

# PRECONFERENCE SESSIONS



## **2:00PM - 5:00PM: PRECONFERENCE SESSIONS #2 (CONTINUED):**

### **MINDFUL JOURNEYS: AN INNOVATIVE APPROACH TO HEALING FOR MOTHERS/PARENTS EXPERIENCING PERINATAL LOSS: DAVID M. STEINHORN, MD AND JANA DIN, BA**

This session will introduce the attendee to concepts of mindfulness and explain how a mindful state, in contrast to a state of emotional upheaval, can contribute to reconciling grief and achieving personal growth. The process of journeying to a quiet, mindful, internal place for self-reflection will be discussed as an introduction to transpersonal psychology. Tools for moving into a transpersonal space will be offered, including an experience of gentle drumming as a non-verbal way to achieve mindfulness.

### **RECOGNIZING MISCARRIAGE THROUGH STANDARDIZED RESPECTFUL DISPOSITION PRACTICE AND INCLUSIVE RITUAL: ANN TYNDALL, MDIV, BCC, CPLC**

Research shows that 75% of women who experience a miscarriage view it as the loss of a baby, yet not all healthcare systems have a way of respectfully disposing of miscarriage remains. This workshop highlights Resolve Through Sharing's respectful disposition practice at Gundersen Health System and references its annual burial as an example of inclusive ritual. Considerations for establishing hospital-based respectful disposition, including data gathering and crafting institutional policies and standards of practice, will be discussed. Working in small groups, participants will explore the challenges and possibilities for creating a respectful, broadly inclusive ritual.

## MAIN CONFERENCE SESSIONS

**THURSDAY, OCTOBER 1, 2020**

### **8:30AM - 9:45AM: MORNING OPENING PLENARY SESSION:**

#### **MORNING MAIN CONFERENCE PLENARY SESSION: UNNATURAL TRAGEDIES AND THE NATURE OF TRAUMATIC GRIEF: JOANNE CACCIATORE, PHD**

Little is understood about the nature and trajectory of traumatic grief in perinatal death. Current standards of practice, even in bereavement care, overlook the trauma inherent for many families after perinatal death. This session will review the biopsychosocial nuances of perinatal death and its relationship to traumatic grief. Participants will learn effective, immediate, and long-term caregiving and what trauma informed compassionate care looks like.

### **11:15AM - 12:15PM: CONCURRENT SESSION #1**

#### **EFFECT OF PERINATAL PALLIATIVE CARE ON OUTCOMES OF FAMILIES OF CHILDREN WITH TRISOMY 13 AND TRISOMY 18: IRENE CHERRICK, MD**

The recommendations for care of children with Trisomy 13 and 18, as with other diseases has moved from a classic non-interventional approach to that of shared decision making based upon individual circumstances. The role of Pediatric/Perinatal Palliative Care in the care of these children is underutilized, especially during the perinatal period. This session will help participants become more aware of the current outcomes data for children with Trisomy 13 and 18 as well as the role of Pediatric/Perinatal Palliative Care from time of diagnosis and how this care affects outcomes.

#### **PERINATAL BEREAVEMENT CARE IN SCOTLAND: AN ETHNOGRAPHIC STUDY: DENISE CÔTÉ-ARSENAULT, PHD, RN, CPLC, FNAP, FAAN**

In this session the participant will learn about the ethnographic study conducted in Edinburgh, Scotland. Immersion in the culture of perinatal bereavement care, specifically through attending multiple support groups for bereaved parents and interviewing midwives who care for bereaved families in the hospital and community, led to new understanding of the influence a national health service in a culture other than the US has on post-loss care. Through photographs, case studies, policy analysis, and reflection on differences in approaches, the session features multiple implications for US care providers.

#### **HOPING FOR A MIRACLE: PALLIATIVE CARE . . . THE BEGINNING: BERNADETTE FLYNN-KELTON BSN, RN, IBCLC, RLC AND SUSAN STRASZYNSKI MSN, RN, RNC-OB, C-EFM, CPLC**

This presentation will provide attendees with the beginning steps to create an evidence-based palliative care program. Curriculum content will include methods for developing an interdisciplinary collaborative program to meet the individualized needs of families. Speakers will share personal experiences and methods used to create relationships with families and guide them through decision making and palliative care options. The presentation will conclude with a video documentation of a journey through preserving hope, birth, and death.

#### **THE INTERSECTION OF FETAL THERAPY AND PERINATAL/NEONATAL PALLIATIVE CARE: KATHIE KOBLER, PHD, APRN, PCNS-BC, CHPPN, FPCN, FAAN**

A tremendous evolution in fetal diagnostics and procedural techniques have resulted in an increased spectrum of fetal conditions that can be addressed by in utero surgery. Multidisciplinary team members should be prepared to address the unique fetal, maternal, and neonatal challenges that arise for families receiving diagnoses of serious fetal illness. This session will highlight palliative care principles and strategies that can be implemented, at the time of delivery, and in the neonatal period.

# MAIN CONFERENCE SESSIONS



## **11:15AM - 12:15PM: CONCURRENT SESSION #1 (CONTINUED)**

### **PERINATAL MOOD AND ANXIETY DISORDERS AND THE INTERSECTION WITH GRIEF AND LOSS: BIRDIE GUNYON MEYER, RN, MA, PMH-C**

Many institutions still do not teach basic knowledge of Perinatal Mood and Anxiety Disorders (PMADS), leaving patients without care and treatment and tragic consequences. This concurrent session will provide attendees the basic accurate knowledge of perinatal mood and anxiety disorders, treatment options, and resources available. As the title indicates, the presenter will focus on PMADS and their relationship to perinatal grief and loss, providing a specific context to the preconference on PMADS.

### **BEYOND TRADITIONAL KEEPSAKES: CREATING INTANGIBLE MEMORIES THROUGH MEANINGFUL EXPERIENCES: MEGHAAN R. NGUYEN, MSW, CCLS AND HEATHER EPELHEIMER, CCLS, CPLC**

There has been increased attention given to the importance of creating tangible keepsakes for families during bereavement. However, equal attention should be given to the importance of offering bonding opportunities through normalizing experiences and supporting family rituals. Myths, misconceptions, and personal biases can all be barriers in creatively adapting care and supporting the needs of families. This session will explore how care can be personalized through meaningful experiences and address how to work through potential barriers.

## **2:00PM -3:15PM: AFTERNOON PLENARY SESSION: AN INTERACTIVE DISCUSSION WITH A PANEL OF EXPERTS: INNOVATIONS IN PERINATAL AND NEONATAL PALLIATIVE CARE: BRIAN S. CARTER, MD; KATHIE KOBLE, PHD, APRN, PCNS-BC, CHPPN, FPCN, FAAN; REBECCA HANNA, LCSW; CHARLOTTE WOOL PHD, RN, FAAN; AND MODERATOR RANA LIMBO, PHD, RN, CPLC, FAAN**

PLIDA is proud to offer a multidisciplinary panel of known experts to present the latest research and clinical practice in perinatal and neonatal palliative care. Each presenter will speak individually and, as a group, respond to audience questions. With a physician, advance practice and nurse researchers, and a social worker as speakers, this unique educational experience promises to bring you new ideas, challenging reflections, and hope for growing competencies in caring for families who experience perinatal and neonatal palliative care.

## **3:30PM - 4:30PM: CONCURRENT SESSIONS #2**

### **CAREFARMING, ABUSED ANIMALS, AND THE NATURAL WORLD: THE SELAH MODEL FOR TRAUMATIC GRIEF: JOANNE CACCIATORE, PHD**

Most providers do not understand restorative spaces and therapeutic communities, taking a more individualized rather than socialized approach to traumatic grief. This session will introduce participants to a novel green care intervention to help those suffering the biopsychosocial effects of traumatic grief. Participants will explore the elements of restorative spaces and therapeutic communities.

### **ETHICS & PERINATAL PALLIATIVE CARE: BRIAN S. CARTER, MD**

Dealing with complicated pregnancies and fetal diagnoses, parental stress, and decision making under circumstances of uncertainty may all bring matters of ethical import to light for interdisciplinary clinicians in perinatal-neonatal palliative care. This session will review ethical principles, virtues, values, and other approaches to be used in resolving ethical dilemmas in perinatal-neonatal palliative care.

### **WHAT SHOULD I SAY AND NOT SAY? COMMUNICATING WITH BEREAVED FAMILIES WHEN A BABY DIES:**

#### **VICKI CULLING, BA, MA, PHD**

Many maternity health professionals have not had training on interaction and communication with bereaved parents when a baby or an infant die. As a result, they may feel unsure about what to say and worry that they will say something wrong or "make things worse." This presentation will give attendees the chance to reflect on their own beliefs around grief and how that impacts their practice, offer guidelines around what to say and not say, and provide instruction for instances when things have gone wrong. Ultimately, participants will come away with increased confidence in their communication and interaction with bereaved parents and families.

### **PERINATAL CARE CLINIC: ESTABLISHING A ROAD MAP FOR A FAMILY'S COMPLEX MEDICAL JOURNEY: SHEILA B. FRASCHT, RN, BSN, CHPPN, CPLC AND BRENDA HAAG, RN, BSN, CPN**

Perinatal Care Clinic (PCC) at University of Iowa Hospitals and Clinics (UIHC) utilizes a family care conference model to provide information to high-risk OB patients expecting a baby with a complex medical condition. This collaboration between the OB department and the children's hospital focuses on birth care planning and the development of a post-delivery plan of care. This team approach benefits patients, families, and care providers, and ensures meaningful conversations that will guide care that is most aligned with a family's goals of care for their baby.

### **PERINATAL LOSS: THE CRITICAL ROLE OF PLACE/BELONGING AND PROTECTION: ELIZABETH LEVANG, PH.D. AND CURTIS LEVANG, PH.D.**

Perinatal loss is often viewed as psychological trauma due to its far-ranging impact. We propose a new approach to perinatal loss that provides a necessary and valuable link between basic developmental needs and psychological trauma. This session will present a new paradigm of healing that will form a common understanding of the loss experience with the care team and improve the care of women and their families.

### **MANAGING AMBIGUITY: CARING FOR A MOTHER EXPERIENCING A STILLBIRTH: NATASHA NURSE-CLARKE, PHD, RN**

This session will present the results of a recent dissertation study aimed at describing and conceptualizing the experiences and processes involved when labor and delivery nurses provide care to women experiencing a stillbirth. The theory, "Managing Ambiguity," emerged as the basic social process of how nurses struggle to care for a mother whose baby was stillborn. This theoretical underpinning summed up the substance of what was occurring when nurses cared for a mother experiencing a stillbirth and was characterized in three different categories: experiencing a spectrum of emotions, managing the ambiguous patient, and managing institutional ambiguity.

# MAIN CONFERENCE SESSIONS



## **FRIDAY, OCTOBER 2, 2020**

### **8:15AM - 9:30AM: MORNING PLENARY SESSION: (AN)OTHER: VALUING DIFFERENCE, SAMENESS, AND DISTINCTNESS: BETH PERRY BLACK, PHD, RN, FAAN**

In this session, Dr. Black will introduce concepts of other, othering, and another from social sciences and the humanities to extend the discourse around culture, diversity, and inclusion. She will discuss how “othering” devalues persons, the dimensions of devaluation, and how “anotherness” can support the intrinsic value of persons across the spectrum of human experience.

### **10:45AM - 11:45AM: CONCURRENT MORNING SESSIONS #3**

#### **A CONVERSATION ON (AN)OTHER: VALUING DIFFERENCE, SAMENESS, AND DISTINCTNESS: BETH PERRY BLACK, PHD, RN, FAAN**

Building on the content from her plenary session, Dr. Black will lead a panel discussion and conversation on what it means to be “othered” and what being valued looks like to persons for whom othering is common. The goal of this session is to help participants critique and expand discourses around diversity and inclusion, and to examine ways that valuing difference, sameness, and distinctness can enhance one’s professional practice.

#### **UNDERSTANDING PERINATAL PALLIATIVE CARE: COORDINATOR ROLES: “MEETING THE FAMILY WHERE THEY’RE AT”: DENISE CÔTÉ-ARSENAULT, PHD, RN, CPLC, FNP, FAAN AND ERIN M. DENNEY-KOELSCH, MD, FAAHPM**

In this session, the results of an interview study of 12 expert perinatal palliative care coordinators from across the country will be presented. Using their overarching philosophy of care, the presenters will describe their goals for patient care, the tasks they undergo, and the roles they play in facilitating improved care for patients and families facing life-limiting prenatal diagnoses. In the final 15 minutes, participants will work through a case study as a care coordinator to understand implications for practice.

#### **UNDERSTANDING NURSES’ EXPERIENCES OF CARING FOR THE CHILD WHO IS DYING THROUGH A RELATIONAL ETHICS LENS: KARLIE DEANGELIS, RN, BNSC, MSCN**

Caring for children who are dying requires exploration to understand and validate the meaning of this lived experience for nurses. This session poses the question: What is the meaning of caring for a dying child for nurses within their ethical commitments and responsibilities? Guided by relational ethics and visual expression, five thematic patterns are presented: a) Careful cultivation of a team approach shapes end-of-life decisions; b) Resilience and affirming of self as nurse arise with alleviating suffering; c) Navigating sustained turmoil; d) Willingly sojourning in loving presence; and, e) Facilitating and valuing a family’s role in their experience of end-of-life.

#### **HOW TO RECOGNIZE AND DEAL WITH SHAME IN PREGNANCY LOSS: IRENA MILENTIJEVIC, PSYD**

Shame is an essential part of grieving that is often ignored. Currently, most of the focus is on grief following pregnancy loss, while women experience a range of feelings. In this session, Dr. Milentijevic will help participants to recognize and address shame in women after pregnancy loss.

#### **PATERNAL PERINATAL MENTAL HEALTH DISORDERS AFTER PERINATAL LOSS: ELYSE SPRINGER, MA-CLP, LMFT, PMH-C**

Perinatal loss impacts fathers profoundly, but they do not always receive the kind of support they need. Gaps in knowledge around Paternal Perinatal Mental Health Disorders (PPMHD) and their intersection with perinatal loss, along with stigma and bias around men’s experience of loss, impacts the whole family system, and has significant clinical implications for future pregnancies and childrearing. This session focuses on increasing participants’ skill in recognizing, referring, and treating PPMHD following perinatal loss.

#### **THE DEVELOPMENT AND SUSTAINABILITY OF AN INTERDISCIPLINARY PERINATAL LOSS COMMITTEE: PREGNANCY, INFANT AND REPRODUCTIVE LOSS (PIRL) COMMITTEE: AIMEE VANTINE, LMSW**

While reproductive loss occurs in many areas of a large health system, it can be challenging for care providers outside the obstetrics and neonatal care units to be prepared for the unique needs of those experiencing perinatal and/or newborn loss. While these patients are provided the necessary physical care, emotional needs are often overlooked, which can create further pain and isolation. In this session, participants will learn to recognize the significant impact policies, staff training, and working together collaboratively can contribute to positive outcomes for bereaved families.

# MAIN CONFERENCE SESSIONS



## **FRIDAY, OCTOBER 2, 2020**

### **2:00 PM – 3:15PM: PLENARY SESSION #5: “LOVING WYATT: A JOURNEY THROUGH INFANT LOSS AND RECURRENT PREGNANCY LOSS”: MANDY KELSO, AUTHOR**

Join author and artist Mandy Kelso as she describes the many phases and faces of grief experienced after child loss and through years of recurrent pregnancy losses (12 miscarriages over the course of 4 years). She will read excerpts from her book entitled *Poems for Wyatt* (published November 2018) and share original artwork produced throughout her family's ongoing grief and transformation. Mandy and her husband, Robbie Kelso, will engage with audience members in a conversation that will add depth and meaning to their story told through art, poetry, and rich narrative.

### **3:30PM – 4:30PM: AFTERNOON CONCURRENT SESSIONS #4**

#### **PROMOTING PERINATAL LOSS HEALING THROUGH GROUP PARTICIPATION: UNDERSTANDING DIFFERENT SUPPORT GROUP MODALITIES ACROSS THE SPECTRUM: NANCY BERLOW, LCSW AND SARA VASILIOU**

This session will offer the opportunity to learn about different types of support groups for women and couples. Participants will learn about the strengths and weaknesses of closed, open, online, and alternative support group models. The learner will be able to assess which type of group is appropriate depending on the goals of the group and needs of the intended participants, and to take steps to plan and initiate the support group.

#### **PSYCHOLOGICAL OUTCOMES FOLLOWING PREGNANCY LOSS: AGATA FREEDLE, MA, LPC, NCC**

Historically, research has focused on parental grief reactions and affective responses following pregnancy loss. Extant literature shows that women can experience negative mental health outcomes following pregnancy loss such as symptoms of depression, anxiety, and acute and posttraumatic stress disorder. However, there is a growing recognition that in order to fully understand the psychological outcomes following a traumatic event, negative as well as positive transformations the individual may undergo need to be considered. This presentation will focus on increasing participants' understanding of differential outcomes following pregnancy loss.

#### **MOMENTS HELD PHOTOGRAPHY; JOURNEYS OF LOVE AND LOSS IN PERINATAL PALLIATIVE CARE: TODD HOCHBERG, BA**

A veteran documentary bereavement photographer will share images and stories of three families' journeys through engagement with "The Chicago Institute for Fetal Health." From first prenatal consults through end of life, the photographer provides family images of the intimate, precious moments along the way with their baby. Participants will learn how these photographs benefit families and experience them personally. The photography project also provides a visual narrative of the unique experiences of parents choosing perinatal palliative care for their baby and illustration of a working perinatal palliative care team. It serves as an educational tool/model for the program and the professional community.

#### **ARAB MUSLIM IMMIGRANTS' PERCEPTIONS OF PERINATAL LOSS CARE IN THE USA:**

##### **MARIANNE H. HUTTI, PHD, WHNP-BC, FAANP, FAAN**

In the US, Islam is the fastest growing religion, and women of color and women who are immigrants from developing countries are at highest risk of perinatal loss. Cultural values have a major influence on the significance and impact of the loss for parents. This session will review literature-supported Islamic perspectives on fetal and infant death, bereavement, and mourning rituals. These will be compared with the perceptions of 79 Arab Muslim adult immigrants who completed an investigator-developed survey regarding US perinatal bereavement practices. Participants will compare the study findings to the literature to determine discrepancies and suggestions regarding care.

#### **CAPTURING THE VOICES OF BEREAVED PARENTS: THE CREATION OF VIDEOS TO EDUCATE HEALTHCARE PROFESSIONALS ON SKILLED AND COMPASSIONATE BEREAVEMENT CARE:**

##### **MICHELLE LA FONTAINE, BAA, CLS AND MEGAN FOCKLER, RN MPH**

In order to advocate for an increased incorporation of the lived experience of bereaved parents in educational strategies, PAIL Network created three new videos in 2019 where families were asked about their experiences of both helpful and hurtful bereavement care. The first Canadian videos of their kind, they allow professionals to hear directly from families and to advance best practice and quality improvement in education while engaging with families as partners. In this session, participants will explore how incorporating the parent voice into all aspects of perinatal bereavement education supports best practices and creates opportunities to improve their own bereavement care for families.

#### **CHERISHING TIME AND THE ABSENCE OF REGRET IN CONTINUING A PREGNANCY AFTER A LIFE-LIMITING DIAGNOSIS: CHARLOTTE WOOL PHD, RN, FAAN**

Parents, after learning of a life-limiting fetal condition, experience emotional distress and must consider options that impact the remainder of the pregnancy, their future lives, and family members. Researchers examined the concept of decision regret in 405 parents who opted to continue a pregnancy affected by a life-limiting fetal condition. The contextual factors, conditions and consequences surrounding the presence or absence of regret were examined. This session will step participants through the study results so that the information can be easily shared to support parents and inform colleagues.



# MAIN CONFERENCE SESSIONS



**SATURDAY, OCTOBER 3, 2020**

**9:00AM - 10:15AM: CLOSING PLENARY SESSION: REDUCING THE "COST OF CARING" AFTER PERINATAL LOSS**  
**MARIANNE H. HUTTI, PHD, WHNP-BC, FAANP, FAAN**

Caring for families who have experienced the trauma of losing a much-loved baby through miscarriage, stillbirth, or newborn death may be difficult and heart-wrenching. This work affects the emotional, physical, and spiritual aspects of clinicians' lives. Clinicians must nurture and care for themselves, as well, to make sure the personal cost of such caring is not excessive. This session will review the research related to perinatal loss and compassion fatigue symptoms, risk and protective factors, and provide practical, innovative suggestions for self-care to enable clinicians to continue with this critically important and tender work.

## BOOK SIGNING RECEPTION

PLIDA will be hosting a Book Signing Reception on Friday, October 2, 2020 from 4:30PM – 6:30PM in the French Room. The conference bookstore will be provided by Centering Corporation. Additionally, the below authors will be on site with their books available for purchase (and an autograph) in the exhibit hall. Please join us for hors d'oeuvre!

Authors participating in the Book Signing include:

- Beth Perry Black, PhD, RN, FAAN
- Joanne Cacciatore, PhD
- Brian S. Carter, MD
- Mandy Kelso
- Rana Limbo, PhD, RN, CPLC, FAAN
- Charlotte Wool PhD, RN, FAAN

Book Authors and/or Editors: By invitation only



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