

**Pediatric Palliative Care Southern California Coalition: Meeting #1**

**Date: February 9, 2007**

**Time: 12:30pm – 3:30pm**

**Location: UCLA**

**Meeting Consensus/Next Steps:**

- **Created Name for the Group: Southern California Pediatric Palliative Network (SCPPN)**
- **Dave Andrade (Children's Hospice and Palliative Care Coalition – CHPCC) will assemble SCPPN roster; roster will be checked for accuracy, updated with members' clinical specializations, and re-sent**
  - **Roster will be redistributed as new members/organizations join**
- **Miller Children's Hospital (Long Beach) will host next SCPPN meeting during the week of April 23<sup>rd</sup>**
  - **Host will provide lunch, note-taker, and one-hour presentation of institution-specific pediatric palliative care program, upcoming developments, etc.**
  - **Specific time, date, and location information will be sent out by host once institution's available accommodations have been reserved**
  - **For the next meeting: SCPPN members will review the mission statement of the Northern California Collaborative, brainstorm ideas for the SCPPN mission statement, and bring list of known community resources for medically fragile children**

**I. Welcome/Introduction- Elana Evan, PhD, Coordinator, UCLA Children's Comfort Care Resource Program**

- a. Meeting attendance and organization represented: Suzanne Engelder (St. Joseph Hospice), Christy Torkildson (George Mark Children's House), Devon Dabbs (Children's Hospice and Palliative Care Coalition – CHPCC), Lori Butterworth (CHPCC), Scott Peterson (CHPCC Parent Advisor), Suzanne Peterson (CHPCC Parent Advisor), Janet Thomas (Kaiser Permanente), Tracy Kruger (Kaiser Permanente), Randi McAllister-Black (City of Hope), Clarke Anderson (City of Hope), Kim Bower (San Diego Hospice and Palliative Care), Lisa Schoyer (Los Angeles County Children's Medical Services), Linda Gorman (Cedars-Sinai Medical Center), Gay Walker (Trinity Kids Care Hospice), Glen Komatsu (Trinity Kids Care Hospice), Terri Warren (TrinityCare Hospice), Candy Varner (TrinityCare Hospice), Joetta Wallace (Miller Children's Hospital), Tom Klitzner (Mattel Children's Hospital), Elana Evan (Mattel Children's Hospital), Danielle Roubinov (Mattel Children's Hospital (took minutes))

II. Update regarding the Waiver & State Meetings- *Gay Walker, RN, Program Development and Clinical Manager, TrinityKids Care; Devon Dabbs and Lori Butterworth, Executive Directors, Children's Hospice & Palliative Care Coalition*

Nick Snow Hospice and Palliative Care Act – Assembly Bill 1745 (packet of informational materials was provided to meeting attendees)

- b. Bill was passed on September 19, 2006
- c. Consists of 1915C community-based waiver: Pilot sites deemed eligible will be able to provide a pediatric palliative care benefit; evaluation of whether, and to what extent, such a benefit should be offered under the Medi-Cal Program will be conducted
  - i. Palliative care services will be provided to all children 21 years of age and younger who are diagnosed with a life-threatening illness, regardless of the estimated length of the individual's remaining life
  - ii. Curative and palliative services may be provided simultaneously
  - iii. Provision of palliative care services will not reduce or eliminate services currently offered under Medi-Cal or California Children's Services (CCS)
  - iv. Waiver content is very specific – a “single issue waiver” – such that other organizations (such as CCS) cannot include their interests on the waiver
- d. Advisory board consists of 3 subcommittees involved in the development and evaluation of the waiver
  - i. Service Delivery Model Committee
    - 1. Additional services to be included in waiver; case management versus case coordination
  - ii. Eligible Child Committee
    - 1. Based on article by Himmelstein and Hilden (2004) published in the Journal of Palliative Care, Committee selected the broadest possible eligibility criteria: Children 21 years old and younger who are diagnosed with life-threatening conditions and their families
      - a. ICD-9 codes are available but currently not referenced in order to prevent children with omitted conditions from feeling slighted and not receiving pediatric palliative care services
    - 2. Number of California pilot sites and children that will be served under the waiver is being discussed
      - a. California identified over 16,000 children from CCS that would benefit from palliative care services (if children with progressive illnesses were included in this estimate, number of children would rise to 172,000)
      - b. Model in Florida includes 7 established sites (with 2 additional sites pending), with approval for up to 20 sites; 940 total children in Florida are being served

- c. Only children who qualify for CCS are eligible ---> leads to question of what can be done for children who have private health insurance and/or parents who earn a steady salary who do not qualify for CCS
        - i. Coalition is in touch with private insurance companies who wish to be kept informed; historically, private insurance companies often follow in the lead of Medi-Cal
  - 3. Committee is working closely and receiving feedback from individuals involved in Florida waiver
    - a. Families in Florida were reluctant to participate because waiver language included the word “hospice” (families assumed this indicated a prognosis of death)
    - b. Need to ensure that families in California understand that their children will continue to receive life-prolonging treatment even with provision of palliative care services
  - 4. Evaluation Committee
    - a. Evaluation of tools to be used to measure outcomes; outcomes will then be presented to meet federal waiver requirements and provide evidence that palliative care services are keeping children out of the emergency room and saving money
  - e. Department of Health (Sacramento) has established a website to receive feedback on this issue (<http://www.dhs.ca.gov/pcfh/cms/ppc/default.htm>) and they will respond/bring the feedback into their meetings
    - i. If you do e-mail the Department of Health, Lori Butterworth and Devon Dabbs (Co-Executive Directors of the Children’s Hospice and Palliative Care Coalition) ask that you carbon copy them
- II. The Children’s Hospice and Palliative Care Coalition: Lori Butterworth and Devon Dabbs (Co-Founders/Co-Executive Directors)
- a. Eligibility of children for hospice care was brought to their attention, “lighting the fire” of righteous anger to make a change; Coalition was established on September 11, 2001
  - b. Foundation of the Coalition is its interdisciplinary philosophy (comprised of professional perspectives from hospital, community facility, CCS, etc.) and shared goal of improving care for children with life-threatening conditions and their families
    - i. Membership is free and currently made up of 500 providers around the state and countless parents (who then forward to list serve to additional parents who are not formal members)
- III. The Northern California Collaborative – Christy Torkildson, *MSN, RN, PHN, National Director: Education, Research and Professional Relations, George Mark Children's House.*

- a. Northern California Collaborative was established after several professionals met at a conference in 2003 and were all working in areas of pediatric palliative care or wanted to become involved in the area
  - i. Began as 12 organizations (tertiary care centers, pediatric hospice and palliative care facilities, adult hospice and palliative care facilities, non-profit agencies, and home health care organizations who primarily serve adults but occasionally care for pediatric patients)
  - ii. Approximately 30 centers now involved in the Collaborative
- b. First project of the Collaborative: Development of a master order set for pediatric palliative care ----> this led to Pediatric Palliative Care Order set at UCSF (a recognized leader of pediatric palliative care in a tertiary setting)
  - i. Order set consists of 10 pages of discharge planning and all facets of writing pediatric palliative care orders
  - ii. Care providers and agencies can take this document and use all/part of it, adapt it for their purposes, and use it as an educational document to support changes in their institution
  - iii. Next project of the Collaborative: Perinatal order set (will come out of UCSF as well, but includes input from Stanford, Kaiser, and CHLA)
- c. Northern California Collaborative is focused on finding and sharing resources, improving care coordination and the continuum of care, and enhancing education (usually at the provider level)
  - i. Collaborative polled people in the area to establish the type of services and resources provided; In northern California, each agency has a geographic area that they cover; Example: if a child is in Marin County, the agency serving that county can be called – if they cannot admit the child, another nearby facility will be suggested
    - 1. Collaborative is in the process of posting this information on their website so it can be used during the referral process
    - 2. An example of pediatric palliative care resource: Moment by Moment, founded by photographer Karen Heinrich
      - a. When best friend experienced neonatal loss, Heinrich held a professional photography shoot of child in the NICU
      - b. Heinrich later learned about Comfort for Kids and George Mark Children's House - offered to take professional photographs for any child diagnosed with a life-threatening illness
        - i. Each child receives 175-200 black and white, 4 x 6 photograph in an album and on a CD-ROM; photographs are never used or

reproduced without permission from  
child/family

- c. Heinrich learned about the Collaborative and formed a group of 42 professional photographers (trained in pediatric palliative care, communication, and confidentiality) who provide this service for agencies in northern California (and many agencies in southern California are beginning to request this service)
  - ii. This type of resource database necessary for resources and facilities in southern California; often there are resources in southern California that few people know about (e.g. Now I Lay Me Down To Sleep)
    - 1. Los Angeles has approximately 600 agencies that address the needs of children in some way – must begin to identify and “sift through” the agencies
    - 2. Currently, great need for grief and bereavement services in southern California; there are therapists available and individual families who gather informally, but few regional services
  - d. Northern California Collaborative is specifically termed a “collaborative” in order to do away with competition among organizations
    - i. Professionals involved in the Collaborative conduct Grand Rounds at various hospitals, provide presentations to residents, and represent each other’s organizations
    - ii. Collaborative co-sponsors conferences, helps increase attendance
  - e. Collaborative meets every other month for three hours
    - i. Meeting of representatives from across Northern California (employers accommodating, often provide leave time for employees)
    - ii. Individuals that cannot attend can receive minutes and provide feedback by email
    - iii. Additional details: non-parliamentarian structure, host provides lunch, no fee required
- IV. Establishing an organization dedicated to pediatric palliative care in southern California: Brainstorm session led by Elana Evan.
- a. Needs and tasks of a southern California group
    - i. Name: Southern California Pediatric Palliative Care Network (SCPPN)
    - ii. Mission statement: Adapt mission statement from Northern California Collaborative (Christy Torkildson will be sending this information to Elana to be emailed out to all SCPPN members), SCPPN members will review this information in preparation to establish SCPPN mission statement at next meeting (April)
      - 1. SCPPN mission statement may want to include parents and other non-professionals in description of its members (only

professionals are included in Northern California Collaborative mission statement)

- iii. Meeting times/sites: SCPPN will meet for four hours (suggested: 12pm – 4pm) every other month, meeting sites have been scheduled through the end of 2007 (exact date and time will be determined by hosting institution once room availabilities determined):
  1. Week of April 23<sup>rd</sup>: Miller Children’s Hospital
  2. Week of June 18<sup>th</sup>: City of Hope
  3. August: Children’s Hospital Los Angeles (CHLA)- Gay Walker suggested this month on behalf of CHLA
  4. October: San Diego Hospice and Palliative Care
  5. December: the home of Scott and Suzanne Peterson
  6. Additional details regarding meeting host responsibilities:
    - a. Host will provide lunch
    - b. Host will provide individual to take minutes and will send copy to all SCPPN members
    - c. Host will provide one-hour presentation about their facility, operations, challenges, solutions, upcoming developments, etc.
    - d. Host may provide parent/survivors (and their transportation to the meeting, if necessary) if it is appropriate
      - i. Lisa Schoyer offers \$10 to any CCS family that can participate
    - e. SCPPN members ask that meetings not be held on Mondays or Fridays; it is noted that if meeting are held on same day, certain members will never be able to attend due to prior commitments
- iv. E-mail list serve
  1. Current roster of SCPPN members (all individuals who were invited to this meeting) will be sent to Dave (dave@childrenshospice.org) at Children’s Hospice and Palliative Care Coalition (sent by Danielle Roubinov at UCLA)
  2. Dave will put roster information into an Excel spreadsheet and send document out to current SCPPN members
  3. SCPPN members will review personal information and e-mail Dave any necessary corrections and additional information about clinical interests and or professional specialty to be added to roster (additional column of this information added to roster by Dave)
    - a. Subject line of email to Dave should read: SCPPN
    - b. If individuals are not on the Children’s Hospice and Palliative Care Coalition list serve, indicate that you would like to be added in same email to Dave

4. Dave will add this information, make any changes, and send out updated roster to SCPPN members; SCPPN members will be encouraged to send this information to other professionals in the area of pediatric palliative care to encourage participation; if they wish to be added to roster, they will send all information to Dave
  5. Dave will update and maintain SCCPN list serve for now, management of list serve may change in future
  6. E-mail etiquette to be determined at next SCCPN meeting – should members be allowed to “Reply to All”, how often will updated roster be distributed?
    - a. “Reply to All” is not an option on Coalition e-mails because distribution list is 500 e-mails
- v. Next SCPPN meeting: week of April 23<sup>rd</sup> at Miller Children’s Hospital (Joetta Wallace); time, date, and location to be determined
1. Review mission statement of Northern California Collaborative and bring ideas for SCPPN mission statement
  2. Bring list of general community resources (not specific to your area) for medically fragile children and families
  3. Minutes of this meeting will be sent to Dave before next SCPPN meeting, members are asked to review and send him any corrections
  4. (Reminder) Current roster will be sent to Dave at Coalition– he will be sending it out, asking for corrections and your professional specialization, making changes, and sending out updated copy for SCPPN members to distribute in this area to encourage additional participation in southern California before next meeting
- V. Question and Answer: Additional Coalition-related information
- a. Pilot sites in the state of California
    - i. Sites have not been designated yet and will be decided by the Service Delivery Committee (and the type of services to be provided); decisions will be made in January of 2008
    - ii. Hospitals, home health agencies, etc that are currently providing this type of care may be eligible to serve as pilot sites; eligibility criteria to be determined
      1. Coalition would benefit from information from SCPPN regarding appropriate and necessary eligibility criteria
      2. Model in Florida: Pilot sites are required to complete a pediatric module (ELNEC, CHIPPS) within 18 months of being designated and show that the team is qualified to care for children
        - a. This may not be the optimal criteria for California pilot sites as it allows care to be provided before pediatric module and training fully completed; goal

is to have staff at site trained and ready before pilot begins