



**PEDI-HOPE
11TH ANNUAL
CONFERENCE**

JULY 26 & 27, 2019

**PRECONFERENCE
SESSIONS**

JULY 25, 2019

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

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

PEDI-HOPE 11TH ANNUAL CONFERENCE

Creating Compassionate Community 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 2019 is jointly provided by Texas Children's Hospital and Texas Pediatric Palliative Care Consortium.

PRECONFERENCE SEMINAR: THURSDAY, JULY 25, 2019

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 - **Compassion at Work**
- Rachel Thienprayoon MD, MSCS, FAAP, FAAHPM
9:30 - 12:30pm MORNING SESSIONS (includes 15 minute break)

PRECONFERENCE A: PART 1* Experiential Integrated Medicine - Sanghamitra M. Misra MD Evidence Based Approaches to Palliative Care include a wide variety of techniques. This fast-moving, experiential session will guide learners in activities that promote well being for pediatric palliative care patients and their families.

The morning session begins with an introduction to Evidence Based Approaches to Palliative Care, Yoga therapy in children, Guided Imagery and Clinical Hypnosis, as well as demonstration sessions in small groups. This preconference is designed for full day participation. However, registration for either morning or afternoon program is permitted. Please dress comfortably.

PRECONFERENCE B: Compassionate Connected Care Model – Julie J. Samuelson RN, MSN, Press Ganey Senior Associate Press Ganey is noted for its work in Transformational Services to improve patient care. This workshop will emphasize the Six Key Themes of Press Ganey's Compassionate Connected Care model and will guide participants in identifying opportunities for improvement in Compassionate Connected Care through small group simulation and varied techniques. Julie Samuelson has more than 35 years of professional nursing practice as a clinician, administrator and consultant. During her career in health care quality and performance, she has been a coach, consultant and project leader and has used her data analysis and change leadership skills to drive effective and efficient improvement efforts.

PRECONFERENCE C: Mind the Gap: Community Based Pediatric Palliative Care Program Development Forum -Glen Medellin MD, Devon Dabbs, Melody Hellsten DNP, RN, PPCNP-BC, CHPPN and Rachel Thienprayoon MD, MSCS, FAAP, FAAHPM Pediatric palliative care has experienced substantial growth over the past two decades, however there remain substantial challenges in providing continuity of care across



FEATURED SPEAKERS

Devon Dabbs
Co-founder
Children's Hospice
and Palliative Care
Coalition (CHPCC)

D. Micah Hester PhD
Clinical Ethicist
Arkansas Children's
Hospital
Professor of Medical
Humanities and
Pediatrics, University
of Arkansas for
Medical Sciences

Glen Kamatsu MD
Chief Medical Officer
Providence Trinity
Care Hospice
and Regional
Palliative Care

Julie J. Samuelson
RN, MSN
Senior Associate
Press Ganey
Transformational
Services

Rachel Thienprayoon
MD, MSCS, FAAP,
FAAHPM
Medical Director
Star Shine Hospice
and Palliative Care
Cincinnati Children's
Hospital

Janice H. Wheeler EdD
Founder and Director
Project Joy and Hope
for Texas

hospital, home and hospice settings. Concurrent Care and state waiver programs provide opportunities to supplement services in the community, however gaps in care remain. As PPC enters its third decade of growth, there is a need to develop a sustainable community based care model that provides seamless, cost-effective care between hospital, home and hospice. This session will explore current community based models of care; challenges related to staffing and reimbursement; and policy/legislative issues with the goal of creating an ongoing work group focused on community based care program development.

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 (includes 15 minute break)

PRECONFERENCE D Part 2* Experiential Integrated Medicine

- Sanghamitra M. Misra MD *The afternoon session of Evidence Based Approaches to Palliative Care explores the utilization of Acupuncture, Art Therapy, Aromatherapy, and Massage Therapy for pediatric patients. Participants will develop basic understandings of each intervention and participate in experiential sessions. This preconference is designed for full day participation. However, registration for either morning or afternoon program is permitted. Please dress comfortably.*

PRECONFERENCE E When Predictions Don't Come True: Surviving and Thriving Despite Prognosis

- Kathy Rose RN, CHPPN, Audra Stewart DO and Stacy Smith MA, MLS, BSN, RN, CHPPN, HEC-C - *Explore in-depth cases in which parents were given a definitively short prognosis in the prenatal consultation or at birth. Join in discussion and learn strategies for redirecting conversation and care planning when predictions don't come true. Reframing, redirecting the conversation and plan of care, and navigating conflicts are valuable skills for hospice and palliative care providers when assisting caregivers. There will be a comparison and contrast of the choices in each case offered to families and ultimately what decisions each family made.*

PRECONFERENCE F: Search Inside Yourself®

- Glen Kamatsu MD *Originally developed at Google by leading experts in neuroscience, emotional intelligence and mindfulness, this 3 hour program will introduce practical tools and techniques to improve clinical performance, enhance leadership skills and foster well-being and resilience in our work. Glen Komatsu MD is a certified Search Inside Yourself® teacher and will lead this shortened version of the standard 2 day, 16 hour curriculum.*

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

CONFERENCE DAY 1: FRIDAY, JULY 26, 2019

COURSE OBJECTIVES

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

- 1) Identify opportunities to expand pediatric palliative care services across care settings
- 2) Explore the role of compassion in caring for children with terminal and life-threatening conditions
- 3) Integrate principles of pediatric palliative care into clinical practice, education and policy locally and nationally

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

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

8:30 - 9:45am PLENARY A: Compassion Comes to Town: Developing Community Connections for Medically Fragile Children and Their Families - Jan Wheeler EdD

9:45 - 9:55am BREAK

9:55 -10:55am BREAKOUT SESSION 1

- a. **A Simple System for Symptom Assessment in Pediatric Palliative Care Patients with Cancer: A Preliminary Report** - Kevin Madden MD
- b. **Courageous Parents Network: Utilizing the Family Experience to Support Parents and Empower Providers** - Janet Duncan MSN, CPNP
- c. **Case Study Presentations: A Terribly Awesome Story: A Case Study of Pediatric Hospice** - Kelly Cox CCLS
- d. **Ghosted: Moral Distress among Providers & the Absent Parent** - Claire Crawford LMSW

10:55 -11:05am BREAK

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

- a. **Keeping It Down: A Case-Based Approach to Pediatric Nausea & Vomiting** - Melissa Hunt PharmD
- b. **Understanding the Utility of a Brief Reflection Tool to Support Staff Surrounding Pediatric Patient Deaths: A mixed Methods Study** - Veena Ramgopal DO
- c. **Grieving the Living: Integrating Grief Theory Early in Pediatric Palliative Care** - Faith Kinnear CPNP-AC
- d. **Building Resilience: Individual and Team Approaches for Palliative Care Providers** - Regina Okhuysen-Cawley MD

12:05 -12:15pm BREAK

12:15 -1:45pm KEITH FRAZIER MEMORIAL LUNCHEON: Compassionate for Whom? Forgoing Life Sustaining Treatment and Moral Distress at the End of Life - D. Micah Hester, PhD

1:45 - 1:55pm BREAK

1:55 - 2:55pm BREAKOUT SESSION 3

- a. **Palliative Sedation: Indication, Techniques, Practical Considerations** - Nancy Glass MD
- b. **Impact of Integrating Palliative Care into Neuro-Oncology Clinic** - Lauren Hancock MSN, RN, CPNP-AC, CHPPN

THE
GREATNESS
OF A
COMMUNITY
IS MOST
ACCURATELY
MEASURED
BY THE
COMPASSIONATE
ACTIONS OF
ITS MEMBERS,
A HEART OF
GRACE AND
A SOUL
GENERATED
BY LOVE.

CORETTA
SCOTT
KING

- c. **Dignity Therapy in Pediatrics: A Novel Application of a Psychological Intervention** - Jared Rubenstein MD
- d. **May I Teach You How to Help? Teaching Primary Pediatric Palliative Care Skills to Adult Trained Palliative Learners and Medical Students** - Rachel Vandermeer MD, and Tandy Mellard, DNP, RN, CPNP-PC/AC, CHPPN
- e. **Frank's Heroic Journey** - Kara Maison RN

2:55 - 3:05pm BREAK

3:05 - 3:40pm THE YELLOW BOAT - A Dramatic Performance by ART PARK PLAYERS

3:45 - 5:00pm PLENARY B: Whole Child Care – Addressing Suffering and Finding Healing in Pediatric Palliative Care - Glen Kamatsu MD

5:30 - 7:00pm NETWORKING and POSTER PRESENTATIONS
(Complimentary hors d'oeuvres & cash bar)

CONFERENCE DAY TWO: SATURDAY, JULY 27, 2019

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

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

8:30 - 9:45am PANEL: Navigating the Complexities of Compassion: An Interfaith Council Discussion - Moderator, Kirstin Springmeyer Ddiv, BCC

9:45 - 10:00am BREAK

10:00 - 11:00am BREAKOUT SESSION 4

- a. **Feeding Intolerance and Self-injurious Behaviors in Cornelia de Lange** - Holly D. Smith MD and Ebony Beaudoin MD
- b. **Postpartum Depression: Screening Mothers of Infants Receiving Pediatric Palliative Care** - Patricia K. DeForest MD
- c. **Narrative: A Compelling Tool to Process Provider Distress** - Steven Smith MD
- d. **Seven Common Concepts that Clinicians Hold that Impact Persons of Faith Should Know...and What That Means for Us!** - Dane Sommer Dmin, Mdiv, BCC & Brian Carter MD FAAP

11:00 - 11:15am BREAK

11:15am - 12:30pm PLENARY C: Building Intentional Communities of Compassion - Devon Dabbs, Co-founder of Children's Hospice and Palliative Care Coalition (CHPCC)

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 3, 2019.

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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In Pediatric Palliative Care

JULY 26 & 27, 2019
preconference July 25, 2019

Register online at texasppcc.org
or email/mail/fax the form below to:
email: 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 2019. 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, 5:30-7:00 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

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, 2019.** We are planning a wonderful conference and hope you will join us!



TPPCC is an affiliate of Project Joy and Hope.

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



