

**Roger's House Family Advisory Committee Meeting**  
**Monday September 20, 2010**

**Present:** Ruth Hartanto, Georgina Neville, Osama Abdali, , Aicha Mansir, Nora Ullyot, Barb Cummings

**Regrets:** Francois Dumont, Sharon Liff Neilson, Jennifer Walker

**Guest:** Lloyd Cowin

1. **Minutes of last meeting:** the minutes of June 21, 2010 were accepted.

- **Follow Up Items:**

- A. **Sibling Recognition:** Lloyd reiterated that Roger's House had a commitment to provide comprehensive psychosocial care to the whole family but was cognizant that there were limitations on what we could offer due with existing staff. Nora noted it could be difficult to do something just for siblings at either of the current family parties due to space and the program during the parties. Lloyd will investigate partnering with a community organization to see if they have an activity they could offer. Darling House in Toronto has outings 3 times a year for siblings Nora will investigate what other Canadian Hospices do and report back at the next meeting. We will look to do something in the Spring, possibly at a 5<sup>th</sup> Anniversary celebration.

**Action:** Nora

- B. **Family survey:** Lloyd reported that there has been a declining response rate which may be due to the fact that many of the families have been surveyed several times. Lloyd has suggested that new families be surveyed in the year they first come to Roger's House and every 2-3 years subsequent. This year we have had about 40 new families in the program.

Lloyd noted that we still do not have a complete data base of e-mail addresses and are working to get this updated. A paper survey will be mailed to families. When we collect more e-mail addresses future surveys will be done on line using Survey Monkey.

2. **New Business:**

- A. **Letters of Support:** Lloyd presented the suggestion that we request letters of support from families that would be send to their MPP to educate/inform them about Roger's House and

paediatric palliative care. Members endorsed this and suggested that a template be developed for families and volunteers. Lloyd and Ruth will present this at the next Board meeting. If the Board endorses this, Lloyd circulate a draft for feedback and discussion at the November meeting.

**Action:** Lloyd & Ruth

B. **Renovations:** Renovations to the nursing station to create a staff bathroom and separate med room started September 20<sup>th</sup>. During renovations we will be reduced to 6 beds.

C. **Volunteer Orientation:** Lise has requested to have 2 parents present at the Palliative Care Training for volunteers and staff on November 16<sup>th</sup>, 7:15-8:00. Ruth will e-mail members who were not at the meeting and she will put together a Power Point presentation. She suggested that presenters include family photographs.

**Action:** Ruth

D. **National Palliative Care Conference:** Ruth is coordinating a panel of 3 parents from Roger's House, Canuk Place and Darling Home to speak on The Family's Role in Changing the National Perspective on Palliative Care at the Canadian Hospice and Palliative Care Association Conference on Friday Oct. 29<sup>th</sup>. She would like to focus on how families collaborate with staff and strategies to promote the family perspective nationally. Ruth received feedback from FAC members and will incorporate this in her presentation. Nora will ask for feedback/input from Roger's House staff to be sent to Ruth.

**Next Meeting**  
**November 8th, 2010**  
**6:00-8:00**