

Roger Neilson House

Summer 2018 Newsletter

Executive Director Update

As we are approaching the end of another summer and I reflect on the past few months, it's hard to believe that we have accomplished so much in such a short period of time. The house has been hustling and bustling with activity! For the second year in a row we held summer camp at RNH over three weeks in July and August. It was wonderful to see and hear all of the fun activities taking place around the House. The children enjoyed seeing a circus, hearing fairy tales, listening to music, having their faces painted, and of course what every camper loves to do — making tie dye shirts! Thank you to all of the staff and volunteers who worked together to make camp a very special adventure for the kids. Your extraordinary efforts shone through in all of the smiling faces!

We have been fortunate to receive a large donation from the Moghadam family. We would like to extend our thanks to Dr. Hassan Moghadam, his wife Litsa Karamanos, and their three children; Victoria, David, and Alexander for their generosity in support of Roger Neilson House. It was our pleasure to dedicate a plaque in their family's honour by one of Roger Neilson House's patient rooms. These rooms are important and help ensure that patients are provided with compassion, love, and skilled palliative



care. We would like to take this opportunity to also thank everyone who supports the work we do. The children and families served at Roger Neilson House deserve the very best of care and our community ensures that happens by way of their generosity.

On October 22nd we will be holding the annual Palliative Care Symposium at CHEO and Roger Neilson House. This year's symposium, *Pediatric Palliative Care: An Integrated Approach*, promises to be an opportunity for learning, sharing and networking. Sessions will be held on various topics, and our keynote speaker will be Dr. Scott Maurer from the University of Pittsburgh School of Medicine and the Children's Hospital of Pittsburgh, UPMC. Medical professionals, volunteers, and families are all welcome to attend. For full conference details and to register, please click here.

Lastly we are very pleased with the growth of our team. This summer we welcomed Anne Jones to the new position of Admissions and Care Coordinator. Anne has worked at Roger Neilson House for over 10 years as a Registered Nurse and will be familiar to many of you. In addition, Lesley Sabourin and Jodi Ouellette, also Registered Nurses at Roger Neilson House, will job-share the new Perinatal Hospice Coordinator position beginning in September. These staff members will enhance service delivery with new programs to support children, youth, and their families. Check out the new Virtual Tour of Roger Neilson House.

Megan Wright, Executive Director

Volunteer Service Update

In June, new volunteers attended the mandatory in-class Palliative Care Training, which is offered twice a year. It is designed to complement the online training that all volunteers are required to complete. The time we spent together was filled with great and insightful discussions. During one of our exercises, we asked ourselves:

"Hospice Palliative Care aims to treat all active issues, and promote opportunities for meaningful experiences, personal and spiritual growth, and self-actualization." (HPCO online training). What does this mean for RNH children and their families?

Here are some of the themes raised and discussed by our group of new volunteers:

- Building legacies, for both the children and their families
- Giving children a sense of autonomy through play
- Exploring through senses
- Using play to express emotions (SIBS group)
- Normalizing experiences through connections (social/parties/groups)
- Bereavement groups
- Letting the child choose and have opportunities THEY enjoy (empowerment)
- Safety, belonging, community, network
- Feeling respect
- Promoting children having ownership of their life

Congratulations team for completing the training and best wishes for a successful volunteer experience at RNH! Before pausing for the summer, the Volunteer Advisory Committee (VAC) approved a workplan that will guide our work when we get started again in September. A VAC working-group did meet over the summer to start working on one of our goals, which is to create a more comprehensive support system for volunteers. We will be ready to present our proposed plan in the fall. I look forward to continue collaborating with the VAC, under the leadership of our volunteer chair and co-chair, Carole Brulé and Scott Gunn. They are an amazing, passionate, and engaged group of volunteers.

Bruno Perrier, Manager, Community Engagement and Volunteer Relations



What's New in Social Work?

Over the past few months, we have been fortunate to have in our midst, Katrina Mallette, a BSW student from Carleton University. Katrina was supervised part-time by RNH social worker Carol Chevalier. During Katrina's placement, it was agreed that she would submit a Legacy Project based upon the needs assessment previously completed by a group of Carleton University Master of Social Work students titled, "Pregnancy After Loss: Exploring the needs, services and supports of bereaved parents who are considering pregnancy or are pregnant following a perinatal loss."

The result of Katrina's Legacy Project is a comprehensive Pregnancy After Loss (P.A.L.S.) Support Group format, outlining eight sessions that focus on topics that were identified in the needs assessment. Topics include:

- Facing the Stress
- Anxiety and Fear: what if it happens again?
- Reconciling the New Normal
- Will I Ever Get Over this Guilt?
- Life After my Angel Baby
- Coping With the Outside World
- Dads Need to Grieve Too
- Bringing my Rainbow Baby Home
- Introducing your Angel Baby to your Rainbow Baby

The group will be offered beginning in September and it will take place on a monthly basis. It will be facilitated by Carol Chevalier and Barb Juett.

Madelena Arnone, Carol Chevalier & Barb Juett, Social Workers

Pregnancy After Loss Support Group—P.A.L.S

The Palliative Care team is committed to providing on-going bereavement support to families following the loss of their child. The development of the P.A.L.S group was research based and informed by focus groups involving families who experienced a perinatal loss. It was identified that many families who experience the death of a child do go on and plan for more children. There is growing evidence that these families would benefit from increased emotional support during future pregnancies, and be surrounded by other families who understand that during subsequent pregnancies, it is possible to be anxious, happy and sad all at the same time!

Criteria for group: RNH will be offering an open, monthly drop-in group for families who 1) have already accessed RNH services and 2) are currently pregnant and struggling emotionally. Topics that will be explored include managing guilt; impact on relationships; managing the expectations of others, etc...

The group will be offered every first Wednesday of the month from 5:30p-7pm, starting September 5th, 2018!

Please RSVP to: Carol Chevalier, MSW, RSW at cchevalier@cheo.on.ca

Recreation Therapy Update

Roger Neilson House Summer Camp

We had such a fun and exciting summer with our second year of summer camp. Three weeks this summer we played, dressed up, and went on adventures around Roger Neilson House. We had a blast with fairytales, circus, carnival, fear factor, escape room, and life size game themes. We did a mix of arts, scavenger hunts, baking, music, and more.

This year we had multiple community members who came to spend some time at the house with our campers. Thank you to Derek McKinley, the painted pixie, and the zoo crew. The house was full of fun and laughter, and all the staff, families, and volunteers joined in.

Our second summer of summer camp at RNH was such a great success - thank you to everyone who contributed and participated, we can't wait for next year!







Children's monthly drop in bereavement group

Roger Neilson House's recreation therapy team has started a children's drop in bereavement group that occurs monthly. This group will allow children to receive peer support in a facilitated play environment. This group is facilitated by the recreation therapists and is open to children who have already attended a children's bereavement group in the past or who has been involved in one-to-one support and are referred to the group by recreation therapy. The children will be given a space to express their emotions, work on coping strategies, and express themselves in a safe space around understanding peers. If you are interested in attending this group please contact recreation therapy.

Upcoming Events

Click on the picture for more information



24 Hour Tremblant is fast approaching! Consider supporting a wonderful organization and event that supports Roger Neilson House. December 7 - 9, 2018.





