



# Preemie Family

## Preemie Life

### *Maddox Alan Rawn*



*Photo Credit: Rawn Family*

#### **Gestational Age:**

24 weeks, 1 day

#### **Weight:**

1 lbs. 12 oz.

#### **Days in the NICU:**

153 days

#### **Proudest Moment (NICU):**

After choosing to not sign a DNR, Maddox cleared the infection that was life-threatening. He was given a 1 in 3 chance of surviving.

#### Coming Soon!:

Check [www.PreemieWorld.com](http://www.PreemieWorld.com) for an update on Maddox now!

### Parent Tip:

*Be involved in your child's care as much as possible and ask a lot of questions.*

## Advocate: NIDCAP Needs You!

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>

## To Do List



**Deadline Approaching:** 30 April 2013 is the end of the "For the Love of Babies" campaign by Hand to Hold ([www.HandtoHold.org](http://www.HandtoHold.org))



Can't sign up for "For the Love of Babies" campaign? Deb Discenza has a page - consider donating here: <http://bit.ly/Discenza>



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



#### MARK YOUR CALENDAR!

**Fragile Beginnings Support Call**  
JF & CS Boston  
April 9, 2013 NOON - 1 p.m. ET  
Worldwide  
<http://bit.ly/FragileBeginnings>

**8<sup>th</sup> Annual Golf Tournament**  
Katelyn Hall Foundation  
April 22, 2013  
Washington, DC area  
<http://ow.ly/9N1w>

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

*Tools and Resources  
for the Preemie Community*

## Preemie Resource: Risk Factors & Need for Help

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 "Risk Factors & Need for Help."** "In reviewing the Love & Logic ([www.LoveandLogic.com](http://www.LoveandLogic.com)) series, I realized how preemie parents are at a real disadvantage," comments Deb Discenza, co-Founder of

PreemieWorld, LLC. "With the focus on the child's needs, setting limits takes a back seat. This tool gives you clues of when to seek help." 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/RiskFactor> **And check out many more here:** <http://bit.ly/PreemieFreebies>

## Term: Colostrum

## Support: Dallas Premie Parents

**Colostrum:** The yellow-ish breast milk that comes out after you start pumping breast milk or breastfeeding. It is also known as "Liquid Gold" by the nurses because it provides much-needed fats and nutrients for your baby.

*the pump since no one had come around to talk about pumping or breastfeeding in general.*

**Deb's Take:** *In my recovery room, I stared at the breast pump the morning after delivering Becky. Looking at my husband, I said we should consider my starting to use*

*I was disappointed with the tiny amount of yellow stuff that had come out after the 20 minutes of pumping. I told Gregg to take it to the nurse and see if we just needed to throw it out or not. Gregg came back and excitedly told me the nurse was thrilled and was currently rushing it down to the NICU – that it was "Liquid Gold."*



*The Gold Rush had nothing on how I felt at that moment. I felt like I had won the lottery and could do something to help my daughter.*

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



**Founder:**  
Jacqueline Neyland, BSW

**Year Established:** 2011

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

**Focus:** Providing support to families of NICU babies in the Dallas/Ft. Worth, TX region through in-person support and handmade gifts.

**Programs:** NICU get-togethers, holiday events, resources. Coming is a mentor program, antepartum support program, postpartum support and specialized NICU support.

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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 4/1/13 to 4/26/13  
and you could win a copy of the  
award-winning *little man* DVD  
from PreemieWorld!**

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

## Preemie Genius: Parenting Children w/Spec Med Needs

### The Details:

#### **Name:**

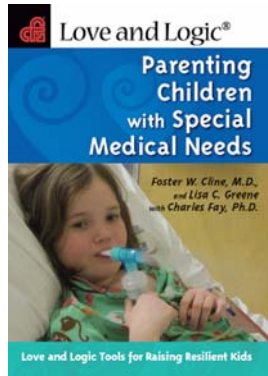
*Parenting Children with Special Medical Needs*

#### **By:**

Love and Logic Institute, Inc.

#### **The Website:**

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



### The Genius:

Parenting a child without needs is challenging. But when you add in special needs (medical, developmental, behavioral and more) parents are often at a loss how to bring up their child to be confident and self-sufficient in terms of life but especially in terms of the daily treatments and therapies that are needed in childhood and even into adulthood. Love and Logic's special series on special medical needs provides solid tips to get there. *And it works.*

#### **COOL:**

We are giving away two books and a DVD in the "Parenting Children with Special Medical Needs." The winners will be selected from the new subscribers to *Preemie Family* 4/1/13 - 4/26/13. <http://bit.ly/preemie1>

## After the NICU: Asking for Help

*In the early days and months of a NICU stay and even at discharge time, families are scrambling to tackle urgent matters at the hospital alongside maintaining demands of home, work and more.*

If someone offers help – ask him/her to set up and coordinate a "team list" for the family needs for meals, childcare, etc. These sites take the work out of coordinating:

- CaringBridge - <http://caringbridge.org>
- Lotsa Helping Hands - <http://bit.ly/HelpingH>
- Sign Up Genius - <http://bit.ly/XiLmVp>

## Preemie Support Online

### On the Preemie Support Forum on INSPIRE:

Want to connect with almost 14,000 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 forum has "rooms" that range from "In the NICU" to "Going Home and Family" to "Growing Up and Education" and more. Check out some of our more recent topics:

"CP Worries"

"Feeding Issues"

"Preemie and Walking"

### On PreemieWorld's Twitter Page:

"Special Preemie Update from our latest issue of 'Preemie Family': Henry Joseph Anicker - <http://bit.ly/HenryAnicker>"

### On PreemieWorld's Facebook Page:

"ARTICLE: Pain drug may prevent preemie lung damage - <http://ow.ly/jhq9P>"

### On PreemieWorld's LinkedIN Group:

"STUDY: NICU Understaffing Leads to Higher Infection Rates - <http://ow.ly/jhq97>"

"ARTICLE: Omega-3 DHA May Prevent Earliest Premies - <http://ow.ly/jhpR0>"

## 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

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## Q & A: The Hand to Hold "For the Love of Babies" Program

*Hand to Hold, a national NICU parent support program has launched its "For the Love of Babies" campaign happening now until 30 April 2013. Public Awareness Director, Amy Carr gives us the background on this event:*

**Q:** *How did this special fundraiser come about?*  
 "For the Love of Babies" is a 100-day fundraising and awareness campaign designed to help not only raise awareness of the challenges associated with a baby's hospital stay and infant loss, but also to fund Hand to Hold's efforts to expand parent support, education and resources to NICU families across the country.

**Q:** *No walking, just email and social media right? That will make RSV lockdown families happy. Any prizes?*  
**A:** Exactly. And yes, as part of the "For the Love of Babies" campaign, families who raise \$1,000 or more by April 30, 2013 may gift a one-year subscription to Hand to Hold's new [NICU Resource Library](#) to the hospital of their choice. Those who raise a total of \$500 or more during the campaign are entered into a random drawing for an Apple iPad Mini (16GB) valued at \$329. The drawing will be held May 2013.

**Q:** *Where do families go to sign up?*  
**A:** <http://donate.handtohold.org/forthelove>