



# Preemie Family

## Preemie Life

### Zachary Nicholas Jackson



Photo Credit: Nurtured By Design

**Gestational Age:** 28 weeks

**Weight:** 1 lbs. 15 oz.

**Days in the NICU:** 155 days

**Proudest Moment (NICU):**  
When we took him home after 5 months of hospitalization.

**Most Terrifying Moment:**  
When Tropical Storm Allison shut down the hospital and all of his life-support equipment.

*Coming Soon!:*  
Check [www.PreemieWorld.com](http://www.PreemieWorld.com) for Zachary's full journey from NICU to now.

### Parent Tip:

*For the best possible quality of life for a lifetime, be in the NICU 24/7 (or as long as possible) and kangaroo your baby at least 80% of the time you are there.*

## Advocate: Pediatrics Article/NIDCAP

With her research to help reduce neonatal stressors in the NICU and the creation of the NIDCAP Federation International training program, Dr. Heidi Als has made a difference for preemie families worldwide. Yet AAP's journal *Pediatrics* printed an article that is misleading and serves to discredit NIDCAP. **Please sign & pass on this petition:** <http://bit.ly/NIDCAP>

## Preemie Resource: Important Information Sheet

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 "Important Information."** "With so much paperwork, it gets overwhelming," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "This sheet provides the caregiver with the numbers and

other information, all in one place. That way in an emergency people can be easily contacted because the information is at your fingertips." 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/ImpInfo> **And check out many more here:** <http://bit.ly/PreemieFreebies>

## To Do List



**CONGRATS:** to Dorothy Martinez (little man DVD contest) and Marissa Esquivel (Love & Logic Special Medical Needs Books/DVD)



What are you doing for International Kangaroo Care Awareness Day on May 15<sup>th</sup>?



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



**MARK YOUR CALENDAR!**  
*For the Love of Babies Celebration & Reception*  
Hand to Hold  
May 17, 2013  
Austin, TX  
<http://www.handtohold.org>

*Carter's Run for Dandy-Walker*  
Dandy-Walker Alliance  
May 19, 2013  
Ashburn, VA  
<http://www.cartersrun.org>

Have an event to share? Email us details at [connect@preemieworld.com](mailto:connect@preemieworld.com)

*Tools and Resources  
for the Preemie Community*

## Preemie Terms: Kangaroo Care

### **Kangaroo Care (also known as Kangaroo Mother Care):**

A wonderful way to connect with your baby and give him or her the amazing comfort and stability of health. This procedure involves placing your diaper-only baby (plus leads, etc.) on your chest. Quickly you notice that the monitor shows your baby's stats improving and that your baby is much more



peaceful and can fall into a very deep slumber. This is something that both moms and dads can do (though dads need to be prepared for a little chest hair pulling).

One thing that's difficult sometimes in this high-tech world in which we live is to begin to rely more on the monitors and machines than the mother. This is where the natural course of mothering turns out, indeed, to be the best medicine.

*This excerpt is from **The Preemie Parent's Guide to Survival to the NICU** at [www.PreemieWorld.com](http://www.PreemieWorld.com)*

## Support: Irish Premature Babies



**Outreach:** Ireland

**Established:** December 31, 2009

**Web:** [www.irishprematurebabies.com](http://www.irishprematurebabies.com)

**Focus:** All families who have had a premature infant regardless of outcome.

**Programs:** Support, with workshops for mothers, a buddy system, meet and greet, online connections.

**Advocacy:** Working on a 24-hour neonatal transport service in collaborating with NICU staff and government politicians.

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



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

**"Like" our FB page  
from 5/1/13 to 5/27/13  
and you could win a copy of the  
award-winning *little man* DVD  
from PreemieWorld!**

**<http://bit.ly/FBPreemie>**

*Parents & Professionals:  
Subscribe to our FREE newsletters today @  
[www.PreemieWorld.com](http://www.PreemieWorld.com)*

## Preemie Genius: Preemie Pathway NICU Necklace

### The Details:

#### **Item:**

Preemie Pathway NICU Necklace

#### **Company:**

Peek A Boo ICU

#### **Founder:**

Jodi Dolezel, R.N.

#### **Website:**

[www.PeekABooICU.org](http://www.PeekABooICU.org)



### The Genius:

Have a NICU doctor or nurse who went beyond the call of duty during the NICU stay?

The Preemie Pathway NICU Necklace is the perfect way to say thank you. The necklace is hand-stamped and hand-painted with 3 preemie footprints so as to represent a specific step in your preemie's path - courage, strength and victory.

#### COOL:

100% of the proceeds from the sale of this necklace will go towards PeekABooICU's new NICU Now Program which provides Journey Necklaces to NICUs across the country by sponsoring a mother and her baby on the NICU journey.

## After the NICU: Changes to Your Address Book

*With RSV season and germs in general parents of preemies are likely to find their address book of family and friends changes that first year.*

Family and friends believe the NICU is in the past and so you should just "relax." But life has irrevocably changed and so have you. When is a connection toxic and it is time for a break? When the person:

- Isn't willing to accept that you have been through was life-altering and you need to heal.
- Cares more about his/her needs or about fun than your baby's fragile immune system.
- Lacks respect for your role as your baby's parent and caregiver.

## Preemie Support Online

### On the Preemie Support Forum on INSPIRE:

Want to connect with almost 15,000 other parents of preemies online? Check out the [www.Inspire.com](http://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" and "Preemies with Feeding Issues." Check out some of our more recent topics:

"Child Care Options"

"New Feeding Aversion Blog"

"Preemie Success Stories"

### On PreemieWorld's Twitter Page:

"ARTICLE: Music therapy can comfort premature babies - <http://ow.ly/knuCu> "

### On PreemieWorld's Facebook Page:

"PREEMIE UPDATE: Maddox Alan Rawn - <http://bit.ly/MaddoxRawn> "

### On PreemieWorld's LinkedIn Group:

"ARTICLE: Parents not informed premature babies at risk in study - <http://ow.ly/jZXtE> "

"ARTICLE: Lullabies Sooth Preemies, Parents Alike - <http://ow.ly/k5y10> "

## Get "Social" With Us!



[www.PremieWorld.com](http://www.PremieWorld.com)  
[www.LittleMantheMovie.com](http://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
- Little Man the Movie


*Tools and Resources  
for the Premie Community*




Prolonged, effective, safe, and hands-free Kangaroo Care sessions. Guaranteed.




[www.nurturedbydesign.com](http://www.nurturedbydesign.com)



"Little man" is every preemie parent's story



[www.littlemanthemovie.com](http://www.littlemanthemovie.com)

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## Q&A: About International Kangaroo Care Awareness Day - May 15<sup>th</sup>

*Nurtured by Design, Inc. came about when Founder Yamile Jackson, Ph.D., PE, PMP had a premature infant and wanted a way to be with her son during the NICU stay. 12 years later, Yamile sponsors "International Kangaroo Care Awareness Day."*

**Q:** *How did this special day come about?*

When my son Zachary was in the NICU in 2001 I kangaroo'ed him for 5-7 hours every day. Today, regardless of all of the science behind KC parents are not kangaroo'ing their babies nearly that much. So the day is to raise awareness and educate everyone on the lifelong benefits of Kangaroo Care for NICU and in postpartum babies.

**Q:** *What do you want parents to know about KC?*

**A:** Kangaroo Care is not just for bonding. KC is the opportunity for a baby to develop and mature as much as possible outside of the womb, as stated by clinical evidence. Rule of Thumb: Premies kangaroo for 6 months.

**Q:** *What types of resources are you providing for this?*

**A:** We help facilitate longer kangaroo sessions. Our website has information about Kangaroo Care for NICU parents: <http://bit.ly/Y0iKPK> Also for NICUs we have resources at <http://bit.ly/KangaCare> For more information email [kangaroo@nurturedbydesign.com](mailto:kangaroo@nurturedbydesign.com)