



# Family Advisory Committee Annual Report 2016- 2017

June 2017

Respectfully Submitted by:  
Mindy McHardy (Chair) & Nancy Graham (FAC Staff Liaison)



Celebrating our 10 year anniversary as an organization was also the perfect time for the Family Advisory Committee (FAC) to refresh our connection to and relationship with the Roger Neilson House (RNH) leadership team, staff and volunteers on behalf of families and included a review of our terms of reference, establishment of a recruitment strategy and focus on structure and process that included our own priorities for the 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.

With the support of the RNH Board of the Directors, the FAC voted on our top priorities for the 2016-17 year. Within this Annual Report are our recommendations to the RNH leadership team regarding our priorities.

Our committee was also busy with objectives brought to us by the leadership team. We worked together to highlight the importance of admission and discharge times, additional family support groups and took part in the RNH strategic planning process. FAC members are committed to improving communication between families and the RNH team and to identifying opportunities where the FAC can facilitate these connections.

Sincerely,

Mindy McHardy (FAC Chair) and Nancy Graham (FAC Staff Liaison)



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.

## 2016-2017 Membership:

- Mindy McHardy (Chair)
- Nancy Graham (Roger Neilson House Staff Liaison)
- Alex Vanzyl
- Kimberley Waara
- Katelyn Fleming
- Richard Ouimet
- Yara Saikaly
- Lillian Kitcher
- David Bell
- Jean Murray (Volunteer Recording Secretary)
- Anne Jones (Roger Neilson House Nursing Representative)
- Beatriz Alvarez (Roger Neilson House Volunteer Representative)

- 1. Enhance communication between FAC and families to ensure that families are being accurately represented by FAC**
- 2. Establish recommendations for involvement of RHN families in fundraising and external events**
- 3. Increased social activities for RNH children and families**
- 4. Increased education and networking between RNH FAC and other similar organizations**

# Ensure accurate representation and enhance communication between FAC and RNH families

## Progress:

- FAC contributed to the RNH fall and spring newsletters
- Across FAC priorities, emphasis in recommendations on:
  - Use of RNH website events calendar as the 'go to' place for families to get details on events, support groups etc.
  - Consistent communication with families reinforced by email, social media posts (Facebook and Twitter) and FAC members talking to their networks of friends and other RNH families

# RNH family participation in fundraising and external events



## Background:

Such events have the potential to be open and welcoming for RNH children/families. They can also help showcase to all participants -- donors, opinion leaders, and the general public -- both the concrete, positive impacts of RNH services/supports as well as the many special gifts of RNH children.

## Recommendations:

1. Ensure the faces & stories of RNH children/ families are reflected in CHEO foundation events
  - The new fundraising relationship between RNH and the CHEO foundation, which builds on the close ties already in place with the Sens Foundation, will provide new opportunities for RNH families to share their experiences and to increase awareness of the importance of pediatric palliative care.
  - We welcome the CHEO foundation's commitment to ensure that RNH children and their families -- many of whom also receive care/support through CHEO-OCTC -- are appropriately represented in the full range of CHEO-OCTC events.

## Recommendations:

2. Aim to provide advance notice of upcoming/planned external events
  - The main place to find information would be the calendar of events on RNH's website.
  - An updated e-mail distribution list and promotion of events on RNH's Facebook and Twitter accounts could all be used to get the message out and point to the website.
  - Including the contact information for the organizer to limit the need for RNH staff to "coordinate".



## Recommendations:

### 3. Encourage event organizers to consider accessibility/inclusion

- When approached by groups who are organizing fundraising events, encourage organizers to seek the participation of RNH families, structure their events so that RNH children/families can participate to the fullest extent possible (e.g., accessible parking and venue/route; change/feeding facilities), and identify a contact person in case RNH parents have questions about the event.
- The idea is not to create formal "rules" and "requirements", but rather to promote empathy and inclusion.

## Recommendations:

### 4. Promote fairness of opportunity and diversity of voices

- To the greatest extent possible, when approached by organizations to seek an "ambassador" or representative RNH child/family, effort should be made to ensure that different children/families have the opportunity to share their stories.
- Explain the selection process to RNH families (i.e. on the website or by email) and consider asking families to self-identify while also explaining that RNH staff will ultimately use their professional judgement in choosing appropriate events.

# Increased social activities for RNH children and families



## Background:

Events such as the Halloween and Christmas party are highly anticipated by RNH children/families and for many families are the only 'parties' they feel can safely take their child to.

RNH social activities provide recreation and normalcy around popular holidays, create memories and support the welcoming community of friends the children/families have found at RNH.

## Recommendations:

1. Introduce one or two additional social events spread throughout the year (spring and summer)
2. Aim to provide advance notice of upcoming/planned social events
  - Update RNH website events calendar as soon as events have been confirmed so that parents have ample time to make arrangements to attend and a consistent place to check at their convenience should they miss an event email.

## Recommendations:

### 3. A consistent communication strategy for informing families about social events

- The main place to find information would be the calendar of events on RNH's website.
- An updated e-mail distribution list and promotion of events on RNH's Facebook and Twitter accounts could all be used to get the message out and point to the website.
- Important details for families include:
  - Whether or not childcare is available;
  - Who is invited (current families, bereaved or any family connected to RNH);
  - If RSVP is required (by what date and to whom);
  - Contact information for the organizer.

# Increased education/networking between RNH FAC and similar organizations

## Progress:

- RNH FAC are confirmed as Canadian Family Advisory Network (CFAN) members
- FAC Staff liaison will receive Canadian Association of Pediatric Health Centers (CAPHC) e-newsletter to forward on to FAC members
- CHEO-OCTC Family Forum was approached – More to come
  - CHEO-OCTC is presently working on the formation of their 'new' family advisory function(s) as a result of recent review



# Growth in Collaboration

## Opportunities:

- Fostering an even closer relationship between the RNH leadership team and families coordinated through FAC staff liaison or FAC chair – “Nothing for us, without us”
  - Capitalize opportunities to co-design with families
  - Inclusion of family members in the hiring process for key positions
  - FAC to review family-oriented written materials or co-create to incorporate the family perspective

# Growth in Collaboration

## Opportunities:

- As per our terms of reference, running by the FAC new programming ideas or changes to programs and policies
  - Not intended to slow down process or be seen as an approvals process
  - To provide family impressions/ feedback
  - Or at a minimum, concurrently informing the FAC Staff Liaison or FAC chair before going out to all families



# reflections... FAC members

It has been an honor to contribute to RNH as an FAC member. The importance of family voice and partnership with leadership, staff and volunteers cannot be understated. Collaborating with families enables services that are not only essential, but lends to the feeling of family so many talk about in reference to RNH. This year we said goodbye to some of our longest contributors to the FAC and welcomed new members who have brought their energy and fresh perspectives to our group.

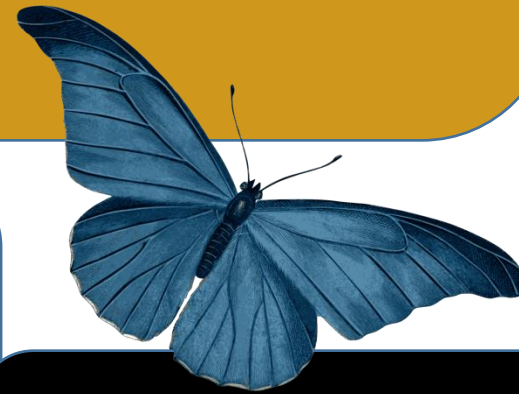
Thank you to every FAC member past and present for your dedication and the contributions you bring to our meetings. I left a part of my heart at RNH with the passing of my son Connor and will remain forever connected to the house and those within who care so very deeply.

In Gratitude

– Mindy McHardy, Chair  
(FAC Family Member since 2010)

I have not been an FAC member for a long time, however I feel like I am part of a group working towards a common goal that is to help achieve the needs of all involved so that we can provide good quality pediatric palliative care.

– Yara Saikley (FAC Family Member since 2016)



As recording secretary I like to think that I am lessening the workload for RNH staff, Nancy and the FAC Chair, and am contributing to the wonderful service RNH provides to children and families in Ottawa and the surrounding area. Being a member of FAC has kept me informed; it has also increased my already great respect for and admiration of the parents whose children come to RNH.

Thanks for all you do,  
– Jean Murray (FAC Volunteer Recording Secretary since 2015)

Being a FAC member means I have been able to reflect on the challenges and joys of our son's life and offer my perspective on issues that contribute to the development of this House that I love so very much.

– Kimberley Jordan (FAC Family Member since 2015)

# reflections... FAC members

Being a FAC member has given me the opportunity to give a little back to RNH, who supports our family so much. I also enjoy being a part of and hearing about past, present and future changes and improvements.

– Alex Vanzyl (FAC Family Member since 2015)

I'm the Father of a special needs son Christian Ouimet (I'm known as Christian's Dad!) My son has had several life threatening surgeries from birth with a few more to come. He's now 16 years old. We're very grateful for the time Christian has spent at RNH. The care has been second to none. I would like to express my sincere gratitude to the FAC committee members and RNH staff for the opportunity to sit on the FAC committee. It's been an enjoyable experience in the short period of time I've had. I've often times wondered how I might be able to give back to RNH families and staff. FAC has given me that chance. I feel I have a voice and I've been part of a wonderful organization helping us to move forward to share views and future possibilities. I look forward to the next few years serving the committee and RNH families and staff.

Sincerely,

– Richard Ouimet (Christian's Dad) (FAC Family Member since 2016)

My time on the FAC has allowed me the privilege to grow in appreciation and respect for the parents whose perspectives and dedication to their children are ever-inspiring. This has also helped me to understand the complex balancing act that RNH administrative, support and nursing staff must walk between professional policies and procedures who, while striving towards best practices, recognize the value of being reflective when listening to the families.

Sincerely,

– Bea Alvarez (FAC Volunteer Representative Member since 2009)



It's an honour to be a part of the FAC. This gives me an opportunity to do my part in giving back to Roger Neilson House, after all they have done for me and little miss m.

– Katelyn Fleming (FAC Family Member since 2016)