



Preemie Family

Preemie Life

Micah Donald & Zachary Chester Canvasser



Photo Credit: Leslie Napolitano

Parent Tip:

Insist that your baby receive an exclusive human milk diet until they are at least 34 weeks gestation and insist on having a team of primary nurses care for your baby.

Gest. Age:
27 weeks, 5 days

Weight:
Micah: 2 lb. 7oz.
Zachary: 2 lb. 12 oz.

Time In NICU:
Micah: 299 days
Zachary: 91 days

Proudest Moment (NICU):
Carrying Zachary into Micah's room for the very first time when the boys were 3 months old (they had been separated since birth).

Coming Soon:

Check www.PreemieWorld.com on an update of Micah and Zachary.

Advocate: The Preemie Petition Update

PreemieWorld is aware that the American Academy of Pediatrics (AAP) has officially further restricted their guidelines surrounding the drug Synagis (for RSV prevention in preemies and high-risk infants). Join over **6,000 parents and professionals** who do not agree with this by signing **The Preemie Petition**.

Please sign and pass it on: <http://bit.ly/PreemiePetition>

To Do List



CONGRATS: Congrats to Cristal Grogan, our winner of the *little man* DVD in our July Facebook contest!



LIKED US YET?: PreemieWorld is doing another PreemieWorld Facebook page contest. See page 2 of this newsletter for details!



Download PreemieWorld's **FREE** tools <http://bit.ly/PreemieFreebies> to use and to pass onto others.



MARK YOUR CALENDAR!

Golfing for Graham's Foundation
Graham's Foundation
August 17, 2014
Bowling Green, OH
www.GrahamsFoundation.org

USPA Rossmore Cup & White Party to Benefit Miracle Babies
Miracle Babies
August 31, 2014
San Diego, CA
www.miraclebabies.org

Have an event you want to share with our community? Contact us at:
connect@preemieworld.com

*Tools and Resources
for the Preemie Community*

Preemie Freebie: Necrotizing Enterocolitis (NEC)

PreemieWorld provides a number of free handouts to be used in the **NICU and beyond** in its "Freebies For You" section of the website. **This month's freebie is "Necrotizing Enterocolitis (NEC)."** "NEC is often not heard about until the baby contracts it," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "So we teamed up with **The**

Morgan Leary Vaughan Fund, Inc. to create a resource that is simple, straight-forward and helpful." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. **Download it here now:** <http://bit.ly/NECfreebie> and check out more like this on our site here: <http://bit.ly/PreemieFreebies>

Term: Necrotizing Enterocolitis (NEC)

Necrotizing Enterocolitis

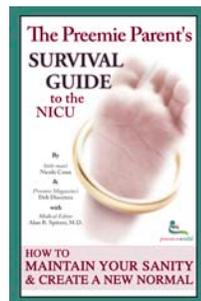
(NEC): A disease that primarily infects the immature bowel of the premature infant. Intestines are perhaps the weakest in the body's systems and are easily infected by infection and blood flow changes. NEC is a toxic inflammation in the intestine that literally kills the intestine.

Your baby's medical team knows that it is so very important to watch for this and catch it immediately since it can spread so quickly and cause significant and quite serious damage.



Often, NEC is caught by the signs of sepsis in the blood stream.

The least invasive measure of treatment is to have your infant be treated with a series of antibiotics while remaining off foods and being fed through a central line or Broviac. In the worst-case scenario your baby will be subjected to surgery where the sick part of the intestine is removed.



This excerpt is from
**The Premie Parent's
Guide to Survival in the
NICU** on sale at
www.PremieWorld.com
**We do bulk orders for
hospitals**
connect@premieworld.com

Support:



Year Established: 2012

Web: www.morgansfund.org

Outreach: National

Background: After the birth of her twin boys at 28 weeks, founder Stephanie Vaughan's son Morgan developed NEC and lost approximately 20% of his small intestine. The charity is dedicated to promoting public awareness about NEC and to raising funds to advance research efforts surrounding diagnosis, treatment and ultimately, a cure.

Programs: The organization is currently planning its inaugural event, set to occur in the fall of 2014.

PreemieWorld: "Like" Us On Facebook & You Could Win!



Visit PreemieWorld's FB page at:
<http://bit.ly/FBPreemie>

**"Like" our FB page
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winning *little man* DVD from
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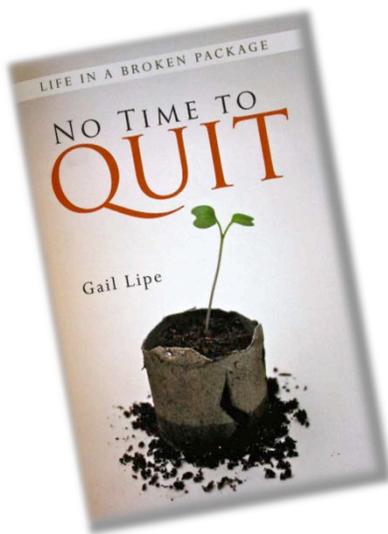


BOOK: No Time to Quit

The Details:

By:
Gail Lipe

Website:
www.naturescanvas.org



No Time to Quit: Life in a Broken Package is the biography (as told by her daughter Gail Lipe) of Gail Johnson, a surviving twin born at 6 months gestation in 1932 and later diagnosed with Cerebral Palsy. Page after page is filled with the courage and tenacity of a woman focused on living life to the fullest despite being disabled.

This book is a perfect read for parents of preemies, for professionals and for former preemies themselves. It serves as a reminder that preemies are tough in spirit and can lead incredible lives regardless of any challenge placed before them.

One new @PreemieWorld Twitter follower during 8/1/14-8/24/14 could win a copy of this book! Go here: www.twitter.com/preemieworld

After the NICU: After Having NEC in the NICU

Stephanie Vaughan of The Morgan Leary Vaughan Fund, Inc. had these suggestions for post-NEC and post-NICU:

- Learn about resources available at discharge (our sons qualified for a visiting nurse and Birth-to-3 Services and with Jan/Feb discharges we were grateful to not have to leave the house).
- Consider your preemie's NICU team as a resource after coming home (we were still in contact with Morgan's surgeon with questions after his release).

Online Resources:

NEC Group on Facebook
<http://bit.ly/FBGroupNEC>

NEC Parents Support Group:
<http://bit.ly/NECParentsFB>

Preemie Support Online

On the Preemie Support Forum on INSPIRE:

Connect with *over 19,000 other parents of preemies online* at www.Inspire.com/preemie for the **Preemie Support forum**. It is the largest and most active forum online, *moderated by PreemieWorld's own Deb Discenza*. Whether you are in the NICU, just home or working through the school years, we have discussions you won't want to miss.

"Picky Eaters - Tips and Tricks" - *in 33-36 week preemies*

"TPN and Vaccinations - Anyone else with concerns?" - *in the NICU/PICU*

"Anyone's child using a portable battery operated oxygen?" - *in Open Discussion*

On PreemieWorld's Twitter Page:

"COOL: Film Review - 'MATT' in Preemie Family - <http://bit.ly/PreemieFamily28> "

On PreemieWorld's Facebook Page:

"ARTICLE: Preterm Babies Do Better in a Larger NICU - <http://ow.ly/z5gY7> "

"RESEARCH: Babies' Brains Prep for Speech Long Before First Words Come Out"

On PreemieWorld's LinkedIN Group:

"PREEMIE UPDATE: Amelia - <http://bit.ly/PreemieAmelia> "

Get "Social" With Us!



www.PremieWorld.com
www.LittleMantheMovie.com



@PremieWorld



- PremieWorld
- Premie Parent's Survival Guide to the NICU



PremieWorld



Check out other LinkedIN groups we moderate:

- NICU Professionals
- Early Intervention Professionals
- Premie Parent Support Group Leaders
- Premie Parents

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AWARENESS: Necrotizing Enterocolitis (NEC)

Stephanie M. Vaughan of The Morgan Leary Vaughan Foundation, Inc. (www.morgansfund.org) talks about the challenges surrounding NEC:

"One of the greatest challenges that I see with Necrotizing Enterocolitis (NEC) is awareness. When Morgan was diagnosed, we had never heard of NEC; and no one that we spoke to outside of the NICU had ever heard of NEC. Recently, one of Morgan's former nurses commented that until you (as a parent) are faced with NEC, you don't know about it. That is where we need to affect a change. According to Eunice Kennedy Shriver National Institute of Child Health and Human Development: "All newborn infants born preterm or born with a low birth weight (less than 5.5

pounds) are at increased risk for NEC. The smaller the infant or the more premature the delivery, the greater the risk." Our son Morgan's development of NEC was atypical (he underwent emergency surgery to remove 20% of his small intestine and afterwards was when we first heard the words **Necrotizing Enterocolitis**). In our case, I strongly believe that there was nothing that we could have known or done that would have prevented Morgan from developing NEC. However, we were also very lucky to be at a level 3 NICU when Morgan's symptoms occurred. So I strongly encourage parents-to-be to know what hospital in their area has the highest level NICU, and put a safety plan in place."