

**CANADIAN NETWORK OF PEDIATRIC HOSPICES**  
**November 23<sup>rd</sup>, 2012**

**Present:** Janet McFarlane, Dr. Marli Robertson, Rauni Salminen (Chair), Tanis Miller, Margaret MacNeil, Lloyd Cowin, Lyse Lussier

**Regrets:** Anna Cooper, Kathryn DaSilva, Kristin Horrell, Joanne Gallevo, Laureen Nickerson,

1. **Approval of Agenda** – Approved by all
2. **Approval of Minutes of May 25, 2012** – Approved by all
3. **Follow up Action items from last meeting:**

**3.1. Pediatric Hospice document**

1. Marli invited dialogue with respect to two questions.
  - Are people finding The Children's Hospice Service Toolkit from Short Lives Together an appropriate template for our document?  
Janet and Marli found that for the Section they are doing little if any of the content is applicable and it is clear that a large portion of content proposed by the CNPH Workshop group is not covered wrt Service provision. Others in the group (Lloyd) felt that it was reasonably helpful to use it as a template for their Section 1.
  - Do we still agree that producing a document aimed at groups wanting to start a new children's hospice in Canada is a worthwhile endeavour given a relatively small number of potential end-users?  
The group felt that this would be a good use of the Committee's time and Resources rather than the alternative where everyone who might be interested in the idea of starting a Hospice can be referred to the Document to get a start on understanding an approach and what the expectations would be.  
*Action: Send sections to Janet and she will collate them into one document and email back to group to initiate discussion at the next meeting*
2. Marli commented on a discussion she had had with Hal Siden wrt a BC initiative called Tiers of Service Project thinking that it might be helpful to inform the Toolkit as it pertains to the Canadian experience/ needs analysis/ As well the data from the large epidemiology study that has been undertaken in BC would be useful. Tanis outlined some more details about this project and thought that published data might be available in the next months.  
*Action: Tanis to keep committee informed.*

**3.2. Palliative Care Week**

1. Rauni will connect with Ian Brown (Globe & Mail) to determine if he might be interested in doing an article or a series on pediatric hospices for Palliative Care Week in May 2013

### 3.3. Transition of New Chair and Co-Chair

1. Janet will be taking over as Chair beginning next meeting and Lloyd will step in as Co-Chair.

### 3.4. CNPCC Update

1. CNPCC Executive is looking for a way to capture a Members list. Some suggestions to see if for a nominal membership fee people doing pediatric palliative care can join the Network at the same time as CHPCA.
2. Confirmed that CNPH is a Standing Committee of CNPCC. It was not felt that combining CNPH and CNPCC Executive would be as productive as CNPH has a very specialized focus on the Residential Hospice. CNPCC Executive had discussion about Terms of Reference and a draft of new TOR will be discussed at the next meeting in January 2012.

*ACTION: At the next CNPCC Executive meeting Marli will clarify further where the CNPH fits into the Vision and goals of the CNPCC.*

**This is off the website:**

"The Canadian Network of Palliative Care for Children (CNPCC) has developed out of the [Pediatric Hospice Palliative Care Special Interest Group \(SIG\)](#) of the [Canadian Hospice Palliative Care Association \(CHPCA\)](#). It remains under the umbrella of the CHPCA, and reports to its Executive Director as described in the [CNPCC Terms of Reference](#).

It is envisioned that the CNPCC will be comprised of a broad group of individuals involved in palliative and end-of-life care of children, including those who may see palliative care in general as being rather peripheral to their primary clinical field, such as pediatric cardiology, nephrology, respirology, neurology, genetics, and specialties related to metabolic diseases.

The formation of a network whose focus is to address issues unique to palliative and end-of-life care for children will facilitate standards development, advocacy, and education, perhaps raising the profile of pediatric palliative care into the awareness of the broad group of caregivers mentioned above, and of the community in general." –

#### 4. Business Arising None

#### 5. Other Business

##### 5.1. Accreditation (Update)

1. Tanis and Margaret outlined some of their experience with the third Accreditation cycle for Canuck Place . Congratulations to Canuck Place. The survey report came in and it went very well with 99% of the criteria being met. This was an extensive process involving many many months of intensive work as well as an ongoing awareness and commitment to the criteria and the process between cycles. The accreditors were also able to

share some of the successful strategies that other Hospices use. They were most impressed by the quality of care and the culture of caring – things not necessarily measured by Qmentum but very evident to them.

2. Once final results are out work will be done with Accreditation Canada to get messages out to the community at large.
3. This is the 3<sup>rd</sup> Accreditation for Canuck Place--the first being a pilot 2006.

#### **5.2. Terms of Reference**

1. Agreement of the group to re-look at the Terms of Reference and to choose smaller number of goals primarily to meet the Mandate of fostering collaboration among pediatric hospices in Canada. Janet spoke to the usefulness of sharing knowledge and experience among the committee members. There are 7 goals some of which are very ambitious, not very specific and not all relevant to the specific mandate of CNPH. Janet would like to have more discussions around what our purpose and goals are and how realistic they are. Discussions will begin at the next meeting. ***Action:** Janet and Lloyd will come up with a structure for these conversations for the next meeting*

**6. CNPCC – Update** See 3.4.

**7. Adjournment – 11:56am**

**Next meeting January 25, 2013 1:00pm EST**