



Fall · 2016

Roger Neilson House Chronicles

Upcoming Events:

Palliative Care Training for staff & volunteers

Thursday evenings 6:00 - 9:00 pm
September 15 - October 13

The CHEO Palliative Care Program Education Seminar

Journeying Together Along the Illness Trajectory

Monday, October 3

Please contact:

Lynn Grandmaison Dumond
LGrandmaisonDumond@cheo.on.ca

Volunteer Information Session

Thursday, October 20
6:00 - 8:00 pm

RNH Kids Halloween Party

Invitation to follow
Saturday, October 22, 2:00 - 4:00 pm

Annual Bereaved Families' Holiday Memorial Celebration

Sunday, December 4
1:30 pm - 3:30 pm

RNH Kids Christmas Party

Invitation to follow
December 11, 2:00 - 4:00pm

IT'S BEEN A BUSY SUMMER WITH FUNDRAISING AT RNH

57 Ride



Toronto to Ottawa on a bike!
Sounds crazy right? A group of incredible bikers cycled from Toronto to Ottawa to raise money.

They raised \$12,757 to buy the large musical instruments for our new outdoor patio, and to support our bereavement program.

Barrhaven Run for Roger Neilson House



Check out our amazing dream team from the annual **Walk, Roll, and Run** hosted by the **Ottawa Senators Foundation**! What an afternoon full of fun. \$32,000 was raised for Roger Neilson House. Thank you to everyone for their generous donations.



Check out our new social media pages!!



Twitter @RNeilsonHouse



Instagram: rogerneilsonhouse



Facebook: Roger Neilson House



A Message from our Executive Director, Megan Wright

During our 10th year anniversary celebrations we had an opportunity to celebrate our successes, to thank our staff, volunteers and our community, and most importantly a chance to honour the children and families we serve. The work we do is very much a team effort.

To that end I would like to thank our very dedicated staff. Every day they go above and beyond to make sure that kids and families have what they need. When I first started here a little over two years ago I asked the team what ideas they had. They advocated for more bereavement support, for a family Christmas party, for a sibling support group and for a visiting home hospice. All of these ideas have been put into place because of their support and commitment. Roger Neilson House was built by our community; a big family that keeps pulling together when circumstances demand it and remains a staunch ally in its generosity and resourcefulness to this facility. There are many annual events that are community driven, many of which you support and even host, and we are very grateful. We have 325 active volunteers who collectively have contributed over 153,000 hours to making Roger Neilson House the amazing facility it is today. Dedicated individuals devote their time, efforts, skills and talents to enhance the quality of care the House offers to children and their families. Volunteers fulfill roles on the Board of Directors, with play therapy, with cooking (many, many cookies), at reception and daily activities in the house. With your unfailing dedication and support we are providing exceptional patient care every day to the children and families who need it.

The 2.2 million dollar donation to our endowment fund from the Ottawa Senators Foundation further speaks to another very special relationship we have in the community. Together the Ottawa Senators Foundation and the CHEO Foundation have grown our endowment to 6.6 million dollars. I am grateful to both the Ottawa Senators Foundation and the CHEO Foundation boards, and in particular their leaders Danielle Robinson and Kevin Keohane whose drive to support pediatric palliative care in our region has never wavered.

I would like to share some of our successes over the past couple of years. We have created greater access to bereavement support by adding another social worker to the team. We no longer have a waiting list for this very important service. We have developed a support group for siblings: S.I.B.S. - Spectacular, Incredible, Brave Siblings. The House has worked with Hospice Care Ottawa and the Champlain Hospice Palliative Care Program to create a transition plan for our patients to adult hospice care. Our perinatal loss support group has grown to ensure participating families receive the unique care they need. We have also 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.

Yes, it is definitely a great opportunity to celebrate and thank our team and the community. It is a chance to extend our appreciation to the Ottawa Senators Foundation and CHEO Foundation. Above all, I continue to be grateful to and humbled by the courage and tenacity of all the parents who place their sick and fragile children in our care in the face of sometimes unspeakable odds. We heard that Roger Neilson always had his door and heart open to those who needed it most. Let Roger Neilson House always have its door and heart open to all children and families who need our care.

We are fortunate to be able to do this work at Roger Neilson House. I am fortunate to be part of this amazing organization. This is an environment that is like very few others, where care and compassion is exhibited every day and, above all else, where the model of collaborative care allows us to ensure that the children and families keep receiving the care they need and deserve.

Thank you for celebrating 10 years of success with us!

Megan Wright





WHAT'S BEEN GOING ON AT ROGER NEILSON HOUSE?



Let's Make Friends with Salad!

Who doesn't love salad at Roger Neilson House. We hosted our very own salad bar lunch called "Let's Make Friends with Salad" to raise funds for team Mito Canada for the Ottawa Race Weekend!

Together we were able to raise over \$400 in memory of a very special little girl who loved to make salads.



Lemonade Standemonium!

This year Roger Neilson House hosted our third annual **Lemonade Standemonium to raise money for the Ottawa Cancer Foundation**. By squeezing a bunch of lemons and making some yummy treats, **we raised over \$920!!** Way to go RNH kids!

Star Wars Visits RNH

Use the force my friend. Roger Neilson House had some super special visitors come invade the house from a galaxy far far away!



Little Rays Reptiles



Thank you to Little Rays Reptiles for the creepy and slithery time.



10 Years of Volunteering at Roger Neilson House:

Lise Beauchemin

Volunteers are members of the team who provide care to the children and families accessing Roger Neilson House services. The positive impact of their service and dedication is priceless.

Our hospice continues to evolve and be responsive to the growing needs of the population we assist. One such example, is the **Home Hospice Program**.

This new program is additional respite for families accessing Roger Neilson House. A volunteer is carefully matched to a child and visits in the home regularly to be a play companion and give a few hours of deserved respite to parents. The volunteers have a minimum of one year experience as a hospice volunteer and have participated in the Hospice Palliative Care of Ontario Home Visiting Training. Families receiving the Home Hospice service have expressed positive feedback. One parent states:

"I honestly couldn't be more pleased with the Visiting Volunteer Service. The volunteer is punctual, appropriate, respectful, and there is no denying how much he enjoys his time with my child."

Do you want to learn more about volunteering or the Home Hospice Program? Contact Lise Beauchemin, Coordinator of Volunteer Services, at lbeauchemin@cheo.on.ca or 613-523-6033 ext. 605.

Admission Update

Nancy Graham, Quality Coordinator

Since changes were made to admission & discharge times in January 2016, numerous families have told us that these time changes are not always convenient for them. The leadership team at Roger Neilson House is listening to this feedback and re-evaluating times in collaboration with the medical and nursing teams. We appreciate your input and anticipate communicating any changes in the early Fall. Thank you for your patience. Our number one goal is to make sure we can safely care for all the children in our trusted care. To accommodate increasing requests for pre-booked admissions over the summer months, the leadership team has agreed to increase the number of pre-booked admissions per day from 3 to 4. This increase will be tried and analyzed to determine if it would be sustainable during peak periods in the future. These changes will also be communicated to families by e-mail, social media & the website.

Under the direction of the Quality Committee of the Board of Directors, Roger Neilson House is moving toward goal-oriented admissions. Starting with transition from hospital to home admissions, families will be asked to identify their goals for coming to Roger Neilson House after discharge from hospital. They will also be asked to provide evidence that their goals have been achieved prior to discharge. For example, if families want to gain comfort in assuming care of their child's new gastrostomy tube, including administration of feedings, this would be their identified goal at admission. Prior to discharge they will also be asked if they are confident to assume this new task independently at home. Admissions for symptom assessment will be the next goal-oriented admission to be implemented.

Petting Zoo Fun



Family Advisory Committee Update:

Mindy McHardy

The Family Advisory Committee (FAC) provides the opportunity for families who use Roger Neilson House to give feedback and advice to the Executive Director, leadership team and staff about programs, practices, policies and initiatives. This respectful collaborative partnership between families and the leadership and staff of Roger Neilson House helps to ensure that the services provided meet the needs of the families served.

In the spring of 2016, the FAC began a campaign to recruit new family members. We are happy to report that four new members will be joining the committee in September 2016: Lillian Kitcher, Yara Saikaly, Katelyn Howse and Richard Ouimet. They will be oriented to the committee under the guidance of outgoing members who have served for more than 6 years!

Family members who are interested in joining FAC in the future or who would like more information about this committee are encouraged to contact the committee Chair, Mindy McHardy (mindymmchardy@gmail.com), or the staff liaison, Nancy Graham (ngraham@cheo.on.ca), for further details.

IN REMEMBRANCE OF...

**WE HONOUR THE CHILDREN WHO DIED AT
ROGER NEILSON HOUSE SINCE OUR LAST
CHRONICLES**

Sendos Al Sahhar

Cecilia Bell

Evelyn Furniss

Elise Gammon

Masa Ghazi

Erin Gravelle

Sam Leveque

Sohma Nakanishi-Suzuki

Aaron Samulack

Davin Stone

