



Speaking of
NEC
NECROTIZING
ENTEROCOLITIS



The
Morgan Leary Vaughan
Fund

Dedicated to Necrotizing Enterocolitis (NEC)

PROMOTING AWARENESS. ADVANCING RESEARCH.

The Morgan Leary Vaughan Fund (Morgan's Fund)

is proud to offer a companion piece

to our audio podcast series entitled

Speaking of NEC: Necrotizing Enterocolitis.

This series is intended for clinicians and parents

of very low birthweight babies, those who have

the greatest risk of developing NEC.

Produced by *The Morgan Leary Vaughan Fund,*

and funded by *The Petit Family Foundation,*

Speaking of NEC is a series of one-on-one conversations

with relevant NEC experts—neonatologists, clinicians

and researchers—that highlights current prevention, diagnosis,

and treatment strategies for NEC and the search for a cure.

Our goal in founding *Morgan's Fund*, and in turn

developing and producing *Speaking of NEC*, has always

been to be the resource for others which we could not find.

We want parents to know that they are not alone

and that help and support are available.

Finally, we would like to acknowledge

Prolacta Bioscience's financial support of this project.

Table of Contents

- Ep. 0: **Morgan's Story**—The Prologue to *Speaking of NEC*
- Ep. 1: **Surgical NEC**—Perspectives from Surgeon and Scientist
Dr. Gail Besner
- Ep. 2: **What is NEC?**—A Comprehensive Overview of Necrotizing
Enterocolitis with Dr. Adam Matson
- Ep. 3: **More on Surgical NEC**—Perspectives from Dr. R. Lawrence Moss
- Ep. 4: **100% Human Milk Diet**—Perspectives from Dr. Martin Lee
- Ep. 5: **What is TANEC?**—An Overview of Transfusion-associated
Necrotizing Enterocolitis with Dr. Naveed Hussain
- Ep. 6: **Joseph's Story**—An Expert Parent's Perspective on Late-onset
NEC and Short Bowel Syndrome
- Ep. 7: **The NEC Society**—Perspectives from Parents of Infants Impacted
by NEC
- Ep. 8: **GutCheck^{NEC}**—A Comprehensive Overview of
Risk Assessment with Dr. Sheila Gephart
- Ep. 9: **Developmental Care in the NICU**—Perspectives from
Yamile Jackson, Ph.D., PE, PMP
- Ep. 10: **Current Trends in NEC**—Perspectives from
Dr. Sergio Golombek
- Ep. 11: **Nutrition Practices in the NICU**—Perspectives from
Dr. Corrine Hanson
- Ep. 12: **Year in Review**—The Epilogue to *Speaking of NEC*

{ep 0}



Morgan's Story — The Prologue to *Speaking of NEC*

Necrotizing Enterocolitis, or NEC, is probably something you're just learning about. Stephanie Vaughan is an expert parent and Co-founder of *The Morgan Leary Vaughan Fund*, and six years ago, she knew nothing about NEC.

How did Stephanie get introduced to NEC?

On October 29th, 2010 Stephanie and her husband Jeff welcomed their twin sons, Shaymus and Morgan, into the world. Both boys were born at 28 weeks, 1-day gestation. Morgan weighed 2 pounds 5.5 ounces, and he measured 14.25 inches long. Four days later Morgan was diagnosed with NEC and Stephanie began a crash course in learning about the disease.

A frightening turn of events

Shortly after Shaymus and Morgan's first feeding, the NICU nurses realized there was something wrong with Morgan. After x-rays were taken, it was determined there was a possibility he was suffering from NEC. Morgan was transferred from one hospital to another, some thirty minutes away, for an emergency surgical consultation. At the second hospital, it was decided that Morgan needed to undergo exploratory surgery to see if he did indeed have NEC, if he did, how extensive was it.

What is NEC and what can be done?

When Stephanie and Jeff met with the surgeon after the surgery, he confirmed that Morgan had NEC, an inflammatory disease that leads to necrosis (death) of the intestine. They were told that the situation was serious: Morgan was extremely sick; and approximately 20% of his small intestine had been removed during surgery.

Becoming an expert parent

Morgan went through two surgeries because of NEC. In addition, few people could answer the questions Stephanie and Jeff had about NEC. The lack of information was extremely frustrating, and Stephanie began to search for anything she could find out about the disease.



Morgan and Shaymus
at 4-1/2 months old

Helping others

When Stephanie and Jeff were approached about allowing Morgan to participate in a study of babies with NEC, both of them agreed. They wanted to know as much as possible about the disease, and they didn't want future parents to suffer the fear and anxiety they did. This participation in the study helped Stephanie and Jeff decide to found *The Morgan Leary Vaughan Fund* which was incorporated in 2012. *Morgan's Fund* is an organization that seeks to share information about NEC and to promote awareness about NEC as well as advance research in NEC.



To listen to Stephanie's interview, visit our website at morgansfund.org.
The complete *Speaking of NEC* series is also available on iTunes.

{ep 1}

Surgical NEC—Perspectives from Surgeon and Scientist Dr. Gail Besner



Who is Dr. Gail Besner?

Dr. Besner is a leading surgeon and scientist who specializes in NEC. She is the Chief of Pediatric Surgery at *Nationwide Children's Hospital* in Columbus, Ohio. Few people in the United States are as qualified as Dr. Gail Besner to speak on NEC.

What can be done about NEC?

Dr. Besner tells us that when a baby is diagnosed with NEC, surgery may be an option. While surgery on anyone is risky, the removal of the diseased intestine is a necessity. Thankfully, there are specialized pediatric surgeons like Dr. Besner who can perform this delicate surgery.

What research is being done for the future prevention of NEC?

Dr. Besner is one of the leading researchers in the field of NEC. She has located naturally occurring proteins and stem cells, which she hopes will one day promote growth as well as healing in babies affected by NEC.

Who is leading the way against NEC?

Surgeons and scientists like Dr. Gail Besner and numerous other researchers across the globe are seeking ways to cure as well as prevent NEC. They are able to do this through the support of such organizations as the *National Institutes of Health (NIH)* in the U.S. and *National Institute for Health Research (NIHR)* in Great Britain. There is a strong commitment to curing NEC, and the future looks bright.



To listen to Dr. Besner's interview, visit our website at morgansfund.org. The complete *Speaking of NEC* series is also available on iTunes.

{ep 2}

What is NEC?—A Comprehensive Overview of Necrotizing Enterocolitis with Dr. Adam Matson



Who is Dr. Adam Matson?

Dr. Adam Matson is an attending neonatologist at *Connecticut Children's Medical Center-Newborn Intensive Care Unit* in Hartford, Connecticut. He is an Assistant Professor of Pediatrics and Immunology at the *University of Connecticut's School of Medicine* in Farmington, Connecticut.

How significant is birth weight in regards to NEC?

Dr. Matson tells us how a premature baby's birth weight directly affects their chances of developing NEC. Those babies born at or below 3 ½ pounds (1500 grams) have the greatest risk.

How do we detect NEC early on?

This is one of the pressing questions in the field of neonatology. Dr. Matson discusses some of the early warning signs of NEC and what steps can be taken when the disease is suspected. Also, he speaks about how x-rays are used to diagnose NEC.

What does Dr. Matson believe should be done for the future prevention of NEC?

Dr. Matson is a firm believer that ultimately the best way to reduce the incidence of NEC is to reduce the number of babies born prematurely. The longer a baby can be carried, the better it is for their overall health. Because Dr. Matson understands that this is not always possible, he continues to foster research in NEC as well as promote current prevention strategies.



To listen to Dr. Matson's interview, visit our website at morgansfund.org.
The complete *Speaking of NEC* series is also available on iTunes.

{ep 3}

More on Surgical NEC— Perspectives from Dr. R. Lawrence Moss



Who is Dr. R. Lawrence Moss?

Dr. R. Lawrence Moss is the Surgeon-in-Chief at *Nationwide Children's Hospital* in Columbus, Ohio. Prior to his position at *Nationwide Children's Hospital*, Dr. Moss was the Surgeon-in-Chief at *Yale New Haven Children's Hospital*. In addition, to his accomplishments as a surgeon, he has been a key player in studies concerning NEC.

What are the two surgical options?

Dr. Moss discusses two commonly used surgical options, *laparotomy* and *peritoneal drainage*. A laparotomy is a major incision made in the abdomen. Peritoneal drainage is the insertion of a drain into the abdomen.

Can NEC be detected any earlier?

Dr. Moss has been part of a medical investigation team which discovered some babies might be more prone to developing NEC than others. He and his colleagues discovered several biomarkers in premature babies that can allow doctors to identify which babies will develop NEC. More importantly, their discoveries can help identify those babies who will require surgery because of NEC.

How important is research to the treatment of NEC?

Dr. Moss stresses the importance of research done not only by not-for-profits but by industry. Also, he talks about how important it is to help ensure funding for not-for-profits researching treatment and prevention of NEC. By supporting clinical as well as basic scientific research, we can continue to find better treatment for our smallest and most fragile babies.



To listen to Dr. Moss' interview, visit our website at morgansfund.org.
The complete *Speaking of NEC* series is also available on iTunes.

{ep 4}

100% Human Milk Diet— Perspectives from Dr. Martin Lee



Who is Dr. Martin Lee?

Dr. Martin Lee is a leading researcher in the field of human milk. He is the Vice President of Clinical Research and Development at *Prolacta Bioscience*. *Prolacta* developed the world's first human milk fortifier made exclusively from human milk.

Why a 100% human milk diet?

Through clinical research at *Prolacta*, Dr. Lee has shown that a 100% human milk-based diet for premature babies, those weighing less than 1250 grams (2 pounds 12 ounces), has had remarkable results. For those preemies who took part in the research, there was a 70% reduction in babies developing NEC. For those who did develop the disease, there was a significant drop in babies requiring surgery.

What is a 100% human milk diet?

Dr. Lee talks about how there are human milk fortifiers on the market, however most are made from cows milk. At this time, only *Prolacta* is producing a human milk fortifier made from human milk. This means that when we are giving our babies a bottle of breast milk fortified with human milk-based human milk fortifier, they are getting a 100% human milk diet.

How safe is the fortifier made from human milk?

Dr. Lee stresses the importance of safety in the human milk industry. By copying the standards set for blood donors, Dr. Lee and *Prolacta* have ensured that they follow rigorous standards for breast milk donors. This focus on safety ensures the well-being of our smallest and most fragile babies, those who have the greatest risk for developing NEC.



To listen to Dr. Lee's interview, visit our website at morgansfund.org.
The complete *Speaking of NEC* series is also available on iTunes.

{ep 5}

What is TANEC?—An Overview of Transfusion-associated Necrotizing Enterocolitis with Dr. Naveed Hussain



Who is Dr. Naveed Hussain?

Dr. Naveed Hussain is the Director of Neonatal Research as well as a neonatologist at *Connecticut Children's NICU* at *University of Connecticut Health Center* in Farmington, Connecticut. He is an Associate Professor of Pediatrics at the *University of Connecticut School of Medicine*.

What is TANEC?

TANEC stands for “Transfusion-associated Necrotizing Enterocolitis”. One of Dr. Hussain’s concerns is the role that blood transfusion may have in the development of NEC in premature babies. He talks primarily about how TANEC relates to those babies who have extremely low birth weights, those weighing less than 1,000 grams (2 pounds 3 ounces) or those born very premature at less than 28 weeks gestation. Premies who fall into these two categories have the highest chance of developing NEC.

Is TANEC a real concern?

Dr. Hussain admits that there is some controversy as to whether or not TANEC is a real concern. However, Dr. Hussain believes that it is and that since so many premature babies require blood transfusions, more research needs to be done on TANEC.

When is TANEC most likely to occur?

Dr. Hussain explains that research has shown that premies seem to be at the greatest risk of developing NEC within 48 hours after a transfusion. This is a critical time for those premies who have extremely low birth weights or were born prior to 28 weeks.



To listen to Dr. Hussain’s interview, visit our website at morgansfund.org. The complete *Speaking of NEC* series is also available on iTunes.

{ep 6}

Joseph's Story—An Expert Parent's Perspective on Late-onset NEC and Short Bowel Syndrome



Who is Laura Martin?

Laura Martin is a writer, blogger, and expert parent. Laura's son Joseph, born prematurely, developed a near fatal case of late-onset NEC. Laura writes about this incident in her family's life, as well as the long-term effects it has had on Joseph and the rest of the family.

What is late-onset NEC?

Late-onset NEC is NEC that develops after the 40-week mark of a premature baby's development. While it is rare for a baby to become afflicted with NEC after this point in time, there is still a chance that they may develop NEC. Laura's son Joseph, who was past the 40-week mark and weighed 13 pounds did develop NEC.

What complications can occur with NEC?

In some cases, such as Joseph's, there can be severe complications for those babies who develop NEC. With Joseph, the doctors were required to remove two-thirds of his small intestine. Because of this, he developed Short Bowel Syndrome as well as several other secondary medical issues.

What is Short Bowel Syndrome?

Short Bowel Syndrome, also known as Short Gut Syndrome or Short Gut, is a disease in which the person isn't able to fully absorb all of the vitamins and nutrients from their food. This can lead to fatigue, malnutrition, weight loss, etc. Although it is a rare disease, NEC is a leading cause of Short Bowel Syndrome in children.



To listen to Ms. Martin's interview, visit our website at morgansfund.org. The complete *Speaking of NEC* series is also available on iTunes.

{ep 7}

The *NEC Society*—Perspectives from Parents of Infants Impacted by NEC



Who founded the NEC Society?

The *NEC Society* was founded by Jennifer Canvasser in 2014. She founded the society after the tragic loss of her son, Micah, to NEC. It reflects her dedication to the prevention of NEC in fragile infants.

How is the NEC Society working to prevent NEC?

The *NEC Society* seeks to prevent NEC through educating and empowering parents in the NICU. The *NEC Society* created an online survey to build up a large body of information regarding parents and their perspectives on NEC. The survey was international in nature and looked to see what could be learned from these families.

How does the NEC Society promote awareness of NEC?

The *NEC Society* promotes awareness of the disease through advocacy as well through its work with other organizations. Two of these organizations are *Best for Babes Foundation*[®] and the *Miracle Milk*[™] *Stroll*.

What are the NEC Society's future plans?

The *NEC Society* is planning a conference in partnership with the *University of California at Davis*. Its aim is to bring professionals from all areas together in order to improve the outcomes of those babies and families impacted by NEC.



To listen to the *NEC Society's* interview, visit our website at morgansfund.org. The complete *Speaking of NEC* series is also available on iTunes.

{ep 8}

GutCheck^{NEC}—A Comprehensive Overview of Risk Assessment with Dr. Sheila Gephart



Who is Dr. Sheila Gephart?

Dr. Sheila Gephart is a neonatal nurse scientist. She is an Assistant Professor at the *University of Arizona College of Nursing*. In addition, Dr. Gephart is the creator of GutCheck^{NEC}.

What is GutCheck^{NEC}?

GutCheck^{NEC} is a risk index that came about through Dr. Gephart's work as a bedside nurse in the neonatal intensive care unit. An early warning system for NEC, it looks at various risk factors in "real time".

What makes up GutCheck^{NEC}?

GutCheck^{NEC} is made up of ten risk factors which medical staff need to look for. The system developed by Dr. Gephart educates the personnel on what these risk factors are and what are the corresponding symptoms. In addition, Dr. Gephart's system shows how those risks are communicated.

What is the goal of GutCheck^{NEC}?

The long-term goal of Dr. Gephart's system is to achieve what she calls "NEC-Zero". "NEC-Zero" is the total elimination of NEC as a disease. While there are those who don't believe that this can ever be achieved, Dr. Gephart is confident that if the causes of NEC can be identified, then eventually NEC can be eliminated. This is the main reason for the creation of GutCheck^{NEC}.



To listen to Dr. Gephart's interview, visit our website at morgansfund.org.
The complete *Speaking of NEC* series is also available on iTunes.

{ep 9}

Developmental Care in the NICU—Perspectives from Yamile Jackson, Ph.D., PE, PMP



Who is Yamile Jackson?

Yamile Jackson is a neonatal ergonomics expert. Ms. Jackson is the founder and CEO of *Nurtured by Design*. In addition to this, Ms. Jackson won awards for the design and creation of The Zaky. Also, she is an advocate of developmental care and family-centered care in the NICU.

Why are developmental and family-centered care important?

Ms. Jackson states that developmental and family-centered care are important for a baby's over-all health and growth. Developmental care in the NICU focuses on who your baby is as an individual, emotionally and mentally. Family-centered care means that the professionals and families recognize and respect the knowledge that each bring to the care of the baby and work together to provide the best care possible.

(Source: Nebraska Medicine)

Why did Ms. Jackson found, Nurtured by Design?

Ms. Jackson's experience, as well as her family's, with the premature birth of her son, Zachary, led to her founding of *Nurtured by Design*. She wanted to create a way to actively nurture her baby even when she wasn't able to be at the bedside. As a result, she developed The Zaky. *Nurtured by Design* leads the world in neonatal ergonomics with The Zaky.

What is The Zaky?

The Zaky is an ergonomically designed device that has been clinically tested and has delivered amazing results. There is clinical evidence that the use of The Zaky reduces by half the number of apnea (when breathing temporarily stops during sleep), and bradycardia (abnormally slow heart rate) events in babies.



To listen to Ms. Jackson's interview, visit our website at morgansfund.org.

The complete *Speaking of NEC* series is also available on iTunes.

{ep 10}

Current Trends in NEC— Perspectives from Dr. Sergio Golombek



Who is Dr. Sergio Golombek?

Dr. Sergio Golombek is an attending neonatologist at *The Regional Neonatal Center, Maria Fareri Children's Hospital at Westchester Medical Center* in Valhalla, New York. He is a Professor of Pediatrics and Clinical Public Health at the *New York Medical College*.

What are some of the current trends in NEC?

Current trends focus on the continued development of better ways to both diagnose and prevent NEC. The signs and symptoms of NEC can be very similar to other diseases of prematurity, so researchers are continually trying to narrow the definition of NEC to help provide better care for these patients.

What does Dr. Golombek mean by individualized patient care in the NICU?

Over three decades of practice, Dr. Golombek has seen individualized patient care continually evolve in the NICU. As a result of the development of better technologies and laboratory testing, he has seen a shift from a “one size fits all” approach to a treatment based on the specific needs of each baby.

What are some new research trends in NEC?

Some new research trends include but are not limited to the study of *intestinal microbiome* (also known as microbiota, these microbes live in the intestine and help our bodies and can directly affect both physical and mental health), and how it can affect inflammatory diseases as well as the immune system. Also, Dr. Golombek is actively involved in current research of NEC. He and his team are working on a way that a specific stimulant for *granulocytes* (a type of white blood cell) may help prevent and treat NEC.



To listen to Dr. Golombek's interview, visit our website at morgansfund.org.
The complete *Speaking of NEC* series is also available on iTunes.

{ep 11}

Nutrition Practices in the NICU— Perspectives from Dr. Corrine Hanson



Who is Dr. Corrine Hanson?

Dr. Corrine Hanson is an associate Professor in the Division of Medical Nutrition Medical Center at the *College of Allied Health Professions, University of Nebraska Medical Center* in Omaha, Nebraska.

What is a standardized feeding protocol?

A standardized feeding protocol is an outline, a schedule of when and how to feed babies in the NICU. This schedule makes sure that a baby is getting the right type of nutrition, in the right amount, at the right time. As the baby grows and develops, the protocol changes, making sure that the baby gets exactly what is needed.

Why is a standardized feeding protocol important in the prevention of NEC?

Dr. Hanson explains that studies have shown a standardized feeding protocol is important for two reasons. First, standardized feeding protocols seem to cut down on the chances of a premature baby developing NEC. Second, standardized feeding protocols improve the overall outcomes for babies in the NICU.

Why is a standardized feeding protocol important to very low birthweight babies?

Dr. Hanson tells us how very low birthweight babies, those born at or below 3 ½ pounds (1500 grams) are not only at the greatest risk for developing NEC but have the highest nutritional needs. Standardized feeding protocols address the difficulties and challenges of initiating feedings of these babies.



To listen to Dr. Hanson's interview, visit our website at morgansfund.org.
The complete *Speaking of NEC* series is also available on iTunes.

{ep 12}

Year in Review—

The Epilogue to *Speaking of NEC*



Awareness

Morgan's Fund, co-founded by Stephanie Vaughan, started as a small charity focused on bringing awareness and attention to the little-known disease NEC. This was accomplished in part through the podcast series, *Speaking of NEC*. These podcasts are interviews with a wide array of experts on NEC, and the series has a listenership of over 1,900 individuals (as of this printing).

Advocacy

One of the great accomplishments of *Morgan's Fund* has been to have NEC recognized as a rare disease. With the help of Doctors Adam Matson and Arvin Bundhoo, *Morgan's Fund* wrote a paper concerning NEC, which was then presented to the *National Organization of Rare Disorders (NORD)*. It was this paper which convinced *NORD* to include NEC in its rare disease database.

Outreach

Morgan's Fund has been able to reach out to other members of the NEC community not only as a charity but also as an active participant. This participation comes in the form of attending conferences, presenting papers, raising awareness and funds for research, and supporting other like-minded organizations. This interconnected community of groups and individuals focused on prematurity and rare diseases has helped strengthen *Morgan's Fund*, and allowed *Morgan's Fund* to strengthen others. Spreading the word and being active in the global community will be major focuses for *Morgan's Fund*.



To listen to Stephanie's interview, visit our website at morgansfund.org. The complete *Speaking of NEC* series is also available on iTunes.

{a call to action}

Morgan's Fund through its support of research hopes to change the lives of thousands of our smallest and most fragile babies like Morgan, who have the greatest risk for developing NEC.

For more information about *Speaking of NEC* or *The Morgan Leary Vaughan Fund*, visit our website at morgansfund.org.

The complete *Speaking of NEC* series is also available on iTunes.



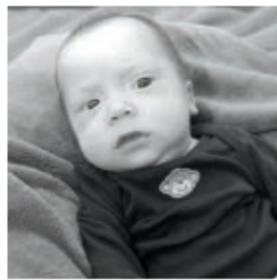
Morgan (5), Jeff,
Stephanie and
Shaymus (5)

This brochure was produced by *The Morgan Leary Vaughan Fund*
and funded by *Prolacta Bioscience*.

The opinions expressed in *Speaking of NEC: Necrotizing Enterocolitis* (the Brochure) and by *The Morgan Leary Vaughan Fund* are published for educational and informational purposes only, and are not intended as a diagnosis, treatment or as a substitute for professional medical advice, diagnosis and treatment. Please consult a local physician or other health care professional for your specific health care and/or medical needs or concerns.

This Brochure does not endorse or recommend any commercial products, medical treatments, pharmaceuticals, brand names, processes, or services, or the use of any trade, firm, or corporation name. It is for the information and education of the viewing public, and the mention of any of the above in the Brochure does not constitute an endorsement, recommendation, or favoring by *The Morgan Leary Vaughan Fund*.





The Morgan Leary Vaughan Fund

Morgan's Fund is an all-volunteer, public charity dedicated to Necrotizing Enterocolitis (NEC). Its mission is to promote public awareness about NEC and the potentially devastating effects it can have on preemies and their families, and to advance research to prevent, diagnose, treat, and ultimately, cure NEC. Named after Morgan, it celebrates his survival, courage and strength.

Morgan and his twin brother were born at 28 weeks, one day gestation—nearly three months early—each weighing less than 2.5 pounds.

At four days old, Morgan developed NEC and lost approximately 20% of his small intestine. Morgan not only survived but also has thrived since his bout with NEC. This is his family's way of paying it forward. Morgan's Fund is a proud member of the Premie Parent Alliance and the National Organization for Rare Disorders.



The Morgan Leary Vaughan
Fund

Dedicated to Necrotizing Enterocolitis (NEC)

PROMOTING AWARENESS. ADVANCING RESEARCH.

