

Preemie Professional

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Melanie Potock, MA, CCC-SLP & Author



Photo Credit: Potock, Robert

Professional Tip:

Feeding is a developmental process, just like learning to crawl, cruise, walk and run. My book (right) co-authored with pediatrician Dr. Nimali Fernando, guides parents on the journey from first feedings to the school cafeteria, taking into account the gross, fine and oral motor skills necessary to become an adventurous eater. Preemies, too!

Organization:

My Munch Bug, LLC

Website:

www.mymunchbug.com

Focus: Melanie's love for working with preemies began when she was a feeding specialist in the NICU. Today, Melanie sees babies and children in their homes and at school to address feeding challenges and is a national speaker on feeding development.



Advocate: Prematurity Awareness

November is **Prematurity Awareness Month** and November 17th is World Prematurity Day. Looking to join an organization's event or fundraiser? Check out our handy World Prematurity Awareness Events Sheet chock-full of events from very worthy organizations looking for attendees, donations and volunteers. Download the list: http://preemie.us/Prematurity2015

To Do List



CONGRATS: Brenda Lewis won the "Preemie Tag" while Columbia **University Bioethics** and **Rachelle** Thunberg have won a copy of the little man DVD.



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



Download PreemieWorld's FREE and pass them onto NICU Parents as part of your welcome packet.

MARK YOUR CALENDAR!



Parent/Provider Conference **Preemies Today** October 19-21, 2015 Dallas, TX

Prematurity Awareness Day November 17, 2015 Worldwide

Have an event you want to share with our community? Contact us:

Tools and Resources for the Preemie Community

FREE: Preemies Are Warriors

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 another preemie symbol: Preemies Are Warriors. "November is the month for World Prematurity Awareness and we want to celebrate preemies as the fighters that they are known for being," notes PreemieWorld's **Deb Discenza**. "My hope is that parents will share this logo to remind the world that premature babies are stronger and more resilient than expected. They are amazing!"

Download it here & share with #preemiewarriors: http://preemie.us/PreemieWarriors

Support: Connect 2 NICU, Inc.

Founded by Shante Nixon, mother to a 26 ½ week preemie that died at 18 days old, Connected 2 NICU, Inc. has created a support app for families.

Established: 2013

Outreach: National

Web: www.connect2nicu.com

Focus: Providing resources for parents who have babies in the NICU in a mobile app. Later versions will also include parents whose babies have already graduated the NICU and are dealing with ongoing issues.

Programs: Interview parents and others connected to the NICU via Google Hangouts. Please contact us to share your story!



Org: Preemie Parent Alliance

Back in 2012 we highlighted the Preemie Parent Alliance. Over three years later, PPA continues to expand its footprint in the parent and provider space.

Mission:

PPA is a network of organizations Preemie Parent Summit by offering support to families of premature infants. To ensure best outcomes for preemie families, PPA is dedicated to representing the needs and best practices of preemie families in all facets of healthcare policy, care guidelines, advocacy, education and family support. As a national network, PPA is establishing a unified parent voice to advocate for infants who cannot speak for themselves and their families. Together the organizations represent more than 250,000 NICU and bereaved families across the country.

Web Site:

www.PreemieParentAlliance.org

Background:

In 2010, Keira and Richard Sorrells of The Zoe Rose Memorial **Foundation** hosted the Inaugural bringing together 27 parents of preemies from 24 preemie parent support organizations from 14 different states. Since then the membership boasts 27 member organizations and an annual summit that provides a venue for collaboration (A NICU Parents Bill of Rights as well as a full-fledged Speakers Bureau), shared best practices and more all in the goal of support families of preemies. Coming Up: Contact PPA today for details on the 2016 Summit!



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



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

"Like" our FB page from 10/27/15 to 11/22/15 and you could win a copy of the awardwinning little man DVD from PreemieWorld!

http://bit.ly/FBPreemie

Parents & Professionals: Subscribe to our FREE newsletters today @ www.PreemieWorld.com



Book: A Giraffe Called Neo

The Details:

By:

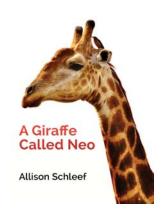
Alison Schleef

Available at:

www.Amazon.com

Cost:

\$13.95 USD



Preemie Moms worldwide have suffered in silence for decades in relation to Postpartum Depression (in Schleef's book it is referred to as Post Natal Depression or PND). But thanks to brave souls like Mrs. Schleef, the stigma is quickly being shattered. PPD/PND is something that Schleef describes with refreshing honesty as she relates the story of her son's traumatic birth at 28 weeks gestation, his and her transport to another hospital and a three month NICU stay that left this mother, naturally, alone and scared. This should be required reading in every NICU, parent and professional alike.

We're giving away this book! Follow us on Twitter by 11/22/15 to enter: http://bit.ly/PreemieTweets

After the NICU:

Preemie Myths & the Public Eye

Out of the NICU and ready to bang your head against the wall because no one gets RSV season, gets your child's delays, etc.? Here's why:

- The press is full of heartwarming preemie stories, not the reality check of what happens to the infant and the family before, during, and after the premature birth and NICU stay.
- People love a good competition and parenting is no exception even with preemies. To be sure, someone thinks you are a hysterical parent because of this "RSV" thing you constantly talk about. They have no idea that a small cold could land your child in the PICU.

Tell us your (#preemiemyth) with a post to our Twitter or Facebook pages by 11/22/15. The top 3 entries picked will win a "little man" DVD.

Preemie Professional Online

NICU Professionals Group: (www.LinkedIN.com)

What impact has initiation of CPAP in the Delivery Room Had Since 1st Recommendation by the NRP?

Let Us Not Forget

When It Comes to ROP Is It All About Nutrition?

Early Intervention Professionals Group: (www.LinkedIN.com)

Do You Know What Parents Should Consider?

Tongue-Tie Release

ELEVEN Articles on Feeding!

How Do You Address Reading Comprehension for Students at the K-3 Level?

Preemie World (www.Twitter.com):

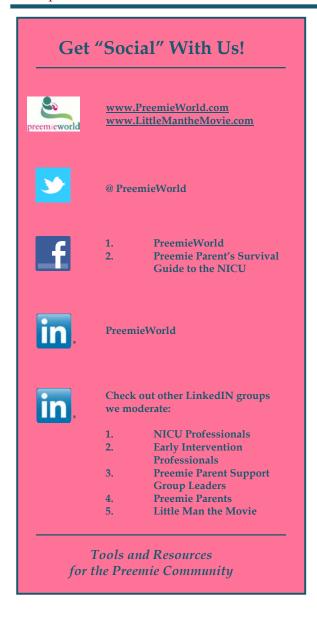
POLICY BRIEF: Protecting Premature Infants from Infectious Diseases

RESEARCH: Gut Bacteria Tied to Asthma Risk

BE THE SMART PRO: Tell Your Families about the "Preemie Network" on Inspire.com:

Deb Discenza of PreemieWorld moderates this FREE global network of over 23,000 parents from NICU to home to school. 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@preemieworld.com









Interested in advertising? Contact us at connect@preemieworld.com

Reality Check: Real Awareness is that Prematurity is Lifelong

As we head into World Prematurity Awareness Month, PreemieWorld's Deb Discenza has some poignant words to say about the reality of premature birth.

It has been 12 years since my daughter Becky was born at 30 weeks. By now, one would have thought that her early birth would be a distant memory. However, it still feels as if the NICU stay was only yesterday. Why? Because twelve years later, our family is still quietly working through the ramifications of her early birth. *And we are not alone.*

While the public sees only tiny babies growing and thriving, they don't see the complicated reality that so

many parents of preemies do: that prematurity has a life-long component to it. It may play out in terms of therapies, treatments and surgeries in the early years and then *appear* to dwindle to minimal needs as the child grows into adulthood. But the reality check is that society and the taxpayer as a whole need to keep the follow-ups going, keep the research up to date and fully focused. With 15,000,000 preemies born globally each year, that is a huge number of people over a generation that are at-risk for ongoing health, mental health and developmental challenges.

How has prematurity played out in your family? Tell us via Facebook/Twitter using #preemiereality