



# Preemie Family



## Preemie Life

### *Matthew Cross and Callia Faith Castleberry*



Photo Credit: Castleberry Family

#### **Parent Tip:**

Learn and get familiar with NICU rules. Make sure to find out if you can help with your baby's care and get involved. Take a pic and write in your journal every day.

Editor's Note: Check out Made for a Miracle [here](#).

**Gestational Age at Birth:**  
31 weeks

**Weight at Birth:**  
Matthew: 5.2 lbs.  
Callia: 3.3 lbs.

**Time in the NICU:**  
Matthew: 143 days  
Callia: 56 days

**Proudest Moment (NICU):**  
Matthew: Getting off the vent entirely after having both lungs collapse.  
Callia: When she tolerated being held for Kangaroo Care at 5 days old.

Coming Soon:  
Check [www.PreemieWorld.com](http://www.PreemieWorld.com) to learn more about Matthew & Callia's journey.

## Advocate: Multiples Awareness Month

Many preemies in our community are twins, triplets, and more. Imagine having more than one baby in the NICU?! With this in mind, we are proud to celebrate all multiples as **April, 2016 is Multiples Awareness Month**. For information on multiples, especially the supertwins kind, check out our friends at **Mothers of Supertwins** at [www.raisingmultiples.org](http://www.raisingmultiples.org) #preemiemultiples

## Preemie Resource: Preemie Multiples are More to Love

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 "Preemie Multiples are More to Love."** "Multiples have been on the rise for a while now," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "In honor of Multiples Awareness Month we wanted

to create a graphic that represented multiples in our preemie community. They are true miracles!" Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce.

**Download it:** <http://preemie.us/PreemieMultiples>  
And **check more freebies right here:**  
<http://bit.ly/PreemieFreebies>

### To Do List



**CONGRATS:** [Judy Hess](#) won our little man DVD and C. Michael Gibson, MD won the *Tiny Steps My First Year Record Book*.



**LIKED US YET?:** PreemieWorld is doing another PreemieWorld Facebook page contest. See page 2 of this newsletter for details!



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



**MARK YOUR CALENDAR!**

*Tournament of Hope*  
Lily's Hope  
April 15, 2016  
Coopersburg, Pennsylvania, USA  
[www.pspplunge.com](http://www.pspplunge.com)

*Miracle Babies Run/Walk 2016 5k*  
May 1, 2016  
San Diego, California, USA  
[www.miraclebabies.org](http://www.miraclebabies.org)

Have an event you want to share with our community? Contact us at: [connect@preemieworld.com](mailto:connect@preemieworld.com)

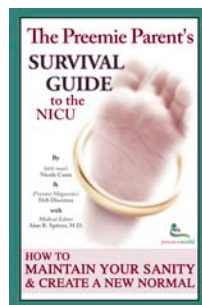
*Tools and Resources  
for the Preemie Community*

## Term: Therapy

**Therapy:** Anything being done to treat your baby for any condition. Most commonly, therapy is used to help stimulate your baby’s body to heal itself and catch-up in developmental milestones. You may find that your baby’s NICU has therapists on staff to help with this and/or that your baby will be prescribed a variety of therapies to receive

once home. All of it is helpful and will make a difference for your baby down the road.

**Some Types of Therapy:** Occupational Therapy, Physical Therapy, Speech Therapy, Vision Therapy, Music Therapy, Feeding Specialists.



This excerpt is from **The Preemie Parent’s Guide to Survival in the NICU** on sale at [www.PreemieWorld.com](http://www.PreemieWorld.com)  
\*\*We do bulk orders for hospitals\*\*  
[connect@preemieworld.com](mailto:connect@preemieworld.com)

## Support:

### Maison Alexander Support Group

*With the birth and survival of her 28-weeker son, **Maison, Mariann Shaw** learned a lot about faith and determination and felt a calling from God to help others in the form of a support group.*

**Established:**  
2014



**Outreach:**  
National

**Website:**  
[www.masgnicu.org](http://www.masgnicu.org)

**Programs:**  
Supporting families during their journey with gas/food cards, preemie clothes, items, breastfeeding information and more. We take heart in a place of encouragement, prayer, and donating items.

---

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



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

“Like” our FB page from 3/29/16 to 4/22/16 and you could win a copy of the award-winning *little man* DVD from PreemieWorld!

<http://bit.ly/FBPreemie>

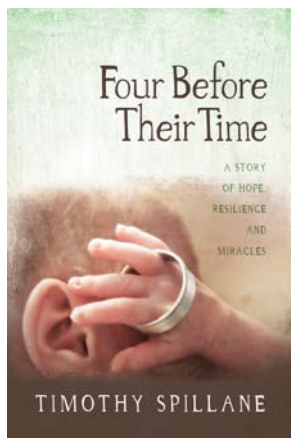
Parents & Professionals:  
Subscribe to our FREE newsletters today @ [www.PreemieWorld.com](http://www.PreemieWorld.com)

**The Details:**

**By:**  
Timothy Spillane

**Available at:**  
[www.4b4theirtime.com](http://www.4b4theirtime.com)

**Cost:**  
\$17.66 USD



## Book: Four Before Their Time

The arrival of quadruplets will throw any family into disarray and this book details that perfectly. Written by the grandfather who delivered the 24-week preemies, he filters their experiences through the lens of Christian spirituality. From PDA to brain bleeds to Hydrocephalus, from NEC to Cerebral Palsy, these tiny babies endure many of the common NICU nightmares. To add to this, it is set within the structures of the U.S. Army medical system and its own bureaucracy, which lends its own chaos to the tale. This is a solid read for parent and pro alike, specifically those who are preparing for the birth of multiples of any quantity.

*We're giving away this book! Follow us on Twitter by 4/22/16 to enter: <http://bit.ly/PremieTweets>*

## After the NICU: You are the Expert of Your Child

*After the push and pull of control in the NICU, you are likely feeling rattled and not sure where you fit into the medical and therapeutic maze post-NICU. You are the expert of your child and here is why:*

- You knew your baby first, before anyone else did.
- You have a physical connection to your child unlike anyone else.
- Your child seeks out your voice and your smell for comfort.
- Your child knows you are the voice for him/her.

*Have a preemie parent expert moment with a professional? Tell us and inspire our community! - #preemieparentexpert*

## Premie Support Online

### On the Premie Support Forum on INSPIRE:

Connect with *almost 26,000 parents of preemies for free* at <https://www.inspire.com/groups/preemie> for the *Premie Support forum*. It is the largest and most active forum online, *moderated by our own Deb Discenza*.

Looking for Hope - *In the NICU/PICU*

23 Weeks, 2 Days - *Introduce Your Very Important Premie*

Micropreemie Mom-Low Milk Production - *Premie Tips*

Mom of Micropreemie, Need Encouragement - *Premie Hope*

### On PremieWorld's Twitter Page:

ARTICLE: NICU Mom Guilt is Real

### On PremieWorld's Facebook Page:

STUDY: Drug Used for Premie Eye Disease Tied to Disabilities

### On PremieWorld's LinkedIN Group:

TRUTH: Neonatologists have One of THE Toughest Jobs in Medicine

COOL: Neos are Lifesavers Logo in Premie Pro

SMART: Music Therapy Helps NICU Babies Go Home Sooner

## 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:

- PremieWorld
- NICU Professionals
- Early Intervention Professionals
- Premie Parent Support Group Leaders
- Premie Parents

*Tools and Resources  
for the Premie Community*



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



**kangaroozak.**



**www.nurturedbydesign.com**



**TOWELS ARE NOT SAFE!**

**"SO MUCH BETTER!"**

**HUG ME JOEY** Infants and Children's Products

**WWW.HUGMEJOEY.COM**

NICU *Hope* Beads



COMMEMORATE & SHARE

Your NICU journey through jewelry...

*facebook.com/NICUHopeBeads* | 979.635.0825

*Interested in advertising? Contact us at [connect@preemieworld.com](mailto:connect@preemieworld.com)*

## UPDATE: International Neonatal Consortium

*In early March Deb Discenza attended the 2<sup>nd</sup> International Neonatal Consortium at the FDA.*

With neonatal drugs often being a minimized dosing of adult medications, not enough research has been done to 1) check the effectiveness of these medicines and 2) to consider new therapies specifically for this field. [The International Neonatal Consortium](#) recently convened at the FDA to take steps to rectify this across the areas of Retinopathy of Prematurity (ROP), Infections and Necrotizing Enterocolitis (NEC), hemodynamics (conditions relating to blood pressure), seizures and Bronchopulmonary Dysplasia (BPD).

*What is your #neonatalresearch priority?*

*Follow us on FB, Twitter & LinkedIn!*



*Left to Right: at the INC meeting - Deb Discenza (Mom to 30-weeker, PremieWorld, Inspire Premie, and Premie Parent Alliance), Wakako Eklund, DNP, APRN, NNP-BC (National Association of Neonatal Nurses), and Carole Kenner, PhD, RN, NNP, FAAN and CEO (Council of International Neonatal Nurses) and speaker at the event.*