



Preemie Professional

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Paula Tarver, OTR/L and Jeanne Martin, OTR/L
Co-Authors of **Advance My Baby Handbook**



Photo Credit: Paula Tarver, OTR/L

Professional Tip!

Parent education is key. These families need training on how to help promote their baby's overall development and not just on "how to care" for the baby. Providing opportunities for sensory experiences throughout the day help to calm the central nervous system where it has been over-stimulated, and stimulate the CNS where it has been deprived.

Web:

www.AdvanceMyBaby.com

Focus:

Bring awareness to Sensory Integration through education and training of parents and caregivers of NICU babies.

Cool:

Check out their Sensory 4 Child Foundation at:

www.sensory4child.org



Advocate: Pregnancy & Infant Loss Month

We as a community mourn alongside our fellow preemie parents who have lost a baby in pregnancy, at birth, in the NICU and beyond. October is **Pregnancy & Infant Loss Month** and we give thanks to organizations like **Share Pregnancy & Infant Loss Support**, **Zoe Rose Memorial Foundation**, **Now I lay Me Down to Sleep**, and **Still Standing Magazine**, for their ongoing efforts.

Preemie Resource: Staying #RSVfree

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 "Staying #RSVfree." "You can never prepare enough for this season," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "Our handout provides some

nice tips not only for home but also for when you are also out and about such at the doctor's office. This is the list I would have wanted for those first few years."

Get this month's freebie here and pass it on: <http://bit.ly/RSVFREE> and look at our other freebies here: <http://bit.ly/PreemieFreebies>

To Do List



CONGRATS: Congrats to **Emma Hostetter** on winning the little man DVD in our latest 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!



AAP National Conf & Exhibition
American Academy of Pediatrics
October 11-14, 2014
San Diego, CA
www.AAPExperience.org

NPA's 35th Annual Conference
National Perinatal Association
October 16-17, 2014
St. Louis, MO
www.NationalPerinatal.org

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

Tools and Resources
for the Preemie Community

Support:

From a little Gund Bear in Beth Maclin's son's incubator came the nickname "Little Bear" which now represents the organization to help preemie families around the world.

Year Established: 2006

Web:

<http://thelittlebearfoundation.org>

Outreach: U.S., Canada & England

Focus: Supporting families with preemies as well as families going through a post-preemie pregnancy.

Programs: NICU Survival Kits for new preemie families, peer-to-peer support program, and mentor program.

Org: High Risk Hope

*Out of her own experience with preterm labor at 24 weeks into pregnancy, **Heather Barrow** managed to hang on 59 more days and gave birth to her son, **Hill**, at 32 weeks. As Barrow received no support from a local or national non-profit throughout the ordeal, she created **High Risk Hope** to give others hope.*

Established: 2011

Type of Outreach:

State and Local, Tampa, Florida

Website:

www.highriskhope.org

Focus: To provide items to the families during hospital bed-rest and to NICU families with preemies to make their stay more manageable and comfortable.

Programs:

High Risk Hope reaches 1,200 new families per year with Bed Rest Baskets (for bed-rest) and NICU Napsacks (for families) filled with items to make the stay easier and the hope to bring home a healthy infant.

Event:

Tot Trot to raise funds for HRH and bring awareness to the global premature baby epidemic. It is on November 15, 2014 at 9:30 a.m. at Gadsden Park in Tampa, Florida. www.tottrot.org

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

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

"Like" our FB page from 9/30/14 to 10/26/14 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

**The Details:**

By:
Mighty Tykes

Website:
www.mightytykes.com



Mighty Tykes' Infant & Child Weights

Mother and Inventor Isabella Yosucio created these innovative weights after her son was born with Down Syndrome and she learned he would be affected by hypotonia, low muscle tone, and weakness common in many other conditions including prematurity. These were created with input from OTs and PTs.

Soft and colorful, these weights are not only made in the U.S.A. but are also lead-free and washable. They come in 1/8, 1/4 and 1/2 pound weights.

COOL: One new @PreemieWorld Twitter follower during 9/30/14 - 10/26/14 could win a copy of this book! Go here: www.twitter.com/preemieworld

EXTRA COOL: Mighty Tykes is offering PreemieWorld readers a one-time discount code on their weight products: PREEMIE14

After the NICU: Paying for Synagis (palivizumab)

With RSV season just about here, there are many preemies preparing for Synagis injections. This effective monoclonal antibody is not cheap. Approved but need help paying for it? Consider contacting these organizations for help:

- **Access 360:** Synagis Manufacturer Medimmune has a program that will help families needing assistance with the cost of the drug. Find out more here: www.MyAccess360.com
- **Patient Access Network (PAN Foundation):** PAN is dedicated to providing help and hope to people with chronic or life-threatening illnesses for whom cost limits access to breakthrough medical treatments: www.PANfoundation.org

Preemie Professional Online

NICU Professionals Group: (www.Linkedin.com)

NEWS: NIH officials cleared of interfering in oversight of preemie study - <http://ow.ly/C1nyr>

NEWS: Improvements in NICU nursing care could boost health outcomes for underweight black infants - <http://ow.ly/C1mUf>

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

PREEMIE UPDATE: Jackson Chance Meghie - <http://bit.ly/PreemieJackson>

COOL: Milestone Blog Post from Preemie Mom & Author Jennifer Degl - <http://ow.ly/BC544>

Preemie World (www.Twitter.com):

RESEARCH: Lahav Group Study on Maternal Sounds Lowering Preterm Newborn Heartbeat - <http://ow.ly/BC65d>

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

Deb Discenza of PreemieWorld moderates this global network of over 19,000 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

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Q&A: What are the Top Myths Surrounding RSV?

RSV season is less than a month away, so we are grateful to our friends at the Alliance for Patient Access (AfPA) for dispelling myths surrounding RSV.

1. **RSV is a common cold.** *False!* While RSV may "look" like a common cold, in older adults and young infant, it can be life threatening. RSV is 10 times more deadly than the flu.

2. **RSV is spread through coughing.** *False!* RSV is spread through droplets and the live virus can live for hours on surfaces such as countertops. RSV is highly contagious and this is why good hand washing is so important to prevent the spread of RSV.

3. **There is a medication to help prevent RSV.** *True!* Synagis (also known as *palivizumab*) is a medication that can help prevent RSV. Babies at risk for RSV are given Synagis every month during RSV season (Oct-March in most places).

4. **My baby can only get RSV once a year.** *False!* After recovering from an RSV infection, your baby is still susceptible to getting it again if exposed, as we do not build immunity to this virus after getting it once. This is why babies who get Synagis need to have the injections monthly, because the antibody in the injection "wears off" in ~28days.

Sign the Premie Petition: <http://bit.ly/PremiePetition>