

**SOUTHERN CALIFORNIA PEDIATRIC PALLIATIVE CARE NETWORK (SCPPN)**  
**BI-MONTHLY MEETING – City of Hope**  
**June 21, 2007**  
**Minutes**

**Attendance:** See attached

Topics	Discussion	Conclusion/Comment
Welcome	Dr. Anderson called the meeting to order at 11:30am. Introductions at attendees were made.	
Children's Hospice & Palliative Care Coalition Update	Lori Butterworth presented an update on waiver information. A letter from Department of Health recently went out to home health Y hospice agencies seeking interest in serving children with pall. Care needs. They also sent out a letter prior to this to county offices. Need to get information on # of children in need before waiver sites selected. Met with lobbyist to get a new bill for rates for home health & hospice; educate them on why palliative care should be reimbursed at a higher rate than other services. They see CA as setting the pace for child pall care. What should be the name of the waiver program? Someone suggested something like HOPE (Healthy Opportunities for Partnership at End of Life). Lori also presented the new website. It will be launched in the next couple of weeks.	Members are encouraged to submit articles and guidelines they have found helpful.
General Discussion	Two examples were given regarding community help for families. Should articles be written for local paper to highlight these? Somehow this should be documented. Should this be something called Heroes of Palliative Care?	
End of Life Education	Rose Varani from City of Hope described ELNEC, developed in 2001, a basic end of life course for RNs that is now nationwide; a pediatric palliative course for RNs developed in 2003, and a critical care course developed in 2005.	
Presentation of Guest Program Site – City of Hope	<p>Clarke Anderson, M.D. described the unique population at COH; many transplant patients 12 years and above, and a bone tumor program with patients through their late 20's. Need for development of adolescent palliative care program. He described how he and Dr. McAllister-Black have already surveyed the staff and ran a focus group as a starting point. Dr. Anderson also described the cuddle pillows that Child Life Program makes for families whose child is dying.</p> <p>Randi McAllister-Black, Ph.D. described an ongoing monthly bereavement support group for parents, and concurrently for siblings. She leads the parent group and her intern leads the sibling group. Food is provided. The group was informed that these support groups are open to the community. She also described a poster presented at an International Palliative Care meeting in Budapest recently which documented</p>	

	themes from this ongoing support group. She stated a desire to research parents who have been bereaved longer than 8 years. She was given some information to pursue for possible database of parents to interview. Randi also described the yearly Pediatric Memorial Service conducted every fall at COH.	
Creation of Palliative Assessment Guidelines that leads to Plan of Care	Elana Evan, Ph.D. discussed the importance of creating a template that can be used to create palliative plans of care. This is important for documentation, uniformity of care, and to enhance the efficiency of the Waiver Program. Seattle Children's Hospital has a good one that we could look at and adapt or modify for our purposes. The group stated that getting parent and CCS input on this would be helpful as well.	Elana will post the Seattle template for us to all view and give input on.  She asked that if we have other models, to please send them to her. eevan@mednet.ucla.edu Elana will also contact Bruce Himmelstein from Milwaukee.
Palliative Care Grant Pool	Elana Evan, Ph.D. informed us that ACS now has a palliative care grant pool.	
Spanish Speaking Bereavement Group	Martha Montealegre, a parent who lost her child to cancer 10 years ago provided her business card to the group. She runs Spanish speaking bereavement groups in the Culver City area.	
Teleconferencing Meetings	Dr. Anderson brought up the need to possibly teleconference some of our meetings. There is a source called <a href="http://freeconference.com">freeconference.com</a> that we can look into. You can participate just by the cost of a long distance call. Should we also look for a central meeting place? Perhaps after this first year of holding meetings at different institutions, we should consider a central meeting place. How do we define Southern California in terms of who participates in our meetings?	Ongoing discussion.
Free Standing Hospice	Dr. Anderson brought up the issue of the need for a free standing pediatric hospice facility. Discussion around whether or not families would really use it. Perhaps what they need more is respite care.	
Next Meeting	The next meeting will be in August and hosted at CHLA. Watch email for details.	
Mission Statement	Add infants, children & adolescents to statement.	
Tour	Dr. Anderson conducted a brief tour of COH Pediatric inpatient facility & the Koi pond.	
Next Meeting	The next SCPPN meeting will be at Children Hospital Los Angeles sometime in August. Barbara Britt will get back to us with exact date/time/location.	

Respectfully submitted,  
Randi McAllister-Black, Ph.D.