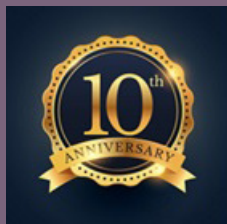




# LOOKING TO THE FUTURE

**MULTIDIMENSIONAL APPROACHES TO  
PEDIATRIC PALLIATIVE CARE**



## **PEDI-HOPE 10TH ANNIVERSARY CONFERENCE**

**JULY 27 & 28, 2018**

**PRECONFERENCE SESSIONS  
JULY 26, 2018**

**SOUTH SHORE HARBOUR  
RESORT & CONFERENCE CENTER  
LEAGUE CITY, TEXAS**

**JOINTLY PROVIDED BY  
TEXAS CHILDREN'S HOSPITAL AND  
TEXAS PEDIATRIC  
PALLIATIVE CARE CONSORTIUM**

# PEDI-HOPE 10TH ANNIVERSARY CONFERENCE LOOKING TO THE FUTURE

## MULTIDIMENSIONAL APPROACHES TO 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 2018 is jointly provided by Texas Children's Hospital and Texas Pediatric Palliative Care Consortium.

### THURSDAY, JULY 26 PRECONFERENCE SEMINAR

#### 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
- Administrators
- Government Employees
- Caregivers

**7:15 - 7:45am**      **REGISTRATION and continental breakfast**

**7:45 - 8:00am**      **WELCOME and Announcements**

**8:00 - 9:15am**

**KEYNOTE ADDRESS - Justin Baker, MD**

**Pediatric Palliative Care 2.0: Making the Case to Take Your PPC Program to the Next Level**

**9:30 - 12:30pm**      **MORNING SESSIONS**

**PRECONFERENCE A: Brothers and Sisters of Children with Serious Illnesses: Unique Concerns, Unique Opportunities** - Don Meyer, EdD

\*PRECONFERENCE A is designed to be a full day learning session, however participants can register for either the morning or afternoon session individually.

**PART 1\*** *Siblings are often the silent sufferers in families with seriously ill children or those with special health care needs. The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns. Project director, Don Meyer, created the Sibshop® model and trains Sibshop facilitators throughout the world. This session, led by Meyer, will provide an extensive look at the challenges these brothers and sisters face. This full day seminar also includes an adult sibling panel, as well as interactive activities sure to spark new ideas.*

**PRECONFERENCE B: Cultivating Moral Resilience in Response to Moral Adversity** - Cynda Hylton Rushton PhD, RN, FAAN. *Dr. Rushton, Professor of Nursing and Pediatrics at Johns Hopkins University is a recognized leader in clinical ethics, whose work in moral distress and resilience has led to recognition as a Hastings Center Fellow. This interactive session will focus on the important role of developing moral resilience in health care professionals faced with the moral uncertainties and value laden decisions faced in pediatric palliative care settings.*

**PRECONFERENCE C: It's What You Say AND How You Say It.**

**Communication, Family Centered Care and Inter-professional**

**Collaboration** - Justin Baker MD, Tammy Kang MD, Melody Hellsten DNP, Jan Wheeler EdD. *This session will utilize content from the Education in Palliative and End of life Care (EPEC) project to increase skill in high quality communication and collaboration aimed at enhancing care planning and coordination for children and families with complex medical conditions across their trajectory of care. Interactive scenarios and debrief sessions will*



## FEATURED SPEAKERS

Fernando Stein  
MD, FAAP  
Section Chief  
Progressive Care Unit  
Texas Children's Hospital

Brian Carter  
MD, FAAP  
Pediatric Bioethicist  
University of  
Missouri-Kansas City  
School of Medicine

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

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

Terri L. Major-Kincade  
MD, MPH, FAAP  
Neonatologist  
Murphy, TX

Cynda Rushton  
PhD, RN, FAAN  
Professor of Nursing  
and Pediatrics,  
Johns Hopkins University

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

*provide participants the opportunity to increase confidence in communicating with families and colleagues around difficult clinical decision making and care planning.*

**12:30 - 2:00pm LUNCH BREAK** Options on site and nearby locations

**1:30 - 2:00pm REGISTRATION for Participants attending Afternoon Session Only**

**2:00 - 5:00pm AFTERNOON SESSIONS**

**PRECONFERENCE A Part 2\* A Panel of Siblings of People with Serious Illnesses and Special Healthcare Needs.** *This panel discussion, facilitated by Don Meyer, will provide insights and an intimate view into the lives of people who have siblings with special health care needs.*

**PRECONFERENCE A Part 3\* Models of Support for Siblings throughout the Lifespan** - *Don Meyer will introduce the Sibshop program model and discuss a variety of techniques and activities that engage siblings in playful experiences designed to provide encouragement and support for those living with a seriously ill or special needs child, as well as supportive opportunities for these "unsung heroes" throughout the lifespan.*

**PRECONFERENCE D: Navigating the Minefield: Developing Skills to Manage Conflict in Challenging Clinical Situations** - Autumn Fiester PhD *Conflict, both big and small, can arise in even the most cohesive of teams and families when caring for children with complex medical conditions. Often, these conflicts can lead to frustration, misunderstandings, poor communication, and dissatisfaction with care. Dr. Fiester is the Executive Director of the Penn Program in Clinical Conflict Management and a skilled trainer in the art of conflict resolution, and brings incredible energy, realism and humor to her training sessions. Join Dr. Fiester as she shares tools to navigate complex, emotionally charged conflicts with diverse stakeholders. Participants will gain practical skills in conflict resolution in this lively, interactive session.*

**PRECONFERENCE E: Life, Death and Birth: A Collaborative Journey** - Patricia Heale DNP, RNC-OB, Donna Beecroft MSN, RN, NE-BC, Brian Carter, MD FAAP. *Somatic survival to prolong fetal gestational age and promote fetal well-being when the mother has a Traumatic Brain Injury (TBI) is a rare occurrence, and one few clinicians have experienced. The objectives of this session are to provide participants with: The knowledge to be able to care for the mother with a TBI while prolonging gestation to ensure the best fetal outcome and basic ethics principles to resolve the dilemma of beneficence for the baby and non-maleficence for the mother.*

*Walk through this case with a meandering path that seems to have brought a measure of good to many people in need. However, at what cost? In collaboration with the interdisciplinary team from Children's Memorial Hermann, Dr. Brain Carter will facilitate this complex and thought provoking case. Dr. Carter will direct some of the ethical discourse around the words we use/speak/think in such matters and an analysis using varied approaches.*

**5:30 – 6:30pm WELCOME RECEPTION for Preconference and Conference Attendees.**

## COURSE OBJECTIVES

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

**1) Identify** opportunities to expand pediatric palliative care locally and nationally

**2) Examine** institutional practice and policies related to pediatric palliative care

**3) Integrate** principles of pediatric palliative care to clinical practice and policy issues locally and nationally

## FRIDAY, JULY 27 CONFERENCE LOOKING TO THE FUTURE

**7:30 - 8:15am REGISTRATION and continental breakfast**

**8:15 - 8:30am WELCOME: Announcements & Introductions**

**8:30 - 9:45am PLENARY A: Defining Clinical Success and The Importance of Compassion** - Fernando Stein, MD, FAAP  
Past President (2017) of the American Academy of Pediatrics

**9:45 - 9:55am BREAK**

**9:55 -10:55am BREAKOUT SESSION 1**

- a. **Looking to the Future: A Novel Biopsychosocial Communication Framework** - Daniel Mahoney MD
- b. **Research Priorities in Pediatric Palliative Care** - Justin Baker MD
- c. **The Death Vigil - Waiting, Watching, Supporting** - Taryn Schuelke  
CPMT, CCLS, Kirstin Springmeyer M.Div, BCC and Sarah Korenbilt LCSW
- d. **Pediatric Medication Management “Perils”** - Melissa Hunt Pharm D
- e. **Parental Preferences in Decisional Autonomy and Values-Guided Approaches in Tracheostomy Decisions** - Rohini Majumdar BS

**10:55 -11:05am BREAK**

**11:05am -12:05pm BREAKOUT SESSION 2**

- a. **You want ME to have the conversation? Putting the fun in advance care planning!** - Debra Lafond DNP, PPCNP-BC, CPON, CHPPN and Kathy Perko MS, CPNP, CHPPN, CPLC
- b. **Program Development in Pediatric Palliative Care:**
  - **Care Connections: Development and Implementation of a Perinatal/Neonatal Palliative Care Program** - Marion Acheson-Silver  
NNP-BC and Katherine Brandt MD
  - **Can We Serve Them All? The Expanding Pediatric Palliative Care Program** - Rachel Vandermeer MD
- c. **Seven Religious Presumptions that All Palliative Care Practitioners Should Understand** - Dane R. Sommer, DMin, MDiv, BCC
- d. **Methadone for Analgesia: A Primer for Use in Clinical Practice**  
- Kevin Madden MD and Eden Mae C. Rodriguez PharmD, BCPS
- e. **Creative ArtWork: A Dimension in the Multidimensional Approaches to Pediatric Palliative Care** - Joan J. Pruitt MS, MA, LPC

**12:05 -12:15pm BREAK**

**12:15 -1:45pm KEITH FRAZIER MEMORIAL LUNCHEON: Reframing “Difficult”: Exploring Ethical Challenges Through the Lens of Conflict Transformation** - Stacy Smith MA, MLS, BSN, RN, CHPPN

**1:45 - 1:55pm BREAK**

**1:55 - 2:55pm BREAKOUT SESSION 3**

- a. **It’s All About That Relationship! Leveraging Relationships at the Bedside to Improve Access to Care and Decrease Moral Distress**  
- Debra Lafond DNP, PPCNP-BC, CPON, CHPPN

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MITOCHONDRIAL  
MYOPATHY,  
POET,  
MOTIVATIONAL  
SPEAKER,  
PEACEMAKER

**b. Advancing Community Based Care**

- **Promoting a Life of Joy and Dignity for Medically Fragile Children Using a Special Needs Medical Home Model** - Celeste Fisher RN, BSN, CPPS
- **Caring Community: A WestSide Story** - Faith Kinnear CPNP-AC, Katie Evans LCSW and Riley Hammond MS, CCLS

**c. Health Care Professionals' Awareness of a Child's Impending Death**

- Kathy Kobler PhD, APN, PCNS-BC, CHPPN, FPCN

**d. A Structured Approach to Refractory Symptoms in Pediatrics**

- Regina Okhuysen-Cawley MD

**e. Healing Through Play: Helping Siblings Cope with Death**

- Meghaan Nguyen MSW, CCLS

**2:55 - 3:05pm BREAK**

**3:05 - 4:20pm PLENARY B: Accepted, Anticipated, and Negated: The Paradox of Repetitive Child Loss and Management of Chronic Bereavement in the African American Community: A Health Disparities Perspective** - Terri Major Kincade MD

**4:30 - 6:30pm NETWORKING and POSTER PRESENTATIONS**

(Complimentary hors d'oeuvres & cash bar)

**SATURDAY, JULY 29 CONFERENCE LOOKING TO THE FUTURE**

**7:30 - 8:15am REGISTRATION and continental breakfast**

**8:15 - 8:30am WELCOME, TPPCC News and Announcements**

**8:30 - 9:45am PANEL: Journey Through Hope: Perspectives from Families of Organ Donors.** Facilitator Elise Passy, Life Gift

**9:45 - 10:00am BREAK**

**10:00 - 11:00am BREAKOUT SESSION IV**

**a. Feasibility of an Inclusive Shared Decision Making Process Regarding Tracheostomy Placement in Medically Complex Children**  
- Rina Meyer MD

**b. Moral Distress in the NICU: Palliative Care to the rescue?**  
- Kathy Perko MS, CPNP, CHPPN, CPLC

**c. A Paradigm of Grief and Hope** - S. Vance Goodman MDiv

**d. Practical Solutions to Incorporating Pediatric Palliative Care Best Practices Into the Electronic Medical Record** - Tammy Kang MD

**e. Expanding Perspectives: Cultivating Respect for EOL Decisions in a Pediatric Setting** - Christa Rogers BSN, RN, CCRN

**11:00 - 11:15am BREAK**

**11:15am - 12:30pm PLENARY C: Looking at the Future of Pediatric Palliative Care through the Lens of the Humanities & Bioethics** - Brian Carter MD, FAAP

**12:30 - 1:00pm CLOSING REMARKS & EVALUATIONS**

# You'll love our conference location!

## OUR CONFERENCE SITE

is just 25 minutes from Downtown Houston on the shores of Galveston Bay, you'll find the communities of League City, Clear Lake, 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 LODGING

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

Group Rate:  
\$129 single/double  
occupancy per night.  
*Includes free parking  
for overnight guests*

**RESERVATIONS**  
**281-334-1000**  
Ask for the  
**TPPCC room block**

NOTE: \$129 rate is available  
until July 7, 2018.  
Make your reservations soon!

**SCHOLARSHIPS:** A limited number of scholarships are available for students. All scholarship recipients are expected to attend the Conference in full. Visit the website to learn more and apply. <http://texasppcc.org/scholarships>

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JULY 27 & 28, 2018

PRECONFERENCE JULY 26

Register online at [texasppcc.org](http://texasppcc.org)  
 or email/mail/fax the form below to:  
 email: [director@texasppcc.org](mailto:director@texasppcc.org)  
 mail: TPPCC, PO Box 5111, Pasadena TX 77508  
 fax: 713-944-5533

Name: \_\_\_\_\_ Credentials: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

email: \_\_\_\_\_ best phone: \_\_\_\_\_

Professional Affiliation: \_\_\_\_\_

Enclosed:  Check payable to TPPCC  
 Credit card (VISA MCARD AMEX DISCOVER)

Card Number: \_\_\_\_\_

EXP: \_\_\_\_\_ Security Code: \_\_\_\_\_

Signature: \_\_\_\_\_

MY PURCHASE/AMOUNT ENCLOSED:

- Preconference Half Day Early Bird (\$109) \_\_\_\_\_
- Preconference Half Day full price (\$129) \_\_\_\_\_
- Preconference Full Day Early Bird (\$179) \_\_\_\_\_
- Preconference Full Day full price (\$199) \_\_\_\_\_
- Conference Early Bird (\$359) \_\_\_\_\_
- Conference full price (\$389) \_\_\_\_\_
- TOTAL ENCLOSED \_\_\_\_\_

REGISTER by  
 JUNE 1st for  
 EARLY BIRD  
 RATES!

Preconference  
 Seminars

Half Day:  
 \$109 (Early Bird)  
 After June 1st \$129  
 Full Day:  
 \$179 (Early Bird)  
 After June 1st \$199

Conference

\$359 Early Bird  
 After June 1st - \$389

Please tell us your role:

- Physician
- Educator
- Child Life
- Nurse
- Administrator
- State Employee
- Chaplain
- Volunteer:
- Social Worker
- Parent
- Other \_\_\_\_\_

**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

For hotel reservations call  
 281-334-1000 Ask for the  
 TPPCC room block

# 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 2018. There are several levels of participation for exhibitors, and all are appreciated.

## PREMIER EXHIBITORS:

### Platinum Exhibitor - \$10,000

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

### Gold Exhibitor - \$5,000

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

### Silver Exhibitor - \$3,000

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

### Bronze Exhibitor - \$2,500

- Quarter-page ad in program brochure
- Special Signage & Website Recognition
- Conference admission for two
- Membership in TPPCC
- Special name tag identification
- Exhibitor space - one 6' table w/chairs

## SPECIAL EXHIBITORS:

### Luncheon Exhibitor - \$3500

- Luncheon will be shown in the program brochure as the (Name of Exhibitor) Luncheon.
- Conference admission for two
- Opportunity during luncheon to welcome attendees
- Special Signage & Website Recognition
- Membership in TPPCC
- Prominent Exhibitor space - one 6' table w/chairs

### Networking Reception Exhibitor - \$2500

- Reception will be shown in the program brochure as the (Name of Exhibitor) Networking Reception (held on Friday evening, July 26, 4:30-6:30 pm)
- Conference admission for two
- Special Signage & Website Recognition
- Membership in TPPCC
- Prominent Exhibitor space - one 6' table w/chairs

### Coffee Break Exhibitor - \$2,000

- Conference admission for two
- Acknowledgment in program brochure [Coffee Breaks provided by (Name of Exhibitor)]
- Special Signage at Break Location
- Website Recognition
- Exhibitor space - one 6' table w/chairs

### Table Exhibitor - \$1,000

- Conference admission for one
- Acknowledgment in program brochure
- Exhibitor space - one 6' table w/chairs

**To become an exhibitor, contact:**

**Jan Wheeler, EdD**

Executive Director, Project Joy & Hope

**713-851-9792**

email: [jan@joyandhope.org](mailto:jan@joyandhope.org)

Limited space is available and will be assigned on first-response basis. **If you wish to be assured of an exhibitor listing in the final conference program, you must respond by July 7, 2018.** We are planning a wonderful conference and hope you will join us!



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 at [www.tppcc.org](http://www.tppcc.org)



TPPCC is an affiliate of Project Joy and Hope.