

**Family Advisory Committee**  
**March 16, 2009**

Present: Ruth Hartanto, Jennifer Walker, Georgina Neville, Sharon Liff-Neilson, Osama Abdali, Francois Dumont, Nancy Graham, Nora Ullyot, Lloyd Cowin

Regrets: Mathoni Sansoni

1. Follow Up:

Ombudsman Role: Ruth reported that if there is a concern that cannot be resolved by Lloyd, Marion or other Roger's House employee, the matter will go to the Board of Trustees.

Communication Log: Nora reported that volunteers and child life have started using the communication log. Nora will monitor the use.

Family Activities: Nancy and Nora reported that due to the high occupancy rate at the House, it was not felt to be necessary to follow up with some of the initial recommendations to increase occupancy. Trying to organize special nights out for families (hotels, restaurants etc) has been difficult and time consuming. Some meals prepared by a volunteer chef have been prepared for parents staying at the House. Child life continues to organize activities for children and families on weekends and will continue to have at least 3 special events per year: Roger's House Anniversary, Halloween and Christmas. The FAC will investigate hosting a family picnic.

**Action:** FAC

2. New Business:

Lloyd presented the FAC with the Strategic Plan goals.(see attached) These were established at the Board meeting in the fall and discussed by the Palliative Care team at a retreat day in January. This is a 2year strategic plan. The Board identified four themes and a fifth was added by the Palliative Care Team. Action items have been identified for each goal and Lloyd asked for feedback from FAC on prioritizing these action items. He would like feedback on key priorities, what is missing and whether any point need to be better developed.

Lloyd stated that his priorities are: A 1,2, 3; B1; C2; E 2, 3.

FAC will examine where they can be involved have action items that fit with the strategic plan. FAC will look to developing a plan that corresponds with the Board plan.

Member discussed what FAC could do to help contribute to the goals.

A1: Will examine the Roger's House /FAC in regional palliative care and methods to get the message out about what paediatric palliative care is.

A2: FAC can participate in orientations and nursing education days

A3: Web site updating; Family stories from the telethon could be added. A link to FAC could be enhanced to include tips to families

B1: FAC agrees that renovations are a priority.

B2:FAC supports examining the feasibility of a day program where children would come for the day but go home at night. This would involve having increased staffing to implement it as a program.

B3: Transition to adult services is a priority. It was noted that this is also a priority for CHEO and the FAC will send a letter of support to Family Forum indicating our support of this. A letter will also be sent to Rotary home supporting their request for funding for an age extension to 21.

C1: FAC could speak to this.

C2: Members defined this as a priority. This could take the form of support groups for families and siblings to address psychosocial needs of at the time of diagnosis and ongoing.

A1 and C2 were identified as biggest priorities.

Next meeting will focus on the web site and ways to emphasize the benefits of palliative care.

**Next meeting June 8<sup>th</sup>  
6:00-8:00**

