

*Completing the Circle of Care*  
**Preliminary Program for CHI's 15<sup>th</sup> World Congress**  
September 14-17, 2003  
*As of May 19, 2003*

**Sunday September 14, 2003**

1:00pm-5:00pm Registration at the Radisson Hotel Old Town

5:30pm-7:30pm Welcome and 20<sup>th</sup> Anniversary Reception at the Historic Carlyle House in Old Town Alexandria  
Limited attendance available; please note if you would like to attend.

**Monday, September 15, 2003**

7:00am-8:30am Breakfast

7:00am-throughout Registration  
Tourist Information/Sight-seeing Bookings  
CHI Bookstore and Central Information

8:30am-9:15am Plenary Session  
Opening of World Congress: U.S. Senator Robert Bennett (R-UT), U.S. Congressman John Murtha (D-PA), and U.S. Congressman Jim Moran (D-VA)

Keynote Address:  
Barbara Bush, Former First Lady (invited)  
Tommy Thompson, Secretary of Health and Human Services, United States Department of Health and Human Services (invited)

9:15am-10:00am Plenary Session  
"When to be Heard is to be Healed"  
Shelly Wagner, Poet and Parent

10:00am-10:30am Plenary Session  
"International Overview of Pediatric Hospice and Palliative Care"  
Stefan Friedrichsdorf, MD

10:30am-10:45am Morning Break

10:45am-12:30pm "International Perspectives on Children's Hospice and Palliative Care: Examining Cultural Differences"  
Moderator: Stefan Friedrichsdorf, MD  
Australia: Jenny Hynson, MBBS, FRACP  
Belarus: Anna Garchacova  
Costa Rica: Lisbeth Quesada Tristán, MD  
Israel: Lynne Halamish, MA  
USA: Dan Tobin, MD

12:30pm-1:30pm Lunch  
Roundtable Discussions

1:30pm-2:00pm Poster Session

2:00pm-3:30pm Plenary Session  
Panel I: "Care for Children in Urban and Rural Environments"  
Dennis Johnson, MD -- M.S. Hershey Medical Center  
Burton Grebin, MD -- St. Mary's Health Care System for Children  
Others TBA

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3:30pm-3:45pm Afternoon Break

3:45pm-4:45pm Concurrent Sessions I:

- A. Diane Smith, MD, Loralyn Franke, BS, and Gwen Feather, RN, CHPN "Protocols for Pain and Symptom Management"
- B. Chriss Nelson, RN, "Have Fun, Bring Home the Party"
- C. Carol Quayle, MSW, RN, and Jenny Hynson, MBBS, FRACP, "Creating Links in Pediatric Palliative Care: Bring Pediatrics to Palliative Care & Palliative Care to Pediatrics"
- D. Barry Sherman, PhD, "Improving Quality of Life for Dying Children and their Families"
- E. "Funding Opportunities for Developing a CHI PACC<sup>®</sup> Program," including representatives from the Centers for Medicare & Medicaid Services, Health Insurance Association of America (invited), Association of Fundraising Professionals (invited), and Virginia Department of Medical Assistance Services (invited)

**Tuesday, September 16, 2003**

7:00am-8:30am Breakfast

7:00am-throughout Registration

Tourist Information/Sight-seeing Bookings  
CHI Bookstore and Central Information

8:30am-9:15am Plenary Session

Carol Taylor, CSFN, RN, PhD, "Ethical Issues in Pediatric Hospice and Palliative Care"

9:15am-10:30am Plenary Session

Panel II: "Neonatal Care: Providing Comprehensive, Integral Care for Our Youngest Patients"  
Stephen Buenaga  
Susan Huff, RN, MSN  
Charles Palmer, MB, ChB, FCP(SA) PAED, DCH, FAAP

10:30am-10:45am Morning Break

10:45am-12:15pm Concurrent Sessions II:

- A. Kate Faulkner, MD, "Palliation of Neurological and Neuromuscular Symptoms"
- B. Marion Taylor, RN, MN, CPNP, and Joyce Conway, RN, "Proactive Pediatric Care: The Kids Path Consortium"
- C. Everett Charette, MA, Anna Garchacova, Laura Hagerty, CMSW, Peter Hanlon, and Janis Keyser, PhD, "Providing Ongoing Support for Families: Developing Compassionate Bereavement Programs"
- D. Beth Seyda, BS, Linda Pegram, MD, and Ann Fitzsimons, MBA, "Through the Looking Glass: What It's Like to be on the Inside and Outside While a Child is Dying"
- E. Zohreh Saunders, MS: Moderator, "CHI PACC<sup>®</sup> Forum: Program Development"

12:15pm-1:30pm CHI Achievement Awards Luncheon

Presented by Mrs. Joyce Murtha

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1:30pm-3:00pm Concurrent Sessions III:

- A. Chris Brown, MS, CCLS, "Facilitating Therapeutic Expression & Communication through Play and the Creative Arts"
- B. Golnaz Aliyazadeh, BA, Lynne Halamish, MA, Jenny Hynson, MBBS, FRACP, and Terry Trimeloni, RN, "International Perspectives on Staff Support"
- C. Stephanie Lester, RN, BSN, CHPN, Sandra Macomber, MSW, ACSW, Jeanette Osbourne, RN, and Karen Paradise, RN, BSN, "Building Pediatric Teams for Better Care of Children with Life-Threatening Conditions and their Families"
- D. Beth Seyda, BS, Linda Pegram, MD, and Ann Fitzsimons, MBA, "Through the Looking Glass: What It's Like to be on the Inside and Outside While a Child is Dying"
- E. Zohreh Saunders, MS: Moderator, "CHI PACC<sup>®</sup> Forum: Project Design"

3:30pm-3:15pm Afternoon Break

3:30pm-4:30pm Concurrent Sessions IV:

- A. Diane Smith, MD, Loralyn Franke, BS, and Gwen Feather, RN, CHPN, "Protocols for Pain and Symptom Management"
- B. Chriss Nelson, RN, "Have Fun, Bring Home the Party"
- C. Kate Faulkner, MD, Kate Eastman, Psy.D., LCSW, and Deborah Lielasus Tombleson, "Making Dreams Come True: Developing the Resources to Fund Program Visions"
- D. Carol Quayle, MSW, RN, and Jenny Hynson, MBBS, FRACP, "Creating Links in Pediatric Palliative Care: Bring Pediatrics to Palliative Care & Palliative Care to Pediatrics"
- E. Gary Allegretta, MD, "From Oncologist to Hospice Physician: Lessons from the Pediatric Perspective"

**Wednesday, September 17, 2003**

7:00am-8:30am Breakfast

7:00am-throughout Registration

Tourist Information/Sight-seeing Bookings  
CHI Bookstore and Central Information

8:30am-9:15am Plenary Session

"Who Will Speak for This Child: Medical Decision Making in the Care of Children with Incurable Illness"  
Javier Kane, MD

9:15am-11:15am Plenary Session

Panel III: "Looking Forward: Developing Curricula for Pediatric Hospice & Palliative Care Workers"

Introduction: Marilyn Field, PhD, The Institute of Medicine (invited)

Paul Brenner, M.Div., Children's Hospice International, CHI Program for All-Inclusive Care for Children and their Families (CHI PACC<sup>®</sup>)

Stephen Connor, PhD, National Hospice and Palliative Care Organization, Children's International Project on Palliative/Hospice Services

Mildred Solomon, EdD, Center for Applied Ethics and Professional Practice, Initiative for Pediatric Palliative Care

Anne Rhome, RN, MPH, American Association of Colleges of Nursing, End-of-Life Nursing Education Consortium

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11:15am-11:30am Morning Break

11:30am-12:30pm Concurrent Sessions V:

- A. Jeanne Chirico, MPA, "It Takes a Village to Provide All-Inclusive Care for Children"
- B. Kate Faulkner, MD, Kate Eastman, Psy.D., LCSW, and Deborah Lielasus Tombleson, "Making Dreams Come True: Developing the Resources to Fund Program Visions"
- C. Lisbeth Quesada Tristán, MD, "Costa Rican's Pediatric Palliative Care Clinic: A Good Model of Work in an Undeveloped Country"
- D. Gary Allegretta, MD, "From Oncologist to Hospice Physician: Lessons from the Pediatric Perspective"
- E. Zohreh Saunders, MS, and Paul Brenner, M.Div., "Developing a CHI PACC<sup>®</sup> Program"

12:30pm-1:30pm Lunch

Peer Group Discussions

1:30pm-2:00pm Plenary Session

Tribute to Jeni and Mattie Stepanek and All the Children and Families We Serve

***We ask that each participant send in photos of children and families they care for to be compiled into a video presented at the conclusion of the World Congress. Please send these to [info@chionline.org](mailto:info@chionline.org) or to 901 N. Pitt Street, Suite 230, Alexandria, Virginia, USA.***

2:00pm-2:30pm Plenary Session

Closing of 15<sup>th</sup> World Congress

Ann Armstrong-Dailey, CHI Founding Director & CEO

For more information, contact CHI at 800.2.4.CHILD or 703.684.0330,  
or e-mail CHI at [info@chionline.org](mailto:info@chionline.org)