



Preemie Family

Preemie Life

Shaw Richter



Photo Credit: The Richter Family

Gest. Age: 27 weeks
Weight: 2 lbs. 7 oz.
NICU Stay: 122 days

Proudest Moment (NICU):
 The day our son graduated from the isollette to a BIG BOY BED and REAL CRIB!

Parent Tip:

Sometimes taking it 'day by day' can be too much. Some days it is okay to take it 'hour by hour' on those days, as that is almost all we can bear.

Coming Soon:

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

Advocate: Vote on World CP Day

October 2, 2013 is a special day in the Cerebral Palsy community. As a sister community we know the high risk of preemies to have Cerebral Palsy, let's help make a difference. Join the vote to help decide on ideas gathered worldwide so one of those plans can become a reality and help CP families continue to thrive. Vote here on 10/2/13: <http://en.worldcpday.org>

Preemie Resource: RSV Education Handout

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 "RSV - What Parents Should Know"** courtesy of our friends at the Alliance for Patient Access (AfPA) (www.allianceforpatientaccess.org). "You can never be too careful when it comes to RSV season. Professionals are always on the look out for great

materials to educate their families in the NICU and at home," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "This one has it all and is backed up by cited research." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. **So go download it here now:** <http://bit.ly/RSVLetter> and check out many more here: <http://bit.ly/PreemieFreebies>

To Do List



Are you going? The Preemie Parent Alliance is having its summit in Nashville, TN Oct 4-6, 2013
<http://bit.ly/PreemieParentA>



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!

Pictures for Preemies Event
 Dallas Preemie Parents
 September 7, 2013
 Dallas - Ft. Worth, TX area
<http://bit.ly/DPParent>

WILD Family Event @ the Zoo!
 The Tiny Miracles Foundation
 September 26, 2013
 Bridgeport, CT
<http://www.tmf.org>

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

*Tools and Resources
 for the Preemie Community*

Term: Respiratory Syncytial Virus (RSV) Support: Quiet Light Foundation

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.

Free Resources:

Revvin' Up for RSV Season:
<http://bit.ly/RSVSeason>

Access to Synagis:

<http://bit.ly/A5vsTZ>

Websites:

The Centers for Disease Control's RSV Information:

<http://bit.ly/CDCRSV>

Medimmune (Synagis):

<http://bit.ly/RSVHelp>

Hand to Hold's RSV Info:

<http://bit.ly/RSVinfo>

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



After having premature twins at 26 weeks, Amy Forsythe wanted to help other parents, creating the Quiet Light Foundation in 2010.

Website: www.quietlight.org

Outreach:

Regional – Nebraska/Western Iowa

Programs:

Provide peer counseling, lactation counseling, local service referrals, breastfeeding support and support group meetings. Also offers events throughout the year for families and for parents. Support can be provided to any family at any time, regardless of a child's age.

The EVENT of the YEAR: Premie Parent Summit



2013 Premie Parent Summit

<http://bit.ly/PremieParentA>

October 4-6, 2013 • Nashville, TN

Preemie Genius: The Imagine Project

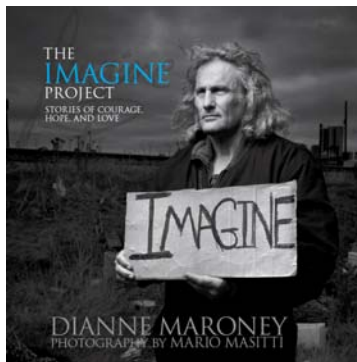
The Details:

By:

Dianne Maroney

Website:

www.theimagineproject.com



The Genius:

Dianne Maroney, known for her *Your Premature Baby & Child* as well as for her insight as both parent and professional in the NICU is back with a book that takes prematurity to the next level.

With stories preemie-related and some not, Maroney has collected incredible stories of strength and courage and combined them with amazing photos to provide the perfect gift for new NICU parents, NICU units, as well as anyone going through a challenging time of any type.

You could win a copy of "Imagine" by "liking" our FB page 9/1/13 - 9/26/13 at <http://bit.ly/FBPreemie>

After the NICU: RSV & the Diaper Bag Check

RSV season is coming into full throttle so make sure these items are included in the diaper bag until the season is over:

- Hand sanitizer for hands
- Sanitizing wipes for surfaces
- Sanitizing spray for areas that might be compromised
- Extra pacifiers in case the one in use goes out of commission
- Change of clothes
- RSV Awareness Info: <http://bit.ly/RSVLetter>

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:

"Just need some support going through this hard time"

"Kindergarten advice?"

On PreemieWorld's Twitter Page:

"RESEARCH: If you were a preemie, take heed for your heart - <http://ow.ly/nTqBd>"

On PreemieWorld's Facebook Page:

"STUDY: VLBW Infants Often Miss Rotavirus Vaccination Upon NICU Discharge - <http://ow.ly/nZOUr>"

On PreemieWorld's LinkedIn Group:

"ARTICLE: Preemie Born with Only One Percent Chance of Survival Defies Odds - <http://ow.ly/06vvp>"

"COOL: Saint Peter's welcomes former preemie pursuing career as nurse - <http://ow.ly/o6wb2>"

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- 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 3 Things A Parent Can Do to Prevent RSV?

RSV season is quickly approaching and it sends preemie parents and professionals into a frenzy of activity. The Alliance for Patient Access (AfPA) gives us some great tips on preventing RSV:

- 1. Hand washing, hand washing and more hand washing.*
Using hand gel or soap and water before and after contact with your baby is the *most* important prevention measure. Put hand gel in each room of the house, in each car, in the diaper bag, your purse, etc.
- 2. Limit exposure.*
This means that once RSV season starts (in early October) you screen people who come to visit to

make sure they don't have a cold or cough. Visitors should wash their hands before and after contact with your baby. Limit trips to places with lots of people – the mall, grocery stores, church, etc.

- 3. Know your baby's risks.*
There are certain babies that are more susceptible to getting RSV when exposed. This includes babies born before 36 weeks, babies with lung issues or heart issues. Talk to your baby's health care provider to find out if your baby is at increased risk and if a monthly injection of a medication is needed.

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