

PEDI-HOPE 9TH ANNUAL CONFERENCE

CREATING
BALANCE

Through the Journey in Pediatric Palliative Care



July 28 & 29, 2017

Preconference July 27

**South Shore Harbour Resort & Conference
Center**

League City, TX

Jointly provided by **Texas Children's Hospital,**
the Texas Pediatric Palliative Care Consortium
and **Project Joy and Hope.**

JULY 27 PRECONFERENCE TOPICS:

- Track A: Quality Improvement 101: How to incorporate Quality Improvement into Hospice and Palliative Care
- Track B: Augmenting Clinical Care through Indigenous Healing Traditions
- Track C: Navigating Moral Distress: How Can We Best Intervene?

Pedi-HOPE 9th Annual Conference

Creating Balance Through the Journey in Pediatric Palliative Care

Join us in beautiful League City, Texas as we gather with many of Texas'—and the nation's—most noted practitioners of pediatric palliative care for the annual conference of the Texas Pediatric Palliative Care Consortium. Our program focuses on the needs of children with life-limiting conditions and is designed to enable healthcare professionals to be better prepared, confident, and equipped to provide the best quality of life possible for children and their families. Pedi-HOPE 2017 is jointly provided by **Texas Children's Hospital** with the **Texas Pediatric Palliative Care Consortium** and **Project Joy and Hope**.



Target Audience for Pedi-HOPE:

Anyone caring for children with complex medical conditions and their families:

- Physicians
- Advanced practice nurses
- Nurses
- Social workers
- Chaplains
- Child life specialists
- Genetic counselors
- Hospice staff
- Policy/legislative staff
- Parents

Thursday, July 27 - PRECONFERENCE SEMINAR

- 11:45-12:15** **Registration**
- 12:15-1:15** **OPENING PLENARY: Creativity in Caring: Holding the Tension between Rigidity and Chaos** – Ryan Campbell MTS BCC
- 1:15-5:15** **PRECONFERENCE A: Quality Improvement 101: How to incorporate Quality Improvement into Hospice and Palliative Care** - Tammy Kang MD, Joy Hesselgrave RN MSN, Jill Ann Jarrell MD, Lindsey Gurganious BSHA
- Dr. Kang and providers from the Texas Children's Hospital Palliative Care Team will provide an overview of the basic principles of quality improvement (QI) in pediatric palliative care. Examples of QI projects will be provided to augment learning. Participants are encouraged to bring a project idea to develop during group discussion.
- 1:15-5:15** **PRECONFERENCE B: Augmenting Clinical Care through Indigenous Healing Traditions** - David Steinhorn MD, Jana Din
- This session will introduce the use of Shamanic healing for children with complex medical conditions. For several years Din, Co-Founder/ Director of the Tao Center for Healing in Sacramento, California, has provided shamanic healing services in collaboration with PICU and palliative care physician Dr. Steinhorn for his critically ill, terminally ill or injured pediatric patients. Their collaboration was featured in the nationally broadcast show "Healing Quest" in a segment titled "Shamans in the ICU." [Watch here.](#)
- 1:15-5:15** **PRECONFERENCE C: Navigating Moral Distress: How Can We Best Intervene?** - Ann Hamric PhD RN FAAN
- Dr. Hamric is an international expert in ethics and moral distress and the developer of the *Moral Distress Scale – Revised*. Her work has emphasized the experience of moral distress in health care settings as well as the consequences to health care providers. She will offer an in-depth discussion of moral distress and strategies for addressing it in our daily work. Interactive 'table talk' sessions will enhance opportunities for learning
- 5:30 – 6:30** **Welcome reception for preconference and conference attendees**

Friday, July 28

- 7:30-8:15** *Registration and continental breakfast*
- 8:15-8:30** **WELCOME, Announcements & Introductions**
- 8:30-9:45** **PLENARY A: Excellence in Provider/Parent Interactions in PPC: More than "Communication Protocols."** – Betty Davies, PhD RN FAAN
- 9:45-9:55** *Break*
- 9:55-10:55** **Breakout Session I**
- a. **The Darkening Veil of Do Everything** – Justin Baker MD
 - b. **Shared Decision Making or Shared Decision Avoidance – Calling a Spade a Spade** – Nadia Tremonti, MD
 - c. **All the Voices at the Table** – Joy Hesselgrave RN MSN, Nancy Glass MD, Sarah Korenblit LCSW, Taryn Schuelke CPMT CCLS, Kirstin Springmeyer M.Div BCC
 - d. **Balance: The Heart and Soul of Compassion** – Regina Okhuysen-Cawley MD & Faith Crozier RN CPNP
- 10:55-11:05** *Break*
- 11:05 -12:05** **Breakout Session II**
- a. **Outside the Bagel Box: Getting Real about Compassion Fatigue, Burnout and Self-Care** - Emily Riegel MD
 - b. **Teaching through the Transition between Life and Death: The ABC's of Withdrawal of Life-Sustaining Therapies** – Ryan Coleman MD
 - c. **Creating and Implementing a Pediatric Massage Program: A Non-pharmacological Symptom Management Strategy within an Inpatient Pediatric Palliative Care Setting** – Samantha Nocito CCLS, Sarah Patterson CCLS
 - d. **Neo-Natal Symptom Management in Hospice Care** – Melissa Hunt Pharm D
- 12:05 -12:15** *Break*
- 12:15-1:45** **Keith Frazier Memorial Luncheon: The Difficult Patient Reconceived: Learning the Skills of Mediators in Managing Challenging Clinical Encounters** - Autumn Fiester PhD
- 1:45-1:55** *Break*
- 1:55-2:55** **Breakout Session III**
- a. **It's About Time to Reimagine End-of-Life Care for Children** – Kathleen Hull MD
 - b. **Planning for the End of Life: Celebrating the Life of a Child** – Susan Steinbruecker LMSW, Nancy Glass MD
 - c. **Border Medicine in our Hospitals: Providing Palliative and Complex Medical Care for the Undocumented Patient** – Rachel Vandermeer, MD
 - d. **High-Intensity EOL Care: More than Meets the Eye** – Heidi Russell MD PhD, Melody Hellsten DNP PPCNP-BC CHPPN
- 2:55-3:05** *Break*
- 3:05-4:20** **PLENARY B: To Play in the Deep End of the Pool** – Thomas Lynch, Author of *The Undertaking* and *Bodies in Motion and at Rest*.
- 4:30-6:30** **Networking and Poster Presentations** (*Complimentary hors d'oeuvres & cash bar*)

COURSE OBJECTIVES

Upon completion of this activity, participants will be able to:

- 1) Discuss opportunities for improving patient care in pediatric palliative care
- 2) Identify ethical challenges and moral distress in the care of children with complex medical conditions
- 3) Apply current advances in pediatric palliative care in local institutions

FEATURED SPEAKERS

Thomas Lynch
Author,
The Undertaking

Ann Hamric, PhD
Professor Emeritus,
Virginia
Commonwealth
University, School of
Nursing

Autumn Fiester, PhD
Director, Penn
Program for Clinical
Conflict
Management,
University of
Pennsylvania

Betty Davies, RN PhD
University of Victoria,
Victoria, British
Columbia

Tammy Kang, MD
Section Chief, Texas
Children's Hospital
Palliative Care
Baylor College of
Medicine

Saturday, July 29

- 7:30-8:15** Registration and continental breakfast
- 8:15-8:30** **WELCOME, Announcements & TPPCC News**
- 8:30-9:35** **PARENT PANEL: From the Perspective of Grandparents** -- Gina Jones RN CPLC, Panel Facilitator
- 9:35-9:45** *Break*
- 9:45-10:45** **Breakout Session IV**
- a. **Perinatal Loss: Caring for the Grieving/Bereaved Sibling** – Cindy Beckwith RN & Erin Anderson
 - b. **Provider-Reported Barriers to Integration of Pediatric Palliative Care into Oncology Practice** – Holly Spraker-Perlman MD
 - c. **Safeguarding the Use of Opioids for Children, Adolescents and Young Adults in Pediatric Palliative Care** – Kevin Madden MD
 - d. **The Darkening Veil of Do Everything** – Justin Baker MD
- 10:45-11:00** *Break*
- 11:00-12:30** **PLENARY C: Balancing the needs of Patients, Families, Team and Self: Can it be done?** - Tammy Kang MD
- 12:30-1:00** **Closing Remarks & Evaluations**

About our conference location

Just 25 minutes from Downtown Houston on the shores of Galveston Bay, you'll find the communities of League City, Clear Lake Bay, Kemah, and Seabrook. Known for great seafood restaurants, sailing and other water activities, the Bay Area is often called the "**Boating Capital of Texas.**" Visit the **Kemah Boardwalk** for amusement rides, shopping and waterfront dining. Head over to **Space Center Houston** to see NASA's Mission Control and learn what it's like to be an astronaut. Or experience the **region's natural beauty on the trails at Armand Bayou Nature Center**. The Clear Lake/Bay area has earned its reputation as a Houston hot spot.



CONFERENCE REGISTRATION FORM

Pedi-HOPE 9th Annual Conference

*Creating Balance Through the Journey
in Pediatric Palliative Care*

July 28 & 29, 2017

Preconference July 27

REGISTER ONLINE AT TEXASPPCC.ORG OR COMPLETE THE FOLLOWING:

Name _____ Credentials: _____

Address _____

City _____ State _____ Zip _____

Email _____ Phone _____

Cell _____

Professional Affiliation: _____

REGISTER BEFORE JUNE 1 TO GET EARLY BIRD RATES!

Preconference seminar: **\$129** (or **\$109** Early Bird rate) _____

Conference: **\$389** (or **\$359** Early Bird rate) _____

Total Cost: _____

Make checks payable to TPPCC.

Circle Method of Payment: VISA MCARD AMEX DISCOVER

Credit Card Number: _____

Expiration: _____ Security Code: _____

Signature: _____

Please indicate your role:

- | | | | |
|-------------------------------------|---|--|--|
| <input type="checkbox"/> Physician | <input type="checkbox"/> Nurse | <input type="checkbox"/> Chaplain | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Educator | <input type="checkbox"/> Administrator | <input type="checkbox"/> Volunteer | <input type="checkbox"/> Parent |
| <input type="checkbox"/> Child Life | <input type="checkbox"/> State Employee | <input type="checkbox"/> Other (list): _____ | |

Email: director@texasppcc.org

Mail: TPPCC, PO Box 5111, Pasadena, TX 77508

Fax: 713-944-5533

Cancellation policy: Cancellations received in writing by July 13 will be entitled to a refund, less a \$20 administrative fee. Conference "no shows" forfeit their entire registration fee. Substitutions are welcome, but please inform TPPCC in writing if a substitute is attending in your place. Telephone cancellations cannot be accepted; faxed cancellations are acceptable.

LODGING

South Shore Harbour
Resort & Conference
Center
2500 South Shore Blvd
League City, TX 77573

Group Rate:

\$119 single/double
occupancy per night
*Includes free parking for
overnight guests*

RESERVATIONS

281 334 1000

Ask for the TPPCC
room block

NOTE: \$119 rate is
available until July 7,
2017. Make your
reservations soon!

Space is limited--please
register early.

Questions? Call
713-944-6569 or
1-866-JOYHOPE.

For more information
about Joining the Texas
Pediatric Palliative Care
Consortium, see next
page or visit the TPPCC
[website.](#)

Conference exhibitor opportunities available

Do you know a company (or are you one) that would benefit from gaining exposure to professionals in the field of pediatric palliative care? If so, please consider an exhibitor presence at Pedi-HOPE 2017. There are several levels of participation for exhibitors, and all are appreciated.

Platinum Exhibitor - \$10,000

- Full-page ad in program brochure
- Conference admission for eight (8)
- Special signage and website recognition
- Membership in TPPCC
- Special name tag identification
- Prominent exhibitor space - two (2) 6' tables w/chairs

Gold Exhibitor - \$5,000

- Full-page ad in program brochure
- Conference admission for four (4)
- Special signage and website recognition
- Membership in TPPCC
- Special name tag identification
- Exhibitor space - one (1) 6' table w/chairs

Silver Exhibitor - \$3,000

- Half-page ad in program brochure
- Conference admission for two (2)
- Membership in TPPCC
- Special signage and website recognition
- Exhibitor space - one (1) 6' table w/chairs

To become an exhibitor, contact:

**Jan Wheeler, EdD,
Executive Director
(713) 851-9792**

Email: director@texasppcc.org

Limited space is available and will be assigned on a first-response basis. **If you wish to be assured of an exhibitor listing in the final conference program, you must respond by July 7, 2017.**

We are planning a wonderful conference and hope you will lend your support and join us at Pedi-HOPE in League City, TX this summer!

Other exhibitor opportunities are available: [CLICK HERE](#) to view full list.

The Texas Pediatric Palliative Care Consortium (TPPCC)

The TPPCC is an alliance of interdisciplinary pediatric palliative care providers, advocates, and parents in the Lone Star state who are dedicated to improving the quality of life and the care for children living with life-threatening conditions and their families.



Learn more and join online at www.tppcc.org.

The Texas Pediatric Palliative Care Consortium (TPPCC) is an affiliate of Project Joy and Hope.

