



Preemie Family

Preemie Life

Adelynn Evans



Photo Credit: Bethany Hubbard

Parent Tip:

Make a friend. Find a fellow preemie parent who is currently in the NICU or has been there before. Unfortunately, many people don't understand how scary the NICU can be and you need a strong support group.

Gest. Age:
24 weeks, 1 day

Weight:
1 lb. 2 oz.

Time In NICU:
5 months

Proudest Moment (NICU):
The first time they offered her a bottle, she took it like a champ. We have had no feeding worries since!

Coming Soon:
Check www.PreemieWorld.com for Adelynn's journey from preemie to now!

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> to use and to pass onto others.



MARK YOUR CALENDAR!

Scrap booking for Preemie Parents
New York Hospital Queens
January 10, 2014
New York
<http://bit.ly/PreemieScrapbooking>

32nd Annual Snoball Softball Challenge
March of Dimes - Nevada Chapter
January 24, 2014
Stateline, NV
<http://bit.ly/SnoballMOD>

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

*Tools and Resources
for the Preemie Community*

Term: Retinopathy of Prematurity (ROP)

Retinopathy of Prematurity (ROP):

An eye disease that affects the Premie population. ROP has a number of stages and can ultimately lead to vision damage or even partial/full blindness as a result of *too* oxygen, or frequently changing blood levels of oxygen and carbon dioxide.



Questions to Ask the Doctor:

1. Is my baby at risk for ROP?
2. If my baby is at risk, when will the specialist do the eye exam?
3. When will you know that he is no longer at risk for ROP?
4. Is there anything I can do to make my baby more comfortable during this exam?
5. If there is ROP, what is the stage?
6. What interventions will be taken?
7. What is my baby's prognosis?

*This excerpt is from **The Premie Parent's Guide to Survival in the NICU** on sale at www.PremieWorld.com*

Support: Little Giraffe Foundation



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.

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My Bubble Wrap Girl – Sofia’s Story

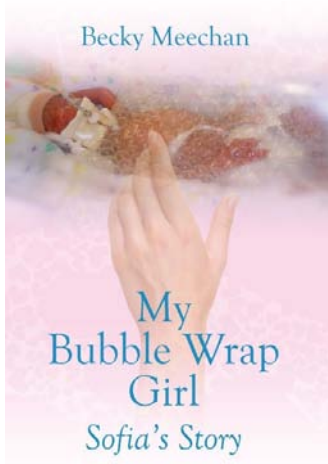
After the NICU: ROP Exams

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>

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 Support Online

On the Premie Support Forum on INSPIRE:

Want to connect with *almost 17,000 other parents of preemies online?* Check out the www.Inspire.com **Premie Support forum**. It is the largest and most active forum online and *moderated by PremieWorld’s own Deb Discenza*. The “rooms” range from “In the NICU” to “Going Home and Family” to “Growing Up and Education” along with more in-depth areas such as “Preemies with CP,” “Preemies with Feeding Issues,” and “Premie Tips.” Check out some of our more recent topics:

“Inpatient Feeding Clinics”

“Still Can’t Tolerate Feeds After Ostomy”

On PremieWorld’s Twitter Page:

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

On PremieWorld’s Facebook Page:

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

On PremieWorld’s LinkedIN Group:

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

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

Parents of preemies 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.

