



Schedule

- Palace Hotel 2 New Montgomery Street

Date	Start	End	Function	Room	
Sunday, November 16, 2008	1:00 pm	3:00 pm	TOURS		Tours are available of George Mark Children's House 2121 George Mark Lane, San Leandro, CA 94578
	5:30 pm	7:00 pm	Reception	French Parlor	WELCOME RECEPTION by Supervisor Michela Alioto-Pier, San Francisco Board of Supervisors
Monday, November 17, 2008	7:30 am	8:30 am	Cont. Breakfast	Ralston	CONTINENTAL BREAKFAST
Welcome, Introductions, Ann Armstrong-Dailey, John Golenski, The Rev. Mpho Tutu	8:30 am	9:40 am	Plenary Session	Ralston	OPENING PLENARY Welcome by Senate President Pro Temp Don Perata, Democrat 9th Senate District
	9:40 am	9:50 am	Break		BREAK
CONCURRENT SESSIONS 1	9:50 am	10:50 am	Concurrent Session 1a	Monterey	Perinatal Palliative Care: The Brief Spark of Light that Lasts for Generations - Liz Sumner(The Elizabeth Hospice, Center for Compassionate Care) <i>Fragile hopes, brief lives, enduring memories, their impacts lasts decades. A practical offering of tools, resources, expertise and consultation for participants to be able to initiate perinatal palliative care + grief support in a variety of settings.</i> The Transitions in Pediatric Palliative Care - Aara Amidi-Nouri (University of California, San Francisco) <i>The care provided at a palliative care and end-of-life house is uniquely different from that at home or hospital. Health care providers have a key role in helping families foster sense of community during end-of-life and through bereavement by providing a safe, nurturing environment.</i>
	9:50 am	10:50 am	Concurrent Session 1b	Mendocino	District of Columbia Pediatric Palliative Care Collaboration: A Regional Approach to Pediatric Palliative Care – Susan Rogers(District of Columbia Pediatric Palliative Care Collaboration) <i>An overview of the District of Columbia Pediatric Palliative Care Collaboration, a regional, community collaborative program in pediatric palliative care.</i> Promoting Pediatric Palliative Care: The Texas Pediatric Palliative

Schedule

					<p>Care Consortium- Melody Brown Hellsten & Glen Medellin MD (University of Texas Health Science Center San Antonio, Department of Pediatrics) <i>There are numerous challenges to providing consistent, quality pediatric palliative care services due to limited community services and expertise in managing seriously ill children. This presentation will outline the development of a statewide pediatric palliative care consortium and present activities to date.</i></p>
	9:50 am	10:50 am	Concurrent Session 1c	French Parlor	<p>Partnering for Children- Building a Sustainable Pediatric Palliative Care Program through Communication, Funding and Advocacy- Gwynn Sullivan & Stacy F. Orloff(National Hospice & Palliative Care Organization) <i>The words we use have power, and messaging is the foundation of any sustainable pediatric palliative care program. In this session, participants will learn how to develop, communicate and deliver clear and concise messages when advocating, communicating or fundraising for their program. The session will highlight some of the tools and resources available through Partnering for Children, a national awareness campaign to bring attention to the needs of children with life-threatening conditions.</i></p> <p>Building Coalitions for Change-Children's Hospice and Palliative Care Coalition- Lori Butterworth& Devon Dabbs (Children's Hospice & Palliative Care Coalition) <i>Improving care for children with life-threatening conditions is possible when people come together toward a common goal and a common vision. The Children's Hospice and Palliative Care Coalition is a committed, inspired and diverse group, which emerged from the ground up to address a healthcare crisis for children with life-threatening conditions in California. In this session you will learn how and why to build collaborations to bring about change and to improve care for children with life-threatening conditions and their families.</i></p>
	9:50 am	10:50 am	Concurrent Session 1d	Ralston	<p>An Emerging Paradigm for Pediatric Palliative Care – Jeffery Goldhagan MD, MPH & Kelly Komatz MD, MPH (Department of Pediatrics, University of Florida) <i>Model systems will be required as pediatric palliative and hospice medicine continues to develop. This session will present a model interdisciplinary private-public-academic-community collaboration to sustain a comprehensive pediatric palliative and hospice care program in Jacksonville Florida.</i></p> <p>Outcome Evaluation of a Pediatric Palliative Care Model to Improve Quality of Life- Jeffrey Goldhagen MD, MPH , Kimberly Pierce & Kelly Komatz MD, MPH (Institute for Health Policy & Evaluation Research) <i>The evaluation assessed the impact of a pediatric palliative care program on hospital utilization and costs and parental perceptions of health related quality of life. This study also demonstrates methodological challenges in identifying health service outcomes in research in pediatric palliative care.</i></p>
	10:50	11:00	Break		BREAK

	am	am			
CONCURRENT SESSIONS 2	11:00 am	12:00 pm	Concurrent Session 2a	Monterey	<p>Hope is the Thing...The Challenges of Communicating- Maureen Horgan & Jane Fleming (Providence Hospice of Seattle-Stepping Stones Program)</p> <p><i>Children with life threatening conditions and their families often hold hope as a guiding principle in their decision making and daily living. Hope sustains. Palliative care teams are called to hold this hope and walk with families as they face changes amidst their hope. This session will provide practical approaches to dialogue that promotes hope while introducing palliative care concepts and eliciting goals of care.</i></p>
	11:00 am	12:00 pm	Concurrent Session 2b	Mendocino	<p>Innovations in Care: Using Home Telehealth to Support Pediatric Palliative Care Delivery in Queensland- Helen Irving & Mark Bensink (Queensland Children's Cancer Centre, Brisbane, Australia)</p> <p><i>The Queensland Children's Cancer Centre has been investigating the use of web videoconferencing directly to the home of palliative families, as an extension to the current 24hr telephone "on call" service. This presentation will provide an overview of this work, the results of a recent 12-month acceptability study and the research underway to develop a cost-effective model of integrated care for paediatric oncology patients.</i></p> <p>Addressing End of Life Care Issues in A Tertiary Treatment Centre- Rosie Midson (Great Ormond Street Hospital for Children, NHS Trust)</p> <p><i>This presentation describes how palliative care approaches can be introduced in a hospital culture that often regards death as failure. Using the power of parents' voices is supporting the on going development of an End of Life care Pathway at Great Ormond Street Hospital.</i></p>
	11:00 am	12:00 pm	Concurrent Session 2c	French Parlor	<p>Community Based Care Coordination- California's Waiver Service Delivery Model- Lori Butterworth & Devon Dabbs (Children Hospice and Palliative Care Coalition)</p> <p><i>As a result of the Nick Snow Act of 200, the Children's Hospice and Palliative Care Coalition (CHPCC) has partnered with the California State Department of Health Care Services to create a comprehensive model of pediatric palliative care, which seeks to open access to community-based hospice and palliative care services through a federal waiver. The program utilizes a Community Based Palliative Care Coordinator (RN or MSW) to facilitate a seamless continuum of care across all settings and is due to begin implementation in early 2009. The Partnership for Children, the care coordination model developed by CHPCC for the waiver, will be presented as a budget neutral, replicable model of integrated curative and palliative care for children with life threatening conditions.</i></p> <p>The Tea Party and Pediatric Palliative Care: A Boston Revolution-</p>



Schedule

					Jennifer Loff, Patricia O'Malley MD & Maureen Forbes (Massachusetts Department of Public Health) <i>Overview of the development of the MA Pediatric Palliative Care Network (PPCN): from lobbying the state legislature to admitting the first child and family. Workshop will include perspectives from state, a hospice providing services, and a physician who refers and follows families.</i>
Set-up for awards luncheon	11:00 am	12:00 pm	Concurrent Session 2d	Ralston	No Session
Awards Luncheon	12:15 pm	1:30 pm	Awards Luncheon	Ralston	CHI AWARDS LUNCHEON Master of Ceremonies - John Golenski, awards presented by Ann Armstrong-Dailey
Networking Break	1:30 pm	2:15 pm		Ralston	No Session
				Monterey	Hosted by Barbara Sourkes, PhD
				Mendocino	Hosted by Myra Bluebond-Langer, PhD
				French Parlor	Hosted by Javier Kane, MD
Terry Pratt & Ann Armstrong-Dailey	2:15 pm	3:00 pm	Plenary Session	Ralston	PLENARY – A Road More Traveled CHI Program for All-Inclusive Care for Children & Their Families, Next Steps <i>CHI PACC is an innovative, Bi-partisan “Partnership” between the US Congress, Centers for Medicare & Medicaid Services (CMS), CHI, States and programs that allows for reimbursement for Children with life-threatening conditions from time of diagnosis with hope for cure through bereavement.</i>
	3:15 pm	3:25 pm	Break		BREAK
CONCURRENT SESSIONS 3	3:25 pm	4:25 pm	Concurrent Session 3a	Monterey	Providing Perinatal and Pediatric Palliative and End of Life Care: COLCCs Experience with cohort of 57 patient's, 2006-2008- Onajovwe Fofah MD , Norma Godin Millison RN , Shelia Lenihan Walsh APRN, BC, MA, Sarah Ur MMH & James Oleske MD, MPH, FAAP(Circle of Life Children's Center) <i>Our 2 1/2 years of experience of providing perinatal and pediatric palliative and end of life care in Newark, NJ has demonstrated that not only are children under-diagnosed and under-treated for pain, but that this need extends to include the</i>

Schedule

					<p><i>unborn and newborn infant, especially the extremely premature. Most of the referrals to COLCC were from hospital based subspecialists indicating that primary care providers should be more involved in the recognition and referral of children with chronic life-limiting conditions.</i></p>
	3:25 pm	4:25 pm	Concurrent Session 3b	Mendocino	<p>Building Resilience in Life-Limited Children in Poorly Resourced Areas- Sue Boucher (International Information Officer of the International Children's Palliative Care Network) <i>Children living with life-limiting conditions in sub-Saharan Africa are subject to many social stressors such as orphanhood, poverty and abuse. To help them cope with their condition within this context, palliative care practitioners may implement simple activities that promote resilience despite adverse conditions.</i></p>
	3:25 pm	4:25 pm	Concurrent Session 3c	French Parlor	<p>Achieving the Vision that All Children and Young People with Life Limiting Conditions and Their Families Receive the Care and Support They Need- David Strudley CBE (Acorns Children's Hospice Trust) <i>Following on from the promulgation of a groundbreaking strategy by the UK Government for the development of paediatric palliative care services, Acorns Children's Hospices are leading the way in the West Midlands in the development of framework partnerships with the statutory sector for the provision and care and support for children and young people and their families in the Region. Participants will be encouraged to consider how to reach as many as three times the number of children and young people than has been previously possible.</i></p>
	3:25 pm	4:25 pm	Concurrent Session 3d	Ralston	<p>CHI PACC (Session I): A CHI partnership with US Congress, CMS, States & Programs; A Program for All-Inclusive Care for Children and Families Moderated by Brian Greffe, M.D., CHI PACC National Director a) Terry Pratt Overview of CHI PACC History, Overview of CMS Waiver Options b) National and Regional CMS Representatives c) CO & FL First States to Implement CHI PACC – review of their programs and results to date: Colorado and Florida; Implementation Strategies Following CHIPACC Waiver Approval- What Lies Ahead- Brian Greffe MD, Nancy King RN, CPNP, Christine Staberg, Erin Denholm RN, MS & Ashley Mead LCSW (The Children's Hospital, Denver and The Butterfly Program) <i>As more programs become successful in their submission and approval of a Medicaid waiver based on the CHI-PACC model of care, these organizations must continue to work closely with the state Medicaid office to ensure successful implementation. This session will discuss the issues facing successful implementation of these waivers.</i></p>

Schedule

	4:25 pm	4:35 pm	Break	Sunset Court	BREAK
CONCURRENT SESSIONS 4	4:35 pm	5:35 pm	Concurrent Session 4a	Monterey	<p>Transition Barriers Shattered by a Community Partnership: A Successful Model Integrating Palliative Care into Our Cancer Program with Subsequent Expansion of Integrated Palliative Care Services Throughout Our Children's Hospital- Linda Pegram MD, Laurie Barbaro RN, CHPN, Teresa Black RN, CPON, Tom Kral & Shelia McElmurry LCSW (Children's Hospital of the King's Daughter- Pediatric Hematology/Oncology)</p> <p><i>This session will detail how palliative care was successfully integrated into our Cancer Program utilizing existing resources in our community and within our hospital. Our Oncology Palliative Care Team has become a model for our institution and has been successful in fostering expansion of integrated palliative care services throughout the hospital. During this session we will emphasize the importance and impact of partnering with community resources.</i></p> <p>Madison Outpatient Clinic: A New Service Delivery model in Pediatric Palliative Care- Tanice Miller & Kristina Boyer (Canuck Place Children's Hospice)</p> <p><i>This presentation will outline the development of a collaborative, outpatient pediatric palliative care clinic as a service delivery model to enhance access to pediatric palliative care.</i></p>
	4:35 pm	5:35 pm	Concurrent Session 4b	Mendocino	<p>Collaboration: A Catalyst for Change, The Implementation of a Pediatric Palliative Care Training Program- Hollye Harrington Jacobs RN, MS, MSW, Rose Virani RN, MHA, OCN, Betty Ferrell PhD, FAAN & Pam Malloy RN, MN, OCN (City of Hope & American Association of Colleges of Nursing)</p> <p><i>This session will identify the value of nursing education in providing quality palliative care to children and families and identify three key barriers in teaching and implementing pediatric palliative care programs.</i></p>
	4:35 pm	5:35 pm		French Parlor	NO SESSION
	4:35 pm	5:35 pm	Concurrent Session 4d	Ralston	<p>CHI PACC (Session II): Options for CMS Waivers, continuation of Session I (above)</p> <ul style="list-style-type: none"> a) Review of pending and developing CHI PACC waivers & programs: b) DoD and numerous other states that CHI & CMS have been working in the waiver process c) International Interest in CHI PACC <p>Brian Greffe, M.D. and Terry Pratt: Wrap-Up;</p> <p>Implementing Florida's Federal Waiver Program (PIC)- Terry Eason RN,</p>



Schedule

				<p>CPHN, Steve Blanchard RN & Kelly Komatz MD, MPH (Community Hospice of Northeast Florida, Community Peds Care)</p> <p><i>Florida received their Federal 1915(b) waiver from CMS in 2000. The Partners for Care (PIC) program developed in Jacksonville Florida can serve as a model for other communities. The session will discuss the services delivered, the collaboration within the local community and the positive fiscal impact to administering agency.</i></p> <p>Key Strategies for Implementation of a New Pediatric Palliative Care Program within the Department of Defense at Walter Reed Army Hospital- Cheryl Naulty MD (Healthcare Consultant; retired Medical Director, EFMP, Walter Reed Army Medical Center, Department of the Army)</p> <p><i>The key aspects of palliative care are: education of all who provide care and services and care coordination across all aspects of care throughout the entire course of the child's illness and in all settings of care. Essential program elements for implementation include identification of a program champion, a site assessment to determine the eligible population, and resources and services available, education of all involved in care delivery, and a process for care coordination. Program models vary in their structure, staffing, and service delivery model, according to the needs of the children and families they serve as well as the availability and qualifications of staff, budget constraints, and the population density of children with life-threatening conditions.</i></p>
--	--	--	--	---



Schedule

Tuesday, November 18, 2008	7:30 am	8:30 am	Cont. Breakfast	Ralston	Continental Breakfast
Javier Kane, MD	8:30 am	9:30 am	Plenary Session	Ralston	PLENARY: Integration of Quality Palliative Care Into the Ongoing Care of Seriously Ill Children <i>This plenary will discuss the Individualized Care Planning and Coordination (ICPC) model, including General concepts about quality palliative care and the need for integration of quality palliative care into the mainstream of care.</i>
	9:30 am	9:40 am	Break		BREAK
	9:30 am	9:40 am	Poster Setup	Gold Ballroom	PRESENTERS DROP OFF POSTERS FOR SET-UP IN GOLD BALLROOM
CONCURRENT SESSIONS 5	9:40 am	10:40 am	Concurrent Session 5a	Monterey	A Strategy for Improving Palliative Care for Children & Young People with Life-limiting and Life-threatening Conditions- Rob Dickman & Liz Morgan (Department of Health, London) <i>The session will set out the UK Government's approach to improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions from a policy, strategy and service delivery perspective.</i>
	9:40 am	10:40 am	Concurrent Session 5b	Mendocino	Withdrawal of Mechanical Ventilation in a Non-ICU Setting- Kristine Boyer, Kerry Keats , & Lynn Straatman (Canuck Place Children's Hospice) <i>This session will present an interdisciplinary model to support the withdrawal of assisted ventilation in a free-standing children's hospice.</i> The Good, The Bad, & The Ugly- Withholding of Artificial Hydration in Pediatric End-of-Life Care – David M. Steinhorn MD, Joel Frader MD , Elaine Morgan MD, Nicolas Porta MD, Sookyong Koh MD, PhD , Erin Mullaney RN, APRN-BC & Nancy Heap LCSW (Northwestern University Feinberg School of Medicine-Children's Memorial Hospital) <i>Few decisions are as challenging in pediatric end-of-life care than the choice to allow death to occur through the withholding of artificial hydration and nutrition in pediatric end-of-life care; yet, this choice is often the best of the poor choices available to families of dying children. In expert hands, the distress of such</i>

Schedule

					care which extends often over days or weeks can be minimized; whereas, in inexperienced hands, the distress experienced by the family and medical staff can be severe. Through the use of numerous recent cases our palliative care service has been involved in, we will interact with the attendees in developing a cogent rationale and practical approach to this important aspect of pediatric end-of-life care.
	9:40 am	10:40 am	Concurrent Session 5c	French Parlor	<p>Addressing the Challenges of Perinatal Palliative Care - Tina Ratto RN, MSN, Linda Hopkins MD, Sally Sehring MD & Robin Kramer RN, MS, PNP (UCSF Compass Care, Pediatric Palliative Care Program) <i>The goal of Compass Care, our hospital-wide pediatric palliative care program, is to provide a seamless continuum of care from fetal life to birth and beyond for our patients with life-threatening conditions and their families.</i> As we began to build Compass Care, we quickly recognized the unique needs around perinatal palliative care diagnoses and loss. We plan to highlight challenges and innovative approaches that have empowered the Obstetrics unit to provide palliative and end-of-life care to families facing life-threatening conditions during pregnancy.</p> <p>Developing a Community -Based Perinatal Palliative Care Program- Kelly Cronin Komatz MD, MPH & Jeffrey Goldhagan MD, MPH (University of Florida, Department of Pediatrics) <i>This session will describe the development of a perinatal palliative care service as part of a community-based pediatric palliative and hospice care program. Session will discuss referral patterns, developing a family's birthing plan, and the interdisciplinary team members' roles in supporting family and hospital staff. Methodologies of transition from hospital to home will be explored.</i></p>
	9:40 am	10:40 am	Concurrent Session 5d	Ralston	<p>The Purple Balloon- Chris Raschka <i>This session will present an overview of the book The Purple Balloon, its inspiration and creation, along with a reading of it, as well as a show a short video created for the project.</i></p> <p>Communicating with the Dying Child- Joanna Lyman MA, CCLS, Scott Maurer MD, Justin Baker MD & Javier Kane MD (St. Jude Children's Research Hospital) <i>The workshop will offer practical recommendations for members of the interdisciplinary care team when directly addressing the issue of death with children. The integration of communication related interventions into the ongoing care of seriously ill children will be explored.</i></p>
	10:40 am	10:50 am	BREAK		BREAK
CONCURRENT SESSIONS 6	10:50 am	11:50 am	Concurrent Session 6a	Monterey	<p>Until We Meet Again- Tanya Ungaro CLS & Susan Finkelstein RN, MAS (Tidewell Hospice and Palliative Care) <i>This session will explore creative ways to allow reticent</i></p>

Schedule

					<p>adolescents to safely explore their feelings using literature and creative writing.</p> <p>Siblings-Developing a Magazine Support Group at Acorns Children's Hospice- Sarah Jasper(Acorns Children's Hospice Trust) <i>The presentation will outline the aims and process of the development of a magazine support group for siblings of life-limited children at Acorns Children's Hospices. This will be supported by examples of some of the articles produced by the group, along with written and recorded narratives of their experiences.</i></p>
	10:50 am	11:50 am	Concurrent Session 6b	Mendocino	<p>Filling the Space: An Alternative Pediatric Model for End of Life Care in the USA- Claire Vesely RN, Judith Dunlop M A, MDiv, Barbara Beach MD (George Mark Children's House) <i>Discover how a pediatric residential care facility, George Mark Children's House, offers families and the health care community a different option and model for end of life care in the USA. Following an overview of our experience with end of life children at GMCH, we will narrow the focus to one aspect of GMCH's end of life care experience- compassionate extubation. In closing, the development of our open ended bereavement program will be described.</i></p>
	10:50 am	11:50 am	Concurrent Session 6c	French Parlor	<p>From Consult to Home: The Development of a Pediatric Palliative Care Medical Home- Melody Brown Hellsten MS, PNP-BC & Glen Medellin MD (University of Texas Health Science Center, San Antonio, Department of Pediatrics) <i>In the past decade there has been enormous growth in pediatric palliative care programs in many countries, with diverse approaches to providing palliative care services. This session will outline the experience of one Pediatric Palliative Care service as it has grown from a Hospice and End-of-Life consult service to a comprehensive, transdisciplinary medical home for children with complex medical conditions.</i></p>
	10:50 am	11:50 am	Concurrent Session 6d	Ralston	<p>Care for the Caregiver: A Toolbox of Strategies to Prevent Compassion Fatigue and Caregiver Burnout in Pediatric Palliative Care- Alyssa Gupton (Compassionnet, Lifetime Care) <i>Participants will have opportunities to address caregiver stress and compassion fatigue of both clinicians and families and be provided with innovative and effective methods to positively influence self-care. Interactive portion of session will allow participants to take home their own "Toolbox of Strategies" with valuable and pragmatic tools to apply in future situations and circumstances.</i></p> <p>Compassion Fatigue in Pediatric Hospice and Palliative Medicine Providers- Justin Baker MD, Sarah Federico & Javier Kane MD (St. Jude Children's Research Hospital) <i>The experience of compassion fatigue is an expected response to caring for children at the end of life. If ignored, compassion</i></p>

Schedule

					<i>fatigue can lead to dissatisfaction and burnout and can compromise patient care and interdisciplinary team dynamics. Specific strategies that span personal, professional, and organizational domains that can help protect health care providers from the damaging effects of compassion fatigue and facilitate compassion satisfaction will be presented.</i>
	11:50 am	12:00 noon	Break		BREAK
Exhibits & Posters <i>They will be up</i>	12:00 pm	1:30 pm	Exhibits & Posters	GOLD BALLROOM	Self Reported Experiences of Pediatric Nurses Regarding Care of CHILdren at End of Life- Gina Santucci & Chris Feudtner(The Children's Hospital of Philadelphia, Pediatric Advanced Care Team) <i>In this poster, qualitative data from 266 pediatric nurses regarding their most difficult clinical encounter with a dying child will be presented. Themes from nurse responses include: unclear goals of care, professional power, inexperience in caring for a dying child, ethical dilemma regarding withdrawing care, and unexpected death. Findings from this study will be used to focus on nursing education and support to improve quality of pediatric palliative care.</i>
<i>from 9.30 am – 4.50 pm</i>					Healthcare Transitions In Adolescents with Cronic or Life-Threatening Disabilities and Conditions- Lynn Straatman MD, Gail Andrews, Susan Cadell, Grant Charles, Shelia Marshall, Lenora Omesi & Richard Young(University of British Columbia) <i>This poster will discuss a review of current literature on the topic of adolescent healthcare transitions. Proceedings of a Canadian workshop that explored the research questions surrounding the various transitions experienced by youth with chronic and life-threatening, cardiorespiratory conditions will be presented.</i>
	12:00 pm	1:30 pm	Box Lunch	GOLD BALLROOM	Location of Death in Pediatric Palliative Care: Hospital, Hospice or Home? Gail Andrews, Hal Siden, Lenora Omesi, John Collins & Mike Miller, (University of British Columbia) <i>Location of death is an important factor to consider when parents experience the death of their child. Our study describes where children with life-threatening diseases die when there is access to care in all settings and support for families to move freely into the setting they deem best.</i>
					Giving Information to Latino and Chinese Families in Pediatric Palliative Care- Betty Davies MD, Nancy Contro & Judith Larson (University of California San Francisco) <i>This session will describe the experiences of Mexican-American and Chinese-American families whose child has dies from a life-limiting condition in order to enhance understanding and provide guidance to PPC practitioners.</i>
					Suffering-A Concept Analysis- Niamh McEnereny (The Children's Sunshine Home) <i>A concept analysis on suffering that relates specifically to parental suffering as experienced in a paediatric palliative care setting in Ireland.</i>
					Starting A New Pediatric Palliative Care Program- Artashes Tadevosyan H. Karapetyan, L. Fuortes (Armenian Pain Control and Palliative Care)

					<p>Association) <i>The health system of Armenia is in transition and has no system for hospice care. The presenter will describe the demographics of Armenian households, palliative care options available and results of on-going focus groups of health care providers and families with terminally ill children and the implications for improvement of in-home care.</i></p>
					<p>Neonatal Pain: What Nurses Do and Do Not Know- Onajovwe Fofah MD, Gloria N. Igwe MSN, BSN, RNC, Shelia Lenihan Walsh APRN, BC & James Oleske MD, MPH (UMDNJ/NJMS/UH) <i>This session will identify the role of pain assessment and management using appropriate published tools such as NIPS in identification of neonates at risk of or in pain. This will help to overcome often inadequate recognition of pain with resulting under treatment despite the availability of effective therapy.</i></p>
					<p>A Comparison of Pediatric Palliative Care Programs- Margaux Barnes, & Diane Tucker PhD (Department of Psychology, University of Alabama at Birmingham) <i>Several organizations have published recommended best practices for pediatric palliative care programs (e.g. American Academy of Pediatrics, 2000; Liben et al., 2007; National Hospice and Palliative Care Organization, 2001) but the degree to which programs have utilized these recommendations is unknown. The overall goal of this study is to analyze the recommended best practices, compare the current range of services offered by programs in the United States, and to delineate future directions for the development of pediatric palliative care programs.</i></p>
					<p>Pediatric Hospice in the US in 21st Century: Who are We Serving? Tara Friedman MD (VITAS Innovative Hospice Care) <i>Using the database of the largest hospice provider in the United States, this paper describes hospice underutilization by patients aged 0-17 and highlights differences between adult and pediatric utilization patterns. Raising community awareness and education of staff in caring for this special population are also discussed.</i></p>
					<p>Developing A Framework to Support Transition from Paediatric to Adult Services- Anne-Marie Carroll (The Children's Sunshine Home) <i>A poster presentation on the development of a framework to identify the needs of teenagers with life limiting conditions as they transition into adult model of services.</i></p>
					<p>Gender Differences on Stress and Growth Scores in Caregiving Parents of Children with Life-Limiting Illnesses- Dr. Susan Cadell, Hal Siden, Lynn Straatman, Betty Davies, Rose Steele, Kathleen Wilson, Stephen Liben, David Hemsworth & Kimberly Kennedy (Wilfrid Laurier University) <i>This presentation offers preliminary findings from the CIHR funded study "Caregiving Parents of Children with Life-limiting</i></p>

					<p><i>Illnesses: Beyond Stress and Coping to Growth". In particular, significant gender differences were found in the areas of self-esteem, optimism, burden, and growth. Implications for secondary analysis and future research are also offered.</i></p>
					<p>Development of a Regional Coalition for the Advancement of Pediatric Palliative Care- Kimberly Downing BSN, JD, Nancy Heap LCSW & Mary Runge BSN, MBA(Northern Illinois Pediatric Palliative Care Coalition) <i>The Northern Illinois Pediatric Palliative Care Coalition formed four years ago in response to an observed need for improved community-based pediatric palliative services in the Chicago metropolitan area and throughout the Northern region of the state. The Coalition (which included 8 nonprofit hospices serving children in 19 counties) strives to enrich staff education, ensure quality care, and secure state reimbursement for the provision of pediatric palliative care. The Coalition has realized the benefits of collaboration and resource sharing, which significantly outweigh the accompanying formation and operational challenges.</i></p>
					<p>Feelings Expressed by Young Adults with Cancer- Sunita V. Jadhav & Mary Ann Muckaden MD (Tata Memorial Hospital) <i>Feelings of young adults.</i></p>
					<p>What Happens When the Pediatric Hospice Patient Continues to Live- Caroline A. McCardell BSN, RN (Vitas Innovative Hospice Care) <i>This poster discusses issues encountered by the pediatric patient, family, and hospice interdisciplinary team in providing supportive care when the pediatric patient survives the initial prognosis, but the ultimate outcome is unchanged.</i></p>
					<p>Successful Implementation of a Pediatric Palliative Care Program- Rosemary A. Hubble RN, MA, MDiv (Children's Mercy Hospitals and Clinics) <i>There are few models which outline best practice for providing inpatient pediatric palliative care. Care for the estimated 54,000 children who die each year in the United States has been described as fragmented, inconsistent and not culturally sensitive¹. To address these concerns, The Pediatric Comfort Care Team (PACCT) was developed and implemented at this hospital. PACCT aims to coordinate care for non hem-oncology children with life-threatening or life-limiting conditions who are at risk of dying in a five year period. The outcome of this coordination is enhancement of the healthcare, psychosocial and spiritual needs of these children and their family members. The purpose of this presentation is to illustrate the model used to develop this program and to present the outcomes achieved by the PACCT.</i></p>
					<p>The Challenge of Meeting the Needs of Pediatric Non-Oncology Palliative Patients- Mei-Yoke Chan, Liis Irwani Mohammad Yursi, Noor Aishah Abdul Rashid & Rosalie Shaw (KK Women's and Children's</p>

Schedule

					<p>Hospital) <i>This poster will discuss how non-oncology patients have different set of problems and expectations, due to their underlying disease and how early referral would help to pre-empt these problems.</i></p>
					<p>Unlocking Silenced Voices- Susan Fowler-Kerry (University of Saskatchewan) <i>Impact of social policies on families.</i></p>
					<p>Nursing Workload Measurement in a Pediatric Hospice- Tanice Miller & Kristina Boyer (Canuck Place Children's Hospice) <i>This poster will outline a nursing workload measurement tool developed for use in a free-standing children's hospice. It will include description of the measurement tool and applications for use.</i></p>
					<p>Developing a Children's Hospice Network in Sub-Saharan Africa- Sue Boucher (International Information Officer of the International Children's Palliative Care Network) <i>There are many children requiring palliative care in Sub-Saharan Africa but very few children's hospices and skilled professionals. Through networking and the development of materials for Africa, including a textbook and Toolkit , an increasing number of children receive palliative care from an increasing number of educated and skilled professionals</i></p>
					<p>Palliative Care for Cancer Children with Limited Resource: Meeting the Challenge in Thailand- Issarang Nuchprayoon MD PhD & Niluobon Channong (Chulalongkorn University and Wishing Well Foundation, Thailand) <i>Thailand is a developing country where palliative care is at its beginning. In this Buddhist-majority country, modern medicine is practiced at limited resource. We describe here a novel program that integrates service, public education, and sustainable funding for pediatric palliative care in Thailand.</i></p>
					<p>Implementing Florida's Federal Waiver Program (PIC)- Terry Eason RN, CPHN, Steve Blanchard RN & Kelly Komatz MD, MPH (Community Hospice of Northeast Florida, Community Peds Care) <i>Florida received their Federal 1915(b) waiver from CMS in 2000. The Partners for Care (PIC) program developed in Jacksonville Florida can serve as a model for other communities. The session will discuss the services delivered, the collaboration within the local community and the positive fiscal impact to administering agency.</i></p>
					<p>Palliative Care for Paediatric HIV/AIDS- Sharing an Experience- Ogunbi Olayinka & Folajh Olusegun Oyebola MD (Federal Medical Center Abedkuta Nigeria) <i>The need of Palliative Care services for Pediatric HIV/AIDS is essential and it should be an integral part of pediatric antiretroviral programme with proper education and training of</i></p>

					<p><i>healthcare providers.</i></p> <p>Maternal HIV Infection Disclosure: It's A Family Issue- Winfrida Wilfred Mwashala & Carol Parker (St. Lucia Nursing Home and Orphanage) <i>In many African countries, HIV infected mothers pass the virus to their infants for fear of disclosing their status to partners or other family members. This problem results in thousands, and perhaps millions, of critically ill children who are often left without appropriate health care or family support. New strategies to empower mothers and families may help to stem the tide of children living with HIV/AIDS.</i></p>
					<p>Awareness of Palliative Care Among Pediatricians in India- Manjiri Dighe MD & Mary Ann Muckaden MD (Tata Memorial Hospital, Mumbai, India) <i>This paper aims to develop a framework to broaden the scope of pediatric palliative care in India. This will be done by assessing the burden of chronic debilitating conditions in pediatric patients and also the attitudes and learning needs of pediatricians in tertiary pediatric centers.</i></p>
					<p>Pediatric Oncology Bereavement Program- Carolyn Russo MD, Alan Wong MD & Nidal Mahgoub MD (Kaiser Permanente, Santa Clara) <i>We describe the structure of an ongoing bereavement program in Pediatric Oncology, along with the parental feedback.</i></p>
					<p>The Impact of Bereavement Photography Program on Medical Staff- Kelly Michelson MD, MPH, Todd Hochberg, Kathleen Blehart & Kristin James (Children's Memorial Hospital) <i>Memory making, such as bereavement photography, may help families heal after the death of their child. The impact of bereavement photography on hospital staff is unknown. This research assesses the impact of bereavement photography on pediatric intensive care unit staff.</i></p>
					<p>Improving Palliative Care Education in Pediatric Residency Training- Kerry M. Moss & Brian Greffe MD (The Children's Hospital of Denver) <i>There is a call for improved pediatric resident education in the discipline of palliative care. This session explores the development of a palliative care curriculum in an effort to improve pediatric resident's comfort and confidence in managing patients at the end-of-life.</i></p>
					<p>Paediatric Palliative Care at the Tata Memorial Centre- Networking for Care – Mary Ann Muckaden MD & Manjiri Dighe MD, (Tata Memorial Hospital) <i>Paediatric Palliative care is one of the most stressful areas of work for both Staff and primary care givers. The supportive care which has been provided by Tata Memorial Centre, India, and its impact on the "Quality of Life" for each family is unique. It is driven by culture, tradition, faith, and rests on timely medical, psycho-social support and financial aid.</i></p>

Schedule

					<p>Pediatric Palliative Care in Portugal: a Study Project - Filipe Almeida, Marta Brites & Helena Moura (Catholic University of Portugal) <i>Paediatric Palliative Care in Portugal: first steps for a better care.</i></p>
Book Signings	12:15 pm	1:15 pm	MEET THE AUTHORS	Gold Ballroom	<p>Partial List of Authors: Ann Armstrong-Daile, Sarah Zarbock Stacy Orlof, Chris Raschka Gretchen Kruger Melody Chantelle Barbara Sourkes Betty Davies Myra Bluebond-Langer Susan Jones Erica Brown</p>
CONCURRENT SESSIONS 7	1:30 pm	2:30 pm	Concurrent Session 7a	Monterey	<p>Implementation, Development and Growth of a Neonatal Palliative Care Program in an Urban Academic Medical Center- Onajowwe Fofah MD, FAAP, James Oleske MD, MPH, FAAP & Shelia Walsh MA, APN, BC (Circle of Life Children's Center, Inc.) <i>This session will identify organizational and motivational approaches utilized to start a neonatal palliative care program. Outcome data related to the care of 27 infants referred in the first year will be discussed, as well as, administrative strategies utilized to further develop the program. Protocol for End of Life Care will be distributed along with an up-to-date bibliography.</i></p>
	1:30 pm	2:30 pm	Concurrent Session 7b	Mendocino	<p>Symptoms and Suffering at the End of Life in Children with Brain Tumors- David Korones (University of Rochester Medical Center) <i>Brain tumors are one of the most common malignancies of childhood and a common cause of death among children with cancer. The symptoms experienced by these children in the last weeks and months of their lives differ from symptoms experienced by children dying of other malignancies. In this session we will focus on the symptoms these children suffer from, and medical, psychosocial, and other support aimed at relieving these symptoms.</i></p>
	1:30 pm	2:30 pm	Concurrent Session 7c	French Parlor	<p>Research and Development- Family Partnership in Practice- Erica Brown (Acorns Children's Hospice Trust) <i>Acorns Children's Hospices commitment to ensuring quality service delivery has involved parents and young people in an evaluation of the care they received. The presentation describes how the study provided an evidence-base for the development of holistic care from a child's diagnosis to their death and beyond. Participants will be able to consider how their own service delivery might be family led.</i></p> <p>Developing Grandparent Support at Acorns Children's Hospice- Erica Brown (Acorns Children's Hospice Trust)</p>

Schedule

					<p><i>Acorns children's hospices recently carried out a study into the experiences of grandparents who had been bereaved through the death of a life-limited grandchild. The presentation describes how the study provided an evidence-base for the development of grandparent support. Participants will be encouraged to reflect on the importance of listening to service users when planning and evaluating service delivery.</i></p>
	1:30 pm	2:30 pm	Concurrent Session 7d	Ralston	<p>Will the Families of Children Dying on PICU Choose to Transfer their Child's Care to a Palliative Care Service & Leave PICU? Maggie Comac, Finella Craig MD, Renee McCulloch MD & Dilni Rajapaske MD (Great Ormond Street Hospital, London) <i>The Great Ormond Street Palliative Care Team is the largest in Europe with an average of 400 new referrals per year. Integration and collaboration with the paediatric intensive care unit at Great Ormond Street has given greater choice for families when a child's death is apparent.</i></p> <p>Optimizing Comprehensive, Interdisciplinary Comfort Management in the Pediatric Cardiac Intensive Care Unit (PCICU-) Sandra Staveski (Lucile Packard Children's Hospital at Stanford) <i>Standardizing and optimizing comfort management in the PCICU can be a challenging and complex process. Nevertheless, the process is important to reduce stress for this vulnerable, complex patient population because many patients require multiple, complex procedures and may have an uncertain futures.</i></p>
	2:30 pm	2:40 pm	Break	Sunset Court	BREAK
CONCURRENT SESSIONS 8	2:40 pm	3:40 pm	Concurrent Session 8a	Monterey	<p>When a Child Dies: Spiritual Struggles and Solace- Beth Seyda (Compassionate Passages, Inc.) <i>Bereaved parents often ask "the big questions" -- why did my child die? are we being punished? is my child in heaven? These parents' soul-searching, spiritual lessons they learned and how they eventually came to peace are presented -- shedding light upon their struggles and providing ways to assist families.</i></p> <p>Everlasting Bonds of Spirit: Deceased Children and Their After-Death Communications with Loved Ones- Ann Fitzsimmons (Compassionate Passages, Inc.) <i>Countless families have confided in trusted healthcare members their experiences of how their babies and/or children have communicated with them from beyond the grave. They speak of the comfort and healing these communications have brought to their broken-hearted families as they've struggled with the loss. The speaker shares some of these families' stories, as well as</i></p>

Schedule

					<p>her own, along with suggestions for supportive care of families after an after-death communication with a deceased baby or child has occurred.</p>
	2:40 pm	3:40 pm	Concurrent Session 8b	Mendocino	<p>Dealing with A Challenging Adolescent with End Stage AIDS- Jennifer Chuang MD, James Oleske MD, MPH & Naimah Campbell RN, BSN (University of Medicine and Dentistry of New Jersey) <i>Palliative Care Teams may be faced with behaviorally challenging adolescents with end stage AIDS. These adolescents may be displaying behavior typical of their developmental stage, yet may be further compounded by various social, psychiatric, and organic factors. This presentation will focus on providing quality care to the adolescent with end stage AIDS.</i></p> <p>Adolescents with Progressive Neuromuscular Diseases and Their Experiences of Health Care Decision-Making- Sarah Derman (University of British Columbia, School of Nursing) <i>Discussion of qualitative study that examines adolescents with progressive neuromuscular diseases experiences of health care decision-making. Findings relevant to clinical care, such as health professional roles in decision-making and how independence, inclusion and decision-making relate will be presented.</i></p>
	2:40 pm	3:40 pm	Concurrent Session 8c	French Parlor	<p>Bereavement Follow-up Services: Report on a Needs Assessment at a Children's Hospital- Nancy Contro & Barbara Sourkes MD (Department of Pediatric Palliative Care, Lucile Packard Children's Hospital, Stanford University Medical Center) <i>This presentation is the latest segment of a comprehensive needs assessment of pediatric palliative care undertaken at Lucile Packard Children's Hospital at Stanford and focuses on the bereavement needs as seen through the eyes of these staff caring for our children and families.</i></p> <p>Therapeutic Relationships in End of Life Care- Mindy Szelap LCSW, & Leah Christensen MSW (Lucile Packard Children's Hospital) <i>The choice to work with critically and terminally ill children is one that requires the deepest commitment and convictions. At this session we will explore what it is about end of life care that challenges professional relationships and at times pushes them towards the more personal, while identifying risk factors for boundary breakdown, we will provide solution focused interventions for individuals and institutions.</i></p>
	2:40 pm	3:40 pm	Concurrent Session 8d	Ralston	<p>Life-Limited Children and Young People's Questions about Death and Dying- Erica Brown (Acorns Children's Hospice Trust) <i>The presentation will outline the aims and scope of a study which involved life-limited children and siblings at Acorns Children's Hospices and then share the findings which will be supported by examples of art work, poetry and written and recorded narrative. Guidelines for adults attempting to answer children's questions will be discussed and participants will have</i></p>

Schedule

					<p><i>an opportunity to consider how they might respond to what children ask.</i></p> <p>Palliative and Terminal Care for Children (PATCH Study) – Parents Perspectives in Northern Ireland- Jayne Price, Joanne Jordan PhD, Lindsay Prior & Jackie Parkes PhD (Queen’s University of Belfast) <i>After establishing the importance of research in advancing care within the specialty of children’s palliative care, the session will discuss an example of such research – the PATCH study. Initially, the discussion will focus on methodological and ethical issues pertinent to the research to date and, where appropriate, outline how these have been resolved. Thereafter, a description of the content of parents’ narratives of their child’s illness and death will be provided, illuminating how these narratives have been analyzed to develop a framework of priorities for subsequent discussion with relevant health and social care professionals with the aim of generating ideas around appropriate practice and service development.</i></p>
	3:40 pm	3:50 pm	Break	Sunset Court	BREAK
	3:40 pm	3:50 pm	POSTERS TAKE-DOWN	GOLD BALLROOM	POSTER TAKE-DOWN
CONCURRENT SESSIONS 9	3:50 pm	4:50 pm	Concurrent Session 9a	Monterey	<p>Home Hospice to Home Funerals- A Natural Extension- Char Barrett , & Maureen Horgan (A Sacred Moment and Providence Hospice of Seattle) <i>Home funeral vigils give grieving parents time and a sacred space to be with their child’s body after death. Discover how to assess whether a home funeral vigil is a good fit for a pediatric family. Dialogue with other conference participants to discover funeral traditions practiced throughout the world. Learn about the valuable service hospice staff can deliver when introducing this innovative approach to your pediatric families that can support their grief journey in a real and profound manner.</i></p>
	3:50 pm	4:50 pm	Concurrent Session 9b	Mendocino	<p>NHPCO’s Initiatives to Improve Pediatric Palliative Care- Gwynn Sullivan RN, MSN & Stacy F. Orloff EdD, LCSW (National Hospice and Palliative Care Organization) <i>The National Hospice and Palliative Care Organization’s work in pediatric palliative care has been guided since its inception by national thought-leaders and clinical practitioners through the Children’s Project on Palliative/Hospice Services (ChiPPS) for ten years. This presentation will provide the opportunity for healthcare professionals to learn about NHPCO’s resources and educational opportunities to assist organizations to improve pediatric palliative care in their respective community and/or state.</i></p>

Schedule

	3:50 pm	4:50 pm	Concurrent Session 9c	French Parlor	<p>Pediatric Palliative Care Facilities: Where Are We? Choices for Seriously Ill Children and Families in Your Community (Facilitator) Rona Renner, RN, Executive Director Childhood Matters</p> <p>Participants: Cincinnati OH: Sarah House, The Sarah Zepernick Foundation, Inc., Kim Marcum-Mercier San Leandro CA: George Mark Children's House, Christy Torkildson Vancouver BC: Canuck Place, Kristina Boyer Phoenix AZ: Ryan's House, Nancy Martin Newark NJ: Circle of Life, Sarah Ur</p> <p><i>Several different models for facility –based pediatric palliative care will be presented with perspectives ranging from established leaders and programs to others in various stages of development. In addition, leaders bring different expertise ranging from administration, clinical, development, etc. This roundtable will provide an opportunity for participants to learn from the lessons lived and share ideas for providing this much needed type of care.</i></p>
	3.50 pm	4.50 pm	Concurrent Session 9d	Ralston	<p>Restoring the Healer: Care for the Carer- Nancy Iverson MD & Gary Malkin (Comfort for Kids-Hospice of the East Bay, Institute for Health and Healing-California Pacific Medical Center, and Clinical Faculty and Healer's Art Faculty-UCSF)</p> <p><i>Through the use of music, arts, and wisdom practices, participants will engage in deep listening, creativity, and contemplative practices. Renewing our relationship to beauty through music, rhythm, words, and mystery, we will replenish our own natural resources and revitalize our capacity to bring comfort and peace to the bedside, home, and workplace and increase joy and fulfillment in our life work.</i></p>

Wednesday, November 19, 2008	7:30 am	8:30 am	Cont. Breakfast	Ralston	CONTINENTAL BREAKFAST
Myra Bluebond- Langer, PhD	8:30 am	9:30 am	Plenary Session	Ralston	<p>PLENARY: "I Want To Live Until I Don't Want To Live Anymore": Involving Children With Life-Threatening Illnesses In Medical Decisions</p> <p><i>This plenary will discuss the factors to be considered in involving children with life-threatening illnesses in decisions about research, care and treatment for their disease, including a model for involving children in decision making. A thought provoking session to lead us into the international state of the science...</i></p>
	9:30 am	9:40 am	Break		BREAK
	9:40 am	10:50 pm	Plenary Session	Ralston	<p>INTERNATIONAL PANEL – Moderator Dr. Mei-Yoke Chan <i>The international panel includes a presentation on the state of children's hospice in each participant's country and a synopsis of their program followed by Q&A from the audience.</i></p>
					<p>Armenia: Artashes Tadevosyan; H.Karapetyan Australia: Helen Irving; Mark Bensink Canada: Susan Fowler-Kerry India: Mary Ann Muckaden; Sunita Jadhav Ireland: Niamh McEnereny Nigeria: Ogunbi Olayinka Portugal: Filipe Almeida, Marta Brites, Helena Moura Singapore: Mei-YokeChan South Africa: Sue Boucher Tanzania: Winfrida Wilfred Mwashala; CarolParker</p>



Schedule

					Thailand: Issarang Nuchprayoon; Niluobon Channong United Kingdom: Rob Dickman; Rosie Midson, Jayne Price, David Strudley US: Brian Greffe
	10:50 am	11:00 am	Break		BREAK
	11:00 am	12:00 pm	Plenary Session	Ralston	INTERNATIONAL PANEL (cont)
	12:00 pm	12:10 pm	Stretch Break		BREAK
Closing Remarks	12:10 pm	1:00 pm	Wrap Up/Closing		Closing Remarks Facilitator: Sue Boucher (International Information Officer of the International Children's Palliative Care Network); The Honorable Jeanette T. Ndhlovu, South African Consul General - invited
CHECK OUT	10:00 am	2:00pm	Check out/ Evaluation drop off/ Information	Mendocino	
	1:00 pm	2:00pm	Certificate Pick-Up	Mendocino	