

NEONATOLOGY TODAY

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 c/o Mitchell Goldstein, MD
 11175 Campus Street, Suite #11121
 Loma Linda, CA 92354
 Tel: +1 (302) 313-9984
LomaLindaPublishingCompany@gmail.com

November 2025 FCC Webinar Summary: "The Butterfly Project: Supporting Families After Co-Twin Baby Loss" with Professor Nicholas Embleton and Keira Sorrells

Robert C. Cicco, MD

"Keira opened the session by sharing a powerful and deeply personal story about her triplet pregnancy, born at 25 weeks, and the loss of her daughter, Zoe, at just 18 months of age. She spoke candidly about the challenges of parenting her two surviving children while grieving the loss of Zoe and no longer feeling like a mother of triplets."

Keira opened the session by sharing a powerful and deeply personal story about her triplet pregnancy, born at 25 weeks, and the loss of her daughter, Zoe, at just 18 months of age. She spoke candidly about the challenges of parenting her two surviving children while grieving the loss of Zoe and no longer feeling like a mother of triplets. She spoke of the pain that comes when others refer to her children as "twins" or ask whether she

has other children. Nicholas shared his work developing *The Project Butterfly*, an initiative designed to help address and ease the complex emotions families like Keira's experience. Together, their stories highlighted several important considerations clinicians should keep in mind when caring for families who have experienced the loss of a multiple, including:

"Nicholas shared his work developing The Project Butterfly, an initiative designed to help address and ease the complex emotions families like Keira's experience. Together, their stories highlighted several important considerations clinicians should keep in mind when caring for families who have experienced the loss of a multiple"

Organizational Partners



- Parents remember clinicians' small acts of kindness long after their NICU stay.
- There is limited research on how families cope with the loss of multiple, and how clinicians influence that process.
- All losses of multiples matter and should be acknowledged, whether they occur early or later in pregnancy.
- Staff changes can lead to the loss being overlooked; *Project Butterfly* uses a bedside butterfly to remind caregivers that a surviving baby was part of a multiple.
- Discharge can be especially painful, as it highlights that not all babies are going home; support must continue after discharge.
- The loss affects both parents and the surviving child; clinicians should help parents talk with their child about their sibling who died.
- Caregivers should acknowledge ongoing grief while still offering hope for the surviving baby.
- **Never say:** "At least you've got one."
- Ongoing acknowledgment of the loss is essential.

"Newborn Individualized Developmental Care and Assessment Program (NIDCAP): Nurturing and Being Nurtured": Deborah Buehler, PhD

Deborah highlighted key elements of NIDCAP that demonstrate why it should be an essential part of care in every NICU and continue after discharge:

- Preterm birth and subsequent hospitalization present significant challenges that can disrupt parental nurturing and confidence, ultimately affecting infant and family outcomes.
- Preterm birth disrupts fetal development and introduces ongoing stress; if unaddressed, this stress can negatively affect an infant's brain development.
- NIDCAP, "the voice of the newborn," was developed to address these challenges, beginning from birth and continuing after discharge.
- NIDCAP allows infants to actively participate in their care by communicating their needs for supportive care through observable behaviors.
- All infant behaviors — such as breathing, color changes, tone and movements, and arousal level — offer insights into brain organization. These behaviors are continuously observable from birth.
- Behaviors provide an immediate indication of caregiving effectiveness. This understanding helps to individualize care and the environment to support infants and caregivers.
- Recognizing infants' unique behavioral communications offers opportunities to foster relaxation and balance, particularly when stress and disorganization become detrimental.
- Parents are ideally positioned, as their child's lifelong advocates, to provide essential care to promote their infant's stability, health, and development.
- With intentional NIDCAP care, parents are supported in their critical role in their baby's care.

- The NIDCAP approach supports infants, families, healthcare professionals, staff, and hospital systems.
- NIDCAP is associated with important clinical benefits, including fewer ventilator days, reduced IVH, and shorter hospital stays.

"Both presentations offered practical, actionable strategies that listeners can readily integrate into everyday NICU practice. These approaches are designed to be feasible within existing workflows while effectively strengthening family-centered care."

Both presentations offered practical, actionable strategies that listeners can readily integrate into everyday NICU practice. These approaches are designed to be feasible within existing workflows while effectively strengthening family-centered care. By applying these strategies, clinicians can better support the emotional, developmental, and relational needs of both patients and their families, ultimately fostering a more compassionate, responsive, and healing NICU environment.

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Corresponding Author



*Robert Cicco, MD
Retired Neonatologist
Pittsburgh, PA*

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