

Canadian Network of Pediatric Hospices (CNPH)  
Minutes of Meeting  
February 5, 2010

Present: Lloyd Cowin, Lyse Lussier, Rauni Salminen (recorder)

Regrets: Filomena Nalewajek, Kristen, Carol Weldon, Jenna McFarlane

1. Approval of agenda

All approved

Lyse added to agenda "conference in Montreal re: Euthanasia."

2. Approval of Minutes

Approved as presented.

3. Business Arising;

a) Research project in Quebec

Lyse asked if each pediatric hospice could complete the survey she had sent out

Lyse to send CNPH working group due date of survey

Action item: Lyse to contact Fil and Kristen re: survey

b & c) CNPCC: Cheryl provided update

CNPCC Interested in working with CNPH

Agreed relevant topics for conference - "when to stop nutrition & withholding"

Strong speakers needed for Challenge Panel

Topics could include:

-Children Making Decisions about their own care

-Transitioning from Pediatric to Adult Care

Suggestions of Speakers for Panel:

Christine Harrison Sick Kids Hospital; Christine Vedeboneour; Annie Jeanveau; Cathy Glass;

Ellen Tsai

CNPC has requested 2 members of our group to work with them on finalizing workshops

Action: Lloyd will speak with Fil and Kristen about who should be joining this group

Action: Cheryl will pass on names to CNPC, upon hearing from Lloyd

This group will also be responsible for coming up with the theme

Action: if any recommendations for Panel speakers pass them onto Cheryl by April 1<sup>st</sup>.

Lyse would like to remain on both committees ours and CNPCC. She would be our rep to CNPCC

Action: need to solicit feedback on the above from Fil, Dristen and Carol

d) Marketing of Pediatric stream at Conference

Need to broaden the audience and awareness of pediatric palliative care so we don't preach at ourselves

Perhaps consider a press release

Action: Lyse to advertise at her conference

Action: Lloyd and Rauni to mention at Senator Carstairs meeting

Inform other pediatric palliative care providers in our community about conference

Availability of conference materials for distribution

Action: Cheryl to contact Sharon to contact CAPHC (academic health centers)

Lloyd suggested Senator Sharon Carstairs might be a good conference speaker

(she is currently holding palliative care community reviews of her paper published 5 Years ago on palliative care, entitled "Still not there")

#### 4. Terms of Reference (develop action plan)

Note: Correct typo in point 5, should read "conduct" not conduce.

##### a) Need to prioritize the goals, can't tackle all at once

Was agreed that we should begin with # 7

We all need to have a common language and definition/description of pediatric palliative care

Action: everyone to look at goals again and come to consensus on this

##### b) Other business:

Lyse: Invited to speak at Conference about Dignity and Death. One of the issues being raised is euthanasia. Lyse is required to address this in context of palliative care.

Action: Lyse is asking if anyone has any articles or resources that would assist her in developing an argument against euthanasia and promote positive palliative care.

Action: Lyse to explore if there is someone at this conference who would be good for challenge panel at conference

Next meeting April 13, 2010. Recorder: Lyse (Cheryl will assist with language)

Adjourned