



## 2019-20 ANNUAL REPORT

### OUR STORY

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.



# 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	Innovation	Excellence	Celebration
Collaboration	Family-Focused Care	Learning	





## REFLECTIONS FROM OUR EXECUTIVE DIRECTOR & BOARD OF DIRECTORS CHAIR

As we reflect upon the past year, we are very proud of many accomplishments and exciting innovations at Roger Neilson House.

The demand for our various programs and services continued to grow. By the end of March 2020, we had cared for a total of 511 children since opening our doors in 2006, for a total of 31,427 days of care.

Our commitment at the regional, provincial and national level continued. Megan Wright, Executive Director of Roger Neilson House, chairs the National Pediatric Palliative Care Hospice Committee, and along with a family partner, is an active member on the Provincial Pediatric Palliative Care Steering Committee. Roger Neilson House is also a proud partner of the newly formed 'Kids Come First' child and youth Ontario Health Team. Dr. Vadeboncoeur, Medical Director of Roger Neilson House, continues on the Board of Directors of the International Children's Palliative Care Network. Nationally she remains vice-chair of the Royal College of Physicians and Surgeons of Canada Examination Committee in Palliative Medicine, and a co-chair of the Canadian Network of Palliative Care for Children. During the COVID-19 pandemic she has participated in a National Collaboration of Pediatric Hospice Medical Directors and an Ontario Collaboration of Hospice Medical Directors, both of which work collaboratively to develop guidelines for maintaining palliative and end of life care in the hospice setting, despite the changes which have arisen due to the need for adjusting the implementation of personal protective equipment and physical distancing.

In 2019, we began designing and renovating the Roger Neilson House playroom and legacy installation. The redesigned room will be a fully accessible, special destination in Roger Neilson House; a place for imagination, peace and reflection; a place to play with a distinct character that will be open and flexible. The room will provide sensory experiences and an opportunity to connect with nature. At the same time, it will remain a place to honour all of the children who we have cared for who have died, as a very special legacy art installation will be highlighted in the room. We are very excited for this work to come to fruition and to share it with our community. We extend profound thanks to all of our parent partners and team members who provided input, and to the Roger Neilson House Legacy Committee for their commitment to this very special and sensitive project.

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## REFLECTIONS FROM OUR EXECUTIVE DIRECTOR & BOARD OF DIRECTORS CHAIR cont'd...

In October 2019, we were very proud of the successful implementation of EPIC, an electronic health record system. EPIC has brought about many improvements to documentation processes for the clinical team. It also offers a secure, online patient portal called MyChart, which connects patients to parts of their electronic health record, anywhere, at any time. Through MyChart, they can see information related to most of their visits.

In late winter 2020, our organization was impacted greatly by the COVID-19 pandemic. We had to make many changes, including to the services and programs we offer. As a team we were swift to respond and we have remained nimble as directives have changed. Unfortunately, it has meant suspending some activities in the house, including pre-booked respite admissions; however, we have remained open and available for our patients and their families in many other ways. We have shifted to providing online support for families, including for both bereavement and support programs, which is a first, and may make services more accessible to all. This will be an area that we will focus our research on in the future. The upcoming year will be full of challenges, but we are well positioned to be adaptable and flexible, while continuing to provide care for children, youth and families in need.

We extend our deep appreciation to our Board of Directors, all of our staff, volunteers, community partners, and most importantly our families. Lastly, we extend our gratitude to our donors. Community support is helping us to continuously improve our methods of caring for our kids and helping us to support families dealing with the most devastating of situations. We are committed to enriching the quality of lives, no matter how short.

*Mike Lupiano*  
*Chair, Board of Directors*

*Megan Wright*  
*Executive Director*





## FAMILY ADVISORY COMMITTEE

Through the winter months the Family Advisory Committee (FAC) continued to be active in fulfilling their advisory directive.

The FAC resumed meetings after the Christmas break and first on the agenda was a visit from Nahal Stoppels, lead for the Safety Review Committee. Nahal began by restating the guiding principles, and then presented recommendations generated by that committee. FAC members then had the opportunity to ask questions and provide feedback on the recommendations.

This year the Children's Healthcare Canada Conference was held in Ottawa. Committee member Yara attended on behalf of FAC. The theme was 'Getting Kids Back on the Radar'. Yara conveyed that there were a broad spectrum of participants and that the sessions she attended were very informative.

The Legacy and Playroom project is of great importance to staff, volunteers, families and caregivers. There have been extensive consultations with all stakeholders, and FAC was grateful to be included as another source for feedback on several elements of the project. As Spring arrived, the committee began conducting meetings by teleconference due to COVID-19. Leadership continued to give updates and provide FAC members the opportunity to respond to the rapid changes at the House.

The RNH Pandemic Leadership Team extended an invitation for a representative from FAC to join the weekly leadership teleconference. The team now has a parent perspective on operational issues such as changes in services, virtual care, visitor restrictions, etc. The FAC was also asked for feedback on a proposal for the Emergency Home-Based Respite Program. The committee's familiarity with RNH services allowed them to provide valuable responses to questions regarding the Companionship Service and In-Home support.

This year the committee was happy to receive two new members, Kristy Parker and Emma Gofton. We appreciate the experience and insight they bring – welcome Kristy and Emma! The approach to summer certainly looks different at the House than it did last year. However, what has not changed is the Leadership team's commitment to involve the FAC as changes are being made and new initiatives are being developed. RNH staff and volunteers continually give of themselves, and I am grateful to have an opportunity to give back!

*Kimberley Waara, Chair, Family Advisory Committee*







## VOLUNTEER ADVISORY COMMITTEE

The Volunteer Advisory Committee (VAC), implemented in April of 2018, continues to be an important integrative link providing timely, constructive feedback between volunteers and RNH's leadership team and staff. The VAC reconvened in October 2019 after a busy and productive spring and was delighted to welcome the following new committee members: Michael Baskey, Leah Bradley (Rec. Therapist), Ann Gordon, Christine Grace, Sarah Khadij, Carinna Moyes and Brenden Spano-Osborne. Members look forward to their input and ideas as the VAC moves into its second year. The VAC also gratefully acknowledged the contributions of four outgoing members: Scott Gunn (outgoing Co-Chair), Alanna Jane, Eva Latourell and Marilyn Stairs.

An initial priority for the group was to review and update the status of the VAC's 2018-2019 key work plan objectives which were: to improve and streamline the volunteer on-boarding process; and, to develop accessible volunteer support systems (with a special focus on bereavement support). Streamlining of the volunteer on-boarding process has been partially accomplished while the support system objective, "Caring for the Carer", has been successfully achieved. The VAC will collaborate with RNH Leadership to ensure that support systems continue to meet the needs and expectations of staff and volunteers. Work on the former objective (streamlining volunteer on-boarding) has been carried over into the current (2020-2021) work plan and will incorporate updated/new policies and procedures from RNH's comprehensive 2019-2020 Safety Review that was undertaken to ensure that the safety, rights and well-being of RNH's guests are at the core of all daily operations. The VAC is also discussing a number of new objectives that are currently being finalized (e.g. ongoing volunteer educational opportunities, volunteer recruitment and retention strategies and continued development of user-friendly on-line Volunteer Information Session resources).

In early March 2020, in light of developments with the COVID-19 pandemic, VAC in-person meetings, April's National Volunteer Week celebrations and a number of other programs and services offered by RNH were put on hold in order to help keep everyone safe and minimize the chance of transmission of infection during these anxious and unprecedented times. As members of the VAC, and more broadly, as part of the incredible *one strong team* of staff and volunteers at RNH, we look forward to the day when we can all be together again to continue our work to enrich the quality of lives of the children and families we are so honoured to serve.

Carole Brulé  
VAC Chair

Christine Grace  
VAC Vice-Chair







*I knew I wanted to volunteer when I heard the philosophy that it is not the number of days that matters, but rather the quality of the remaining days. RNH's community has always been welcoming, inclusive and supportive, so much so that I always look forward to being at the house..—New Volunteer, Kinsley Jura*



*Volunteering at RNH feels like being part of a big family! I get to brighten children's day, learn something new at every shift, and go home feeling gratified.*  
- Sarah Khadij



*Spending time at RNH is as rewarding for the volunteers as it is for the kids. You get to see first-hand how such a small portion of your day can make a world of difference for these kids and their families.*  
-Stéphane Lauzon-Brisson

## VOLUNTEER SERVICES

This has been another amazing year for Roger Neilson House Volunteer Services. We have continued to recruit incredible, enthusiastic and passionate volunteers.

In total, 29 incredible new volunteers joined our team. Along with recruiting new volunteers, a volunteer retention strategy was created as there is substantial value in retaining our trained and experienced volunteers who have developed a strong understanding of the organization, a solid skill set and deeper collaborative relationships with volunteer and staff colleagues. We have been successful in keeping many of our long term volunteers, such as Terry, who's been on the team for 6 years:

*I have seen how much my involvement with RNH can make a difference in a child's life and give comfort to a family. This has made my volunteering a very rewarding experience for me.* -Terry Moxness



Volunteers have continued to be integral members of our 'One Strong Team'. They have been key partners in helping us make the best decisions for our organization and the children and families we serve. As an example, volunteer representatives participated in the Safety Review Task Force, which made recommendations to the leadership team on guest safety. Volunteers subsequently continued their involvement when the work transitioned to the implementation phase.

The Volunteer Advisory Committee (VAC) continued to be strongly engaged in improving the volunteer experience. We have formalized the volunteer support system to ensure that volunteers have access to timely and quality support when facing difficult situations. The VAC was also significantly involved in discussion and planning to streamline the recruitment and on-boarding process. We look forward to reporting on the implementation of those improvements next year. We are very proud of our Volunteer Advisory Committee as it is a unique and successful model of volunteer engagement. We had the opportunity to present on the VAC work at the 2019 HPCO conference and several hospice leaders subsequently contacted us to learn from our experience.

*Cont'd..*





## VOLUNTEER SERVICES cont'd...

A quote from the VAC vice-chair summarizes quite well the goal of our VAC engagement efforts:

*"Being part of the VAC committee is another honour, allowing us to work cooperatively with the Management team to provide feedback and improvements that help us in the retention of Volunteers and the drive to bring new Volunteers on board" - Christine Grace*

A volunteer also co-lead an initiative to improve our Reception Volunteer Procedure Manual. This was important work as reception volunteers have key roles in warmly welcoming families and visitors as well as guiding traffic flow when people enter RNH. Having clear, efficient and up-to-date procedures is therefore of paramount importance.

This year we introduced *Parent Matching* as a new volunteer program. Parents who are further along on their bereaved journey are matched with newly bereaved parents. The support and perspective of someone who has had a similar experience has been a great complement to the counseling services offered by our social work team. Training, guidance and on-going support is offered to volunteer parents to prepare them for this important role.

Roger Neilson House is fortunate to have people who regularly reach out to us expressing their interest in joining our volunteer team. Historically, as a first step in the application process, prospective volunteers attended an information session at Roger Neilson House. In our efforts to make the recruitment process more efficient, we have created an *online information session*. Therefore, someone interested in volunteering can now view the online session at a time that is convenient to them, without having to wait for an in-person option.

On a final note, I would like to share a quote from Carole Brulé, the chair of our VAC:

*"It is only with the heart that one can see rightly; what is essential is invisible to the eye," Antoine de Saint-Exupéry writes in his beloved book, Le Petit Prince. This is one of the many gifts I have received in volunteering with RNH's incredible guests and their families: I now see the world more clearly than ever before - through the lens of a fuller, wiser and forever grateful heart! - Carole Brulé*

Bruno Perrier

Manager, Community Engagement and Volunteer Relations





## CARE SERVICES FOR OUR 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.

### 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 decisions 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 Support 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.





## CARE SERVICES FOR OUR GUESTS

### SYMPTOM MANAGEMENT

Symptom assessment and management is available at Roger Neilson 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 the 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 caregivers 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.





## SUPPORT GROUPS AVAILABLE AT ROGER NEILSON HOUSE

Palliative Care Parent Support Group: This “drop-in” group format 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.





## 2019 BY THE NUMBERS

100 CHILDREN SERVED  
 2,470 DAYS OF CARE PROVIDED  
 2,298 COUNSELLING VISITS  
 15,924 VOLUNTEER HOURS DONATED  
 84% OCCUPANCY  
 13 DEATHS  
 407 TOTAL ADMISSIONS:

- \* 164 SYMPTOM MANAGEMENT
- \* 7 TRANSITION
- \* 222 RESPITE



CHEO  
 Foundation &  
 Other Funding  
 Sources,  
 934,214

Ottawa  
 Senators  
 Foundation,  
 311,044

Ministry of Children,  
 Community and Social  
 Services, 157,500

Ontario  
 Health,  
 1,572,919



REVENUE

Household  
 Operating Costs,  
 701,698



EXPENSES

Staffing and  
 Benefits,  
 2,296,824



SINCE OPENING IN 2006

511 CHILDREN CARED FOR

31,427 DAYS OF CARE PROVIDED

247 CHILDREN RECEIVED END-OF-LIFE CARE

215,614 VOLUNTEER HOURS CONTRIBUTED

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 2019-20 fiscal year, our operating budget was 2.97 million dollars.





**BOARD OF DIRECTORS (2019-20)**

Mike Lupiano, Chair  
Ian Hendry, Vice-Chair  
Les Bell, Past Chair  
Jeff Polowin, Secretary  
Michelle Bouchard, Treasurer  
Alexa Brewer, Director  
Anne Huot, Director  
Caitlin Neil, Director  
Dr. David Creery, Director  
Janet Wilson, Director  
Paul Lalonde, Director  
Robert Houston, Director  
Brad Weir, Ex-officio Director  
Jacqueline Belsito, Ex-officio Director  
Megan Wright, Ex-officio Director



**FAMILY ADVISORY COMMITTEE (2019-20)**

Kimberley Waara, Chair  
Ashlee Barbeau, Secretary  
Anne Jones, Admissions & Care Coordinator  
Beatriz Alvarez, Child & Family Support Volunteer  
Bertran Labonté, Parent  
Bruno Perrier, Manager  
Community Engagement & Volunteer Relations  
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Chloe Benoit, Parent  
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Helen Yoxon, Manager  
Kristy Bedard, Parent  
Lillian Kitcher, Parent  
Megan Wright, Executive Director  
Nahal Stoppels, Acting Manager  
Richard Ouimet, Parent  
Yara Saikaly, Parent

**CLINICAL STAFF (Current)**

Anne Jones, Admissions and Care Coordinator  
Barb Juett, Social Worker  
Ashley Astle, Personal Support Worker  
Buhle Ncube, Personal Support Worker  
Candace Bretzer, RPN  
Carinne Moreau, Personal Support Worker  
Carleigh Sanders, RPN  
Carol Chevalier, Social Worker  
Celine De Rubeis, RN  
Charles Medeiros, Personal Support Worker  
Chris Vadeboncoeur, MD, Medical Director  
Claire Nickerson, RPN  
Courtney Potvin, RPN  
Danielle Hanley, RN  
Danielle Scarlett, Recreation Therapist  
David Ricciardelli, RN  
Dawn Davies, MD  
Emily Fullarton, RN  
Jackie Davis RPN  
Jennifer Quinn, RPN  
Joann Zimmerling, Personal Support Worker  
JoAnne MacNeil, RN  
Kaitlyn O'Connor, RPN  
Katharina Skrzypek, RN  
Katie Patterson, RPN  
Katt Brooks, Recreation Therapist  
Kirstin Neville, RN  
Krista Henneberry, RN  
Laura Cardillo, RN  
Lauren Cavanagh, RN  
Leah Bradley, Recreation Therapist  
Lesley Sabourin, RN  
Lyndsey Fisher, RN  
Lynn Grandmaison Dumond, Nurse Practitioner  
Madelena Arnone, Social Worker  
Mary Farnand, RN  
Maryse Frenette, Fellow  
Maureen Merkley, RN  
Megan Doherty, MD  
Megan Sloan, RN  
Monica Sevigny, RPN  
Nancy Graham, Quality Coordinator  
Sabrina Morin, RPN  
Sarah Allan-wiseman, Social Worker  
Stephanie Toll, RPN  
Stephanie Van Zanten, MD  
Suzanne Henderson, RN  
Tamara Guindon, RPN  
Virginia Meisner, RN  
Wendy Mihell, RN  
William (Bill) Splinter, MD  
Zandra Strnad, RN

**ADMINISTRATIVE / SUPPORT STAFF (Current)**

Megan Wright, Executive Director  
Chris Vadeboncoeur MD, Medical Director  
Helen Yoxon, Manager  
Bruno Perrier, Manager,  
Community Engagement and Volunteer Relations  
Nahal Stoppels, Acting Manager  
Sonja Marshall, Coordinator, Strategic Projects & Governance  
Jennie Wilson, Administrative Assistant,  
Community Engagement and Volunteer Relations  
Caitlin Neil, Legacy Project Coordinator  
Elizabeth Irvine, Housekeeping and Reception  
Harrison White, Bookkeeper  
Kara McDonell, Housekeeping and Reception  
Shokufeh Modanloo, Research Assistant



**VOLUNTEER ADVISORY COMMITTEE (2019-20)**

Carole Brule, Chair, Child and Family/Visiting Home Hospice Volunteer  
Christine Grace, Vice Chair, Reception Volunteer  
Ann Gordon, Kitchen Volunteer  
Brenden Spano-Osborne, Child & Family Support Volunteer  
Bruno Perrier, Manager, Community Engagement & Volunteer Relations  
Carinna Moyes, Child & Family Support/Visiting Home Hospice Volunteer  
Clare Pearson, Child & Family Support/Visiting Home Hospice Volunteer  
Francine Boucher, Child & Family Support/Visiting Home Hospice Volunteer  
Jennie Wilson, Administrative Assistant, Community Engagement & Volunteer Relations  
Joann Zimmerling, Personal Support Worker  
Leah Bradley, Recreation Therapist  
Liz Kelly, Reception Volunteer  
Mac Hiltz, Child & Family Support/Visiting Home Hospice Volunteer  
Michael Baskey, Child & Family Support Volunteer  
Sarah Khadij, Child & Family Support Volunteer  
Terry Moxness, Child & Family Support/Visiting Home Hospice Volunteer  
Villana Murray, Reception/Visiting Home Hospice Volunteer







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

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