference in October.

We are also very involved in contributing to the research literature in pediatric palliative care. We have published 3 articles recently, are preparing 4 more for publication and are currently working with three different organizations on three different research projects. And, we have many more exciting ideas which we would like to embark on when resources permit.

It is clear that the team has taken seriously the role of sharing and contributing to pediatric palliative care knowledge and practices. The leadership they have embraced is not only helping the service we deliver to our own families and children, but all the health care professionals and families from elsewhere who learn about our work.

Lloyd Cowin, Executive Director



It's not knowing what each day will bring but showing up with a smile and opening your heart to what's to come. Even at 9am, when you're too tired, the second you walk in, you are welcomed and smiled at, and your heart melts, and you know it's going to be a good day. Even at 4pm, when you worked all day, you would rather go home and watch TV or sleep once you walk through Rogers Doors, Tv doesn't matter, and you know it's time to make someone's day. It's letting a child hold your hand and guiding you to what they want and you loving it too. It's sitting at the fish tank, sometimes in complete silence but the expression on the child's face says it all. It's hanging out at the Nurses station, talking, singing, watching high school musical, laughing, playing, reading, listening. Sometimes it's in the snoozelen room, one of the most unique places for our unique children, and you see they love it in their eyes and in the way they move. Sometimes it's one kid scooting across the mats, other times the kids singing in the ball pool to the radio, and sometimes it's sitting quietly in the chair holding their hand. Sometimes it's in the play room, letting a child feel the texture of playdoh and helping them sculpt, or maybe it's just dancing around to some silly music. No matter what day it is, tearful or full of laughter the children at Rogers House give as much as they receive, we work together as a community, but love like a family.

-Tiffany

Roger's House: A Volunteer's Perspective

Bell Sens Soirée: Manhattan at a Glance

Join your **Ottawa Senators** on January 22 as the Hilton Lac-Leamy transforms into the hottest tourist destination on the planet: MANHATTAN. There is something to satisfy every type of visitor - from the sightseer to the foodie, the arts enthusiast to the diehard shopper.

What to expect: A cultural epicenter that's fun, fast-paced, and exciting.

What to do: Visit the Statue of Liberty, Central Park, 5th Avenue, enjoy exquisite cuisine and a Broadway revue.

Don't miss: The exclusive rooftop themed after-party.

Don't forget: A black tie, street smarts, and an insatiable curiosity.

ABOUT THE EVENT: Bell Sens Soirée is the premier fundraising event of the Sens

Foundation. Last year the event raised more than \$325,000 for local charities. The money raised this year will support Roger's House, the Children's Hospital of Eastern Ontario, CSSS de Gatineau Foundation, Royal Ottawa Hospital Foundation, Queensway Carleton Hospital, and Rotary Home.

For event and ticket information please visit the Sens Foundation website or phone 613-599-0323.



Photo: Jarkko Ruutu, Chris Kelly, Stuntman Stu, Sens Foundation president Danielle Robinson & Brian Elliott

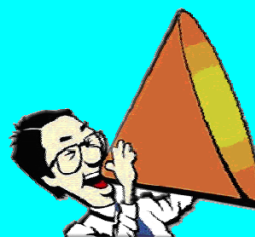
Roger's House would like to welcome the newest members of our family!

Joan Ellis-Hussey- *Personal Support Worker*

Stephannie Bourbonnais-*Registered Nurse*

Celeste St. John-*Registered Nurse*

We are delighted you have joined our team!



“One Thing You Can Do for Your Child is Give Their Parent the Gift of Support”

George Belaire is a 12-year-old boy who loves The Teletubbies and going to school. He literally grabs anyone he sees to involve them in any game involving a ball and has a mischievous bright smile. George also has a complex medical picture and has spent months in and out of CHEO starting with a four week stay when he was born. His parents, Karen and Charles Belaire, began using Roger's House about 4 years ago for respite. Karen reflects on the experience of George being referred to the Palliative Care team: “We had to accept that we will most likely outlive our youngest son. Children are not supposed to die. They are symbols of hope for the future. It took us months to get our heads around this one concept.”

Over time, as George became a more regular visitor to Roger's House, Karen says that she began to reflect on how even though her child's life may not be as long as they would hope for, he has had a huge impact on many people. “It is understood at Roger's House that it is a privilege to care for George and all the other kids who stay there. Every doctor, nurse and volunteer walks away changed by that experience. Also, I know that no child that has touched Roger's House will be forgotten. I believe every single child, like George, is building a legacy for other children. The Team is learning from caring for them, in ways they can apply to their care of all the other kids still to come.”

Karen has been a regular participant in the monthly sessions of the Palliative Care Family Support Group at Roger's House. She refers to it as a “lifeline” and appreciates how the parents all support one another. “You could be having the worst day or week, but you manage to get yourself there, and it's never a bad session. I always feel that inherent connection to the other parent, it's like we are all from the same planet! I leave feeling lighter, unburdened. It's a safe place.” Karen feels that all the parents “speak the same language.” It's the one place they can be truly understood without having to work hard to fill in the blanks as is so common in dealing with the outside world. Recently, on Remembrance Day, Karen heard something that resonated with her deeply. “Soldiers don't reminisce with anyone but each other”. She feels this is true for many parents of children followed by the Palliative Care Team. “We know it's often pointless to try to explain to others what we are going through.” As parents all fighting the same types of battles, they can safely share their experiences with one another. The group is different from what many parents would expect. Although the conversations may be emotional at times, there is also lots of laughter and celebration of the rewards of parenting their children. Each month there are different topics discussed, but it is an informal setting and geared towards the needs of the parents attending group that day. Parents share their successes and coping skills along with challenges and frustrations. They problem-solve together around issues regarding self-care, school, respite and family relationships. Karen encourages parents to try it out: “Come sit with us. Feel the connections. No matter which way the conversations go, it will be a good day.”

Karen would like to remind any parents contemplating attending group the following: “One thing you can do for your child is give their parents the gift of support. Call or just show up! It doesn't have to be so lonely.”



Greetings from Kandahar!



Captain Shawn Neville is looking forward to coming home for Christmas and seeing his family and friends. He's been on tour in Afghanistan with his regiment the 2nd Mechanized Brigade Group since August. Based in Petawawa, Shawn lives with his wife Georgina and children Christopher, 10, and Gillian, 8. Both children are frequent flyers at Roger's House, having been guests four and five when the home opened in 2006.



According to Shawn, he could never have gone on this tour if it wasn't for Roger's House. Thanks to the ongoing support that the Neville's receive including respite, support group, and pain and symptom management, Shawn's commanding officers finally consented to him going on tour because they were satisfied that Georgina would have the support she'd need while Shawn is away.

Shawn's story is contained in this year's seasonal appeal which can be viewed at:

www.sensfoundation.com under Ways to Give. Shawn is looking forward to receiving e-ornaments from online donors with their personalized messages when he visits the House during his holiday back home. With the Sens Foundation now covering 30 percent of the House's operating budget, donations play an ever increasingly important role in allowing the staff and volunteers to provide the outstanding quality of care for which the home has quickly become known.



Thank You To Our Volunteer Translator!

We are extremely grateful for the services of our volunteer, Isabelle Piché. Isabelle has been kept very busy translating several documents, from English to French for Roger's House use. Thank you Isabelle for your support and contribution to Roger's House, we are very appreciative of your work!



Roger's House Founding Sponsors



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Reminder!

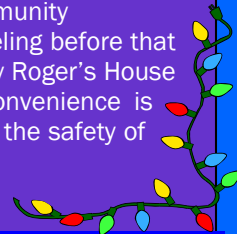
Don't forget to book your guaranteed admissions for 2011!

Families affiliated with CHEO's Palliative Care Team are reminded to start making plans for guaranteed respite admissions in 2011. Each child & family is entitled to 21 days per year of guaranteed time. These visits are offered on a limited basis and will not be cancelled due to occupancy. Available slots book up quickly so be sure to call at least a couple of months in advance if you want to be assured of a specific date. To arrange a visit, contact Nancy Graham, Admissions Coordinator, at 613-523-6300, ext. 619.

Change in Procedure regarding medication labeling



In order to provide safer care to your children we are introducing a new procedure in January. Caregivers will be asked to have medication bottles relabeled by their community pharmacy if they do not reflect the current doctor's order. In the event of a discrepancy at the time of admission, caregivers will be asked to return the medication to their community pharmacy for clarification or relabeling before that medication can be administered by Roger's House nursing staff. We hope any inconvenience is balanced by our efforts to improve the safety of the children entrusted to our care.



Roger's House is pleased to announce ...

Thanks to the Sens Foundation we are now able to service children with palliative care needs from the Outaouais region. This is an exciting opportunity for Roger's House to expand its services and meet the needs of families already involved with CHEO's palliative care team. We extend many thanks to the Sens Foundation for their support of children with palliative care needs on both sides of the Ottawa River.

