

Between the Devil and the Deep Blue Sea

Moral and Ethical Dilemmas in Pediatric Palliative Care

4th Annual Mid-Winter Conference

Friday, February 17, 2017

Cook Children's Medical Center, Hochberger Auditorium
801 Seventh Avenue
Fort Worth, TX 76104

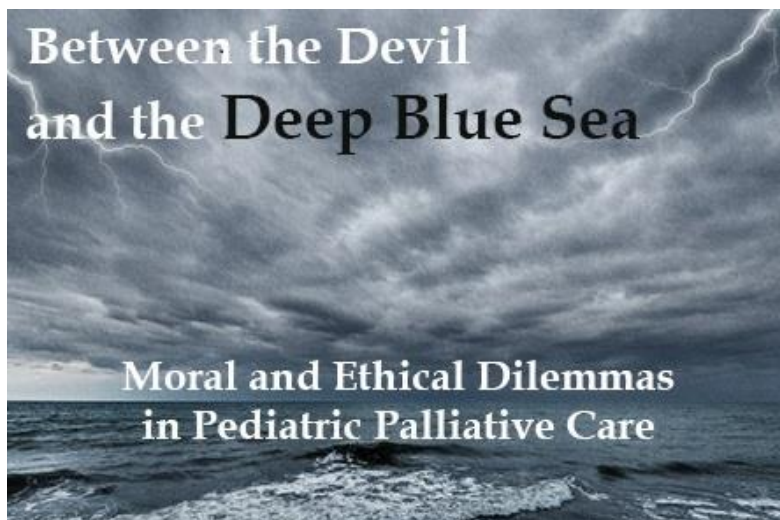
Presented by the
Texas Pediatric Palliative Care Consortium
In partnership with
Cook Children's Medical Center
and **Project Joy and Hope for Texas**



The
**Texas Pediatric Palliative Care
Consortium**
and
Project Joy and Hope for Texas

are pleased to announce the **4th Annual Mid-Winter Conference**, which addresses clinical challenges that arise when families and health care providers are faced with making a medical decision for a child where available options offer “no good choices.”

The format for the conference involves presentation of complex clinical cases that focus on a wide range of moral and ethical dilemmas faced by inter-professional teams as they navigate medical decision making with patients and parents. The conference seeks to provide participants with opportunities to pose questions, engage in discussion, and network with pediatric palliative care experts and providers throughout the country.



Join your colleagues for this captivating one-day seminar!

Keynote Speaker



Franco A. Carnevale, RN, PhD

Franco A. Carnevale, RN, PhD is a nurse, psychologist and clinical ethicist and professor at McGill in Montreal, Canada.

His primary research interests include a wide range of concerns in pediatric ethics. Dr. Carnevale is the founder and principal investigator for VOICE (i.e., Views On Interdisciplinary Childhood Ethics); a McGill-based international initiative to advance knowledge and practices relating to ethical concerns in childhood. Dr. Carnevale's current academic appointments include (all at McGill University): Full Professor, Ingram School of Nursing; Associate Member, Faculty of Medicine (Pediatrics); Adjunct Professor, Counselling Psychology; Affiliate Member, Biomedical Ethics Unit. His clinical appointments include: Co-Chair of the Pediatric Ethics Committee, Nursing Advisor, and Associate Member of Pediatric Critical Care, all at the Montreal Children's Hospital-McGill University Health Centre; as well as Clinical Ethicist

for Child, Adolescent and Family Services at the Douglas Mental Health University Institute and Clinical Ethics Consultant at Le Phare, Enfants et Familles (pediatric hospice and respite care).

Expert Panel

Franco A. Carnevale, RN, PhD
Clinical Ethicist and Founder for VOICE
McGill University, Montreal, Canada

Brian Carter, MD, FAAP
Professor of Pediatrics, UMKC School of Medicine
Bioethics Center, Neonatology & Fetal Health
Children's Mercy, Kansas City

Stacy Smith, MLS, BSN, RN, CHPPN
Clinical Ethicist
Children's Medical Center, Dallas

Pam Foster, DMin, BCC
Director, Pastoral Care
Cook Children's Medical Center, Fort Worth

April Warren, Parent Participant
Houston

Featured Presenters

Advocate Children's Hospital, Oaklawn, IL

- Erin Flanagan, MD
- Kathie Kobler, MS, APN,
- PCNS-BC, CHPPN, FPCN

Children's Hospital of Colorado, Colorado Springs, CO

- Karen Williams, APN, ACHPN
- Brian Greffe, MD

Children's Health, Dallas, TX

- Donald Cochran, MD
- Heather Paterson, RN, PNP
- Suzanne Stephens, LSW

Christina Care Health System, Newark, DE

- Wendy Sturtz, MD
- Barbara Dean, RNC

Miller Children's and Women's Hospital,
Long Beach, CA
Joetta Wallace, NP

Stony Brook University Hospital, Stony Brook, NY

- Ratna Basak, MD, FAAP
- Rina Meyer, MD

University of Texas Health Science Center
at San Antonio, San Antonio, TX

- Cris Johnson, MD
- Rachel Vandermeer, MD

Register Online

<http://www.texasppcc.org/conferences>

\$129 Early Bird Rate

Includes seminar, continental
breakfast and lunch

*Rate increases to \$159
after January 15, 2017.*

**HOTEL: Hilton Garden Inn-Fort Worth
Medical Center**
912 Northton Street, Fort Worth, TX 76104
1-817-921-0788

*Ask for Cook Children's Medical Center
\$135 Rate.*

For more information:
713-944-6569 or
1-866-JOY-HOPE.

Texas Children's Hospital, Houston, TX

- Jessica Casas, MD, MPH
- Karen Johnson, MD
- Daniel Mahoney, MD
- Regina Okhuysen-Cawley, MD
- Perry Ann Reed, MBA
- Alana Thomas, MD

Program Agenda

7:15 – 7:45	REGISTRATION
7:45 – 8:00	WELCOME
8:00 – 9:00	Opening Plenary – Listening to Children's Voices: New Directions in Pediatric Palliative Care Ethics* Franco A. Carnevale, RN, PhD
9:00 – 9:50	Cultural Sensitivity and Disclosure* - Donald Cochran, MD Setting Sail on a Holey Ship* - Jessica Casas, MD, MPH
9:50 - 10:00	BREAK
10:00 - 10:50	Feeding Complications in a Neurologically Impaired Patient - Cris Johnson, MD and Rachel Vandermeer, MD Painful Starvation or Compassionate Withholding of Artificial Nutrition? It Depends Who You Ask... - Wendy Sturtz, MD and Barbara Dean, RNC
10:50 – 11:40	Ethical Challenges in Perinatal Palliative Care* - Alana Thomas, MD and Karen Johnson, MD How to Make the Least Bad Choice* - Daniel Mahoney, MD and Perry Ann Reed, MBA
11:40 – 12:15	Case Study Discussion by Expert Panel
12:15 – 1:00	LUNCH
1:00 – 1:50	Compassionate Extubation in a Child with Quadriplegia and Centrally-Mediated Hyperventilation - Regina Okhuysen-Cawley, MD The Sandbar: Is it a respite from a swim, or are we stuck? - Karen Williams, APN, ACHPN and Brian Greffe, MD
1:50 – 2:40	Role of Autonomy and Justice in Adolescent Decision Making in Inherited Cancer Syndromes* - Ratna Basak, MD, FAAP and Rina Meyer, MD Adolescent Goal Setting and Decision Making: When the Only Thing Worse Than the Past is the Future* -Suzanne Stephens, LSW and Heather Paterson, RN, PNP
2:40 – 2:50	BREAK
2:50 – 3:40	The Adolescent Voice in Medical Decision Making* - Joetta Wallace, NP We Understand, We Agree, But We Cannot Do It: Deferring Compassionate Extubation as an Exercise in Parental Autonomy* - Erin Flanagan, MD and Kathie Kobler, MS, APN, PCNS-BC, CHPPN, FPCN
3:40 – 4:30	Case Study Discussion by Expert Panel
4:30 – 4:50	Closing Plenary - Where Do We Go from Here? Franco A. Carnevale, RN, PhD
4:50 – 5 :00	Wrap-Up, CE Information & Announcements
	Total Credit Hours – 7.0

Accreditation/Approval Statements

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Texas Medical Association (TMA) through the joint providership of Cook Children's and Texas Pediatric Palliative Care Consortium. Cook Children's is accredited by TMA to provide continuing medical education for physicians.

Cook Children's designates this live activity for a maximum of 7 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity. This conference has been designated by Cook Children's for 7 credits of education in medical ethics and/or professional responsibility.

Cook Children's Medical Center is an approved provider of continuing nursing education by the Texas Nurses Association - Approver, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

This activity provides 7.00 contact hours. You must attend the activity in its entirety and complete and return the evaluation tool.

Accreditation/Approval Statements, CONTINUED

Cook Children's is approved as a provider of continuing education for Social Workers by the Texas Board of Social Work Examiners (Provider # 5164). This activity is designated for a maximum of 7.0 Social Worker contact hours and 7.0 hours of professional ethics and social work values.

Cook Children's is approved as a provider of continuing education for Licensed Professional Counselors by the LPC Board of Examiners for the State of Texas (Provider #1022) and Licensed Marriage and Family Therapists by the LMFT Board of Examiners for the State of Texas (Provider #385). These approvals meet the criteria for mandatory continuing education requirements towards relicensure as established by the individual Boards of Examiners for the State of Texas. Cook Children's designates this activity for a maximum of 7.0 contact hours (0.7 CEUs) and 7.0 hours of professional ethics.

These programs (*) are Approved by the Texas Psychological Association (Approval #2015-07) for 5.0 professional development hours. The presentations Cultural Sensitivity and Disclosure and Setting Sail on a Holey Ship have been designated by Cook Children's for 1.0 hour of multi-cultural credit.

About Texas Pediatric Palliative Care Consortium



Established in 2007, the **Texas Pediatric Palliative Care Consortium (TPPCC)** is a statewide coalition of interdisciplinary pediatric palliative care providers, advocates, and parent representatives. TPPCC's mission is to optimize the quality of life for children living with life-threatening conditions and their families in Texas, without regard to care setting, family demographics, or financial status.

Texas Pediatric Palliative Care Consortium goals include:

Collaboration - Enhance the caregiving capacity of health care providers for CLWLTC throughout Texas by sharing resources and information on the development and delivery of pediatric palliative care services.

Advocacy - Enhance the awareness of health care administrators, state agencies and legislators regarding the need for optimal family-centered pediatric palliative care for CLWLTC in Texas.

Research - Optimize the capacity of families and health care providers to care for CLWLTC by increasing the evidence base for family-centered pediatric palliative care through collaborative research.

Education - Enhance the capacity for the delivery of optimal family-centered and pediatric palliative care through the education of families and health care providers on practices and principles of family-centered and pediatric palliative care.

Support Services – Support the TPPCC Workgroup goals through administrative activities that expand the capacity of the organization.

Join the Texas Pediatric Palliative Care Consortium today.

Visit our website at www.texasppcc.org.