

CANADIAN NETWORK OF PEDIATRIC HOSPICES

Teleconference – July 21st 2010
11:00-12:30 EST

Present: Lloyd Cowin (& Andre), Janet McFarlane, Dr Marli Robertson, Lyse Lussier, Cheryl Spencer (& Laureen), Carol Weldon, Rauni Salminen and Sharon Baxter

Regrets: Filomena Nalewajek, Kristin Horrell

Minutes

1. Approval of Agenda

Additions:

- Parliamentary Committee of Palliative Care
- Parent Panel
- New Representative for CNPCC

2. Approval of Minutes of May 28th 2010

- Minutes approved as presented with a note of the correct spelling of Sharon's name

3. Business Arising

a) Update on CHPCA conference 2010 (Sharon, Cheryl and Lloyd)

- "Why are we so hungry to feed", withholding fluids and food at End of Life care.
- Dr Lieben, Dr Rappaport are on panel.
- *Action:* Lloyd will ask Dr Nuala Kenny if she would be willing to join the panel.

b) Marketing Pediatrics at time of CHPCA conference (Sharon)

- Both the CHPCA and Rogers House will have booths at the conference.
- Please forward any materials you would like on display to either Sharon or Lloyd.
- An estimated 600 people will be in attendance, with a small portion of the attendees being French speaking.

c) Pediatric Palliative Care at CHPCA Conference(Sharon)

- Need to look at increasing distribution of information about CHPCA and Meetings to pediatricians. There are currently 5000 people on the CHPCA email list but this mainly targets adult and family medicine.
- *Action:* Sharon and Cheryl will work on revising the flyer to highlight the Pediatric sessions at the conference and will forward the flyer to this group to distribute across their areas. They will also forward out a PDF version to distribute via email.

d) Hospice definition – English (Cheryl) and French (Lyse)

- In Quebec they don't use the Term Hospice. They refer to "House" or "residence" for a residential hospice and "palliative care" to encompass the philosophy of "hospice".

e) (Addition) Parent Panel

- Looking for two more panel members for the parent panel at the CHPCA Conference
- Discussion topic is regarding important issues in Family Centered Care.
- There is unfortunately no funding to bring parents in.
- *Action*": Sharon will email Karen to ask if they have a parent that would be interested from Darling House.

f) (Addition) New Rep for the CNPCC

- Marli is on the Executive committee of the CNPCC and has offered to be the liaison between this committee and the CNPCC committee.
- Next meeting Marli will report Fall meeting of this committee.
- Lyse is stepping down to allow Dr Campeau to sit on the CNPCC committee .

Cheryl to send this CNPH Committee group list to the CNPCC.

g) (Addition) Parliamentary Committee of Palliative Care

- First Day of Testimony was the 2nd week in June.
- It's an ad hoc group with about 35 members with representatives from all the different parties.
- Plan is to develop a position statement for Palliative Care across the Country and goals or suggestions for new legislation.
- This would potentially influence e Federal Legislation – not sure how this will impact on a Provincial level.
- There are ongoing round table discussions.
- Action:
 - Sharon will provide information to each of members of the committee re what was presented in her meeting with the Parliamentary Committee
 - Suggested that each pediatric Hospice representative provide a written brief to the committee if not able to speak in front of them to further their understanding of the critical aspects of Hospice and Palliative Care for children.

4. New Business

a) Action Plan re Goals #4, 5, 6 from Terms of Reference

- Discussion regarding
 - “Standards” OR “Norms of Practice”
 - There are several documents already in existence for Standards and Norms of practice including but not limited to CHPCA Pediatric Norms of Practice, Quebec's “Pediatric Standards”, In addition HAO has a draft of “Residential Hospice Standards of Practice”.
 - Canuck Place has also been through Accreditation Canada for ‘Pediatric Residential Hospice’.
 - It is important to question whether there are any gaps wrt Standards and potential purpose of any new document.
 - Action:
 - Janet and Marli will discuss with Fil Accreditation Canada process to see what their emphasis was and where there may be gaps in the available documentation of appropriate standards for operational aspects of a pediatric residential hospice/House
 - Rauni will share the draft from the HAO Manual with Members of the committee.
- **Goal # 4 – Educate other health care professional about pediatric residential hospice care.**
- See above “Potential Future standards”
- Education of other health care professional is continuous.
- Meeting one-one with practitioners.
- Advising of any upcoming information sessions or Telehealth conferences.
- There is a training program by the CHPCA called LEAP that has been useful for Dr, Nurses, Social Workers and Pharmacists. Sharon has advised she would be able to lend out a copy of the program to anyone who is interested to see whether it is applicable to pediatric hospice, or it is available for purchase.
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- **Goal # 5 - Conduct annual public awareness activities about pediatric hospice care.**
- World Palliative Care Day on October 8th 2011.
- Hospice Palliative Care Week in May.
- Advanced Care Planning for Pediatrics Decision Making Day in Fall 2011.
- **Goal # 6 - Advocate for pediatric hospices.**

5. Other

a) Media Coverage

- There will be a planning meeting the last week of August, regarding coverage in the Globe and Mail for Pediatrics. Lloyd has volunteered to participate in the meeting and be the contact person.
- Suggestion to create a Media Call List - Add Lyse for Francophone.

Next Meeting - September 24th 1200-1300 EST.