



Preemie Professional

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Paula Korelitz, M.Ed.

Outreach Director, VRRF



Photo Credit: Paula Korelitz

Years in Field:
32

Org:
Vision Research ROPARD
Foundation (VRRF)

Preemie Focus:
Dr. Korelitz has a specific
interest in Retinopathy of
Prematurity (ROP).

Check Out:
The Vision Research ROPARD
Foundation's website for all sorts
of resources on Retinopathy of
Prematurity (ROP) here at:
www.vrrf.org

Professional Tip!

NICU staff should emphasize that premature babies need follow-up with a pediatric ophthalmologist after discharge.

Advocate: World Braille Day

The 4th of January 2014 is World Braille Day due to it being the birthday of Louis Braille who invented this code in 1821. In our community of preemie parents we have many families affected by blindness due to Retinopathy of Prematurity (ROP). Braille is used worldwide. To learn more about the individual behind it, go here to find out more: <http://bit.ly/BrailleDay>

Preemie Resource: Retinopathy of Prematurity

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 "Retinopathy of Prematurity (ROP) - A Prep Sheet."** "ROP is frightening to parents because of its complexity," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "Our handout gives parents

the basics, a great resource to be found at our VRRF friends' website, and some questions to ask the doctor." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. **Download it here now:** <http://bit.ly/ROPfreebie> **And check out more like this here:** <http://bit.ly/PreemieFreebies>

To Do List



CONGRATS: Our friends at the [Little Giraffe Foundation](#) won the *little man* DVD through our PreemieWorld 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!



NeoPREP
AAP Section on Perinatal Pediatrics
January 11-17, 2014
San Diego, CA
<http://bit.ly/NeoPREP>

AAP Live CME
American Academy of Pediatrics
January 23-26, 2014
Breckenridge, CO
<http://pedialink.org/cmefinder>

Have an event to share? Email us details at connect@preemieworld.com

*Tools and Resources
for the Preemie Community*

Support: Little Giraffe Foundation Organization: Now I Lay Me Down to Sleep



Year Established: 2011

Focus: National

Web:

www.littlegiraffefoundation.org

Background: With the early birth of their twins, Cheyenne and Evan, and the devastating passing of Cheyenne six weeks later, Mike and Amanda Santoro wanted to help bring comfort to families in the NICU and to fund neonatal medical research efforts.

Programs: Holiday program of gifts to NICUs 6x per year; NICU support grants; funding of neonatal research initiatives.

When Maddux Achilles Haggard was born on 2/4/05 with a life-threatening condition, his parents, Mike and Cheryl Haggard made the excruciating decision to remove him from life support. They asked photographer Sandy Puc' to take portraits of their son before and afterward so they could create a lasting legacy for the family. This inspired Cheryl and Sandy to begin the organization Now I Lay Me Down to Sleep.

Established: 2005

Focus: Parents who have suffered the death of a baby.

Type of Outreach: International

Website:

www.nowilaymedowntosleep.org

Programs:

- Complimentary professional portraits taken by volunteer photographers for families who have suffered the death of a baby.
- Recruitment and training of photographers.
- Mobilizing photographers worldwide.
- Hospital education.

To date, non-profit Now I Lay Me Down to Sleep has provided thousands of babies who are stillborn or are at risk of dying as newborns with free portraits.

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Now I Lay Me Down to Sleep

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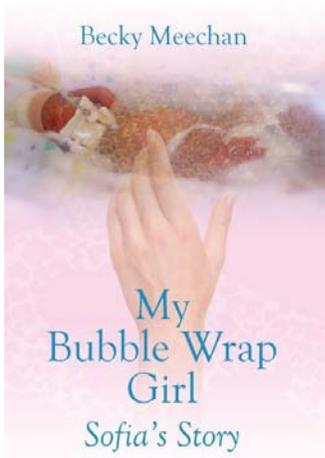
My Bubble Wrap Girl – Sofia’s Story

The Details:

By:
Becky Meechan

Website:

<http://sbpra.com/BeckyMeechan>



The Genius:

Becky Meechan tells her story of her “Poppet” a 24-weeker preemie that had numerous ups and downs in the NICU.

Beyond the incredible story of her daughter’s journey in the NICU is the stark honesty about the day-to-day realities of the parent/professional relationship.

This is a must read for not only parents of preemies but also the general public and most importantly, the professional sector caring for these babies.

Follow us on Twitter between 1/3/14 and 1/26/14 and one lucky winner will be selected to receive this book Find us at: <http://bit.ly/PremieTweets>

After the NICU: ROP Exams

ROP exams after the NICU are enough to set a preemie, not to mention a parent on edge big time. Here are some tips to make that appointment a little easier on everyone involved:

- Request to be placed in a private exam room upon arrival (mainly for germ control but also a sanity saver)
- Have a pacifier ready after drops are placed in the eyes
- Gently sing and talk to your baby during the eye exam
- Swaddle, have a feeding or pacifier handy immediately afterward. Do not schedule anything else for the rest of the day.

Premie Professional Online

NICU Professionals Group: (www.LinkedIN.com)

“Christmas Gifts to the Special Delivery Ward”

“RESEARCH: Physicians Studying Mothers Breast milk for Correct Amount of Nutrients – <http://ow.ly/s5zvW>”

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

“RESEARCH: Understanding How Preemies Grow – <http://ow.ly/rZTss>”

“STUDY: Tiniest Newborns Often Lead Normal Adult Lives – <http://ow.ly/rh8jO>”

Premie World (www.Twitter.com):

“RESEARCH: Bringing MRI to Vulnerable Newborns – <http://ow.ly/rZUH5>”

“RESEARCH: Brain Chemicals May Signal Which Preemies Will Have Delays – <http://ow.ly/s5z2o>”

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

Deb Discenza of PremieWorld moderates this global network of almost 17,000 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

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
- Little Man the Movie

Tools and Resources for the Premie Community



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True or False: *Myths About Retinopathy of Prematurity (ROP)*

Parents of premies are so busy dealing with so many issues in the NICU that it is hard to figure out what is a priority and what can wait. Here to dispel a couple of myths about ROP, is Antonio Capone Jr., M.D. of the Vision Research ROPARD Foundation.

True or False? After the initial eye exam in the NICU, ROP follow-up is not necessary.

AC: FALSE. The initial NICU eye exam is just the start of an infant's ROP-screening career. Retinal evaluation continues until the retina is vascularized, often out to a 50 weeks post-menstrual age.

True or False? ROP as a diagnosis means the child is going to be completely blind.

AC: FALSE. While it is certainly true that ROP can lead to blindness, when diagnosed and treated (retinal ablation, surgery when necessary) in a timely fashion outcomes can be good. Screening is the most important aspect of ROP care, as it is in the infant's into the ROP-care pathway.

