



# Preemie Family

## Preemie Life

### *Sophia Marie Lowrie*



*Photo Credit: Anderson Lowrie*

### Parent Tip:

*As you sit next to your preemie, write down in a journal all of your feelings and your preemie's ups and downs. This will mean the world to you later.*

#### **Gestational Age:**

27 weeks, 3 days

#### **Weight:**

3 lbs. 4 oz.

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

34 days

#### **Proudest Moment in the**

**NICU:** The first time I held Sophia, she was 4 days old, and then I finally knew what love was.

#### Coming Soon!:

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

## Advocate: World Prematurity Day

November 17, 2012 is World Prematurity Day. Organizations and families world-wide are doing many things to help raise awareness about prematurity. What are you planning to do?

**Tell us on our PreemieWorld Facebook page and you could win a copy of the "little man" DVD. To go to our Facebook page simply post it on here - <http://bit.ly/FBPreemie> by 11/26/12**

## Preemie Resource: "We are Excited" Note for RSV Season

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 "We Are Excited."** "Homecoming is nervewracking enough but trying to educate family and friends on RSV season is tough," comments Deb Discenza, co-founder of PreemieWorld, LLC. "Parents often

worry about how to educate people without being demanding. So we give them a hand with that." 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/WeAreExcited> And check out more like this here: <http://bit.ly/PreemieFreebies>**

## To Do List



**SIGN IT AND PASS IT ON:** RSV Petition to give preemies the best shot at surviving RSV season: <http://www.RSVPetition.com>



**WINNER - Kim Searcy** won a copy of Kasey Mathews' book *Preemie: Lessons in Love, Life & Motherhood* - Congrats Kim!



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



#### **MARK YOUR CALENDAR!**

**OK Infant Alliance Toolkit Webinar**  
Nat. Premature Infant Health Coalition  
November 15, 2012  
<http://bit.ly/OKIAWebinar>

**Neonatal Therapy Teleseminar**  
Nat. Assoc. of Neonatal Therapists  
Date TBA - check website!  
<http://www.neonataltherapists.com>

Have an event to share? Email us with the name, date, location and website link at [connect@preemie-world.com](mailto:connect@preemie-world.com)

*Tools and Resources  
for the Preemie Community*

## Term: Necrotizing Enterocolitis

### **Necrotizing Enterocolitis (NEC):**

A disease that primarily infects the immature bowel of the premature infant. Intestines are perhaps the weakest in the body's systems and are easily infected by infection and blood flow changes. NEC is a toxic inflammation in the intestine that literally kills the intestine.



Your baby's medical team knows that it is so very important to watch for this and to catch it immediately since it can spread so quickly and cause significant and quite serious damage. Often, NEC is caught by the signs of sepsis in the blood stream.

The least invasive measure of treatment is to have your infant be treated with a series of antibiotics while remaining off foods and being fed through a central line or Broviac. In the worst case scenario your baby will be subjected to surgery where the sick part of the intestine is removed.

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

## Support: Holding Tiny Hands



**Year Established:** 2010

**Focus:** Provides support services to parents of micro-preemies and infants with chronic health issues who endure lengthy stays in the NICU.

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

**Outreach:** Regional to Iowa, mainly serving Blank Children's Hospital and Mercy Medical Center.

**Programs:** Tiny Treasures Gift Bags, "Meals for Moms and Dads," Educational Outreach, Helping Hands Project and Parent Mentoring program (new in 2013).

*Have a support group you want to share? Contact us! [connect@preemieworld.com](mailto:connect@preemieworld.com)*

## PreemieWorld: Founder in the Media Advocating for Preemies



**preemie**world

*Sign the Premie/RSV Petition at [www.RSVPetition.com](http://www.RSVPetition.com) and pass it on!*

**PremieWorld co-Founder Deb Discenza has a soft spot for preemies and their families.** She should, she's walked the halls of the NICU and cared for her own daughter born at 30-weeks gestation.

So when the American Academy of Pediatrics changed its guidelines regarding the Synagis injections, she felt compelled to speak out through a petition that has garnered over 3,400 signatures and media interviews regionally and nationally. "My daughter received her injections and did well," notes Discenza. "Shouldn't every preemie get that opportunity? To me, it is wrong to take away this treatment." **Sign the Premie/RSV Petition at [www.RSVPetition.com](http://www.RSVPetition.com) and pass it on!**

*Parents & Professionals: Subscribe to this FREE newsletter at [www.PremieWorld.com](http://www.PremieWorld.com)*

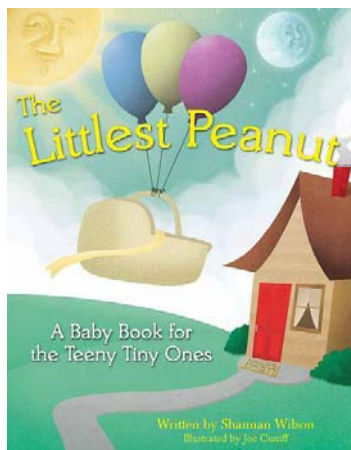
## Preemie Genius: *The Littlest Peanut*

### The Details:

**Name:** *The Littlest Peanut*

**By:** Shannan Wilson  
(<http://www.thelittlestpeanut.com>)

**Focus:** Author Shannan Wilson created this baby book for “the Teeny Tiny Ones” after having two preemies herself.



### The Genius:

Preemie parents feel so isolated in the ability to celebrate their baby and the myriad of truly special milestones achieved in the NICU. This book is for parents who want to capture those special moments in a simple, yet elegant way. With soothing illustrations and text that is friendly and respectful of the ups and downs of the NICU rollercoaster, this is a great gift for family and friends looking to do something caring and unique to help the family.

*COOL:* We have a copy to give away to one lucky new @PreemieWorld Twitter follower that starts following us from 11/1/12 - 11/26/12:  
<http://bit.ly/PreemieTweets>

## After the NICU: *Juggling Life at Home*

Coming home from the NICU is joyful yet stressful for parents of preemies.

In essence they have traded being at the hospital with bringing the world into their house in the form of visiting nurses, nursing care, medical equipment vendors, therapists and more. Here are a couple of tips to keep sanity and a schedule:

**Set Specific Hours.** The doctors have set office hours, why not you? Set up chunks of time for these incoming appointments.

**Be Firm.** It is time to learn the *polite* version of “no” and stick to it. You have done enough working around everyone else. They need to help you for a change. Remember you are your baby’s advocate!

## Preemie Support Online

### On the Preemie Support Forum on INSPIRE:

Want to connect with over 12,000 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 topics:

“So Tired of RSV Season and No One Understanding”

Where to Get Good Shoes post-Stride Rite?”

“I got a ‘You are an Awesome Mom’ Compliment!”

### On PreemieWorld’s Twitter Page:

“Please LIKE us on Facebook – *The Preemie Parent’s Survival Guide to the NICU* –  
<http://bit.ly/PreemieBook>”

### On PreemieWorld’s Facebook Page:

“ARTICLE: NIH study shows drug fails to prevent preterm birth in high risk group -  
<http://ow.ly/eAA0i>”

### On PreemieWorld’s LinkedIN Group:

“ARTICLE: Could Hypertension in Pregnancy Harm Child’s Thinking Skills for Decades? -  
<http://ow.ly.end1B>”

## 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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"Little man" is every preemie parent's story



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## Q&A w/Gigi of Families Blossoming: What is a Premie Coach?

**Q:** What is a Premie Coach?

**A:** A Premie Parent Coach is a Professional Life Coach who specializes in working with parents of premies.

**Q:** How can a Premie Coach help our family?

**A:** Premie parents face unique challenges on a daily basis, different from the norm. Using proven coaching techniques and principles, coaching helps parents overcome these challenges in a positive and forward-moving way. The goal is for parents to reach a point of hope, clarity and optimism for their lives.

**Q:** What are signs that families could use a coach?

**A:** 1) feeling overwhelmed, lonely, isolated and sometimes ill-equipped as a parent, 2) feeling frequent waves of emotions (i.e. guilt, anxiety, anger) 3) experiencing a loss of your identity, anxiety over whether your child will develop normally and/or difficulties in your relationships, and 4) wanting to move forward but feel stuck.

Check out Gigi's full article in the PremieWorld "Freebies4You" section: <http://bit.ly/PremieCoach>

Learn more about Families Blossoming at:  
<http://www.familiesblossoming.com>