

CANADIAN NETWORK OF PEDIATRIC HOSPICES

Teleconference—May 28, 2010

11:00—12:30 EST

**Present : Lloyd Cowin, Cheryl Spencer, Kristin Horrell, Lyse Lussier,
Regrets : Carol Weldon, Janet McFarlane, Filomena Nalewajek, Raunie Salminen,**

Minutes

1. Approval of Agenda

- **Approved**

2. Approval of Minutes of March 26th 2010

- **Approved**

3. Business Arising

- a) Update on CHPCA Conference 2010
 - Topic: Why are we so eager to feed?
 - **Lloyd is in the process of confirming speakers for the Challenge Panel. The list includes a mix of pediatricians, anesthesiologists, nurses, etc. Lloyd will follow up with potential speakers and advise the committee.**
 - Christina Vadeboncoeur has confirmed that she will be the moderator for the challenge panel.
 - The program is being finalized and an error was noted in the description of our Challenge Panel. Cheryl will follow up to ensure this gets fixed.
- b) Marketing Pediatrics at Time of Conference
 - Cheryl will speak with Sharon Baxter from CHPCA to determine how pediatrics can be marketed at the conference.

4. New Business

- a) Goal #7 from Terms of Reference
 - The Committee agreed that page 7 and 8 describe pediatric palliative care quite well. In fact, Lyse mentioned that the Quebec guidelines refer to this definition.
 - The Committee discussed the topic of ‘When do you call a program a hospice?’ Cheryl, Lloyd and Kristin felt that hospices are not just residential, but refers to a broader programming to support individuals.
 - In French, hospice refers to a place, not a program, which provides some confusion in translating. Programming would be referred to as “palliative care”, not hospice. When the Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice document was translated into French, where the term “hospice palliative care”

appeared in the English version the translated version had “palliative care” (the term hospice was removed).

- Wikipedia defines Hospice as: a type of care and a philosophy of care which focuses on the palliation of a terminally ill patient's symptoms. These symptoms can be physical, emotional, spiritual or social in nature.
- **Cheryl will research if CHPCA has a formal definition of hospice and confirm the translation into French.**
- **Lyse will translate the Wikipedia definition into French to see how it translates and follow up with other contacts on the translation of hospice in French.**
- The Committee felt comfortable with the definition provided in the Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice document
- **Lyse will further review the document to see if there are any other differences and circulate to the group.**

b) Next Action from Goals in Terms of Reference

- Goal #1- The committee expressed a willingness to help new and developing hospices, but felt that given how new a lot of our organizations were, developing guidelines may be difficult.
- Was this goal referencing a physical hospice, or pediatric palliative programs?
- The committee was not aware of any new/developing pediatric hospice palliative care facilities in Canada.
- The committee did not select this goal as their next priority.

- Goal #3- **Lloyd will clarify with Fil why “Standards of practice” was used instead of norms of practice or guidelines.**
- The Committee questioned how these standards would be used once developed. **Cheryl will speak with Sharon Baxter from CHPCA to determine if there would be a need for standards in the future (i.e. accreditation).**
- The Norms of Practice in the Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice document could be utilized to help achieve this goal.
- The committee did not select this goal as their next priority.

- Goal #4, #5, and #6- As these three goals are very interdependent, the Committee selected these ones as their next area of focus.
- The conference is an ideal time for a public awareness campaign
- **Cheryl will ask Sheron Baxter if this is also a priority for CHPCA and how involved they would like to be in such a campaign. A joint initiative would be ideal.**

- **Once we hear back from Sheron Baxter from CHPCA we will proceed with the following:**
- **Lloyd will contact the Communications Consultant working with Roger's House to see if they would help with communications for the conference and a public awareness campaign.**
- **Lyse will look into someone who could help with the French translation of materials.**
- **The Committee will need to determine what are our 3 key messages and how would they be best delivered.**

5. Next Meeting Date

- **Wed July 21st 2010 11:00 EDT**

6. Adjournment