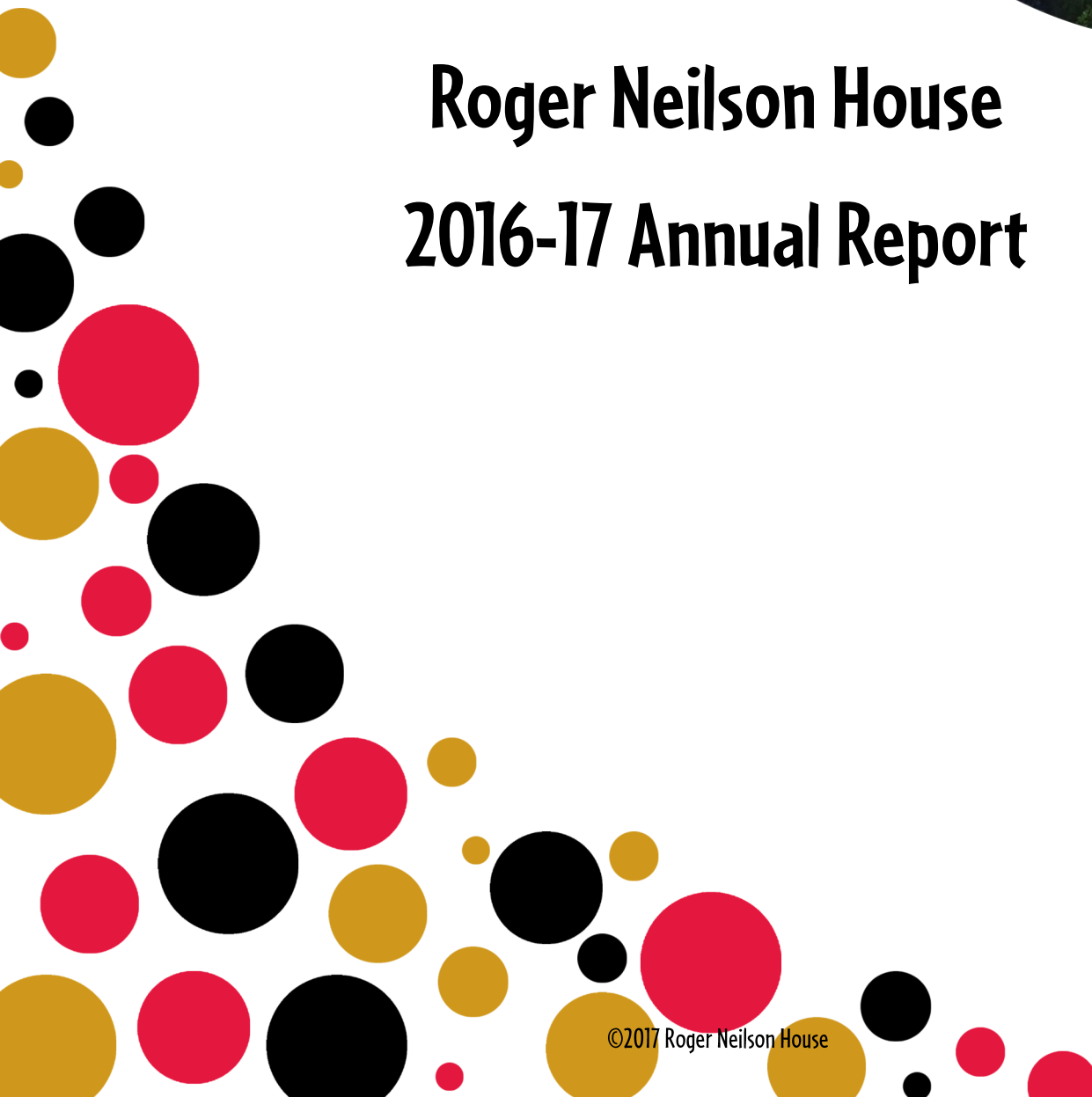






Roger Neilson House

2016-17 Annual Report



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 the Children's Hospital of Eastern Ontario (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.



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

Our team provides respite and end of life care, transition to home support, pain and symptom management, perinatal care, and bereavement counselling 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.



OUR VALUES

Roger Neilson was well known for his generosity, humanity, sense of humour, compassion and love of children. These values as well as respect, family focused care, collaboration, creativity, and excellence will govern our daily work with families, the community, and each other.

OUR VISION

Roger Neilson 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.

Message from the Executive Director



The past year was a year of celebration and a year of renewal for Roger Neilson House. It began with a new name, a new logo, a new collaborative partnership with the CHEO Foundation, and a historical \$2.2 million donation from the Ottawa Senators Foundation that will go a long way to ensuring a firm financial foundation for Roger Neilson House.

We took the opportunity to mark the 10th anniversary of the “House that love built” to open our doors to the community and welcome back all those who helped it become a reality. The provincial government also took the opportunity to announce a large increase in the provincial budget dedicated to palliative care. The new provincial funding is welcome and needed, and indicative of the growing attention palliative care is receiving across Canada.

With the successes of our first decade fresh in our minds, we began, in 2016, a strategic planning process that is now well underway. The new Strategic Plan will help ensure that we can continue to provide the highest quality of services to the children, youth, and families we serve, and to respond to future challenges and opportunities.

Even as we plan, we continue to expand our services and improve the House. New initiatives this year included music care, yoga for families, and coffee chat - a means to connect bereaved and active families. We added a grandparent bereavement support group that has been very successful. This summer we will pilot a day camp program for kids.

Services such as symptom assessment and transition to home have proven successful in keeping children out of the hospital. Symptom assessment admission have more than tripled in the past 6 years and we have taken measures to improve the outcomes of these programs, to better understand and document the needs and goals of families who participate in them, and to ensure we are meeting these needs and goals prior to discharge. We will adapt this process to end-of-life admissions later this year.

We now have eleven families served by the visiting home hospice program. Each family has received, on average, over 45 hours of care per year, and feedback from both families and volunteers has been very positive.

Updates continued at the House this past summer. Our new outdoor play area was completed, and two more lifts were added to upstairs bedrooms. We will continue to improve the House to create beautiful spaces for children and families.

In conclusion, I would like to thank Ruth Hartanto who is completing a three year term as RNH Board Chair. Ruth has been a Board member since Roger Neilson House opened in 2006 and participated in the planning phase of Roger Neilson House as a family representative.

I would also like to thank our dedicated staff and our many volunteers who continue to be our greatest strength, as well as our primary funders, the Ottawa Senators Foundation and the CHEO Foundation, who have clearly shown their continued support for Roger Neilson House.



Megan Wright
Executive Director
Roger Neilson House

Message from the Chair of the Board of Directors



There is no doubt that Roger Neilson House has made a difference.

We are in the midst of our strategic planning process as of this writing, and it has allowed us to hear from others how much of a positive impact we have made.

Both families and the community have commended Roger Neilson House staff and volunteers for their compassion and commitment. We are a respected leader in pediatric palliative care with a willingness to share our expertise and knowledge. And our model of care and partnership with the Children's Hospital of Eastern Ontario enables us to provide children with life limiting conditions continuity and seamless care.

Last spring, we marked our 10th anniversary by celebrating our many successes such as: that of the greater Ottawa community coming together to build and support the area's first pediatric palliative care hospice; of being able to fill many voids by providing exceptional perinatal, pain management, bereavement and respite services to 419 children since we opened our doors; and of being able to respond to the needs of our families in their most vulnerable and stressful times.

This past year, Roger Neilson House started a well-received grandparent bereavement support group as well as visiting home hospice program. Both of these programs demonstrate our commitment to providing holistic services that encompasses both child and family.

Our ability to respond to our families' needs is truly one of our strengths, be it by implementing programs such as the above, or simply allowing a pet to join a grieving family in the house.

As one parent said, "How wonderful to get a few hours of respite in our own home while our child is being cared for by a loving volunteer from Roger Neilson House."

Many thanks to the heart of this home, our staff and volunteers, Executive Director Megan Wright for taking initiatives and being proactive, and the Ottawa Senators Foundation and CHEO Foundation for their long standing support.

Thank you also to the board. As I reflect on my past three years as chair, what foremost comes to mind is how smoothly this board operates because of my colleagues around the table. Thanks to each of you for your expertise and commitment, as well your amicable nature.

While it is reaffirming to hear of the impact we have made, we still have work to do. With palliative care coming to the forefront on a national level, Roger Neilson House is well positioned to be key player in increasing the awareness of pediatric palliative care.

I am confident the next 10 years will see Roger Neilson House continue to play a leadership role in finding opportunities and partnerships to ensure that every child who could benefit from palliative care does.



Ruth Hartanto
Chair of the Board of Directors
Roger Neilson House



Message from the Chair of the Family Advisory Committee



The Family Advisory Committee (FAC) is an important integrative link for families of Roger Neilson House (RNH), the Executive Director, leadership team, employees and volunteers. It aims to provide timely, constructive feedback from a family perspective to RNH.

With the support of the Board of the Directors, our committee voted on our top three priorities for the 2016-17 year. As well as progress on these initiatives, we worked with the leadership team to highlight the importance of admission and discharge times, additional family support groups and took part in the RNH strategic planning process. We remain committed to improving communication between families and the RNH team and to identifying opportunities where the FAC can facilitate these connections.

This year we said farewell to some of our earliest members of the FAC, whom we now refer to as FAC Alumni and welcomed new members who joined the committee in September 2016.

On behalf of the FAC members I would like to express our gratitude to all who have made Roger Neilson House what it is today. You anticipate the needs of children and families and provide exemplary care (body, mind and spirit). You have also given us a place where we are understood, a community of friends and professionals and memories that are integral to helping us live our best lives.

With Gratitude,



Mindy McHardy

Chair of the Family Advisory Committee
Roger Neilson House

419

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

Hope

a poem by Maddie, Katie, Carinee, and Buhle

My wish for you is to be in the moment, recognizing that you
will experience the highs, the lows, the terrible, and the
wonderful.

I will be there to help guide you and to listen to you, enjoying
the days you have, not dwelling on the what-ifs.

Even in your darkest hour, my wish for you is to find light.



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 in the weeks, days and hours leading up to a child's death and beyond into bereavement.

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. Heartfelt guidance and compassionate support is offered at end of life to both children and families.

169

Number of children cared for during end of life at Roger Neilson House.

"I also want to thank you for our son's hand prints that you guys made for us. Every morning I go in my son's bedroom and make sure to touch the hand print. It seems like it gives me the strength to complete my day. It was the best gift we could have received."
- Parent

RESPIRE 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. It also provides an opportunity for the staff to monitor the child's health and support the family with the challenges they might be facing.

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 play games, watch movies, do arts & crafts, bake, go on scavenger hunts, and enjoy many other activities together under the guidance of professional recreation therapists, volunteers and staff.

Eligible families may book up to 28 days of respite care per year and up to 72 hours of emergency respite.

22,932

Days of care provided to children since opening in 2006

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. Care is provided in a timely manner and is dependent on family needs and wishes.

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 during their highly individual experience of grief. From a child's diagnosis, throughout their illness and after their death, grief support and bereavement care are offered to the entire family.

1839
*Number of
counselling visits
in 2016-17.*

*"It was an honour and a complete pleasure to meet the other group members and to hear them tell their difficult story. The sense of comfort that we felt in our group was immediate.
Thank You to Our Volunteers."
– Grandparent*

SUPPORT GROUPS AVAILABLE AT ROGER NEILSON HOUSE

Palliative Care Parent Support Group provides parents a safe space to share their experience with others who understand and an opportunity to connect and develop friendships with other parents facing similar issues.

Parent Bereavement Support Group is open to any parent who has lost a child under the age of 19. Grief is unique for each family member, but 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 families.

Perinatal Loss Parent Bereavement Support Group helps 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 runs concurrently with the Parent Bereavement Support Group. It is facilitated by recreational therapists. The group uses a developmental model to help siblings understand their grief and learn coping strategies through peer interaction and facilitated therapeutic activities.

Spectacular Incredible Brave Siblings (S.I.B.S.) creates opportunities for siblings to receive support from peers going through similar experiences and helps to decrease feelings of isolation. Facilitated by recreational therapists and trained volunteers, art and drama are used to encourage self-expression in a fun and safe environment. Siblings are invited to share their experiences and ask questions of professionals.

*"My husband and I feel so lucky to have found your support group. We're already feeling the benefits of hearing other stories and perspectives. It's become the most important thing on our calendar."
– Parent*



Our Services



TRANSITION FROM HOSPITAL TO HOME CARE

Children who have been hospitalized for surgical or medical reasons 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 and more comfortable with their child's care and needs. Care givers assume responsibility for their child's care while our team of professionals reinforces and support instruction received at CHEO.

6,988

Amount of days families have stayed while their child was in care.



18,468

Number of hours volunteers have dedicated to create a home for families in 2016-17.

VISITING HOME HOSPICE

Caring for a seriously ill child at home can be difficult and can place enormous physical and emotional strain on the whole family. For a child with complex medical needs, it can mean isolation from their usual friends and companions. Siblings can feel they are not receiving as much attention as they would like. Everyone in the family can feel they need a break and some time out.

To meet this need for short-term in-home relief, Roger Neilson House created the Visiting Home Hospice Program which formally launched in early 2016 following recruitment and training of volunteers.

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.

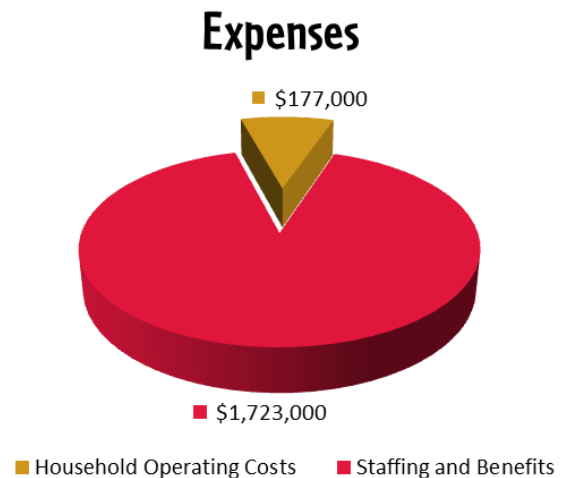
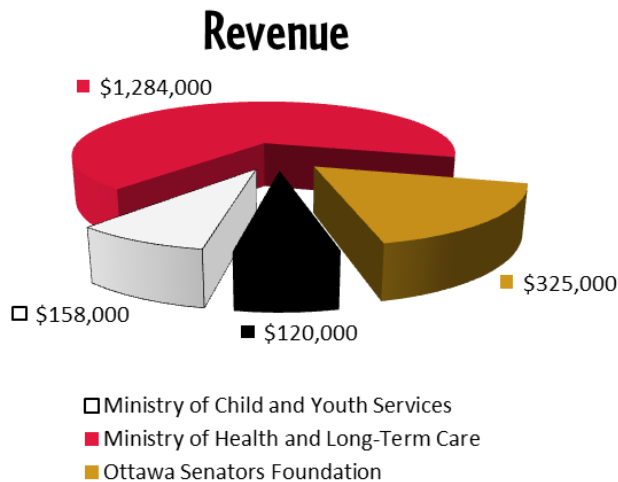
SYMPTOM MANAGEMENT

Each family referred to the Palliative Care Team at CHEO has access to care and support at Roger Neilson House if their child experiences distressing symptoms during the course of their illness. Increasing pain, spasticity and dystonia, seizures, feeding intolerance or constipation, and other issues may require assessment and evaluation, adjustments to medication, observation and changes to the child's care plan as needed. The length of stay is determined by the severity of the symptoms and the child's response to treatment.

Year Ended March 31st, 2017



The majority of Roger Neilson House resources are directed towards programs and service costs at the house and in the community. Our objective is to operate on a break-even basis and for the 2017 fiscal year, our operating budget was \$2 Million dollars.



Volunteer Services

From April 2016 to March 2017, 311 volunteers contributed 18,468 hours of service to Roger Neilson House, and the children and families it serves. Each volunteer donated on average a week and a half of their time to support Roger Neilson House. These volunteers are essential members of the Roger Neilson House team who serve and care for children with life-limiting illnesses and their families. We are extremely fortunate to benefit from such a diverse population of skilled, talented and generous members of the community. Their service and dedication is more than valuable; it is priceless!

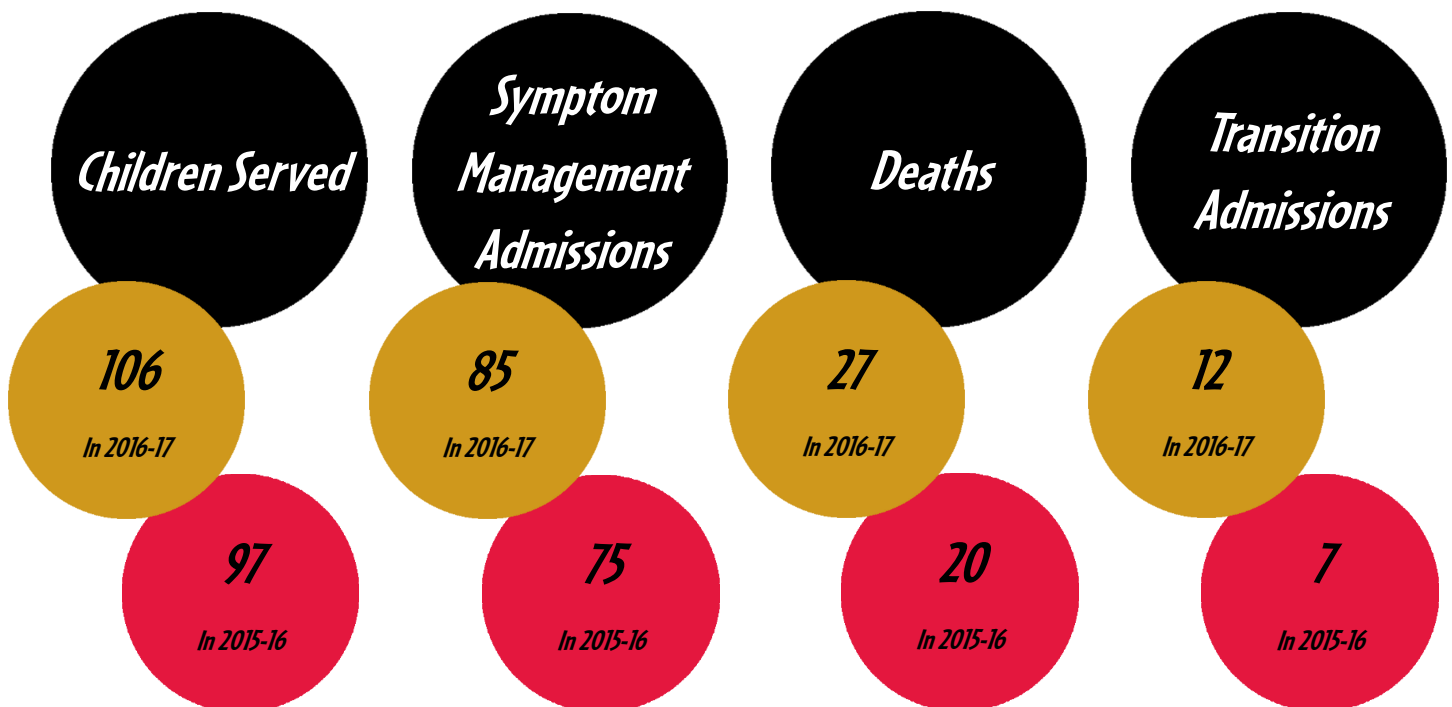
Further development of the Visiting Home Hospice program placed an even greater demand for volunteers to work up to two hours each week with a family receiving respite care from Roger Neilson House. 20 volunteers made 256 visits to homes this year. This service provides additional respite for families accessing Roger Neilson House and allows Roger Neilson House to remain in regular contact with all of our families. Roger Neilson House staff administering the program carefully match volunteer to child and family. The volunteer visits the home regularly to be a play companion and give a few hours of deserved respite to parents.

41 volunteers graduated from our Hospice Palliative Care Training. A 30 hour commitment from volunteers, the training, provided twice a year, is facilitated by the many staff at Roger Neilson House.



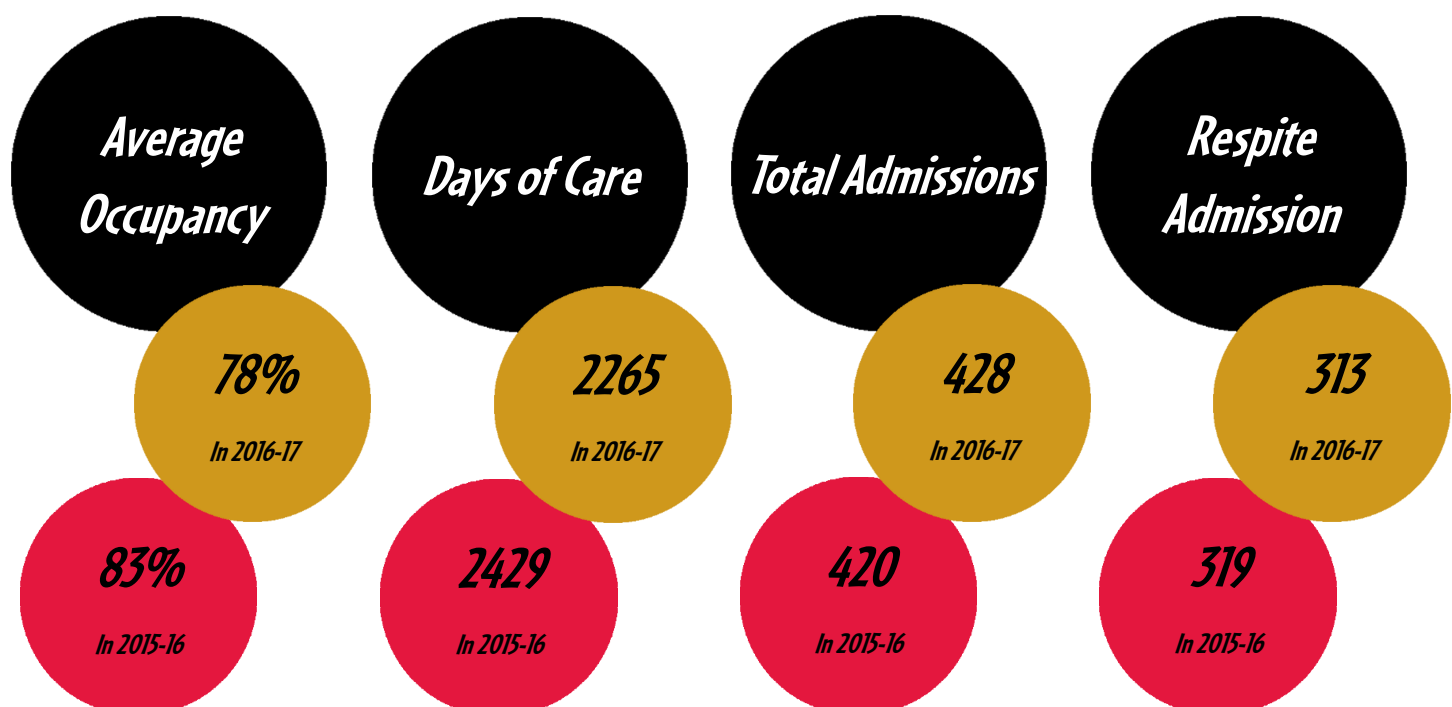
On the Rise

Outcomes increasing by over 7%



Steady as she goes...

Outcomes that have changed less than 7%



Our Team



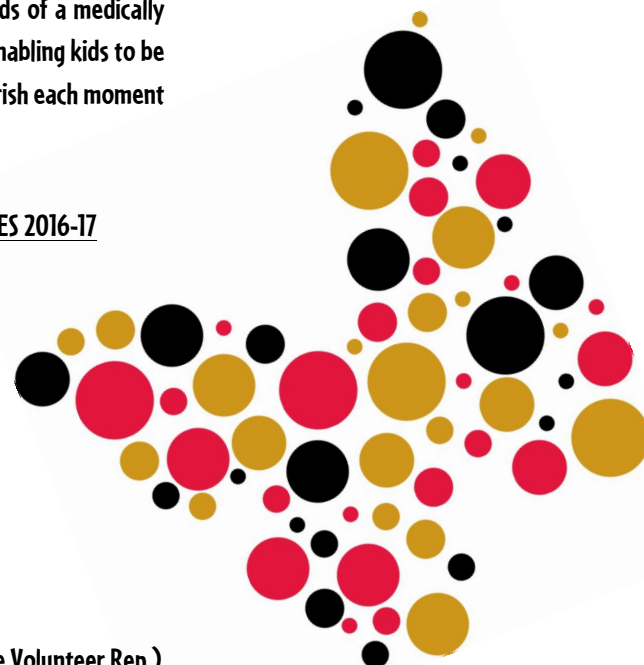
The Roger Neilson House team offers a multitude of services that cater to the unique needs of a medically fragile population. Roger Neilson House also offers an environment that celebrates life by enabling kids to be kids, and it is a special place of comfort and compassion where children and families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

BOARD OF DIRECTORS 2016-17

Ruth Hartanto – Chair
 Les Bell – Vice-chair & Treasurer
 Susan Richardson – Past Chair
 Jeff Polowin – Secretary
 Dr. Pranesh Chakraborty – Director
 Robert Houston – Director
 Ian Hendry – Director
 Mike Lupiano – Director
 Alexa Brewer – Director
 Danielle Robinson – Ex-officio
 Jacqueline Belsito – Ex-officio
 Megan Wright – Ex-officio

FAMILY ADVISORY COMMITTEES 2016-17

Mindy McHardy – Chair
 Alex Vanzyl
 Kimberley Jordan
 Katelyn Howse
 Richard Ouimet
 Yara Saikaly
 Lillian Kitcher
 David Bell
 Jean Murray (Secretary)
 Beatriz Alvarez (Roger Neilson House Volunteer Rep.)
 Nancy Graham (Roger Neilson House Staff Liaison)
 Anne Jones (Roger Neilson House Nursing Rep.)



STAFF (Current)

Megan Wright, Executive Director
 Dr. William Splinter MD, Medical Director
 Helen Yoxon, Manager
 Bruno Perrier, Manager of Community Engagement and Volunteer Relations
 Madelena Arnone, Social Worker
 Katt Brooks, Recreational Therapist
 Danielle Scarlett, Recreational Therapist
 Carol Chevalier, Social Worker
 Nancy Graham, Quality Coordinator
 Lynn Grandmaison Dumond, Nurse Practitioner
 Sonja Marshall, Senior Administrative Assistant
 Valerie Tinkess, Senior Administrative Assistant
 Alexandre Dumond, Clerk
 Sandie Lessard, Bookkeeper

CLINICAL STAFF (Current)

Candace Bretzer, RPN	Brandy Prevost, RPN
Molly Brown, RPN	Jennifer Quinn, RPN
Jacqueline Davis, RPN	Marion Rattray, Bereavement Care Nurse
Dr. Megan Doherty, MD	David Ricciardelli, RN
Wendy Gougeon, RN	Dr. Ben Robert, MD
Ann Hicks, RN	Lesley Sabourin, RN
Anne Jones, RN	Monica Sevigny, RPN
Marissa Majeau, PSW	Katharina Skrzypek, RN
Jenna Marsh, RPN	Megan Sloan, RPN
Charles Medeiros, PSW	Nahal Stoppels, RN
Maureen Merkley, RN	Dr. Chris Vadeboncoeur, MD
Jan Mingie, RN	Dr. Stephanie Van Zanten, MD
Carinne Moreau, PSW	Cheryl Wall, RPN
Buhle Ncube, PSW	Helen White, PSW
Kirsten Neville, RN	Dr. Robin Williams, MD
Jodi Ouellette, RN	Joann Zimmerling, PSW
Katie Patterson, RPN	



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contact info@rogerneilsonhouse.ca**

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Memberships

**Canadian Hospice and Palliative Care Association - Canadian Pediatric Residential Hospice Network
Hospice Palliative Care Ontario (HCPPO) - Volunteer Ottawa**

