

# Preemie Family

# Preemie Life

## Margarita Radzeviciute



Photo Credit: Hall Family

## Parent Tip:

Try to calm down and believe that your baby will get stronger. Be near the incubator as often as possible. Keep visiting, gently caress, talk, and sing to your baby. Let him feel and hear you. Let him know you are always here for him! No blame- everything is in the doctors' and God's hands. Don't cry near your baby. Your baby wants to feel that you are strong and happy.

**Gest. Age:** 26 weeks

Weight: 960 grams

**Time In NICU:** 107 Days

## **Proudest Moment (NICU):**

When after 3 weeks I did my first kangaroo and she was snuggled up with me with all her warmth, sound, and smell.

<u>Coming Soon</u>: Check <u>www.PreemieWorld.com</u> to read Margarita's full journey.

# Advocate: Prematurity Awareness

November is **Prematurity Awareness Month** and November 17<sup>th</sup> is **World Prematurity Day**. What do you and/or your organization have planned? Tell us on our Facebook page 10/28/14 – 11/26/14 and you could be selected to win a copy of Nicole Conn's *little man* DVD. Go here to access the PreemieWorld Facebook page: <u>http://bit.ly/FBPreemie</u>

# To Do List



<u>CONGRATS</u>: January Garcia wins the *little man* DVD and **Dinosaur Pediatric PT** wins the set of Mighty Tykes weights. Congrats to all!



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/PreemieFreebics to use and to pass onto others.



#### MARK YOUR CALENDAR!

**2014** Parent/Provider Conference Preemies Today November 16, 2014 Falls Church, VA www.ProemiesToday.com

World Prematurity Month/Day Preemie Organizations Worldwide November, 2014 & November 17th Global http://bit.kv/WPM2014

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

Tools and Resources for the Preemie Community

# Preemie Resource: World Prematurity Awareness Events

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 "World Prematurity Awareness Month/Day Events." "All of the organizations out there have so much planned," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "Our handout brings everything together in one place so readers can choose what best suits them."

Get this month's freebie and pass it on: <u>http://bit.ly/WPM2014</u> and here are more freebies here: <u>http://bit.ly/PreemieFreebies</u>

Follow us on FB, Twitter & LinkedIN!

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# Term: Respiratory Synctial Virus (RSV)

## **Respiratory Syncytial Virus**

**(RSV):** An illness initially resembling a modest cold in adults. It can be dangerous for newborns – and even worse for preemies – since it is highly contagious and complications from the virus can develop into a major respiratory infection. Many premature infants with Chronic Lung Disease will be eligible for Synagis injections on an annual basis during cold and flu season.

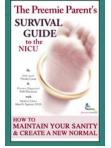
#### Sign the Preemie Petition!

The Preemie Petition was launched by PreemieWorld in mid-2014 to push back against upcoming restrictions to the Synagis guidelines. To learn more about the guideline changes, see page 4 of this newsletter. And join over <u>6,300</u> <u>parents and professionals</u> <u>globally</u> who have already signed

http://bit.ly/PreemiePetition

our petition and pass it on:





This excerpt is from **The Preemie Parent's Guide to Survival in the NICU** on sale at <u>www.PreemieWorld.com</u> \*\*We do bulk orders for hospitals\*\* <u>connect@preemieworld.com</u>

# Support:



Year Established: 1991

**Focus:** Mercy Children's Hospital in St. Louis, MO

Web: <u>www.MiracleBaby.org</u>

**Note:** All of the organization's volunteers have had a baby in the NICU.

**Programs:** Letters from Santa program. For a small donation, Santa will send a personalized letter to the children (young and old) in your life! *Visit the website for more details and the deadline. Hurry! This is a very popular program!* 

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



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

# In honor of Prematurity Awareness Month/Day:

"Like" our Facebook page from 10/28/14 to 11/26/14 and tell us what you are doing for Prematurity Awareness and you could win a copy of the award-winning *little man* DVD

> <u>Parents & Professionals</u>: Subscribe to our FREE newsletters today @ www.PreemieWorld.com



The Details:

**By:** Sara Bingham

Website: www.weehands.com



# The Baby Signing Book

As the mother of two signing children and Founder of WeeHands, Sara Bingham has authored a baby sign language book that is taking the parenting world by storm. In it, Bingham provides easy-to-use steps and tips to make teaching your infant/child signing simple and straightforward. With sections devoted to various age groups and including a specific area for the special needs child, she makes this accessible to all families across the infant/child spectrum. Included in the book are 450 American Sign Language (ASL) signs for babies and toddlers. This is a must-have for all preemie parents.

COOL: One new @PreemieWorld Twitter follower during 10/28/14 - 11/26/14 could win a copy of this book! Go here: <u>www.twitter.com/preemieworld</u>

## After the NICU: <u>Prepping for the Holidays, RSV Style!</u>

#### As we head into the holiday season, what do you get the family that has a preemie enduring RSV season?

- Hand Sanitizer: A great stocking stuffer or a great gift that is greatly appreciated. Our faves are the "Gold Bond Ultimate Hand Sanitizer and Moisturizer" and the 5 for \$5 deal on PocketBac hand sanitizers at Bath and Body Works (bonus: they have a clip-on holder for their sanitizers, perfect for purses and diaper bags.
- Hands Off!: Tags 4 Tots

   (www.Tags4Tots.com) has cool signs and clips to keep strangers' hands off your baby. We love their preemie-specific sign best. NICUs and families these are perfect discharge day gifts!

# Preemie Support Online

## **On the Preemie Support Forum on INSPIRE:**

Connect with *over* 20,000 *other parents of preemies online* at <u>www.Inspire.com/preemie</u> for the *Preemie Support forum*. It is the largest and most active forum online, *moderated by PreemieWorld's own Deb Discenza*.

Encouraging Words Please - in NICU/PICU

Torticollis – in NICU/PICU

Preemie and Food- in Preemies with Feeding Issues

23 month old not walking or crawling– *at Home* (*Years 1-5*)

Dealing with comments - in Preemie Tips

## **On PreemieWorld's Twitter Page:**

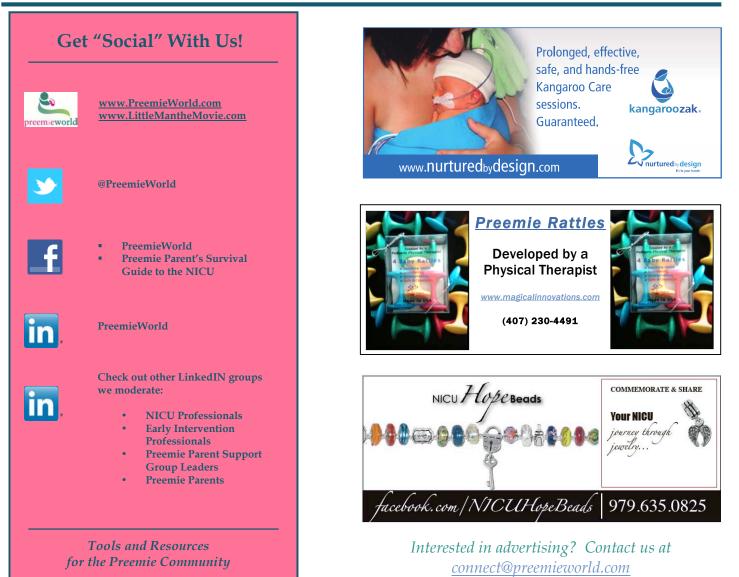
Preemie Parents are AMAZING – Thank you Nurtured by Design & Yamile Jackson! – <u>http://youtu.be/\_kPN\_hXbMgo</u>

## **On PreemieWorld's Facebook Page:**

PREEMIE UPDATE: Ayla's Story – <u>http://bit.ly/PreemieAyla</u>

## **On PreemieWorld's LinkedIN Group:**

STUDY: Slow enteral feeding protocol can reduce instances of death in extreme preterm infants – <u>http://ow.ly/CLEHi</u>



# Tips: RSV Advocacy for Parents & Professionals

With RSV season beginning and in light of the more restrictive guidelines launched by the American Academy of Pediatrics (AAP), the Alliance for Patient Access (AfPA) has launched a toolkit. PreemieWorld also has a couple of tips as well.

#### AfPA Video on RSV.

Professionals from across neonatology speak about RSV and why limited access is a concern: <u>http://allianceforpatientaccess.org/multimedia</u>

## AfPA Parent Resource Center.

In this special toolkit there is a parent education sheet to help parents navigate the confusion surrounding RSV and the drug branded Synagis (also known as *palivizumab*) as well as advocacy materials to help reverse the guidelines. Check it out here: http://allianceforpatientaccess.org/resource-center/

*PreemieWorld's "Access to Synagis" Sheet.* Had a baby been denied access to Synagis? There still may be ways to appeal that denial with our handy sheet: <u>http://bit.ly/RSVPreemies</u>

*Sign PreemieWorld's Petition Surrounding the Guideline Changes.* Join thousands of parents and professionals around the world who have signed the Preemie Petition at <u>http://bit.ly/PreemiePetition</u>

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