

# Preemie Family

## Preemie Life

## Spencer Wayne Mackintosh Howard



Photo Credit: Julie Howard

## Parent Tip:

Keep a journal and ensure you're keeping a record of all of your preemie(s) vitals/feedings, etc. You are their biggest advocate, don't back down! Gest. Age: 29 weeks

Weight: 2 lbs. 5 oz.

NICU Stay: 64 days

**Proudest Moment (NICU):** When I was able to give Spencer his first bath, I felt like a "normal" mom for those few minutes.

#### Extra Cool: Julie is the founder of It's a Preemie Thing: www.itsapreemiething.com Coming Soon!: Check www.PreemieWorld.com for Spencer's journey from NICU to now.

# Advocate: Group Strep B Awareness

Babies born early can often be due to an infection. One such infection is Group Strep B which can affect a baby in utero and for up to 6 months post-birth. Babies can be stillborn, disabled and more due to this very dangerous infection. Help spread the word about Group Strep B Awareness in July so we can educate our community: <u>www.groupstrepbinternational.org</u>

## To Do List



<u>CONGRATS</u>: Dinez Esmail is the winner of the *little man* DVD and Robin Kahn is the winner for the set of Tamiko preemie clothes.



*Families in the NICU now* – Don't wait, ask your NICU team if your child qualifies for Synagis during RSV season. It could save a life!



Download PreemieWorld's FREE tools <u>http://bit.ly/PreemieFreebies</u> to use and to pass onto others.



#### MARK YOUR CALENDAR!

NMA Annual Convention & Scientific Assembly National Medical Association July 27- Aug 1, 2013 Toronto ON www.nmenclorg

Nat'l Black Nurses Assoc. Conf. Nat'l Black Nurses Association July 31 – August 4, 2013 New Orleans, LA www.nbna.org

Have an event to share? Email us details at <u>connect@preemieworld.com</u>

Tools and Resources for the Preemie Community

## Preemie Resource: Giving Back After Having A Preemie

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** "**Giving Back After Having a Preemie.**" "Preemie parents feel strong need to give back after the NICU," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "This is a great sheet to give parents of ideas of ways to help. Giving back is cathartic and a healthy way to come back from such a stressful time. And the positive focus also can directly impact that preemie in a variety of ways." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. **So go download it here now:** <u>http://bit.ly/PreemieDads</u> **And check out many more here:** <u>http://bit.ly/PreemieFreebies</u>

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## Preemie Terms: Brain Bleed

**Brain Bleed (IVH or Intraventricular Hemorrhage):** The blood vessels in your baby's brain can bleed rather easily, even when the infant is moving in some cases. There are generally 4 levels of brain bleeds (from 1 to 4). Grade 4 is the most serious and can be the source of seizures, blindness and severe retardation.



The doctors normally scan for brain bleeds within the first 24 hours (the most critical), then after three days, and then after one week. The chances of a brain bleed after one week are dramatically decreased. Often they will do a final brain bleed check at week six.

#### **Questions to Ask the Doctor:**

- What stage is the bleed?
- What can be done medically or what can I do to help at this point?
- What are the longterm outcomes for this stage of a brain bleed?

This excerpt is from **The Preemie Parent's** Guide to Survival to the NICU at <u>www.PreemieWorld.com</u>

## Support: NICU Helping Hands



Founded in 2010 by Lisa Grubbs, wife of neonatologist Dr. Randy Grubbs, **NICU Helping Hands** was created to address the support, the emotional care and the ongoing educational needs of families during ante partum care, the NICU and beyond.

The organization has an in-hospital parent support program (Project NICU), a One-on-One National Mentoring Program, a Durable Medical Equipment Rental Program, Bereavement Angel Gowns, NICU Mom CONNECT (post-NICU Moms), a Community Parent Education Series and a Financial Assistance Program.

For more information go to: www.nicuhelpinghands.org

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



Visit PreemieWorld's FB page at: http://bit.ly/FBPreemie "Like" our FB page from 7/1/13 to 7/24/13 and you could win a copy of the award-winning *little man* DVD from PreemieWorld!

http://bit.ly/FBPreemie

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

## Preemie Genius: Preemie the Explorer

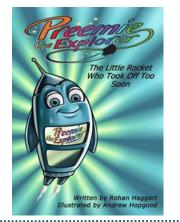
#### The Details:

**Item:** Preemie the Explorer

**By:** Rohan Haggart Andrew Hopgood (Illustration)

#### Website:

www.PreemietheExplorer.com



#### The Genius:

This colorful, kid-friendly book is geared toward the school-age set yet could also be a perfect read-aloud book for the NICU and at home. *Preemie the Explorer* has a universal appeal that sends a clear message to remind parents and professionals that preemies may have "launched" early but they can do amazing things.

#### **CONTEST!**

PreemieWorld and Rohan Haggart have partnered to supply two NICUs with a copy each of the book. The winner will be selected from those NICUs that sign up for our Preemie Family for Pros list 7/1/13 – 7/24/13 at: http://bit.ly/PreemieFam4Pros

## After the NICU: *Having a Nurse in the Home*

Preemies often go home with either a home health nurse visiting regularly or being contracted to work in the home a number of hours per day or week. Some things to think about:

- Use the nurses' time to taking a break: sleep, take a shower, eat a hot meal and spend time with the rest of your family.
- Set up clear ground rules with the provider ahead of time regarding your preferences.
- Having someone in your home helping with the baby does not mean they "own" your child. You are always the parent.

Have a topic for After the NICU? Send it into us at <u>connect@preemieworld.com</u>

### Preemie Support Online

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

Want to connect with *over 15,000 other parents of preemies online*? Check out the <u>www.Inspire.com</u> **Preemie Support forum**. It is the largest and most active forum online and *moderated by PreemieWorld'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" and "Preemies with Feeding Issues." Check out some of our more recent topics:

"Best Bottle/Nipple for Preemie Feeding at Home"

"Is a second pregnancy possible?"

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

"ARTICLE: NIH Chief Rejects Ethics Critique of Preemie Study – <u>http://ow.ly/lUL7Q</u>"

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

"PREEMIE COOL: Preemie Palooza Event – <u>http://ow.ly/m7J6B</u>"

#### On PreemieWorld's LinkedIN Group:

"STUDY: Recession Forced Cutbacks in Care for Special Needs Kids – <u>http://ow.ly/lK8T6</u>"

"ARTICLE: Check young kids for motor delays: pediatricians – <u>http://ow.ly/lGQ3s</u> "

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<b>&gt;</b>	@PreemieWorld	Out of the last list the first transmission       In the first transmission       In the first transmission       If the first transmission         When the first transmission       If the first transmission       If the first transmission       If the first transmission       If the first transmission         When the first transmission       If the first transmission       If the first transmission       If the first transmission       If the first transmission         When the first transmission       If the first transmission       If the first transmission       If the first transmission       If the first transmission         When the first transmission       If the first transmission       If the first transmission       If the first transmission       If the first transmission         When the first transmission       If the first transmission       If the first transmission       If the first transmission       If the first transmission         When the first transmission       If the first transmission       If the first transmission       If the first transmission       If the first transmission         When the first transmission       If the first transmission       If the first transmission       If the first transmission       If the first transmission         When the first transmission       If the first transmission       If the first transmission       If the first transmission       If the first transmission         When t
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## **Q&** A: What is a Newborn Care Specialist or Postpartum Doula?

Many preemie families are juggling so much with their child/ren that they need an extra hand upon discharge time and beyond. That is where a Newborn Care Specialist (NCS) or a Postpartum Doula (PD) can help so we talked to NCS & PD Maryann Kamitian about this specialty.

#### Q: What type of work does each pro do?

An NCS will be trained and skilled in all aspects newborn care and will have experience with preemies and other special needs babies. A doula performs much of the same duties as an NCS but includes nurturing of the family to help educate and support the family so that they will feel confident in caring for their newborn themselves. PDs do not perform medical or clinical procedures.

#### **Q**: What type of training is involved in each field?

*A:* Newborn Care Specialists have taken classes or attended programs specializing in this field or hold degrees or certifications. Postpartum Doulas have taken specialized training with PD-related organizations. Both should have some form of liability insurance. Always ask for references.

## Want to know more? Contact Maryann at: <u>Mkamitian@aol.com</u>

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