



Preemie Family

Preemie Life

Joshua Drake McCormick



Photo Credit: Jenny Regina Reyes

Parent Tip:

Talk to other NICU families and parents of NICU graduates. It will provide immense comfort knowing that you have support from parents who truly understand what you are going through.

Gest. Age: 26 weeks

Weight: 2 lbs. 10 oz.

NICU Stay: 129 days

Proudest Moment (NICU):

After weeks of sprinting, Joshua finally came off the cannula and was on room air. I was so very proud of him! I felt as if we were just that much closer to getting him home. ☺

Coming Soon:

Check www.PreemieWorld.com for Joshua's journey from NICU to now.

Advocate: Hydrocephalus Day

October 25, 2013 is Hydrocephalus Day. As a community that knows this condition all too well, we walk hand in hand recognizing this affliction and its life-long effects on preemies. Learn more and to support this very important cause, check out this PreemieWorld friend: Hydrocephalus Association at <http://www.hydroassoc.org>

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 to [Jenny Reyes](#) on winning *Imagine* by Dianne Maroney in our September 2013 "Preemie Genius" contest!



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 <http://bit.ly/PreemieFreebies> to use and to pass onto others.



MARK YOUR CALENDAR!

Preemie Parent Summit
Preemie Parent Alliance
October 4-6, 2013
Nashville, TN
<http://bit.ly/PreemieParentA>

Little Monsters 5k for a Cause
Preemie Prints
October 26, 2013
Central Park College Station, TX
<http://www.preemieprints.org>

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

*Tools and Resources
for the Preemie Community*

Term: Bradycardia (Brady)

Bradycardia (Brady): When your baby's heart rate goes down below its normal range. You will usually hear the term "he's brady-ing" or "having bradys." This is a very common event in preemies; however, there can be any number of causes, significant and insignificant. It can be something as natural as

the baby trying to pass a stool, or simply experiencing reflux or it may be something more dangerous when the baby's heart rate is lower for more than 15 to 20 seconds.

Most hospitals have a general "brady" rule linked to discharge day (at Cedars, the infant had to be "brady-free" for 5 days before getting off the monitors and going home), though this process will vary dramatically from one NICU to another.

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



Support: Owyn's Butterfly Kisses



Founded in early 2013 by Stephanie Cipriani and Gwen Schoonover, Owyn's Butterfly Kisses fundraises to support West Penn's NICU which specializes in prematurity.

Website:

www.OwynsButterflyKisses.org

Outreach:

Regional - the greater Pittsburgh area

Programs:

Annual preemie calendar, special hats and other mementos/gifts for families. Check out the calendar here: <http://bit.ly/OwynsCal>

The EVENT of the YEAR: Preemie Parent Summit



2013 Preemie Parent Summit

<http://bit.ly/PreemieParentA>

October 4-6, 2013 • Nashville, TN

Preemie Genius: Advance My Baby

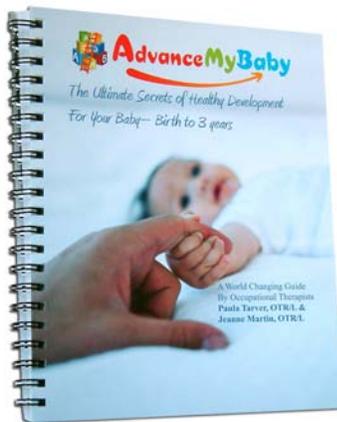
The Details:

By:

Paula Tarver, OTR/L &
Jeanne Martin, OTR/L

Website:

www.advancemybaby.com



The Genius:

Preemie parents worldwide worry about many things upon discharge from the NICU. Alongside health issues and nutrition is the concern for the proper ways to stimulate the development of their babies.

Occupational Therapists Tarver and Martin have created a colorful, clear and friendly guide to provide parents of premature infants with exercises to help advance development. Clearly, this guide should be on every preemie parent's bookshelf.

You could win a copy of Advance My Baby by "liking" our FB page 10/1/13 - 10/28/13 at <http://bit.ly/FBPreemie>

After the NICU:

Please don't give my baby RSV!

RSV season often sends preemie parents into a tizzy worrying about how to handle strangers wanting to touch their baby. Here are some nice ways to say "back off!"

- "My daughter/son has a fragile immune system, so silly faces and sweet words from afar are the best ways to say hello!"
- "Aw, its almost time for a nap/feeding/diaper change, so a 'Hi there!' is the best way to greet him/her right now."
- "Aw you are so nice to say hello. S/he was our preemie so please help us keep her/him healthy by focusing on smiles and giggles."

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

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 www.Inspire.com **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," "Preemies with Feeding Issues," and "Preemie Tips." Check out some of our more recent topics:

"Reflux info"

"Baby won't eat food?"

On PreemieWorld's Twitter Page:

"Feeding Issues with Your Preemie? Check Out the Feeding Matters 'Power of Two' Mentor Program - <http://ow.ly/oNVLQ>"

On PreemieWorld's Facebook Page:

"Happy NICU Nurses Day! PreemieWorld has an FB page dedicated to this very special day - <http://bit.ly/NICUNursesDay>"

On PreemieWorld's LinkedIN Group:

"STUDY: Trauma Therapy May Ease Distress for Mothers of Premies - <http://ow.ly/oNVba>"

"STUDY: Ottawa Study Looks at Outcomes for Extreme Premature Babies - <http://ow.ly/ohB3r>"

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

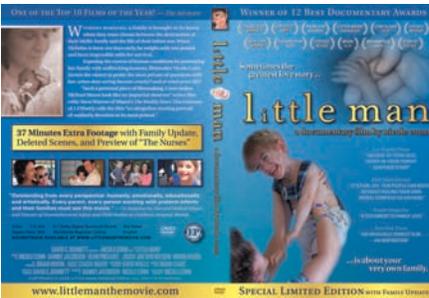
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"little man" is every preemie parent's story



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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.

Get more info on RSV: <http://bit.ly/RSVLetter>