





Roger Neilson House

2018-19 Annual Report



Children Served

96

In 2017-18

107

In 2018-19

In 2003, inspired by the spirit and compassion of Roger Neilson, the much-respected member of the Ottawa Senators Hockey Club coaching staff, the Club and its Foundation approached CHEO with an exciting vision to improve the quality of life for children and families going through the most difficult times imaginable.

The Ottawa Senators Foundation set out to engage the community and raise the money necessary to bring this vision to life; they accomplished a \$5 million fundraising feat in less than two years after the passing of Roger Neilson.

The two organizations entered into a unique partnership in which the hospital's palliative care team designed and developed new programs and a beautiful new facility was built to welcome children and families. Thus Roger Neilson House was born— an eight-bed pediatric residential hospice which offers compassionate care in collaboration with CHEO's palliative care team.



Days of Care

2,621

In 2017-18

2,864

In 2018-19

OUR MISSION

We meet the unique palliative care needs of newborns, children, youth, and their families. We lead by advocating, by advancing clinical care and family support, and by learning through research and sharing knowledge.



OUR VISION

We enrich the quality of lives, no matter how short.

OUR 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
- Innovation
- Excellence
- Learning
- Celebration

Total Admissions

457

In 2017-18

474

In 2018-19

Message from the Chair of the Board of Directors and the Executive Director



As we reflect on the past year and look at all of our accomplishments, we realize how full our year has been. At the end of December 2018 Dr. William Splinter stepped down as Medical Director of CHEO Palliative Care and Roger Neilson House. Dr. Splinter had been the Medical Director for 13 years and played a large role in the opening of Roger Neilson House in 2006. He was instrumental in shaping the course of direction for Palliative Care at Roger Neilson House and helped position the program for many years of future success. While Dr. Splinter continues to be a physician on the Palliative Care Team, we would like to extend to him our sincere thanks for providing excellent leadership over the past 13 years.

In January 2019 Dr. Christina Vadeboncoeur was appointed to the position of Medical Director. Dr. Vadeboncoeur has been a physician member of the Palliative Care Team at CHEO, Roger Neilson House and the Ottawa community for the last 12 years, and has worked at CHEO for 25 years. She was involved at Roger Neilson House when it first opened in 2006 and has been involved in policy development, implementation of clinical standards, and in the development of the current mission, vision and values of RNH. We congratulate Dr. Vadeboncoeur on this appointment and look forward to many years of collaboration together.

In June 2019 we will be bidding a fond farewell to Ruth Hartanto, the Past Chair of the Board of Directors of Roger Neilson House, who has served on the Board since the house opened in 2006. Ruth has provided a tremendous amount of support and guidance to the Board during her tenure, bringing the family perspective as a parent who once used the services of Roger Neilson House. Our sincere appreciation goes out to Ruth for her many years of dedication to the Board, and for helping make a difference in the lives of the children and families who have used our services. We will be welcoming several new members to the Board of Directors in June 2019, and look forward to the work to be done in the upcoming year!

Throughout 2018 and 2019, occupancy at Roger Neilson House has remained at a record high level. Our occupancy rate consistently remained at an average of 99% and the demand for our various programs and services continued to grow. In particular, the number of Symptom Assessment admissions was particularly high, with a 30% increase over last year's numbers. The number of individual encounters in Bereavement Support Groups increased by 141%, and the number of individual counselling sessions increased by 12%.

In the upcoming fiscal year we are looking forward to many new improvements at the house. One of these will be the implementation of *EPIC* (and *MyChart*) in October 2019. *EPIC*, which is an electronic health record system currently in use at CHEO, promises to bring many exciting changes to documentation processes for the clinical team. It has many strong benefits including the ability to share information in real time, and having one record for each patient.

In the summer of 2019 we are very excited to be holding our third year of summer camp, which is designed specifically for the needs of the children and youth we serve. Over three weeks in July and August the house will be filled with fun activities, music and laughter; it promises to be a wonderful and exciting experience for all involved! Camp could not happen without the participation of all of our families, volunteers and staff who make it the success that it is. The community support for our camp also makes a huge difference to our programming!

We wish to extend our deep appreciation to our Board of Directors, staff, volunteers and community partners. In particular we acknowledge the Ottawa Senators Foundation and the CHEO Foundation for their ongoing financial support. The funds received provide direct family and patient supports.

Roger Neilson House continues to remain in a stable position due to the stewardship of our Board of Directors and the excellence of the Roger Neilson House management and staff. It is an honour for us all to continue to proudly serve children, youth and families in need in our community.



Megan Wright
Executive Director



Les Bell
Chair

Message from the Chair of the Family Advisory Committee



Over the past nine months the committee has met monthly to discuss a variety of topics.

We have continued to work on strategies for enhancing Family and Patient Engagement throughout the House. With respect to Programs and Services, we specifically examined how the process of obtaining family feedback can be developed. We will continue to look at engagement strategies from a family perspective to enhance the RNH experience.

The FAC were presented with a number of opportunities to provide feedback on existing programs and new initiatives. For example, Summer Camp, drop-in support groups, the Matching Program, and the Legacy Program were all considered and discussed from a parent/caregiver point of view.

Physicians and staff at RNH are involved in several exciting research opportunities and the FAC was able to learn about and endorse several of them. Earlier in the year Danielle Scarlett, Registered Recreational Therapist attended an FAC meeting to present an overview of a research pilot on Siblings that was being submitted for a research grant. Additionally, we were visited by Dr. Vadenboncoeur several times as she is involved in a number of research projects and studies which the committee supported. We were happy to have her at our last meeting of the year as she gave us a comprehensive update on the status of those research projects.

We were fortunate to have experts from CHEO come to FAC to educate us on the structure of some technical advances such as MyChart and EPIC. We had a good discussion around the benefits and challenges to using these systems for both medical professionals as well as parents/caregivers, and the patient themselves.

As part of the RNH's commitment to family engagement throughout the House, FAC was part of several Human Resources processes this year. There was family advisor participation at interviews for the Perinatal Coordinator, Medical Director, and the Legacy Program Project Manager positions.

I'd like to say thank you to the Family Advisory Committee for the time and attention they give to ensuring the voice of RNH families is heard. I'd also like to thank the management team for continuing to involve families in such meaningful ways.

Kimberley Waara
Chair, Family Advisory Committee
Roger Neilson House



490

*Number of
individual children
cared for since
opening its doors
in 2006.*

'We have been very privileged over the past few days to witness the wonderful care given to our great niece and great nephew. What a truly remarkable place Roger Neilson House is. We have been made to feel very welcome by all the staff and volunteers who work here. We are also grateful for the support offered to the whole family. We hope that RNH will continue to care for children and families well into the future.'

-Family Member

Message from the Chair and Vice-chair of the Volunteer Advisory Committee

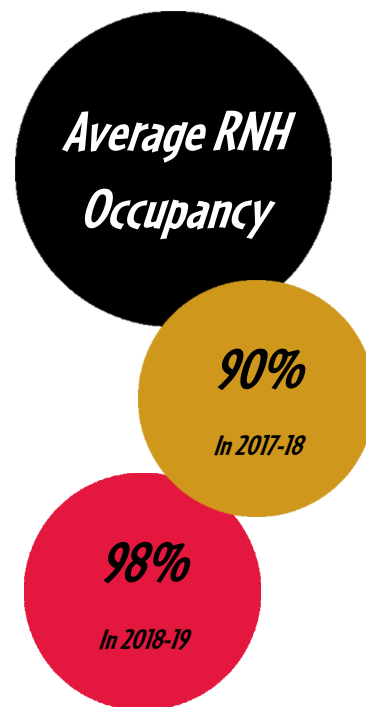


The Volunteer Advisory Committee (VAC), implemented in February of 2018, has enjoyed a busy and productive year. Over the course of the group's first few monthly meetings, the VAC developed an ambitious but achievable work plan that was presented to RNH Leadership in September 2018 for approval. Key objectives of the 2018-2019 work plan were twofold: to improve and streamline the volunteer on-boarding process, and to develop accessible volunteer support systems (including bereavement support). Initial changes are now in place and the VAC will work with RNH Leadership to ensure that the revised training and support systems are meeting the needs of staff and volunteers. Continued work on on-boarding and support systems will be carried over into the 2019-2020 work plan in addition to new objectives currently being discussed by the VAC. In February 2019, RNH submitted an abstract to the Hospice Palliative Care Ontario (HPCO) Annual Conference titled "Involve, Engage, Empower - The Roger Neilson House Volunteer Advisory Committee" which was accepted for presentation. Bruno Perrier, Manager of Community Engagement and Volunteer Relations, Carole Brulé, VAC Chair and Scott Gunn, VAC Vice-Chair were thrilled to have the opportunity to represent RNH and VAC members at the conference. The workshop was very well received and many attendees have been in touch with Bruno to hear more about the process of establishing a volunteer advisory committee. As the VAC moves forward into its second year, members would like to express their gratitude to RNH Leadership, staff, and to all RNH volunteers for their commitment, input and support as we work together as 'one strong team' to support the children and families that we are honoured to serve.



Carole Brulé
Chair, Volunteer Advisory Committee
Roger Neilson House

Scott Gunn
Vice-Chair, Volunteer Advisory Committee
Roger Neilson House



Volunteer Services



This past year, a total of 33 new volunteers came onboard, with a shared goal of contributing to the quality of life of the children and families with whom we have the privilege of working. They joined our team of 250+ volunteers who together donated 18,506 hours of their time. We can never say enough about volunteers' incredible impact in helping Roger Neilson House achieve its mission! In October, we also welcomed Jennie Wilson as the new Administrative Assistant for Volunteer Services. Jennie's talents, experience, knowledge, compassion and her great personality have made her an amazing addition to the team.

Volunteer Services took part in RNH's accreditation review this year, which was a great opportunity to measure our volunteer policies, procedures and practices against recognized standards in hospice palliative care. Although we met most of the standards, we received recommendations for improvement in a few others. As an organization that strives for excellence, we embraced the recommendations and implemented enhancements, including improvements to training processes for new volunteers, adding refresher training for existing volunteers and further developing how we monitor and evaluate their ability to practice. As the accreditation process was starting, we were already introducing a volunteer performance evaluation process. This allows us to offer the volunteers feedback, advice and the support they may need to be as successful as they can be in their role. Equally important, it is an opportunity for volunteers to share their thoughts on ways in which we can continuously improve the volunteer experience at Roger Neilson House.

We are also very happy and proud of having established an enhanced support system, which was a collaborative effort with the Volunteer Advisory Committee. Volunteers regularly tell us how their volunteer experience is so incredibly rewarding. They also tell us that at times, it can be emotionally challenging. With that in mind, volunteers now have access to a greater variety of supports, which include individual support, group debriefs and educational sessions where volunteers receive information and practical advice on different topics.

We look forward to another great year of working alongside our amazing volunteers as core members of our team!

Bruno Perrier

Manager, Community Engagement and Volunteer Relations



182,206

*Number of hours volunteers
have dedicated to
RNH since its
opening in
2006.*



*The happiness and
smiles that I see on my children's
faces while they are playing with you
make your existence in our life
priceless.*

*- Parent about their Visiting
Home Hospice
Volunteer*

646

*Number of hours completed by
Visiting Home Hospice volunteers*

*Number of guests receiving care
through our Visiting Home
Hospice Program*

18

Our Services—Guests



PHILOSOPHY OF CARE

Roger Neilson House is about living life to the fullest. The experience of a “home away from home” fosters freedom, security, pleasure, and quality of family life. Children, youth and their families living with a progressive life-limiting illness are entitled to access comprehensive palliative care services. This timely, holistic, patient and family-focused, culturally sensitive care is enhanced by the experience of Roger Neilson House.

END OF LIFE CARE

End of life care is available when it is determined by the medical team that death is imminent. The team works collaboratively to ensure that the final wishes and needs of each child and family are met in the weeks, days and hours leading up to the child’s death and beyond into bereavement. This involves helping family members make difficult decision around end of life plans, creating memories and sharing mementos as well as addressing emotional and spiritual care needs. Heartfelt guidance and compassionate support is offered to help with transitions at end of life for children and families.

PERINATAL HOSPICE

Pregnancy and infant loss is devastating and impacts those involved forever. Perinatal Hospice & Bereavement offered by the Roger Neilson House team is provided to parents and families in cases where there is a prenatal, perinatal or neonatal diagnosis of a life-limiting illness or a life-ending diagnosis. It is specialized care that prepares parents for the birth, death and sorrow of the impending loss of their much loved child. Care is provided in a timely manner and is dependent on parental/family needs and wishes.

RESPIRE CARE

The word *respite* is synonymous with *pause*. The provision of respite care at Roger Neilson House is a very important form of support for families coping with the many challenges of their child’s life-limiting illness. It allows a family the time it needs to rest and rejuvenate so they are better able to care for their child. It also provides an opportunity for the staff to monitor the child’s health and support the family with challenges they might be facing in the community. During the respite visit children might be offered or require symptom management, recreation therapy and counselling.



*Symptom
Management
Admissions*

131

In 2017-18

170

In 2018-19

*Transition
Admissions*

5

In 2017-18

11

In 2018-19

Our Services—Guests



SYMPTOM MANAGEMENT

Symptom assessment and management is available at Roger Neilson House and is coordinated by the CHEO Palliative Care Team in consultation with the family, members of the care team and CHEO care teams. A child is admitted to the hospice for a period of time to evaluate symptoms, implement treatment modalities and evaluate responses.

TRANSITIONAL CARE

A transition to home admission at Roger Neilson House is coordinated by CHEO Palliative Care Team. Children leaving hospital with new treatments, equipment or medications may be admitted to the hospice for a period of time to enable families to become familiar and comfortable with a new plan of care. Families assume the responsibility for their child's care while also receiving support and reinforcement of the instruction they received at CHEO.

VISITING HOME HOSPICE

To meet the need for short-term in-home relief, Roger Neilson House created the Visiting Home Hospice Program. Screened and trained, volunteers are carefully matched with families to assist with a variety of supportive tasks including care of siblings, playing, or reading with children and light housework. The volunteer's consistent presence in the home becomes a break to look forward to for both care givers and children. Volunteers visit for up to two hours each time. Eligibility is limited to families receiving palliative care at Roger Neilson House. The Visiting Home Hospice is designed to compliment other professional caregiver and respite services.

MEMORY MAKING & LEGACY BUILDING

Throughout a child's involvement in the palliative care program, with Roger Neilson House, families may make lasting memories and keepsakes including handprints, photography, artwork, referrals to wish granting organizations and participation in special events.

RECREATION THERAPY PROGRAM

Children requiring Roger Neilson House services often miss out on parts of their childhood due to being medically fragile. The Recreation Therapy program at Roger Neilson House aims to ensure these children experience normal childhood life, as well as fulfill their wishes however big or small. Developing this program will mean more dreams can come true for these children, resulting in improved quality of life and creating a greater sense of legacy for each family Roger Neilson House supports. Programs under Recreation Therapy include Memory Making, Zen Zone Adaptive Yoga and the Music Care Program.

28,957

*Days of care provided
since opening
in 2006.*



Our Services—Family Supports



SUPPORT GROUPS AVAILABLE AT ROGER NEILSON HOUSE

Palliative Care Parent Support Group: This “drop-in” group format and provides a safe space for parents to share their thoughts, emotions and coping strategies, as well as an opportunity to connect and develop relationships with other parents throughout their child’s illness.

Spectacular Incredible Brave Siblings (S.I.B.S.): The group’s objectives are to create opportunities for siblings to receive support from peers going through similar experiences and to help decrease feelings of isolation. Art and drama are used to encourage self-expression in a fun, safe environment. Siblings are invited to share their experiences and ask questions of medical professionals.

Parent Bereavement Support Group: Open to any parent who has lost a child under the age of 19. The death of a child is believed to be the most difficult loss a family can experience. Different themes such as coping strategies or the impact on other relationships are raised each week for discussion.

Grandparent Bereavement Support Group: Grandparents, who often have a special relationship with their grandchildren, can feel hopeless and isolated in their experience of grief, and may not know how to support their bereaved adult children. As with the Parent Bereavement Support Group, different themes are raised each week for discussion throughout the six-session program.

Perinatal Loss Parent Bereavement Support Group: For parents who have lost an infant to stillbirth over 20 weeks gestation, neonatal death up to the first 28 days of life, or medical termination or induction where a palliative diagnosis or pregnancy existed for the infant or mother.

Pregnancy After Loss Support Group (PALS): This is a monthly drop-in group for families who have already accessed RNH services and are currently pregnant and struggling emotionally. Topics such as managing guilt, impact on relationships, and managing the expectations of others are explored.

Sibling Bereavement Support Group: Facilitated by recreational therapists concurrently with the Parent Bereavement Support Group. The group uses a developmental model to help siblings understand their grief and learn coping strategies.

RNH Bereaved Families Support Night Monthly Drop-in: This is a monthly drop-in group for parents to support one another through their grief experience. Facilitated by a Social Worker, this group is open to any bereaved parent who has previously participated in RNH programming.

*Respite
Admissions*

301

In 2017-18

271

In 2018-19

2,435

*Number of
counselling visits
in 2017-18*

2,786

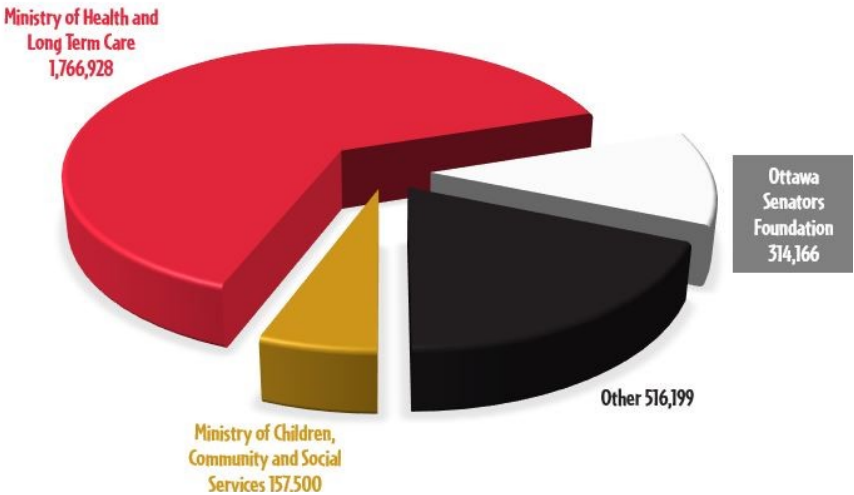
*Number of
counselling visits
in 2018-19*

Year Ended March 31st, 2019

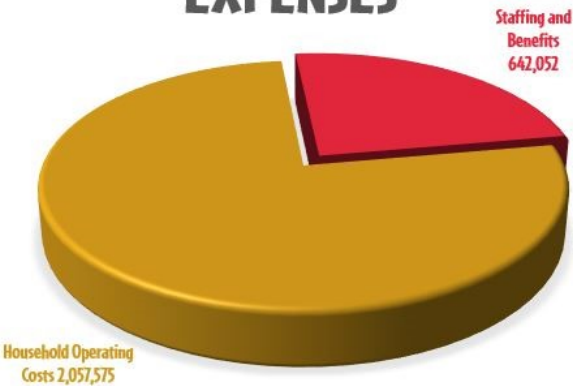


The majority of Roger Neilson House resources are directed towards program and service costs at the House and in the community. Our objective is to operate on a break-even basis and for the 2018-19 fiscal year, our operating budget was \$2.6 Million dollars.

REVENUE



EXPENSES





Our Team

The Roger Neilson House team offers a multitude of services that cater to the unique needs of a medically fragile population. Roger Neilson House also offers an environment that celebrates life by enabling kids to be kids, and it is a special place of comfort and compassion where children and families can cherish each moment spent together.

BOARD OF DIRECTORS 2018-19

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Mike Lupiano, Vice Chair
Ruth Hartanto, Past Chair
Jeff Polowin, Secretary
Ian Hendry, Treasurer
Alexa Brewer, Director
Anne Huot, Director
Caitlin Neil, Director
Dr. David Creery, Director
Robert Houston, Director
Brad Weir, Ex-officio Director
Jacqueline Belsito, Ex-officio Director
Megan Wright, Ex-officio Director

FAMILY ADVISORY COMMITTEE 2018-19

Kimberley Waara, Chair
Betran Labonté, Parent
David Bell, Parent
Caroline Signorini, Parent
Chloe Benoit, Parent
Lilian Kitcher, Parent
Richard Ouimet, Parent
Yara Saikaly, Parent
Jean Murray, Secretary
Beatriz Alvarez, Volunteer
Megan Wright, Executive Director
Helen Yoxon, Manager
Anne Jones, Admissions Coordinator
Bruno Perrier, Manager
Community Engagement and Volunteer Relations

ADMINISTRATIVE STAFF (Current)

Megan Wright, Executive Director
Helen Yoxon, Manager
Sonja Marshall, Coordinator
Strategic Projects & Governance
Harrison White, Bookkeeper

Dr. Chris Vadeboncoeur MD, Medical Director
Bruno Perrier, Manager
Community Engagement and Volunteer Relations
Jennie Wilson, Administrative Assistant
Community Engagement and Volunteer Relations

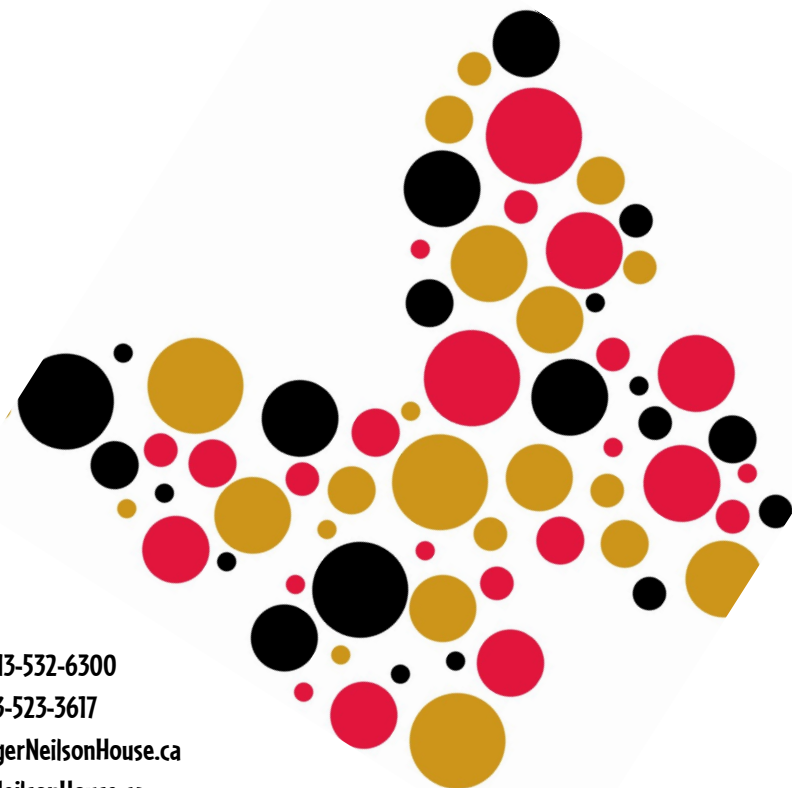
VOLUNTEER ADVISORY COMMITTEE 2018-19

Carole Brule, Chair
Scott Gunn, Vice-Chair
Alanna Jane, Volunteer
Christine Grace, Volunteer
Clare Pearson, Volunteer
Eva Latourell, Volunteer
Francine Boucher, Volunteer
Liz Kelly, Volunteer
Mac Hiltz, Volunteer
Marilyn Stairs, Volunteer
Terry Moxness, Volunteer
Villana Murray, Volunteer
Joann Zimmerling, Personal Support Worker
Danielle Scarlett, Recreation Therapist
Bruno Perrier, Manager Community Engagement and Volunteer Relations
Jennie Wilson, Administrative Assistant, Community Engagement and Volunteer Relations

CLINICAL STAFF (Current)

Ann Hicks, RN
Anne Jones, Admissions Coordinator
Barb Juett, Social Worker
Buhle Ncube, Personal Support Worker
Carinne Moreau, Personal Support Worker
Carleigh Sanders, RPN
Carol Chevalier, Social Worker
Catlyn Halley, RN
Charles Medeiros, Personal Support Worker
Cheryl Wall, RPN
Dr. Chris Vadeboncoeur, Medical Director
Dr. Dawn Davies, MD
Claire Nickerson, RPN
Courtney Potvin, RPN
Danielle Scarlett, Recreational Therapist
David Ricciardelli, RN
Emily Fullarton, RN
Jacqueline Davis, RPN
Jenna Marsh, RPN
Jennifer Quinn, RPN
Joann Zimmerling, Personal Support Worker
JoAnne MacNeil, RN
Jodi Ouellette, RN
Kaitlyn O'Connor, RPN
Katharina Skrzypek, RN
Katt Brooks, Recreational Therapist
Kirsten Neville, RN
Leah Bradley, Recreational Therapist
Lesley Sabourin, RN
Leslie Pottier, RN
Lyndsey Fisher, RN
Lynn Grandmaison-Dumond, Nurse Practitioner
Madelena Arnone, Social Worker
Dr. Megan Doherty, MD
Megan Sloan, RPN
Maureen Merkley, RN
Monica Sevigny, RPN
Nahal Stoppels, RN
Nancy Graham, Quality Coordinator
Raven Barton, RN
Sabrina Morin, RPN
Samantha Day, PSW
Sara Rushton, RPN
Sarah Allan-Wiseman, Social Worker / Admin.
Steven Lozanski, RN
Suzanne Henderson, RN
Dr. Stephanie Van Zanten, MD
Virginia Meisner, RN
Wendy Gougeon, RN
Wendy Mihell, RN
Dr. William Splinter, MD





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Social Media

Twitter: @RNeilsonHouse

Facebook: Roger Neilson House

Instagram: @rogerneilsonhouse

Memberships

Canadian Hospice and Palliative Care Association | Canadian Pediatric Residential Hospice Network |
Hospice Palliative Care Ontario (HPCO) | Volunteer Ottawa | Ontario Hospital Association



Roger Neilson House Board of Directors