

Roger's House
Family Advisory Committee Minutes
June 9, 2008

Present: Ruth Hartanto, Georgina Neville, Sylvie Lamoureux, Francois Dumont,
Osama Abdali, Nancy Graham, Nora Ullyot
Regrets: Mathoni Sanson

1. Review of the Minutes: The April 14th minutes were reviewed and approved.
2. Follow Up Items:

- **Remembrance Stars:** Nora reported that Northern Art Glass is making the stars and brought an example. Everyone agreed that they looked wonderful. There will be a star for Roger Neilson.

Remembrance Ceremony: The committee discussed what the involvement of the FAC would be at the Memorial Ceremony on June 22nd. Francois will do a reading and all members of the FAC will be invited to attend. The memorial ceremony will occur yearly on the weekend closest to the anniversary of Roger's Neilson's death. It was noted that the Balloon Release that is sponsored by Compassionate Friends, CHEO and Roger's House is scheduled the day before the RH ceremony. There was a discussion about whether these events could be held on the same day. Nora will take this back to the memorial planning group.

Nora asked if families should have a remembrance to take home from the ceremony. Family members agreed that this would be important. Nora will create a framed personalized certificate.

It was noted that all the material should be in French and English.

- **Admissions Coordinator:** Nancy reported that she has finished a first draft of prioritizing admissions. This includes:
 1. end of life
 2. emergency admission
 3. transition to home
 4. pain and symptom management
 5. planned secure admission
 6. as available respite care

Some of the other processes she will be formalizing include : the number/amount of time families can book respite admissions ,the appropriate time to send a letter reminding families to book respite time, when a booked admission has to be cancelled or asked to leave for an end of life admission.. FAC members suggested when completed, the admission planning information be included in the admission package and the newsletter. It was also suggested that it could be available on the website as PDF form.

Nancy also reported that staff are using a workload measurement tool to coordinate the level of staffing needed for the

number and types of guests in the house. Staffing now includes an RN, two RPN's as well as PSW for guest care when needed.

Nancy will e-mail FAC members if she needs feedback before the next meeting.

Action; Nancy

3. New Business

- **Family Faculty:**

- ❖ **Public Messages:** FAC members will each take a section of the keymessages and write a short synopsis to be compiled into a document. Osama will do construction, Nancy will do Roger's Legacy and what paediatric palliative care is, and Nora will do Family Centered Care, the bereavement program and the multi-disciplinary team. Ruth has information from Chad Schella he would like included. Jen Empy, a Roger's House volunteer has offered to do give a Toastmaster's in-service to the Family Faculty.

Action: Osama,

Nancy, Nora

- ❖ **Staff Messages:** Ruth circulated the key messages from CHEO's Family Forum. The membership agreed the document was also applicable to Roger's House. It was suggested that the family faculty could also present at the volunteer training. Other suggestions included

- Taking time to introduce yourself, letting parents know who will be looking after their child after shift change
- Board with names of staff/physician on duty
- Adding parents/caregivers names to patient profile
- Respect and acceptance
- Reassure parents that they are making right decisions, respect our choices
- Be empathetic and sensitive to the emotion state of families
- Involve families about changes in the care plan
- When giving 'bad' news try to wait until we have a support person with us
- We like when you give us a warm blanket
- Be in touch/in tune with our changing situations

- **Prayer markings:** It was noted that there is no direction designation on the walls of the guest rooms to for Muslim families who want to pray. Nora will ask Lloyd about this.

Action: Nora

Next Meeting
September 8th, 6:00-8:00 pm
Roger's House