





# **Roger Neilson House**

## **2017-18 Annual Report**

## *Children Served*

**106**

*In 2016-17*

**96**

*In 2017-18*

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*

**2,265**

*In 2016-17*

**2,621**

*In 2017-18*

## 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

428

In 2016-17

457

In 2017-18

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



After a decade of meeting the palliative care needs of children and their families, the Board of Directors and management of Roger Neilson House began a process of renewal. The 10-year anniversary was an opportunity to reflect on the contribution Roger Neilson House has made in the community and to celebrate its accomplishments. It was also a time to formally assess the organization to determine its strengths and weaknesses and the opportunities and challenges going forward.

In 2017 Roger Neilson House embarked on an extensive strategic planning process. We conducted a far reaching environmental scan and gathered input and feedback from our many stakeholders. From this scan themes emerged that were then developed into strategic directions, and the new vision and mission of Roger Neilson House became clear.

With a well-understood road map firmly in hand, the Board of Directors and management of Roger Neilson House are prepared to steer the organization into the next decade. We wish to thank everyone involved with helping Roger Neilson House set our course for the next ten years. Your input was invaluable.

Throughout the year, we continued to see growth in our programs and services. As compared to last fiscal year, the symptom assessment service at Roger Neilson House saw a 64% increase in growth, the perinatal hospice bereavement support group increased by 38%, and we saw an overall growth in occupancy of 15%.

In July and August of 2017, we held our inaugural summer camp program at Roger Neilson House. Our special summer day camp was tailored specifically for the needs of our children. Laughter filled the house during those weeks as the children participated in many fun activities. We thank all of the volunteers, families, and staff that participated in this new program. It was such a huge success that camp will be run again for three weeks over the summer of 2018.

In 2017-18, Dr. David Creery, Anne Huot, and Caitlin Neil were welcomed to the Board of Directors, along with Brad Weir who joined the Board of Directors as an ex-officio member. We also bid a fond farewell to two long standing members, Susan Richardson and Dr. Pranesh Chakraborty.

We would like to take this opportunity to thank our board members, staff, volunteers, community partners, and most importantly, our families. Roger Neilson House is in a stable position due to the stewardship of our Board of Directors and the excellence of the Roger Neilson House management and staff. We constantly hold ourselves accountable to a high level of service excellence. We look forward to caring for families in need in the coming year, and for many, many more years to come.

Roger Neilson House continues to rely on the support of the Ottawa Senators Foundation and the CHEO Foundation. We are extremely grateful for the support of our partners and the community, which ensures that our programs remain available and flexible to meet the growing demand for palliative care services in our region.



Les Bell  
Chair, Board of Directors  
Roger Neilson House

Megan Wright  
Executive Director  
Roger Neilson House

390

*Number of families supported  
through their child's end of life.*



## Message from the Chair of the Family Advisory Committee



The Family Advisory Committee (FAC) fulfills an important role in providing feedback from a parent and caregiver perspective to the Roger Neilson House (RNH) management team. The various ways in which RNH cares for children and their families are represented in the diversity of committee members and their collective experiences.

There has been an exciting and remarkable increase in projects and programs at RNH this year. As a result, it was determined by the FAC that meeting every eight weeks would not be sufficient. Therefore, FAC now meets monthly which allows us to fulfill our mandate to advise and provide recommendations in a timely manner. Over the past nine months our agendas have been full as we provided feedback on the development and implementation of many new programs, research initiatives, and documentation revisions.

In previous years, the FAC created a work plan based on three main priorities identified by the committee and approved by the board. This year, the committee agreed that it would be beneficial to wait for the results of the strategic planning process before setting specific objectives. In December, when the final strategic directions were presented, "Working in Partnership" was identified as an area where the FAC felt they could make a valuable contribution. We discussed the importance of embedding patient and family engagement in all areas of operation at RNH and decided to make this goal a standing item on our monthly agenda. The committee benefited from the knowledge of several guest presenters who are skilled in the process of setting up a formal engagement framework.

Subsequently, the FAC held a special brainstorming session and produced a document created to define a common approach to planning for, and evaluating engagement initiatives across four specific domains. There is still much work to be done in this initial stage, however the FAC is proud to have already been part of several small scale engagement initiatives. For example, parental involvement has been sought in establishing criteria for hiring new staff, summer camp programming, forming the peer matching program and the purchase of softer, more tear friendly Kleenex!

On a personal note, I feel honored to have fulfilled the chairperson role this year, and I truly appreciate each member of the FAC. They are generous with their time and energy and give genuine consideration to all of the items brought forward. The committee is sincerely invested in representing the family perspective to enhance and improve care and the RNH experience. It is gratifying that the management team thoughtfully considers the committee's ideas and perspectives, and integrates them where possible.



Kimberley Waara  
Chair, Family Advisory Committee  
Roger Neilson House

**25,361**

*Days of care provided since  
opening in 2006.*

**445**

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



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



The Volunteer Advisory Committee (VAC), implemented in February of 2018, is an important collaborative link between volunteers of Roger Neilson House and the leadership team & staff. The VAC's primary objective is to provide timely, constructive feedback from a volunteer perspective to RNH. The VAC is composed of eight to twelve volunteers, the Manager of Community Engagement and Volunteer Relations, the Volunteer Services Administrative Assistant, and up to two additional RNH staff members. Members of the RNH leadership team, such as the Executive Director, attend periodically.

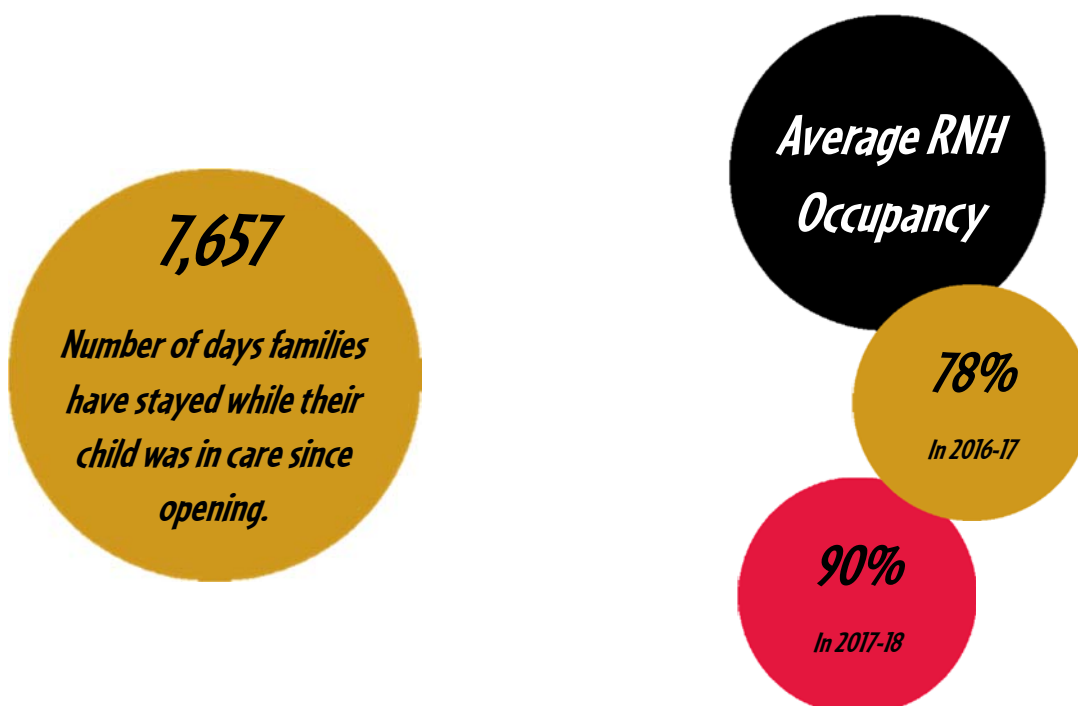
Given that the VAC has only recently been established, a more fulsome annual update will be provided in RNH's 2018-2019 annual report, however, the VAC has already made significant progress in terms of identifying work plan priorities for the coming year. These priorities include reviewing, refining and streamlining the volunteer on-boarding and training process, and developing more comprehensive and accessible support systems such as volunteer bereavement support.

The VAC provides volunteers with a unique opportunity to become integrated with the rest of the RNH team through monthly meetings. We hope to use the VAC as a platform to engage volunteers and make optimal use of their various skill sets. Finally, we are excited to help improve the already amazing care our families receive by facilitating effective communication between staff and volunteers. On behalf of the VAC and all of the volunteers, we would like to thank everyone who makes RNH such a wonderful and engaging place to volunteer, we are looking forward to what the next year has in store!



Carole Brulé  
Chair, Volunteer Advisory Committee  
Roger Neilson House

Scott Gunn  
Vic-chair, Volunteer Advisory Committee  
Roger Neilson House



## Volunteer Services



In the past year, volunteers continued to contribute their diverse talents and experience to improve the quality of life of the children and families we serve. They donated a total of 16,261 hours of their time in countless ways, whether playing with the kids, creating memories for children and families, ensuring the House is well maintained, providing office support, or preparing delicious and healthy meals.

RNH developed a new strategic plan this year which emphasized the value of building “one strong team of staff and volunteers that is nurtured, strengthened, and supported”. With that in mind, volunteers have partnered with staff members on numerous initiatives and committees with a shared vision of improving both the services we offer, and the RNH staff and volunteer experience. For example, we’ve included a volunteer on the strategic planning steering committee; added volunteers to the Joint Health and Safety Committee and the Wellness Team; and created a volunteer music program committee under the leadership of the recreation therapists.

Another exciting initiative was the creation of our Volunteer Advisory Committee. Although it is still a young committee, it has already proven to be quite valuable. Thank you to our inaugural chair and vice-chair, Carol Brulé and Scott Gunn, who will lead the committee in presenting the volunteer perspective on matters that pertain to their experience at RNH.

Finally, volunteers were an integral part of the first ever RNH summer camp, which was a great success. The volunteers were instrumental in offering our kids fun-filled activities and creating lasting memories.



**Bruno Perrier**  
Manager, Community Engagement and Volunteer Relations  
Roger Neilson House

**163,700**

*Number of hours volunteers  
have dedicated to create  
a home for families.*

*‘I walked over one night to say  
hello to [my child]. I was going to give him  
some snuggles and put him to bed, but when I  
arrived, he was being fawned over by 2 volunteers.  
His hands were held and he was sleeping in bliss. It  
made me feel so happy that he was in such good  
hands. Thank you for making him so comfortable  
here.’ - Parent*



## Our Services



### END OF LIFE CARE

For children and families who choose to spend their final days together at Roger Neilson House, end of life care is provided. The Roger Neilson House team works collaboratively to ensure that the final wishes and needs of each child and family are met.

While the child receives assistance with pain and symptoms, families receive the emotional and spiritual support they need, and assistance with often difficult decisions as end of life nears. Every effort is made to maximize the quality of life for both child and family.

### PERINATAL HOSPICE

The Roger Neilson House team provides parents and families with perinatal hospice and bereavement services 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.

### SUPPORT GROUPS AVAILABLE AT ROGER NEILSON HOUSE

**Palliative Care Parent Support Group:** A safe space to share experiences with others and an opportunity to connect and develop friendships with other parents.

**Parent Bereavement Support Group:** Open to any parent who has lost a child under the age of 19. Sharing experiences with others who understand can bring comfort, and being part of a group can help reduce the feelings of isolation common to bereaved parents.

**Perinatal Loss Parent Bereavement Support Group:** For parents who have lost an infant to a stillbirth (over 20 weeks gestation) or a neonatal death (up to the first 28 days of life).

**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.

**Spectacular Incredible Brave Siblings (S.I.B.S.):** An opportunity for siblings to receive support from peers going through similar experiences. Facilitated by recreational therapists and trained volunteers, siblings are invited to share their experiences and ask questions of professionals.

### 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 give up to two hours of their time. Eligibility is limited to families receiving palliative care at Roger Neilson House.

The Visiting Home Hospice is intended to compliment other professional caregiver and respite services.

*Symptom  
Management  
Admissions*

**85**

*In 2016-17*

**131**

*In 2017-18*

## Our Services



### GRIEF AND BEREAVEMENT COUNSELLING

The death of a child is a life-altering tragedy for the families who love them and who must accompany them through this difficult journey. Roger Neilson House provides support to family members from a child's diagnosis, throughout their illness, and after their death, grief support and bereavement care are offered to the entire family.

### RESPITE CARE

Children and youth come to Roger Neilson House for support and a time away from home. This is an opportunity for families to rest and rejuvenate and for children to develop new relationships and have fun.

During their stay, children are assessed and cared for by our specialized team of medical professionals. Immediate family may also stay with their child and receive support and guidance in relation to their child's illness. The goal of the stay is to improve the quality of family life – and to provide an enjoyable and memorable stay for the child.

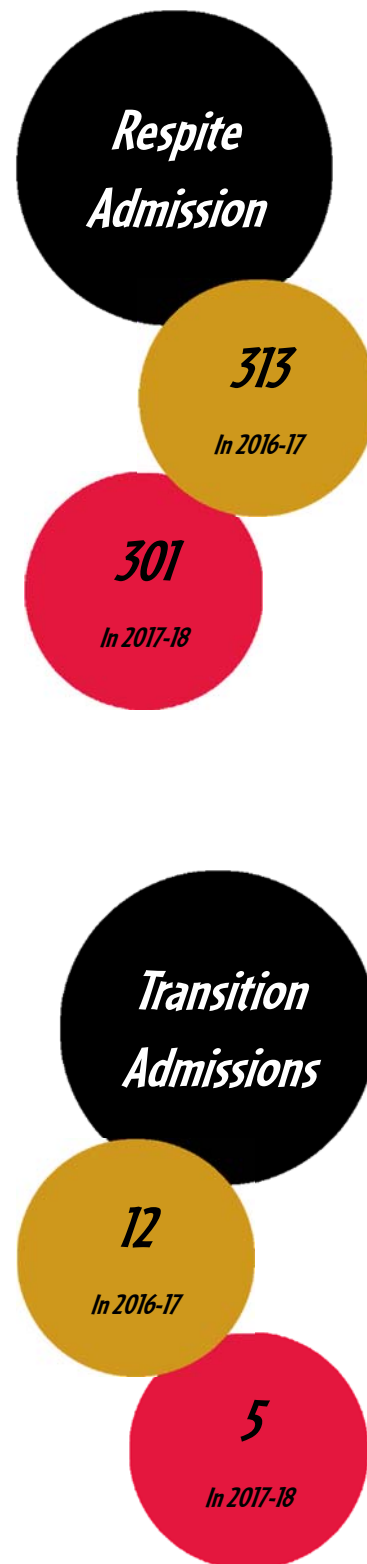
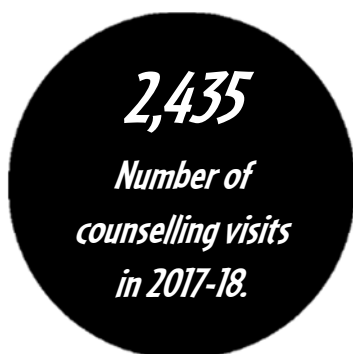
Children staying at the house enjoy many activities together under the guidance of professional recreation therapists, volunteers, and staff.

### SYMPTOM MANAGEMENT

Each family referred to the CHEO Palliative Care Team has access to care and support at Roger Neilson House if their child experiences distressing symptoms during the course of their illness. Issues may require assessment, evaluation, adjustments to medication, observation, and changes to the child's care plan. The length of stay is determined by the severity of the symptoms and the child's response to treatment.

### TRANSITION FROM HOSPITAL TO HOME CARE

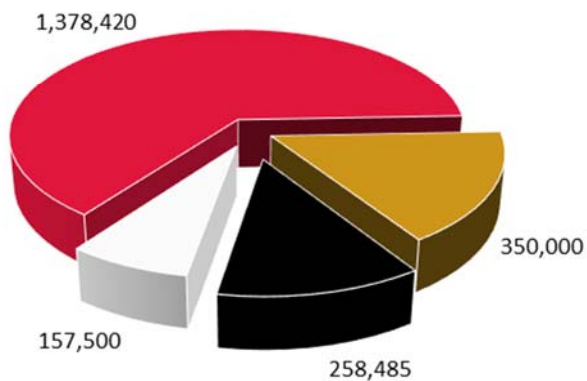
Children who have been hospitalized may transition to home through Roger Neilson House. The transition period allows families and care givers to become familiar with new treatment plans, equipment, technology, and medications. Our team of professionals reinforces and support instruction received at CHEO and families become more comfortable with their child's care.



## Year Ended March 31<sup>st</sup>, 2018

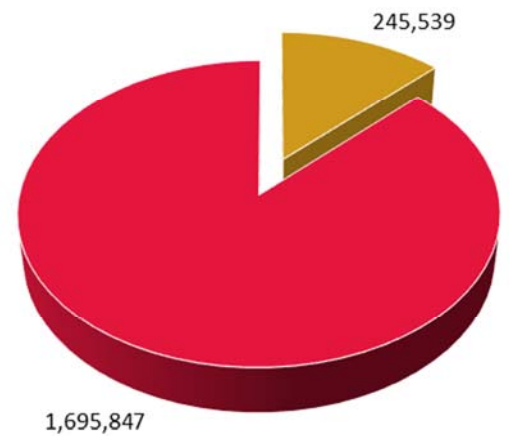
The majority of Roger Neilson House resources are directed towards program and service costs at the House and in the community. Our objective is to operate on a break-even basis and for the 2018 fiscal year, our operating budget was \$2 Million dollars.

### Revenue



Ministry of Child and Youth Services    Ministry of Health and Long-Term Care  
Ottawa Senators Foundation    Other

### Expenses



Household Operating Costs    Staffing and Benefits



## 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 2017-18

Les Bell – Chair  
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 2017-18

Kimberley Waara– Chair  
Betran Labonté  
David Bell  
Caroline Signorini  
Chloe Benoit  
Katelyn Fleming  
Lilian Kitcher  
Richard Ouimet  
Yara Saikaly  
Jean Murray – Secretary  
Beatriz Alvarez – RNH Volunteer Rep.  
Bruno Perrier – Manager, Community Engagement and Volunteer Relations  
Anne Jones – RNH Nursing Rep.

### CLINICAL STAFF (Current)

Ann Hicks, RN  
Anne Jones, RN  
Barb Juett, Social Worker  
Dr. Ben Robert, MD  
Brandy Prevost, RPN  
Buhle Ncube, PSW  
Candace Bretzer, RPN  
Carinne Moreau, PSW  
Carol Chevalier, Social Worker  
Charles Medeiros, PSW  
Cheryl Wall, RPN  
Dr. Chris Vadeboncoeur, MD  
Danielle Scarlett, Recreational Therapist  
David Ricciardelli, RN  
Elliott Strikefoot, RPN  
Jacqueline Davis, RPN  
Jan Mingie, RN  
Jenna Marsh, RPN  
Jennifer Quinn, RPN  
Jennifer Simpson, PSW  
Joann Zimmerling, PSW  
Jodi Ouellette, RN  
Katie Patterson, RPN  
Katharina Skrzypek, RN  
Katt Brooks, Recreational Therapist  
Kirsten Neville, RN  
Lesley Sabourin, RN  
Lynn Grandmaison Dumond, Nurse Practitioner  
Madelena Arnone, Social Worker  
Marion Rattray, Bereavement Care Nurse  
Dr. Megan Doherty, MD  
Megan Sloan, RPN  
Maureen Merkley, RN  
Melissa Heath, RPN  
Monica Sevigny, RPN  
Nahal Stoppels, RN  
Nancy Graham, Quality Coordinator  
Raven Barton, RN  
Sabrina Morin, RPN  
Samantha Day, PSW  
Suzanne Henderson, RN  
Dr. Stephanie Van Zanten, MD  
Wendy Gougeon, RN

### ADMINISTRATIVE STAFF (Current)

Megan Wright, Executive Director  
Dr. William Splinter MD, Medical Director  
Helen Yoxon, Manager  
Bruno Perrier, Manager of Community Engagement and Volunteer Relations  
Sonja Marshall, Senior Administrative Assistant  
Alexandre Dumond, Administrative Assistant  
Sarah Allan-Wiseman, Administrative Assistant/Social Worker





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### **Memberships**

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

