



# Preemie Professional

## Preemie Professional

### *Jennifer Canvasser, MSW*



Photo Credit: Leslie Napolitano

#### **Professional Tip!**

*NICU families must be partners in their child's care. Parents need to be informed and involved so that they can best protect and nurture their premature infant.*

**Org:** NEC Society

**Focus:** Jennifer founded the NEC Society, an organization dedicated to protecting premature and fragile infants from the devastating impacts of Necrotizing Enterocolitis (NEC). To that end, she works to empower families and effect change in NICUs to reduce the risks of NEC. See page 2.

**Web:** [www.NECsociety.org](http://www.NECsociety.org)



## 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> and pass them onto NICU Parents as part of your welcome packet.

#### MARK YOUR CALENDAR!



**NMA Annual Convention & Scientific Assembly**  
National Medical Association  
August 2-6, 2014  
Honolulu, HI  
[www.nmanet.org](http://www.nmanet.org)

**42<sup>nd</sup> NBNA Annual Institute & Conference**  
National Black Nurses Association  
August 6-10, 2014  
Philadelphia, PA  
[www.GrahamsFoundation.org](http://www.GrahamsFoundation.org)

*Tools and Resources  
for the Preemie Community*

## 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>

## 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>

Support:

**Year Established:** 2012

**Web:** [www.morgansfund.org](http://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.

Org: NEC Society

*Out of the tragic circumstances of her son Micah's own loss to complications surrounding Necrotizing Enterocolitis (NEC), came the birth of an organization devoted to supporting families and encouraging change in NICU environments worldwide.*

**Established:**  
2014

**Type of Outreach:**  
International

**Website:**  
[www.NECsociety.org](http://www.NECsociety.org)

**Focus:**  
Families with premature infants and fragile infants who have been impacted by necrotizing enterocolitis (NEC) or at risk of being impacted by NEC. The society also strives to engage

clinicians and researchers who are committed to combating NEC.

**Background:**

Jennifer Canvasser founded the NEC Society, an activist-based organization with members from around the world, a year after losing her son Micah to complications related to NEC.

**Programs:**

- Initiatives to help empower NICU families and reduce NEC.
- Comprehensive list of U.S. NICUs that use donor milk to ensure their most

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

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

**"Like" our FB page  
from 8/1/14 to 8/24/14  
and you could win a copy of the  
award-winning *little man* DVD  
from PreemieWorld!**

<http://bit.ly/FBPreemie>

*Parents & Professionals:  
Subscribe to our FREE newsletters  
today @ [www.PreemieWorld.com](http://www.PreemieWorld.com)*

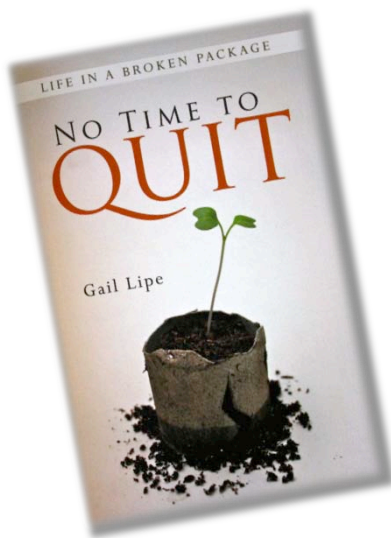


## BOOK: No Time to Quit

### The Details:

**By:**  
Gail Lipe

**Website:**  
[www.naturescanvas.org](http://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 @PremieWorld Twitter follower during 8/1/14-8/24/14 could win a copy of this book! Go here: [www.twitter.com/premieworld](http://www.twitter.com/premieworld)*

## 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>

## Premie Professional Online

### NICU Professionals Group: (www.Linkedin.com)

"What health impact can probiotics have for NICU infants?"

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

### Early Intervention Professionals Group: (www.Linkedin.com)

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

"Professionals in the field of early intervention are aware of how intense the work is not only with the children but also with the parents or caregivers."

### Premie World (www.Twitter.com):

"COOL: Film Review - 'MATT' in Premie Family - <http://bit.ly/PremieFamily28>"

### BE THE COOL PRO: Tell Your Families about the "Premie Network" on Inspire.com:

Deb Discenza of PremieWorld moderates this global network of *over 19,000 parents* from NICU to home to school. [www.inspire.com/preemie](http://www.inspire.com/preemie)

*Check out these groups and more by referring to the "Get 'Social' With Us" on page 4 for more information. Have news or research to share with us? [connect@premieworld.com](mailto:connect@premieworld.com)*

## Get "Social" With Us!



[www.PremieWorld.com](http://www.PremieWorld.com)  
[www.LittleMantheMovie.com](http://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
- Little Man the Movie

*Tools and Resources  
for the Premie Community*



Prolonged, effective, safe, and hands-free Kangaroo Care sessions. Guaranteed.




[www.nurturedbydesign.com](http://www.nurturedbydesign.com)



### Premie Rattles

Developed by a Physical Therapist

[www.magicalinnovations.com](http://www.magicalinnovations.com)

(407) 230-4491



NICU *Hope* Beads



COMMEMORATE & SHARE

Your NICU journey through jewelry...



[facebook.com/NICUHopeBeads](http://facebook.com/NICUHopeBeads) | 979.635.0825

Interested in advertising? Contact us at [connect@preemieworld.com](mailto:connect@preemieworld.com)

## AWARENESS: Necrotizing Enterocolitis (NEC)

Stephanie M. Vaughan of The Morgan Leary Vaughan Foundation, Inc. ([www.morgansfund.org](http://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."

Follow us on FB, Twitter & LinkedIn!

© 2014 PremieWorld, LLC. All Rights Reserved.