

# Annual Report to the Board of Directors 2014-2015

Megan Wright June 25<sup>th</sup>, 2015

### Mission, Vision & Values



#### Mission

Roger's House enriches the lives of children, youth and their families facing progressive life-limiting illnesses. Roger's House was built in memory of Roger Neilson--Hockey Hall of Fame Coach and Member of the Order of Canada.

Our team provides respite, end-of-life, transition-to-home support, pain and symptom management, peri-natal care and bereavement care by ensuring individualized physical, emotional, and spiritual support in a caring, compassionate and continuous learning environment.

Our reward is the peace and comfort of every child, the creation of memories for their families and honoring the legacy of Roger Neilson.



#### Vision

Roger's House will be recognized for providing excellence, innovation, research and leadership in pediatric palliative care through a full-spectrum of family-centered services in a supportive homelike environment. Our dynamic, integrated team will collaborate with, and be accountable to, our families and community partners.

#### **Values**

Roger Neilson was well known for his generosity, humanity, sense of humour, compassion and love of children. These values as well as the following will govern our daily work with families, community and each other:

- Respect
- · Family-focused care
- Collaboration
- Creativity
- Excellence

# Service Descriptions



#### Respite Care

Children / youth are invited to come to Roger's House for support and a time away from home. During their stay the child / youth is assessed and cared for by the specialized team of medical professionals. Immediate family is able to stay with the child / youth and receive support and education in relation to their child's progressive illness. The goal of the stay is to foster the quality of family life.

#### Transition from Hospital to Home Care

Eligible children / youth who have been hospitalized for surgical or medical reasons may transition to home through Roger's House. During this time the family through professional support and education will become more comfortable with their child's care and needs.

#### Pain and Symptom Management

Children / youth may come to Roger's House for a short stay for assessment and monitoring by the specialized team of medical professionals while medication and treatment changes are implemented.



# Service Descriptions





#### End of Life Care

For children / youth and families that choose to spend their final days together at Roger's House, end of life care is provided. The specialized team of medical professionals at Roger's House provides pain and symptom management, emotional and spiritual support as well as assistance with decision making. Every effort is made to ensure ongoing quality of life for the child / youth and family.

#### Grief and Bereavement Counselling

Families who have experienced the loss of a child may receive grief and bereavement support. Individual and group counselling is available from trained professionals.

#### Perinatal Hospice

Perinatal hospice extends the concept of hospice to include comprehensive support from the time of diagnosis through the birth and death of the infant, and into the postpartum period.



#### Improve and Grow -- Quality Program Development

The growing and evolving needs of children and families will be served through excellent quality care in a safe environment. The focus will be on the continuous improvement of existing services as well as in the development and implementation of new initiatives/programs.

- •Implemented a new model of care that enhances the PSW's role and responsibilities. The focus was to:
  - Enhance the PSW skill level in providing direct care to guests and their families
  - Enhance team functioning and job satisfaction
  - · Optimize utilization of all employees working to their full scope of practice
  - Offer safe, competent care by the most appropriate provider
  - Be fiscally responsible
- •Hired an additional Social Worker to create more access for bereaved families.
- •Improved our medication safety.
- •Developed a support group for siblings of children with a progressive illness: S.I.B.S. Spectacular, Incredible, Brave Siblings.
- •Worked with Hospice Care Ottawa and the Champlain Hospice Palliative Care Program to create a transition plan for our patients to adult hospice care.
- •Introduced a perinatal loss support group that touches on the unique realities of these parents.
- •Revised the intake and referral management process as well as the on-call nurse model to be more efficient and to provide more continuity of care.
- •Surveyed families regarding their satisfaction with services.



#### Secure our Future -- Financial Sustainability

Roger's House will ensure its long term financial sustainability by operating within a balanced budget, and looking for new/alternate sources of revenue.

- •Continued to work with OSF in solidifying our long-term and successful relationship.
- •Submitted a proposal based on anticipatory needs for an additional two beds to the Champlain Hospice Palliative Care Program.
- •Finished the year in budget and had a successful audit
- •Established a new agreement with the CHEO Foundation to fund growth in programming.
- •Established funding from the Local Health Integration Network (LHIN) to help support the new Visiting Hospice Program.
- •Received over 60K in direct donations:
  - Received a grant from the Children's Wish Foundation to redo the Snoezelen Room (24K)
  - Received donations to fund the purchase of ceiling lifts in three guest rooms (20K)
  - Received a donation from Enterprise Car Rental to purchase new rocking chairs (20K)
  - Received a grant from the Ontario REALTORS Care Foundation to fund a relaxation lounge upstairs for children and families (4K)



#### Work Together -- Maintain & Build Partnerships & Relationships

Roger's House will continue to maintain and improve existing partnerships and will look for opportunities to build new partnerships, both administrative and clinical. Particular attention will be given to ensure the critical partnerships with CHEO and the Senators Foundation continue to evolve satisfactorily for all and that employees, physicians and volunteers are properly supported in their work.



- Transitioned our IS support and payroll system to CHEO.
- Participated as an active member on the Regional Bereavement Steering Committee.
- Roger's House continued its joint venture with the Ottawa Children's Treatment Centre (OCTC) and Rotary Home, "Making Respite Work":
  - We developed a single intake package for families that we commonly serve.
  - We created a shared database to capture program usage across the three organizations.
  - We improved communication to increase client access to services across our agencies.



#### Advance Knowledge -- Research and Education

Roger's House will continue to develop the academic component to our mission by sharing our expertise with other health care professionals, students and the community at large as well as by adding to pediatric palliative care knowledge through research.



- Mentored 2 MScN students who did research on:
  - Nursing perceptions of referral to Palliative Care Program in NICU and PICU.
  - Mindfulness, memory-making and legacy building in Pediatric Care.
- Advanced Practice Nurse (APN) outreached to build capacity in providing pediatric palliative care at ARCH Hospice in Sault Ste. Marie, Ontario.
- Roger's House and the professional care team were featured in the RPNAO Journal: "All We See is Love..." by Jill Scarrow.
- APN gave an interview on CBC Radio's 'The Current' on palliative care in newborns.
- Carol Chevalier received the Airdrie Thompson Guppy Award for Excellence and Innovation in Social Work Practice, and graduated with her Masters in Social Work.



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#### What we accomplished in the last year... (cont'd)

- APN gave a french video interview on Radio Canada on Roger's House.
- A Roger's House family was featured in *Parenting Times* about their perinatal experience at Roger's House: "There is a Lot of Beauty in this House".
- SW presented on her Perinatal Loss Group at the CMNRP Conference.
- Presentations were given on nursing care for the dying child in CHEO PICU and 4 North.
- Four nurses re-applied for their CNA certification in hospice palliative care nursing and two others wrote the exam for the first time.
- Worked with our national palliative care partners to coordinate and organize the National Palliative Care Conference being hosted in Ottawa this fall.

### Statistics



41 Staff

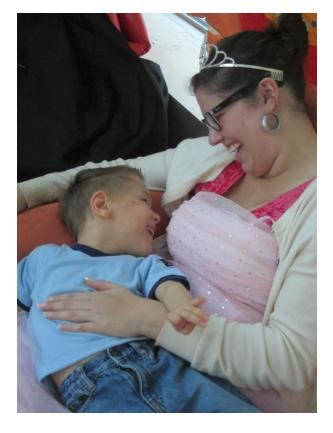
15 Student Placements:

- 3 Nursing
- 11 Medical
- 1 Social Worker

354 Volunteers

17583 Hours Donated by Volunteers (+500K)

1717 People Received a
Presentation or Tour



83% Average Occupancy

2405 Patient Days

18 End-of-Life Admissions

327 Adult Bereavement Support Visits

173 Bereavement Outreach
/ Phone Intervention

74 Children Bereavement Support Visits

### Precious Words



"Thank you so much for being kind hearted people to my sister in her final moments. It was greatly appreciated."

"Thank you for your kindness and love to our granddaughter, along with us, to wait on us, let us spend time together after she passed away to be with Jesus! Our kindness and love was like a family away from family! What a blessing to have such a home for our angels."



"Thank you from the bottom of our hearts for helping us have a special "at home" time with our son. Without you he would've passed in CHEO surrounded by machines."

"I truly appreciate what you all do here. Your help allows us to bond as a family and come closer to one another. I wish all the families in need could receive the care you give."

"Words cannot express our appreciation felt towards Roger's House and the compassionate care we received during our stay with our son. You will all hold a special place in our hearts forever."

# Words From a Bereaved Parent About the Perinatal Loss Support Group...



To Carol and Catherine, I would like to say thank you from the bottom of my heart for the support you have shown us since our child's] passing (...). You both have helped to take what has been the toughest experience I think one would ever have to go through in life and you made it bearable. (...)

Carol, since the day we came in for our intake meeting you were there to greet us with a smile that made us feel welcome (...). Leading a group such as ours must be a difficult task as we all come to you in the beginning feeling lost and broken, not really being able to make heads or tails out of what we had just experienced, over the course of the 4 months you both were able to help guide us "out of the fog" as we like to say and help us all come to a certain peace with our loss. Again, I say this really is a thankless job and we are all fortunate to have you both, along with Roger's House to lean on through our past, present and future.

Thank you!

### Thank You



#### 2014-2015 Roger's House Board of Directors

Ruth Hartanto, Chair
Les Bell, Vice-Chair/Treasurer
Jeff Polowin, Secretary
Susan Richardson, Past Chair
Michael Baine, Director
Dr. Pranesh Chakraborty, Director
Robert Houston, Director
Ian Hendry, Director
Mike Lupiano, Director
Danielle Robinson, Ex-Officio

Thank you to our very dedicated and very talented Board of Directors. The Board has provided excellent leadership and direction to Roger's House.

#### Roger's House Staff

Thank you to all the staff at Roger's House for their dedication and commitment. Their experience, talent and contributions help make Roger's House a home-away-from-home for many patients and families in their time of need. They are essential to our success.

### Ottawa Senators Foundation and

#### Ottawa Senators Hockey Club

Thank you to the Ottawa Senators Foundation and the Ottawa Senators Hockey Club for their continued generous support of Roger's House.

#### CHEO Foundation

Thank you to the CHEO Foundation for their continued generous support of Roger's House.

#### Roger's House Volunteer Care Team

A big thank you to all of our Volunteer Care Team for their continued support of Roger's House. The impact their contributions have on the children and families is priceless. We thank them for helping us celebrate life!

#### Partners and Community Supporters

Partnership and collaboration is a core value of the organization. Many of our programs and services would not be possible without these important relationships. While it is not possible in this space to list each and every one, we would like to express our thanks for their on-going support and work.

# This Spring/Summer



- Family Advisory Committee Focus Group; setting priorities and engaging families.
- Researching the expansion of our bereavement groups, i.e. grandparents.
- Moving forward on Quebec government proposal; contact has been made and a meeting will take place this summer.
- Completed our annual audit with MCYS to be re-licensed
- Busy time of year for us with respite.
- Continue to work with MCYS on how/where we are funded from and advocating for more resources.
- Hosted a representative from MOHLTC last week as they continue to scope out the palliative care funding model.

# In the Coming Months



- Strategic planning to set our new course (Fall).
- Will join CHEO in the development of the inpatient electronic record (January 2016 build Go-Live Summer 2017).
- Will jointly host the bi-annual National Symposium on Pediatric Palliative Care (October 2015).
- Will launch our new brand with OSF and have a joint announcement with the CHEO Foundation around the three organizations working together in a new way.
- Will formally launch our Visiting Hospice Program.
- Will launch our revised website.

# Lastly...in 2016



Ten Year Anniversary!

