



2015-2016

Annual Report

"Words cannot express how we feel about Rogers House and all those who are associated with it. The volunteers, doctors, staff and especially the nurses who made us feel as though we were "home" even when there was so much going on with (Patient name). The compassion that you showed us from the very beginning to the very end, will not be forgotten. Thank you for answering our many phone calls with such care. (Patient name) was a very special boy and he will be forever missed and loved. God bless."

Family of Patient





Roger's House

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's House was born— an eight-bed pediatric residential hospice which offers compassionate care in collaboration with CHEO's palliative care team.



Roger Neilson

OUR MISSION

Built in memory of Roger Neilson, Hockey Hall of Fame Coach and Member of the Order of Canada, Roger's 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's 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 home-like environment. Our dynamic, integrated team will collaborate with, and be accountable to, our families and community partners.

Message from the Executive Director



It has been 10 years since Roger's House opened its doors to serve the children and youth of our community who suffer from life limiting illnesses. In 2004 the need for Roger's House was widely recognized and the community rallied behind the effort to build a modern palliative care centre from conception to full operation in less than two years. Thanks to that community effort, the help of hundreds of volunteers over the years and the continued support of the Ottawa Senators Foundation and the CHEO Foundation, Roger's House has remained a vital and relevant hospice in Eastern Ontario.

The need today for palliative care is as great as it was in 2004. In 2015-16, 97 children were admitted to Roger's House an increase of 7% from 2014-15 and 86% since 2006. The growth in referrals will require us to be efficient and creative in how we use our limited resources to meet the needs of children and families, while continuing to be professional and caring in our work.

Our 10th anniversary is an opportunity to reflect on the contribution Roger's House makes to the quality of life of our guests. We have fine-tuned our services over the past 10 years and continued to do so in 2015-16 to ensure we are responsive to the needs of our guests and their families. We launched new programs as well – SIBS (Spectacular Incredible Brave Siblings) in April 2015 and the Visiting Home Hospice program this past winter. Reviews of both of these new programs have been outstanding thus far.

Keeping our programs relevant and maintaining strong ties with the community is essential to meet the growing need for palliative care for children and youth. In the next few months we will begin a strategic planning process with a view to completing a five year strategic plan in the coming year.

As with any anniversary, there is always some sadness mixed in with our optimism for the future. After 10 years as Manager of Roger's House, Marion Rattray has taken a well-earned retirement. She will be missed. I would like to personally thank Marion for all her hard work and dedication to the children, families and staff. The legacy Marion helped build will be in good hands with Helen Yoxon who joined the team in February.

In conclusion I would like to thank our many volunteers and supporters, our primary funders, the Ottawa Senators Foundation and the CHEO Foundation, and most certainly, the compassionate and professional staff of Roger's House.



Megan Wright
Executive Director

Message from the Chair, Roger's House Board of Directors

For the last 10 years Roger's House has provided the continuity of care that is so essential to the families of children with life limiting illnesses. Our services extend well beyond end of life care to include perinatal care, transition from hospital to home care, pain and symptom management, respite care, and grief and bereavement counselling. Our goal has been not only to care for the child but to care for the entire family before, during and after the child's illness.

This year we launched two new initiatives that further extend our ability to help these families. The successful launch of the Visiting Home Hospice, a volunteer-based home visiting service, has improved our ability to support families receiving respite care. With the SIBS group (Spectacular Incredible Brave Siblings), which launched in April 2015, siblings receive support from peers going through similar experiences, which helps to decrease feelings of isolation. Next year we will study the potential for extending the concept to grandparents.

When parents and care givers come to Roger's House they find not just a hospice; they find a community. Parents meet other moms and dads who face similar circumstances and discover they are not alone. As one mom puts it, they have found their tribe, a safe place to share their fears and hope without judgement.

The full complement of services and home-like environment of Roger's House has significantly improved pediatric palliative care in eastern Ontario, making a difference for nearly 100 families each year.

This is something we can all take pride in as we celebrate our 10th anniversary.

"All" includes a lot of people – doctors, nurses, therapists, managers and other employees, my board colleagues of course, as well as an army of volunteers who freely give their time and love in and out of the home, supporting not just families but also staff. Few organizations can boast of having such a strong and devoted group of volunteers.

Without the Ottawa Senator's Foundation, there might not be a Roger's House. We are grateful for this exceptional partnership and the continued support we receive in carrying on Roger Neilson's legacy.

Our thanks as well to our friends at the CHEO Foundation, who over the years have provided guidance and now as formal partners, will complement our expertise. We are thrilled to be working together to better support the families we share.

On behalf of the board, I would like to formally thank our Executive Director Megan Wright, who has so ably led the board and staff the past two years. Her skillfulness and grace in handling all situations has served Roger's House extremely well.

Our mission is to "enrich the lives of children, youth and their families facing progressive life-limiting illnesses." However, in serving this community, we have ourselves – staff and volunteers alike – become enriched.

It has been an honour and privilege to serve as the board chair of Roger's House.



Ruth Hartanto
Chair of the Board of Directors



The amount of days families have stayed while their child was in care

The amount of children cared for during end of life

6,000

The amount of family/Child counselling visits annually.



283



581

Days of care provided to children since opening in 2006

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



20,661

over
163,700
hours

The number of hours volunteers have dedicated to create a home for families:

378



End of Life Care

For children and families who choose to spend their final days together at Roger's House, end of life care is provided. The Roger's 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.

"To all of the staff at Roger's House, we thank you from the bottom of our hearts for helping us have a special "at home" time with our son. Without you he would've passed in hospital surrounded by machines."

Our Services:



Respite Care

Children and youth come to Roger's 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.

"Thank you so much for taking such wonderful care of [child]! I know it means so much to his parents and brother to be able to have a rest and holiday knowing he's in such good hands. It's lovely to be able to come and visit. Thank you for the always warm welcome!"

Perinatal Hospice

The Roger's 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's 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.

Support groups available at Roger's House include,

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.

Spectacular Incredible Brave Siblings (SIBS), (NEW) which launched in April, 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.

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).

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.

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.



Transition from Hospital to Home Care

Children who have been hospitalized for surgical or medical reasons may transition to home through Roger's 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 reinforce and support instruction received at CHEO.



"Thank you for letting us transition home from here, it was a great experience! The whole team is so awesome."

Symptom Management

Each family referred to the Palliative Care Team at CHEO has access to care and support at Roger's 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.

Visiting Home Hospice (NEW)

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's 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's House.

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

2015

In Review

While occupancy, number of children served and the number of days of care for 2015-16 was similar to the previous year, fewer admissions, fewer respite admissions and increased symptom management admissions in the last fiscal year meant longer lengths of stays and increasing acuity, driven mainly by an increase in palliative work and a decline in respite care.

The Snoezelen Room was renamed 'Nora's Nest' in recognition of Nora Ullyot's many years of contributions to Roger's House.

New admission and discharge timelines were implemented to limit overlaps and mitigate risks related to an increased number of guests in the house. We continue to evaluate the effectiveness of this new policy change.

We hired a second Recreation Therapist to enhance our Recreation Therapy Program. Children who need Roger's House services often miss out on parts of their childhood due to being medically fragile. The Recreation Therapy program at Roger's House aims to ensure these children the opportunity to experience as normal a childhood life as possible, 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's House supports.



The Ontario Ministry of Community and Youth Services approved Roger's House as a 10 bed facility to allow overlap between discharges and admissions and to accommodate urgent requests. We will however continue to operate as an 8 bed facility.

With the debut of the Visiting Home Hospice Program in the winter of 2016, preceded by the need to find and train volunteers to conduct the program in the community, we hired a second Senior Administrative Assistant to support the Coordinator of Volunteers.

Anne Jones was the first recipient of the 'Marion Rattray Award of Excellence in Pediatric Care.'

A tea and a dinner were held in recognition of Marion's long and successful career.



Management and staff of Roger's House worked closely with its Family Advisory Committee to better define their mandate, membership, recruitment process and priority setting.

We made changes to improve the visibility of Roger's House in digital media. Roger's House is now on social media including Instagram, Twitter and Facebook. A new website is under development and will be launched in June. We hope that our community will be able to more closely follow the activities of the house with this new communication plan. Roger's House was featured in the CBC series, 'Keeping Canada Alive', a six-part series capturing one day in the life of Canada's health care system. The program helped increase awareness of Roger's House and its work among a national audience.

As we continue to evaluate our services, we are undertaking a thorough review of all current support services with a view to identify any gaps in those services. Expected completion is winter 2017. To that end one of our Social Workers, Madelena Arnone, is conducting a literature review regarding the establishment of a grand-parent support group. It is hoped that this will turn into a research project. Marion Rattray, Carole Chevalier and one of our bereaved perinatal loss parents presented at the Committee of the Ontario Legislator on Bill-141: Pregnancy and Infant Loss Awareness, Research and Care Act, 2015. The Committee invited Roger's House to submit a funding proposal to expand our program. We are waiting the results of this proposal.

The last few months of the fiscal year were very challenging for staff due to a particularly high number of deaths. The Roger's House team demonstrated exceptional professionalism and support toward one another during this difficult time. To help find new ways to support the health and wellbeing of the team we created a Wellness Committee. A new treadmill, as well as activities such as daily huddles, meditation and yoga classes, have resulted.

We co-planned and hosted the Pediatric Day at the National Palliative Care Conference in the fall. At this event, Katt Brooks (Recreation Therapist) facilitated a youth panel and Carol Chevalier (Social Worker) presented on the Perinatal Loss and Support Group. Dr. Splinter (Medical Director) and Lynn Grandmison-Dumond (Nurse Practitioner) were involved in the planning of the conference with other pediatric hospices.



2015

In Review

Respite Admissions

399

2014-2015

319

2015-2016

12

2014-2015

7

2015-2016

Transition Admissions

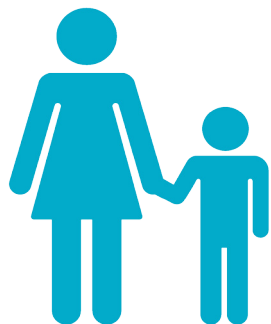
90

2014-2015

97

2015-2016

Children Served



7 5

2014-2015 2015-2016

Deaths Elsewhere

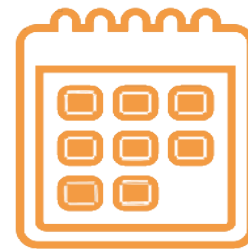
2405

2014-2015

Days of Care

2429

2015-2016



Average
Occupancy

83%

2014-2015

83%

2015-2016

47

2014-2015

75

2015-2016

SM Admissions



474

2014-2015

420

2015-2016

Admissions (total)

15 15

2014-2015

2015-2016

Deaths at RH



Planning

At Roger's House, we are always looking for better ways to serve our community, our children and their families while ensuring that the House continues to operate with the technology, knowledge and skills required by a leading palliative care centre. As Roger's House begins to age, we will have to place a higher priority on maintaining and improving the physical infrastructure of the House as well. Despite these ongoing efforts, the ten year point in the life of Roger's House is a good time to take stock of all our services and facilities. We will begin a thorough review of all current support services this summer with a view to identify any gaps in those services. Expected completion is winter 2017. Starting in the spring of 2016, a broad consultation process will be initiated to develop a new five year Strategic Plan.

With respect to the physical maintenance and improvement of Roger's House, a comprehensive infrastructure assessment was completed to help us plan for repairs to the house that will be required over the next few years. This assessment will help us complete a capital plan. As well we began work to update furniture, flooring, our outdoor space and our playroom.

We continue to work with partners to find new efficiencies and complimentary business processes. As our key partner, CHEO, launches a fully integrated health record, we have begun discussions to include Roger's House in this solution. In consultation with the Ottawa Senators Foundation we decided to rebrand Roger's House to Roger Neilson House. We want to ensure the community knows the legacy that Roger left behind for us. The launch of the new brand coincides with the unveiling of our new web site and our 10th anniversary celebration in June 2016.



Year ended March 31,

2016



Revenue

Contributions from the Ottawa Senators Foundation	\$327,818
Contribution from the Ministry of Health and Long-Term Care	\$ 1,110,882
Contributions from the Ministry of Child and Youth Services	\$157,500
Amortization of contributions related to capital assets	\$153,808
Other contributions	\$58,861
Donations	\$51,866
Investment and other income	\$20,599
	\$1,881,334

Expenses

Salaries and benefits	\$1,447,455
Advertising and promotion	\$3,579
Amortization	\$162,510
Bank charges, interest and service fees	\$6,724
Facility expenses	\$92,180
In-house services	\$16,360
Office and travel	\$55,361
Professional fees and other	\$16,935
Staff recruitment and training	\$19,206
	\$1,820,310

Net Revenue for the Year	\$61,024
Net Assets- Beginning of Year	\$723,923
Net Assets- End of Year	\$784,947



Thank You to Our Volunteers

From April 2015 to March 2016, 321 volunteers contributed 18,698 hours of service to Roger's House and the children and families it serves. Each volunteer donated on average a week and a half of their time to support Roger's House. These volunteers are essential members of the Roger's 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!

The implementation of the Visiting Home Hospice placed an even greater demand for volunteers to work up to two hours each week with a family receiving respite care from Roger's House. This service provides additional respite for families accessing Roger's House and allows Roger's House to remain in regular contact with all of our families. Roger's 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.

Early feedback indicates the program is welcomed. One parent said, "I honestly couldn't be more pleased with the service. The volunteer is punctual, appropriate, respectful, and there is no denying how much he enjoys his time with my child."

Forty 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's House.

Volunteer Program Assistants devoted several hours working in collaboration with the Recreation Therapists to develop, plan and execute the programming to meet the needs of the children accessing care in House.

Quilting Volunteers create unique Legacy Quilts for grieving families. Three quilts were lovingly made for families this year.



Thank You

Roger's House offers a multitude of services that cater to the unique needs of a medically fragile population. Roger's 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.

Family Advisory Committee 2015-2016

Mindy McHardy – Co-Chair
Jennifer Walker – Co-Chair
Osama Abdali
Beatriz Alvarez
Nancy Graham
Andrea Gumpert
Anne Jones
Kimberley Jordan
Sharon Liff
Aicha Mansir-Tounekti
Jean Murray
Alex Vanzyl

Board of Directors 2015-2016

Ruth Hartanto – Chair
Mike Baine
Les Bell
Pranesh Chakraborty
Ian Hendry
Robert Houston
Mike Lupiano
Jeff Polowin
Susan Richardson
Jaqueline Belsito – Ex-Officio
Danielle Robinson – Ex-Officio

Staff (Current)

Megan Wright, Executive Director
Dr. William Splinter MD, Medical Director
Helen Yoxon, Manager
Bruno Perrier, Operations Manager
Madelena Arnone, Social Worker
Lise Beauchemin, Coordinator Volunteer Services
Katt Brooks, Recreational Therapist
Rachael Cale, 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

Clinical Staff (Current)

Luz Bedoya PSW, Candace Bretzer RPN, Molly Brown RPN, Jacqueline Davis RPN, Dr. Megan Doherty MD, Deborah Donnelly RN, Wendy Gugeon RN, Mauri-Anne Guitard RPN, Ann Hicks RN, Anne Jones RN, Jenna Marsh RPN, Jennifer Martin RN, Charles Medeiros PSW, Maureen Merkley RN, Jan Mingie RN, Carinne Moreau PSW, Buhle Ncube PSW, Katie Patterson RPN, Brandy Prevost RPN, Marion Rattray, Bereavement Care Nurse, David Ricciardelli RN, Dr. Ben Robert MD, Monica Sevigny RPN, Katharina Skrzypek RN, Megan Sloan RPN, Nahal Stoppels RN, Dr. Chris Vadeboncoeur MD, Cheryl Wall RPN, Helen White PSW, Dr. Robin Williams MD, Caulette Wiseman RN, Joann Zimmerling PSW

Memberships

Canadian Hospice and Palliative Care Association – Canadian Pediatric
Residential Hospice Network
Hospice Palliative Care Ontario (HCPO) – Volunteer Ottawa

VOICE: 613-532-6300 FAX: 613-523-3617
EMAIL: info@rogershouse.ca
www.rogershouse.ca

To receive our Roger's House Chronicles Newsletter or to be added to our mailing list, please contact info@rogershouse.ca

Twitter: @rogershouse1
Facebook: Roger's House
Instagram: @rogers_house

