

The Second Speaking of NEC: Unplugged

Jennifer Degl

The Second Speaking of NEC: Unplugged was held on March 28, 2019, in Austin Texas at Hyatt Place at Austin Cedar Park. It was presented by The Morgan Leary Vaughan Fund (Morgan's Fund) and sponsored by both Texas nonprofit Hand to Hold and Prolacta Bioscience. The event hosted 65 attendees from the Texas area. Its goal was to share practical solutions for reducing the devastating effects of Necrotizing Enterocolitis (NEC) on premature infants as well as discuss ways to prevent it.

The inaugural Speaking of NEC: Unplugged was held in Connecticut in 2018 was such a success that Morgan's Fund wanted to take it on the road to help spread more awareness on Necrotizing Enterocolitis. You can read about the first conference by clicking below: (1)

<http://www.speakingformomsandbabies.com/speaking-of-nec-2018/>

NEC is a rare, inflammatory disease that leads to necrosis (death) of the intestine and it affects about 9,000 of the 480,000 infants born preterm each year in the United States. Although all newborn infants born preterm or born with a low birth weight (less than 5.5 pounds) are at increased risk for NEC, very low birthweight babies are at an even greater risk for developing this deadly disease.

Conference attendees were approved to receive 4.0 AMA PRA Category 1 credits or 4.5 RN CEU credits through The Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC/LAC) if they were present for the full day of speakers. Guests listened to presentations from relevant NEC experts, including physicians, nurses, and parents of children who were diagnosed with Necrotizing Enterocolitis.

This one-day regional conference was broken up into different segments so that it touched on all aspects of the disease. These segments included the disease itself, prevention of NEC, research, and



development surrounding NEC, and what happens post diagnosis and post-surgery. (2)



The medical speakers included Mitchell Goldstein, MD (Professor of Pediatrics, Loma Linda University Children's Hospital; Medical Director, National Coalition of Infant Health); Tory Meyer, MD (Pediatric Surgeon, Dell Children's Medical Center of Central Texas); Diane Spatz, PhD, RN-BC, FAAN, (Professor of Perinatal Nursing and Nutrition, University of Pennsylvania School of Nursing, Nurse Researcher at Children's Hospital of Philadelphia); Sunyoung Kim, PhD (Professor of Biochemistry at LSU Health, Founder of Chosen Diagnostics); Muralidhar Premkumar, MD, MRCPCH, MS (Associate Director of Intestinal Rehabilitation Services for the NICU at Texas Children's Hospital). The topics of their presentations included information on the neonatologist's perspective, surgical NEC, improving human milk and breastfeeding outcomes, the diagnostics of NEC, and short bowel syndrome.

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What makes Speaking of NEC: Unplugged so special is that there were also several parent speakers. Parents of premature and medical-

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ly fragile babies have experienced trauma that is not well understood by the average person or average physician. This makes it imperative that medical professionals hear from parents. The parent speakers shared their personal stories of pain and how their baby's NEC diagnosis affected not only their baby but the whole family unit.

Not every NICU story has a happy ending, and one parent speaker shared her family's story of love and loss of a NEC baby. Our parent speakers included Stephanie Vaughan (Co-Founder of The Morgan



Leary Vaughan Fund), Kathryn Whitaker, Christine Tester (Hand to Hold), Cristal Grogan (NICU Helping Hand and Premie Parent Alliance), Yamile Jackson (Nurtured by Design), and Heather Tanner (Sister Friend Up). The parent perspective seemed to have an impact on the audience, as it should.

At the conclusion of the conference, attendees were asked to list practice changes they would make as a result of attending this conference. The top three comments were as follows:

- 1st Push for less bovine supplements/more/earlier pumping
- 2nd Increase/earlier Kangaroo care
- 3rd Listen/ask/include parents more

“Leveraging the outcomes of both Speaking of NEC: Unplugged conferences, Morgan’s Fund will continue to empower and educate parents, providers, researchers, policymakers, and the public about NEC.”

A few exhibitors shared space in the back of the conference room and were available to speak to attendees both before and after the conference, and during the breaks. They included Jennifer Degl from Speaking for Moms and Babies, Inc., Yamile Jackson from Nurtured by Design, Kelli Kelley and her team from Hand to Hold, Carolyn Teneyck



and her team from Prolacta Bioscience, and Heather Tanner from Sister Friend Up.

Throughout the conference, a videographer was set up in a separate room, and he was recording personal stories and interviewing speakers and attendees to help create a video for The Morgan Leary Vaughan Fund.

Leveraging the outcomes of both Speaking of NEC: Unplugged conferences, Morgan’s Fund will continue to empower and educate parents, providers, researchers, policymakers, and the public about NEC. The Morgan Leary Vaughan Fund urges all parents to understand their nutritional options and to advocate for low birth weight and premature babies (especially those born under 2.2 pounds) to receive only breastmilk, human donor milk, and human milk-based fortifiers. (1, 2)

The Morgan Leary Vaughan Fund (Morgan’s Fund) is a 501(c) (3) public charity dedicated to NEC. Morgan’s Fund produced a podcast series on Necrotizing Enterocolitis, called “Speaking of NEC.” You can listen to them on iTunes or download them from this link:

<http://www.morgansfund.org/category/podcast/>



Morgan's Fund has also partnered with the National Organization of Rare Disorders (NORD) to create a first of its kind natural history registry where those affected by NEC can enroll to help further the research into both the causes of NEC and what NEC patients may face as they grow. You can find more information on the NEC Registry by clicking below: (2)

<https://www.necregistry.org/>.

..., <http://www.speakingformomsandbabies.com/speaking-of-nec-unplugged-hits-texas/> (accessed May 12, 2019).

Disclosures:

No conflicts of interest or financial disclosures relevant to this article are reported.

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For more information on The Morgan Leary Vaughan Fund, please visit <http://www.morgansfund.org/>

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Figure 1

References:

1. Jennifer Degl's Blog - Goodreads, https://www.goodreads.com/author/show/7328952.Jennifer_Degl/blog (accessed May 12, 2019).
2. Speaking Of Nec: Unplugged Hits Texas - Speaking For Moms