

## **Roger Neilson House Family Advisory Committee Meeting Monday Jan.9, 2017**

**Present:** Nancy Graham, , Kimberley Jordan, Mindy McHardy (Chair), Anne Jones, Sharon Liff, Alex Vanzyl, Jean Murray (recorder), Beatriz Alvarez, Yara Saikaly, Katelyn Howse, Lillian Kitcher, Helen Yoxon, David Bell, Richard Ouimet, Megan Wright

**1. Welcome, Approval of Agenda and Minutes of last meeting:** Mindy welcomed everyone. She expressed thanks for the suggestion that the FAC meet more often and suggested that a decision be deferred until the June meeting to allow everyone time to think about it. **Action:** all committee members. The agenda was accepted with the addition of an update from the Executive.

### **2. New Business**

**2.1 Involvement of RNH families in external events:** deferred to later meeting as Jacqueline Bellsito was unable to attend.

#### **2.2 Executive Update:**

a) Megan reported that RNH is beginning an informal music therapy program with funds for enhanced supportive care from a successful application to the Champlain LHIN. Someone will be hired on a part time basis to coordinate the program and provide direction to volunteers. Danielle will also take some courses in music therapy.

b) Beth Allan, an outside consultant who has worked in health care and has extensive experience in strategic planning, has been hired to help with developing a new strategic plan for RNH.

c) The budget for the next fiscal year is being prepared; no cuts are expected.

d) The flooring in individual rooms and at the Nursing Station will be updated as has already been done in the suites.

e) Re the partnership between the Sens Foundation and the CHEO foundation: the CHEO Foundation will match funds raised by the Sens; all funds will be pooled and the total amount will receive a higher interest rate. The Sens will continue with event focused fundraising while the CHEO group will focus on individual donors. RNH will not be doing any fundraising for itself. Involvement of the CHEO Foundation will provide more opportunities for family involvement. **Action:** all committee members

to think about how to communicate opportunities for involvement to family members.

#### **2.3 Strategic Planning: Beth Allan, consultant**

The majority of things on the previous (first) strategic plan, which focused on sustainability, were accomplished raising the question: what is next?

Beth stressed that strategic planning is concerned with the “big picture” and said that the direction of the plan has to be compatible with our community partners. A Steering Committee has been formed, chaired jointly by Megan Wright and Bill Splinter; Mindy McHardy, FAC chair is on the committee. Beth described the overall approach to planning. The first phase is information gathering; the second is developing a work plan. Information gathering: Beth will consult with a variety of groups including staff and families. Questions are being developed which will focus on 3 areas – Looking Back, Looking Forward: are needs changing? What is the environment like now? What are social policy changes / trends?

Looking Ahead. What needs to happen for RNH to fulfill its mission? Are there emerging needs, compatible with the RNH mission, vision and values, that we wish to address? Are there different ways to provide service? This phase also involves learning from others; ie looking at pediatric palliative care best practice guidelines, new research and at other organizations.

This phase began in December and will last until Sept 2017.

In response to Beth’s question re how best to engage families the following were suggested: (i) use multi modalities: email, teleconferences, a meeting piggy backed onto a family event (would require child care), a specially organized event eg on a Saturday with child care provided and perhaps hosted, co facilitated by FAC members. (ii) wording of an invitation is important; the purpose of the process and questions needs to be clear. (iii) indicating that results / outcome will be communicated is important.

Mindy said that strategic planning will be a standing item on the FAC agenda in future.

**Action: Mindy**

## **2.4 Alumni Advice**

Osama gave a moving account of his journey with RNH. He is sad to be leaving the FAC but thinks it is good that new family members with new ideas are able to participate.

## **2.5 Alumni Thank You**

Osama and Sharon were presented with a certificate of appreciation and a RH pin as a small token of gratitude for their contributions to FAC. Aicha, whose last meeting was in November, 2016 will also be given a pin and certificate.

## **2.6 Medication Review**

FAC members were asked for suggestions about how to get the latest (current) accurate information about medications from parents at the time of admission. A number of suggestions were made including the use of social media to reinforce the fact that this information is required in order for their child to be admitted; it is critical for their child’s safety. The FAC agreed that it is okay to enforce a minimum standard, to have a zero tolerance policy in this regard.

### 3. Follow Up Items

#### **3.1 Review of Support Services:**

a) an email was sent advising families of the availability of childcare during monthly parent support meetings; notice was also posted on the internet. Coffee meetings have also been held.

b) in response to feedback from families discharge times have been changed to better accommodate their needs.

**3.2 Confidentiality agreements:** all now complete,

#### **3.3 THRIVE**

Mindy distributed copies of a letter about this integrated health service planning initiative. FAC members are invited to participate in any of the focus groups and an email invitation will be sent to families.

**NB** Nancy requested that she be advised by email of any dietary restrictions.

**Next meeting: Monday March 6, 2017 at 6:00 pm.**