

CHI World Congress Preliminary Program
L'Enfant Plaza Hotel, Washington DC, USA
October 12 – 14, 2010
www.CHIonline.org

CHI 21st World Congress Preliminary Program

Tuesday, October 12, 2010

7:00am – 5pm Registration

7:00am – 5pm Exhibits and Poster Sessions on Display

7:30am – 8:30am Continental Breakfast

Plenary Session:

8:00am – Welcome – Opening of Congress: Javier Kane, MD, Chairman, Brian Greffe, MD, Co-chairman Planning Committee, Ann Armstrong-Dailey, CHI Founding Director, and Special guests

8:30am: Javier Kane, MD “Care of the Suffering Child”

9:15am: Pam Hinds, RN, PhD, “Decision Making at the End-of-Life”

10:00am – 10:30am Morning Break

10:30am: International Panel: “Spreading the Net: Expanding Children’s Hospice & Palliative Care around the World”
Greffe, M.D. Moderator,

Africa:

Nigeria – Olayinka Ogunbi, MD

South Africa –

Tanzania – Winfrida Mwashala, RN

Australia – Helen Irving, MD

New Zealand – Ngaire Murray, RN

Asia

Singapore – Mei-Yoke Chan, MD

Thailand – Issarang Nuchprayoon, MD, PhD

Noon – 1:30pm LUNCH Jim Oleske, MD, MPH speaker

1:30pm

Europe/Scandinavia

Ireland – Clair Quinn, RN

Italy – Momcilo Jankovic, MD

Norway – Natasha Pedersen

Portugal – Marta Brites, PhD

Scotland – Rosalind Scott, McS

England – David Vickers, MD

2:30pm – 2:45pm Afternoon Break

2:45pm

Americas

Canada – Susan Fowler-Kerry, PhD

Guyana – Andrew Amata, MD

United States of America - Brian Greffe, MD

3:05pm

Discussion –Q&A Facilitated by Brian Greffe, MD

3:35pm – 3:45pm Cape Town Declaration:

3:45pm – 5:15pm Concurrent Sessions (90 minutes):

Concurrent Sessions I

1. Challenges and Opportunities in Program Development #1

“Clinical Outcomes of a Model Regional Pediatric Palliative Care Program: The First 2 Years”

Susan K. Rogers

“Community-based Pediatric Palliative and End-of-Life Care: What Do We Know and What Do We Need to Learn” David Korones, MD

“Parents’ Perceptions of a Hospital-based Pediatric Palliative Care Program” M. Joan Sheetz, MD
Q&A

2. Caregiver Wellness #1

“Caregiver Wellness: We All Need it! Marie Wrinn, RN

“Whose Grief is it Anyway?” Rosalind Scott MSc, DSR(T), DSR(R)

“Listening to the Stories of Healthcare Providers” Laura Campbell, MD, Linda Richter, Alan Stein
Q&A

3. Perinatal Palliative Care

“Facilitation of Neonatal Advance Care Planning through a Perinatal Palliative Care Consult Approach” Janet Dutcher, DNP, RN, NNP-BC

“Perinatal Palliative Care Experience” Irene Cherrick, MD; Carol Dawson, NP

“Perinatal Hospice: Family-centered Support across the Continuum of Care” Suzanne Engelder, MSW; Debra Bolton, RNC, CLE
Q&A

4. Ethics, Decision Making, Care Planning

“Just Because We Can, Should We?” Rosemary Hubble, RN, MA, M.Div; Mary Ann Riesco, RN, MS, CCRN

“Moral Distress in the Neonatal Intensive Care Unit: Caregiver Experience” Gloria Igwe, RN, BSN, MSM

“Communicating Consensus: Coordinating Ethics and Palliative Care in Childhood Illness” Stefan T. Mokrohisky, MD

“Investigating Unexpected Death – Reconciling the Law with Pediatric Care”, David Vickers, MD
Q&A

5. Cultural Aspects of Care

“African Traditional Practices-A Challenge to Palliative Care for Children in Africa”, Ida Kgoroadira, SW

“What Healthcare Professionals Can Do to Better Care for African American and Hispanic Children”, Naimah Campbell, RN, BSN

Q&A

6:30PM: WELCOME RECEPTION

Wednesday, October, 13, 2010

7:00am – 5pm Registration

7:00am – 5pm Exhibits and Poster Sessions on Display

7:30am – 8:30am Continental Breakfast

Plenary Session:

8:00am “House Keeping Announcements, Javier Kane, MD Chairman

8:15am – 9:00am: Kathleen Stevens, RN PhD, “Evidence-Based Practices”

9:00am – 10:15am: Richard Hain, MD: “Education”

10:15am – 10:45am: Morning Break – Manned Poster Sessions

10:45am – 11:30am: Sidney Dy, MD “Quality of Care”

11:30am – 1:30pm: CHI AWARDS LUNCHEON

1:30pm – 3:00pm Concurrent Sessions (90 Minutes)

Concurrent Sessions II

1. Challenges and Opportunities in Program Development #2

“Expanding Comprehensive Services for Children”, Samira K. Beckwith, LCSW, FACHE

“Pediatric Palliative Care in a Medical Center Lacking a Formal Care Program: An Ethnographic Investigation” Jackie Williams Reade

“Partners in Pediatric Palliative Care” Ann Fitzsimons, BS, MBA, Brian Greffe, MD, Beth Seyda

“Completing the Circle with Philanthropic Support” Brian Greffe, MD, Erin Denholm, Kathie Repola, CFRE

Q&A

2. Education as a Bridge to Quality Care

“Residency Training in Home Visits for Pediatric Palliative and End-of-life Care” Alex Okun, MD

“What is the Most Important Skill You Need to Have When Working with Children” Leandra Naudé, BA, MSD

Q&A

3. Neonatal Palliative Care

“Matters of the Heart: Palliative Care for the Child with a Complex Congenital Heart Defect”

Rosemary Hubble, RN, MA, M.Div, Mary Ann Riesco, RN, MS, CCRN

“Care of Neonates with Unknown Prognosis” Nichole Ellis, MD

“A Neonatal Care Pathway” Katrina McNamara-Goodger, RN, RSCN

“To Live or Let Die: Growth and Development of a Neonatal Palliative Program in an Urban Academic Medical Center” Sheila Walsh, APN; Onajovwe Fofah, MD

Q&A

4. Bereavement Care #1

“Steps toward the New Normal: Building from Scratch”, Geri Nelson, MSW, LCSW

“Growth of Circle of Life Children’s Center of NJ Bereavement Program 2006 – 2009” Onajovwe Fofah, MD; James Oleske, MD, MPH

“Evaluation of Bereavement Services for HIV/AIDS Orphans & Vulnerable Children”, Olayinka Ogunbi, MD

Q&A

5. Symptom Control

“Management of Nausea and Vomiting at the End-of-Life in Pediatric Patients” Justin Baker, MD; Javier Kane, MD

“Anorexia Cachexia Syndrome” Carla Cartwright, RD, CNSD; Justin Baker, MD; Javier Kane, MD

“Use of Epidural and Nerve Block Catheters in Children and Young Adults with Cancer: A Collaboration Between Pain and Palliative Care Programs” Doralina Anghelescu, MD Q&A

3:00pm – 3:30pm Afternoon Break - “Manned Poster Exhibits”* (list below)

3:30pm –5:00pm Concurrent Sessions (90 Minutes)

Concurrent Sessions III

1. Tools for Communicating with Children

“The Zozo Playroom: A Play Room with an Attitude”, Elizabeth Scrimgeour, MDiv

“The Talking Mat!”, Brenda Jean Herbert, R.N.

“Assessment of Children – Utilizing Play therapy Techniques to Gather Information Regarding the Social and Emotional Functioning of Children within a Palliative Care Setting” Leandra Naudé, MSD

Q&A

2. Bereavement Care #2

“Hope in and Healing from the Other Side When a Child Has Died” Ann Fitzsimons, BS, MBA

“Learning from the Experts: Bereaved Parents’ Perceptions of Bereavement Programs, and What Helps with Their Grief” Mary-Ann Sontag Bowman, PhD, LCSW,

“After a Perinatal or Infant Loss: Meeting the Bereavement Needs of Mothers in an Urban Community” Mary Fleck, EdD; Naimah Campbell, RN

“Brief Lives, Lasting Losses: Pregnancy Loss and Infant Death” Beth Seyda, BS

Q&A 30 minutes

3. Caregiver Wellness #2

“Care for the Caregiver: Building Resilience – Exploring Ways to Draw on Our inner Strength” Raksha Balbadhur, MBChB

“Stress and Burnout Experienced by Paediatric Palliative Care Nurse”, Noor Aisah Bee Bte Abdul Rashid, RN

“Caregivers Journey from Sudden Onset to Palliative – A Case Study”, Gina Tan Boon Khing, BSW

“What is Stress? What is Burn Out? Steps towards Proactive Prevention”, Lori Weiner, PhD

Q&A

4. Pediatric End of Life Care

“The Experience of Caring for Children at the end of Life: The Views of Irish Specialist Palliative Care Nurses” Claire Quinn, RN; Maria Bailey, MSc

“When a Child is Dying”, Philene Cromwell, RN, MS, PNP

“Quality Care of Imminently Dying Children”, Angela Snyder, RN, PNP

Q&A

5. Quality Assurance in Palliative Care

“Quality Hospice and Palliative Care Practices”, Javier Kane, MD

“Institutional Quality Improvement Initiative in Pain Management”, Doralina Anghelescu, MD

“Improving the Quality of Spiritual Care as a Dimension of Palliative Care”, Justin Baker, MD

“Improving the Quality of Psychosocial Care as a Dimension of Palliative Care”,

Ann Berger, RN, MD.

“Improving the Quality of Interdisciplinary Care and Collaboration”, Javier Kane, MD

Q&A

7:00 pm Film Premier: “Everyday Heroes: Caregivers”

Filmed in Cape Town, South Africa during CHI 20th World Congress as part of a documentary television series. Award winner of the Medal of Peace 2009, Wayne Schoenfeld, Executive producer and Nadia Duguay, cofounder and associate Exeko.

Thursday, October 14, 2010

7:00am – Noon Registration

7:30am – 8:30am Continental Breakfast

8:00am Plenary Session: “Family Centered Care”

8:00am – 8:45am Jeni Stepanek, PhD

8:45am – 9:30am Suzanne Bostick, CMS

9:30am – 9:45am Piper Nieters Su, Esq.

9:45am – 11:15am Concurrent Sessions (90 Minutes)

Concurrent Session IV

1. Care for the Whole Family

“Completing the Circle of Care: Children’s Program for All-inclusive Coordinated Care (ChiPACC)

Moderator Brian Greffe MD, CHI National ChiPACC Director and ChiPACC Team;

Bridging the Gap between Hospice/Palliative Care with the Ongoing Needs of Children with Life-threatening Conditions from Time of Diagnosis

2. Care Coordination and Continuity

“The Transition from Hospital to Hospice in Pediatric Palliative Care” Emily Edlynn, PhD

“I Wasn’t Supposed to Live this Long...HIV Palliative Care at the Transition from Childhood to Adulthood”, Cora Welsh, CCLS, Nancy Hutton, MD, FAAP

Q&A

3. Care of Siblings and Parents

“Within the Circle too?: The Ongoing Experiences of Siblings of Children with a Life-shortening Illness” Jan Aldridge, PhD; Siobhan Hugh-Jones; Cathy Brennan

“The Unmet Needs of Parents/Guardians of Critically Ill Children Admitted into the Intensive Care Unit”

Andrew Amata, MBBS, MD, FMCA

Q&A

4. Coping and Psychosocial Support

“Fostering Resiliency in Ill children” Beth Seyda

“Taming the Teens: Struggles & Suggestions for Providing Supportive Pediatric Palliative Care for Adolescents & Young Adults” Ann Fitzsimons, BS, MBA

“Talking to Children about Dying: More than Words Can Say” Marcella Cameron, MSW; Tina Ulanowski, M.Ed.; Judy McBride, M.Div.

Q&A

5. Spiritual Care

“Hope Lies Not in a Way Out, but in a Way Through” Ann Fitzsimons, BS, MBA

“Spiritual support for Buddhist Children through Computer Games” Issarang Nuchprayoon, MD, PhD, Tippakorn Rungkasivi

Q&A

11:15am – Noon Closing Ceremonies and Morning Break

SITE VISIT: THE CHILDREN’S INN at NIH

Manned Poster Sessions Wednesday, October 13, 2010 during Extended Breaks

Note: International Panel to prepare Posters for the Manned Poster Sessions

“The Role of Home-based Care Workers in South African Paediatric Palliative Care: A Review of Literature”,
Laura Campbell, South Africa

“The Significance of the Social Auxiliary Worker in Providing Holistic Palliative Care in a Multicultural Society”,
Nomvula Mnyandu, South Africa

“Creating a Meaningful Experience through Perinatal Palliative Care”, Kevin Lorah, MD, Carolanne Hauck, BCC,
USA

“Pediatric Palliative Care: A Research Project in Portugal”, Marta Brites, PhD, Portugal

“Volunteers for Paediatric Palliative Care: 7 Seven Colours for Better Care at Rainbow Project”, Marta Brites,
PhD, Portugal

“Development of Toolkits for Terminally Ill Cancer Children”, Issarang Nuchprayoon, MD, Thailand

“When the Miracle Doesn’t Happen – Concurrent Program Development” Beth Seyda, BS, USA

“Challenges in Providing Palliative Care for Pediatrics in KK Women’s and Children’s Hospital, Singapore”, YiYi
Wynn, MBBS

“Yes to Palliative Care”, Natasha Pedersen, Norway

“Overcoming Food & Nutrition Challenges for Children with HIV/AIDS in Rural Tanzania”, Winfrida Mwashala,
RN, Tanzania

“Inpatient Palliative Care Service: Addressing a Gap in Care with a Bereavement Protocol”, Helen Morgan, MSW,
USA

“Barriers to Managing Pain in the Pediatric Palliative Population”, Lilis Yusri, Singapore

“Using Clinical Practice Improvement Programme (CPIP) Tools to Improve the Referral Rate of Appropriate
Pediatric Oncology Patients to the Palliative Services: Chan Mei-Yoke, MD Singapore

“Pediatric Palliative Care in Uganda”, Sarah Nandaula, Uganda

“Shop Talk”, Lori Wiener, PhD, USA

Exhibits: (as of 3/28/10)

Children's Inn Art Exhibit

Children's Hospice International

Exhibition of the Wayne Schoenfeld's works taken during the mission South Africa

Film Festival: (as of 3/28/10)

“Everyday Heroes: Caregivers” 1 hour film (filmed in South Africa during CHI 20th World Congress, Cape Town)
Wayne Schoenfeld, Executive producer of Everyday Heroes and Nadia Duguay, cofounder and associate Exeko
(award winner of the medal of peace 2009), USA & Canada

“Completing the Circle of Life: Just a Phone Call Away”
CHOC, Houghton, South Africa
Lynda Schutte

“Completing the Circle of Life: It's a special Journey”
CHOC, Houghton South Africa
Lynda Schutte

“Tender Healing: A Sibling's Journey through Grief”
Children's Hospital Denver, Denver, Colorado, USA
Geri Nelson, MSW, LCSW

“Art Studio & the Discovery of the Ultimate Concerns of the Dying”
HUMAN Center: The Art Center for Healing and Professional Development, Bangkok, Thailand
Patcharin Sughondhabirom, MD

“Circle of Life”
UMDNJ/Circle of Life Children's Center, Newark NJ, USA
James Oleske, M.D, MPH

“Wen I Die, Don't You Cry”
Children's Hospice International

“The Purple Balloon”
Random House

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