

PLENARY SPEAKERS



PRECONFERENCE PLENARY SPEAKER

MEGHAAN R. NGUYEN, MSW, CCLS



Meghaan Nguyen currently serves as the clinical coordinator for the Child Life and Expressive Therapies team at Children's Memorial Hermann Hospital, Houston. She began her career as a child life specialist working at a pediatric burn hospital. She immediately saw the therapeutic value in supporting families from the start of their trauma and continuing with them throughout their recovery. She implemented group programming for patients and parents to support successful community reintegration after trauma. This combination of trauma and the importance of community became the guiding factors in the remainder of her career. Adding a master's in social work to her existing skill set, Meghaan then worked at a bereavement center for children and families, a pediatric emergency department, and later in a pediatric special care unit. Her noteworthy work with families led to an opportunity to develop a new child life position with Memorial Hermann's inpatient pediatric palliative care team and outpatient hospice program. Working in home settings provided greater insight in how to creatively adapt interventions for the entire family.

Meghaan has been a speaker at multiple regional, national, and international conferences regarding supporting siblings through death, maternal death, therapeutic play, and self-care. She authored a chapter on supporting grieving siblings in the *Handbook of Perinatal and Neonatal Palliative Care*, scheduled for publication (Springer) in late 2019. She has been involved in multiple national committees and task forces with the Association of Child Life Professionals and currently serves as the chair of the Professional Development Mega Committee.

MAIN CONFERENCE PLENARY SPEAKERS

JOANNE CACCIATORE, PHD



Dr. Joanne Cacciatore is a research professor studying traumatic grief at Arizona State University with nearly 70 published studies in top tier journals and directs the graduate Certificate in Trauma and Bereavement. In 1996, two years after the death of her baby daughter, Cheyenne, Dr. Cacciatore founded the MISS Foundation, an international NGO that aids families whose babies and older children die or are dying. The MISS Foundation has been serving families globally through support groups and forums, crisis and long-term counseling, and through psychoeducation and professional training.

In 2016 she founded Selah Carefarm, one of only three carefarms in the U.S. and the first carefarm in the world for traumatic grief. There, grieving families from around the world come to receive counseling, learn healthy coping, and help care for almost 40 animals (farm and domestic) rescued from torture, homelessness, and abuse. Personally, she has five children, four living, and is a meditation teacher. She practices ahimsa and has been a vegan since 1972. Her best-selling book, *Bearing the Unbearable: Love, loss, and the heartbreaking path of grief*, won the Indies Book of the Year Award and is available on Amazon.

INTERACTIVE PLENARY PANEL: PERINATAL AND NEONATAL PALLIATIVE CARE

BRIAN S. CARTER, MD



Dr. Carter is a board-certified Neonatologist who has practiced in academic medicine for 30 years. He is also trained in bioethics and palliative care. His current practice focuses on providing follow-up care to NICU graduates and serving as a consultant neonatologist in the Fetal Health Center. He enjoys mentoring medical students, residents and fellows locally and across the country. He is the local PI for the NIH funded multi-site ECHO study of a cohort of babies born <30 weeks' gestation. He publishes, lectures, and teaches in biomedical ethics and is the Co-Director of the CMH Certificate Program in Pediatric Bioethics. He is a pioneer in pediatric palliative, having contributed to the field for 20 years, and presently focuses on neonatal-perinatal palliative care.

He has authored over 100 peer-reviewed articles and 30 book chapters addressing pediatric and neonatal care, ethics and palliative care and is a contributing author and editor of *Merenstein & Gardner's Handbook of Neonatal Intensive Care*; the 1st textbook on pediatric palliative care, *Palliative Care for Infants, Children & Adolescents*; and the 1st textbook on neonatal-perinatal palliative care, *Handbook of Perinatal & Neonatal Palliative Care* – with Rana Limbo and Charlotte Wool. Dr. Carter is a past chairman of the AAP's Section on Hospice & Palliative Medicine and has received honors from the National Hospice & Palliative Care Organization (2003), the William A. Silverman Lecture in Ethics from the Pediatric Academic Societies (2008), and in 2018 he received the William T. and Marjorie Sirridge Endowed Professorship in Medical Humanities & Bioethics at the University of Missouri-Kansas City, School of Medicine. He previously served on the faculty of Vanderbilt University and the Medical College of Georgia after leaving the US Army as a Lieutenant Colonel in 1996.

PLENARY SPEAKERS (CONT)



INTERACTIVE PLENARY PANEL: PERINATAL AND NEONATAL PALLIATIVE CARE

REBECCA HANNA, LCSW



Rebecca Hanna, LCSW is a Licensed Clinical Social Worker and has been practicing medical social work for 13 years. Rebecca currently serves as the social worker with Maternal Fetal Medicine and the Center for Fetal Care at Advocate Children's Hospital in Park Ridge, IL. She works with a multidisciplinary care team and partners with parents to ensure their psychosocial and emotional needs are being addressed while connecting families with ongoing support and collaboration with the pediatric team. In her role, she provides support and planning for babies diagnosed with life-limiting fetal conditions in collaboration with our pediatric palliative care team and perinatal bereavement team.

Rebecca also serves as a team member and counselor with the Perinatal Ethics Committee for pre-termination counseling. She is a member of the hospital-wide Intimate Partner Domestic Violence Task Force and Mothers and Newborns Affected by Opioids Hospital Initiative. Rebecca has completed certificate training with Postpartum Support International for Perinatal Mood and Anxiety Disorders in 2018. In her past careers, Rebecca has 10 plus years of experience working with children with spina bifida throughout the lifespan as well as providing social work services for children with chronic health care needs with a focus on transition to adulthood.

INTERACTIVE PLENARY PANEL: PERINATAL AND NEONATAL PALLIATIVE CARE

KATHIE KOBLER, PHD, APRN, PCNS-BC, CHPPN, FPCN, FAAN



Dr. Kathie Kobler is an advanced practice nurse with over three decades of clinical experience providing a relationship-based approach to care for infants and children with serious illness, and their families. She currently serves as APRN for the Center for Fetal Care at Advocate Children's Hospital.

Dr. Kobler's commitment to children is reflected through service in national organizations, leading policy, certification, and educational initiatives to advance the fields of perinatal, neonatal, and pediatric palliative and bereavement care. Her scholarship focuses on areas often unnoticed, including the role of ritual in end-of-life care. She is well known for integrating relational and interactive teaching methods to help nurses and interdisciplinary clinicians find their gifts and optimize professional well-being when providing end-of-life care.

Dr. Kobler's clinical expertise has been recognized through awards from national organizations including 2017 Distinguished Career Award from the Hospice and Palliative Nurses Association (HPNA), Fellow Designation by HPNA, and Jonas Nurse Leaders Scholar Award from the Jonas Center for Nursing Excellence.

INTERACTIVE PLENARY PANEL: PERINATAL AND NEONATAL PALLIATIVE CARE

RANA LIMBO, PHD, RN, CPLC, FAAN



Dr. Rana Limbo's 50+-year nursing career began at St. Olaf College, followed immediately by a master's in maternal child nursing from the University of Colorado. She was then hired as a bedside nurse at Colorado General Hospital. She was drawn to the emotional aspects of childbearing, through both her education and clinical experiences in her early career. Specifically, Dr. Limbo found herself wanting to raise the standard of care for those women and families who suffered grief from multiple causes. Eventually, she was hired as the first coordinator of Resolve Through Sharing (RTS) at Gundersen Health System, La Crosse, Wisconsin in 1981. As a co-founder of RTS, she was an educator, curriculum designer, writer, and researcher, roles she continued throughout her career. She earned a second master's in adult psychiatric and mental health nursing (Indiana University) and a PhD in nursing from the University of Wisconsin - Madison.

As an international leader in perinatal bereavement, she has educated thousands of professionals; authored or edited six books, numerous journal articles and book chapters; and brought the teaching/learning theory of guided participation to be central in the RTS core curriculum. Her primary research topic, miscarriage, led to innovative understandings of the early ending of a pregnancy. Dr. Limbo has been involved in numerous organizations, including the Pregnancy Loss and Infant Death Alliance, where she served as president for two terms and numerous conference planning committees. She was recognized as a pioneer in perinatal bereavement at both the 2018 and 2020 conferences. She was an invited member of the International Work Group on Death, Dying, and Bereavement and inducted as a Fellow in the American Academy of Nursing, nursing's highest honor.

PLENARY SPEAKERS (CONT)



INTERACTIVE PLENARY PANEL: PERINATAL AND NEONATAL PALLIATIVE CARE

CHARLOTTE WOOL, PHD, RN, FAAN



Dr. Charlotte Wool's contributions to science and clinical practice have extended palliative care to a new population – families with a diagnosis of a life-limiting fetal condition. Known as perinatal palliative care, it focuses on the needs of parents in the aftermath of a fetal diagnosis when the life of their expected child will be short. With a career in maternity settings as a clinician and educator, Dr. Wool recognized the traumatic nature of these diagnoses. In response, she became a nurse scientist who has expanded the field of palliative care into the perinatal period. She has dedicated her career to development of this model of care, including quality measures specific to perinatal palliative care. Dr. Wool has been the principal investigator in several interdisciplinary studies.

She has examined the perinatal loss experience from parents' perspectives and has worked to identify barriers to implementation of perinatal palliative care. She was an investigator on the first national survey of perinatal palliative care programs. Dr. Wool has examined quality metrics and developed and tested two instruments, which have been translated and used worldwide. Countless families have benefited from evidence-based care at a time of great vulnerability and distress. A prolific writer, Dr. Wool has contributed to many peer-reviewed publications, has co-authored perinatal palliative care position statements, and is co-editor of a clinical handbook on perinatal and neonatal palliative care. Dr. Wool completed a BSN from Bloomsburg University, MSN from the University of Phoenix, and PhD from the University of Texas at Tyler. She enjoys consulting with clinicians interested in implementing or growing perinatal palliative care services. She lives in Pennsylvania with her husband and is a happy mother of 5 children and 4 grandchildren.

BETH PERRY BLACK, PHD, RN, FAAN



Beth Perry Black, PhD, RN, FAAN, Associate Professor at the University of North Carolina at Chapel Hill, has a career in nursing spanning four decades. She became interested in grief and bereavement in perinatal settings early in her work as a labor and delivery nurse in a tertiary care medical center. Perinatal and neonatal deaths were not uncommon, but adequate grief care was guided only by nurses' best intentions, not evidence. The overarching theme of her career involves altered trajectories of pregnancy and parenting, specifically perinatal loss and its aftermath. With colleagues Rana Limbo and Patricia Wright, Dr. Black edited *Perinatal and Pediatric Bereavement for Nurses and Other Health Professionals* (Springer), which won the 2016 AJN Book of the Year Award, end-of-life category. She has had an NIH grant to study end-of-life care after a life-limiting fetal diagnosis, and funding from the Gay and Lesbian Medical Association to study reproductive loss in lesbian couples.

Dr. Black publishes *Professional Nursing: Concepts and Challenges* (Elsevier), now in its 9th edition; this text is widely used in the US, UK, and has been translated for use in South Korea. Dr. Black has a three-year visiting professorship at the Guangzhou (China) University of Traditional Chinese Medicine and Nursing, and has taught content on palliative and end-of-life care, research ethics, and scholarly writing to faculty colleagues there. She also has taught numerous workshops on scholarly writing, and has extensive experience editing research proposals and academic manuscripts. Dr. Black considers her work on the Board of Directors of a large, not-for-profit hospice and palliative care organization in central NC to be her most significant professional contribution. From her research and work with families whose newborn infants had significant life-limiting conditions, Dr. Black realized the severe lack of community resources for these families. At her urging, the Board moved to implement a pediatric palliative and hospice program, the most comprehensive of its type in NC. This program now serves many children and families who would otherwise be without appropriate care at this most vulnerable time.

PLENARY SPEAKERS (CONT)



MANDY KELSO



Mandy and her husband Robbie have experienced the death of their son Wyatt as a newborn and multiple miscarriages. The work, study, travel, and numerous other opportunities Mandy describes below have culminated in paintings and poetry, featured in the book *Poems for Wyatt*. Mandy received her degree in Studio Art and Literature from Rice University, where she attended on full scholarship. In 2001 she was awarded the Zhongua Fellowship, which allowed her to live and study in Guangzhou, China for a year, studying culture, watercolor, and textiles. Originally from Texas, she has worked in Austin costuming short films, and produced several fashion and art shows throughout New York and Texas. As a community leader, she has served on the Board of Managers for the International YMCA, the Friends of Maple Grove nonprofit, and the United Nations Association YP Group as the Asian Affairs Director. She currently serves on the board for Library For All, which provides educational content to students in impoverished countries. She has traveled throughout Asia, South America, Europe, Australia, and Africa painting and speaks Spanish, and limited Mandarin and Polish.

Mandy was the previous Resident Artist at Theceeflat Gallery in Greenpoint, Brooklyn, and now has moved her studio to Beacon, NY. By sharing her artwork and studios, she has been able to support art exhibits and fundraisers for a myriad of global nonprofits and offers community art and design classes to the public on request. She has worked as an instructor, fashion designer, and costumer for over 20 years and has painted over the last 15 years. She has read her written works at various readings across New York City and has been published in abbreviated collections. While her artwork focuses on narrative scenes from around the world (plein aire paintings from her travels) and the power, color, and profundity of the human spirit, her poetry more often comments on the unifying themes of struggle which serve to ignite and magnify such profundity.

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



Dr. Marianne Hutti is a full Professor at the University of Kentucky College of Nursing, and a Women's Health Nurse Practitioner in private practice, managing the care of about 500 women in Louisville, KY. Dr. Hutti publishes often and speaks frequently at national and international meetings on subjects related to women's health care. She is nationally-recognized as an expert Women's Health Nurse Practitioner and is internationally-recognized for her research in perinatal loss. Dr. Hutti is a Fellow in the American Association of Nurse Practitioners and a Fellow in the American Academy of Nursing.

