

Roger's House Family Advisory Committee Meeting
Monday June 21 , 2010

Present: Ruth Hartanto, Georgina Neville, Osama Abdali, Jennifer Walker, Aicha Mansir, Nora Ulyot, Barb Cummings

Regrets: Francois Dumont, Sharon Liff Neilson

Guest: Lloyd Cowin, Andre Lanctot, MBA student

1. **Minutes of last meeting:** the minutes of May 3, 2010 were accepted.

• **Follow Up Items:**

A. **National Palliative Care Conference:** Ruth has contacted the Canadian Hospice Palliative Care Conference and they will be organizing an hour long workshop by families on paediatric palliative care and the families experiences. They will be examining what their organizations could do to get the family perspective heard.

Action: Ruth

B. **Sibling Recognition:** There was a discussion about organizing a party /activity day for siblings that would not include the child receiving care at Roger's House. This would be something in addition to the family parties at Halloween and Christmas. This was seen to be important to allow the well sibling to participate with other children in a celebratory way, not as a support group service. Nora will discuss this with Lloyd.

Action: Nora

2. **New Business:**

A. **Nursing :** Lloyd announced that 7 nursing staff recently passed the Canadian Nurses Association special certification in Hospice Palliative Care Nursing. FAC members asked him to pass on their congratulations.

B. **Family Needs Survey Results:** Lloyd and Andre presented the results of the Needs Assessment Survey. The purpose was to improve services in the long term. Survey results and summary are attached. Discussion included

- Concern with the small response rate and some of the responses
- Concern that the survey may not have been answered by the target audience.
- The response rate was the same for the last annual survey and families may have reached a saturation point with surveys

- Suggestions to improve the response rate including using an on-line program like Survey Monkey.
- We do not have a full database of all families e-mail addresses and volunteers could be utilized call families to update this.
- Having volunteers conduct the survey over the phone. A letter would need to be sent in advance to notify families. It was noted that families may not feel comfortable being candid with this approach.
- Taking care not to extrapolate too much with low response rate
- On a positive note, the Respite Support Group has started and has been very positively received by families. (this is reflective of the need expressed in the survey).
- An update on the survey should be done in the next Newsletter.

Next Meeting
September 20th, 2010
6:00-8:00