



Preemie Family

Preemie Life

Richard Koulbanis



Photo Credit: Koulbanis Family

Gest. Age: 32 weeks

Weight: 5 lbs.

Life in 1946:

Richard's mother was traveling and suddenly went into labor. Dropping almost half of his weight and developing life-threatening jaundice, he was expected to die, as the first NICU did not come into existence until eleven years after his birth.

Coming Soon:

Check www.PreemieWorld.com for Richard's journey from preemie to now as Publisher of Neonatology Today

Parent Tip:

While I am not minimizing anyone's fears, concerns or questions, at least today there are resources for information, and neonatal facilities, physicians and staff, who can provide your preemie the best possible care.

Advocate: Prematurity Awareness

November is **Prematurity Awareness Month** and November 17th is **World Prematurity Day**. What do you and/or your organization have planned? Tell us on our Facebook page 11/1/13 - 11/26/13 and you could be selected to win a copy of Nicole Conn's *little man* DVD. Go here to access the PreemieWorld Facebook page: <http://bit.ly/FBPreemie>

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 starts to bring it together in one place so readers can choose what best suits them. And with it being RSV season, there are families who will want to celebrate from home."

Get this month's freebie here and pass it on: <http://bit.ly/WPMD2013> and look at our other freebies here: <http://bit.ly/PreemieFreebies>

To Do List



CONTEST WINNERS: Congrats to [Diana Mayhew](#) who won Paula Tarver's book *Advance My Baby* & to [Julie Dahl](#) who won *The Preemie Parent's Survival Guide to the NICU*.



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!

Bee Something for Bee Mighty
Bee Mighty
November 16, 2013
Charlotte, NC
<http://bit.ly/BeeSomething>

World Prematurity Day
November 17, 2013
Worldwide

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

*Tools and Resources
for the Preemie Community*

Term: *Developmental Delay*

Developmental Delay: Babies are expected to reach certain milestones (i.e. walking and talking) within a predictable amount of time. Premies, due to their early birth and subsequent medical challenges, may take longer to reach those milestones. Many Premies receive occupational therapy (OT) and/or physical therapy (PT) to deal with all of the



various issues of being born too early; the stress it puts on the muscles, the stiffness in the bodies of infants that are on the vent for any length of time, etc. This therapy is very important for your baby. If your baby is vented, ask your nurse to get an OT/PT consultation. Some infants receive therapy early on after discharge, others do not require it and the parents can take a "wait and see" approach. Your pediatrician can guide you through this and may refer you to your area's Early Intervention program.

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

Support: *NICUPS*



Year Established: 1991

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

Web: www.MiracleBaby.org

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 and hurry – deadline for 2013 is December 12th!

Have a support group you want to share? Contact us! connect@preemieworld.com

The EVENT of the YEAR: *Premie Parent Summit*



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

In honor of Prematurity Awareness Month/Day:

"Like" our Facebook page from 11/1/13 to 11/26/13 and tell us what you are doing for Prematurity Awareness and you could win a copy of the award-winning *little man* DVD from PremieWorld!

<http://bit.ly/FBPreemie>

Preemie Genius: 2014 NICU Calendar

The Details:

By:

Owyn's Butterfly Kisses

Website:

www.OwynsButterflyKisses.com



The Genius:

Owyn's Butterfly Kisses has taken the "Then & Now" photos to a whole new level and all for a great cause.

With a full year's worth of "then and now" photos of former preemies in the NICU at Western Pennsylvania (West Penn) Hospital in Pittsburgh, PA, the calendar celebrates the triumphs of these tiny warriors.

Proceeds of the calendar sales go to benefit Owyn's Butterfly Kisses, which provides programs of support for families in the West Penn Hospital in the NICU.

Order the calendar here:
<http://bit.ly/OwynsCal>

After the NICU: First Pediatrician Appointment

With discharge day behind them, suddenly parents of preemies are thrust into the general public in the need to visit the pediatrician for the first time. Some tips:

- When scheduling the appointment and upon arrival at the office, insist on going to an exam room to wait instead of the waiting room.
- Bring a list of questions for the doctor so you don't forget anything. Doctors appreciate prepared parents.
- If you have a feeding log or other materials, bring those. Data is good! Need a daily log? Go here: <http://bit.ly/PreemieLog>

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 16,000 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:

"Second Winter Advice?"

"First Post-NICU Re-hospitalization"

On PreemieWorld's Twitter Page:

"ARTICLE: 10 Things Not to Say to An NICU Mom - <http://ow.ly/qcVFz>"

On PreemieWorld's Facebook Page:

"11/17/13 - 'Journey Through Prematurity' Conference - <http://ow.ly/qcWql>"

On PreemieWorld's LinkedIn Group:

"COOL: RSV Resource from Hand to Hold - <http://ow.ly/qcZne> "

"ALERT: Mother's Milk Sharing - <http://ow.ly/qcZbD>"

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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Q&A: The "NICU Parent's Bill of Rights"

Officially released at NANN 2013, the Premie Parent Alliance (PPA) has created the "NICU Parent's Bill of Rights." PPA leadership team member Kelli Kelley chaired this crucial document and gives us the scoop:

Q: What is the inspiration behind this Bill of Rights?
These were created to help address and breakdown barriers that often prevent NICU parents from bonding with their baby and playing an active role in their daily care. We know that in order to care for a medically fragile child after the NICU, parents must feel empowered, competent and capable of being their baby's advocate and caregiver. Therefore, they must be encouraged and supported throughout their

baby's NICU journey. The NICU Parent's Bill of Rights will help NICU professionals ensure they are supporting true Family Centered Care practices.

Q: What should parents and pros take away?
Parents should know that they play a valuable and important role in their baby's care team and that they are their baby's best advocates. Professionals should be reminded that Family Centered Care is more than just a catch phrase and is vital to babies' outcomes.



Download here:
<http://bit.ly/PremieBOR>