



# preemiepro

support. educate. advocate.



## HUG AN ANGEL PARENT

*one issue at a time with PreemieWorld*

**Angel Parents Need Ongoing Support.** October is Pregnancy and Infant Loss Awareness Month. Parents (yes, they are *still* parents) around the community will be recognizing their babies, born and in utero that died. Many people think that the best thing to do is to not talk about the death because it might upset the parent. Honestly, *not talking* about the child is upsetting. Ask the parent to talk about their baby. Ask them about their child and if they were able to name the baby, call the baby by his/her name. These parents are desperate to have this baby remembered and every single opportunity they can talk about him/her, they will be grateful. So hug an angel parent, ask about **Zoe**, about **Julian (JU2)**, about **Emma**, about **Graham**. This month, these are the children I choose to remember. - **Deb**

## IN THIS ISSUE:

### **Hug an Angel Parent**

Deb Disenza talks about the importance of continually remembering and talking about a beloved preemie angel.

### **Preemie Genius: Our Only Time**

We highlight the latest Preemie Genius product that is making a difference with preemies everywhere.

### **Preemie Support: Court's Preemie Foundation**

A group that is making a difference in the field of prematurity and neonatology.

*Look for worldwide events*

<https://premieworld.com/events/>



*Above: Honor a friend or colleagues preemie angel with our type-able certificate at [PreemieWorld's website](#).*



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

## TO DO LIST:

- New - PreemieWorld Tags.** Tag you are it, check out page 4 for a section all about **YOU**.

**Freebies.** Get free downloads from PreemieWorld  
 at <http://bit.ly/PreemieFreebies> Have an idea for a freebie? Contact us and let us know.

**Pregnancy & Infant Loss Awareness Month**  
 October, 2018 | Worldwide  
<https://babylloss-awareness.org/>

**COINN Africa Conference 2018**  
 October 5-6, 2018 | Kigali, Rwanda  
<https://coinnurses.org/event/coinn-africa-conference-2018/>

## CONNECT WITH US:

Have an event you want to share with our community? Visit <https://premieworld.com> or drop us a line at [connect@premieworld.com](mailto:connect@premieworld.com)!

 @ [www.facebook.com/PreemieWorld](https://www.facebook.com/PreemieWorld)

 @ [PreemieWorld](#)

 @ [PreemieWorld](#)

 @ [www.instagram.com/premieworld](https://www.instagram.com/premieworld)

## PREEMIE FREEBIE: RSV CHECKLIST (FOR CRIB/INCUBATOR)

PreemieWorld provides a number of free handouts to be used in the NICU and beyond on the "Freebies For You" page of our website. This month's freebie is an **RSV Season Checklist** perfect for the incubator, crib and more.

Parents and even the NICU, PICU team and pediatrics teams can use a reminder of hand washing, not going near the baby if they are sick and more.

*Get this at Preemie Freebies at <https://premieworld.com>*



**Yes, it is cold/flu season. But for the preemie community it is also RSV season. We parents live in fear of our children getting RSV because it can make them very, very sick. This playful checklist is perfect for the NICU/PICU.**

~ Deb Disenza, PreemieWorld



# SUPPORT: COURT'S PREEMIE FOUNDATION

Founded in June of 2017, **Court's Preemie Foundation** is a non-profit organization based out of Columbus, Ohio. Working as an employee at Toys R Us/Babies R Us, **Courtney Smallwood** recognized the struggles many families had finding items for their unexpected babies(s). "Many families claimed the items that were hardest to find were ones for premature babies and my mother always told stories about having difficulty to find items appropriate for me when I was born early," notes Courtney. As a result, Courtney, with the help of her mother, **Stephanie** (co-founder), started to build Court's Preemie Foundation.

In addition to providing families with basic necessities, Court's Preemie Foundation also now strives to educate families on infant mortality and safe sleep in order to ensure individuals can keep their babies as healthy and safe as possible.

**Year Established:** 2017

**Website:** <https://courtspreemiefoundation.weebly.com/>

**Outreach:** Columbus, OH

**Founders:** Courtney Smallwood and her mother, Stephanie



## ORG: THE NURSERY PROJECT

Helping families in a difficult situation celebrate the birth of a baby is truly a gift from **The Nursery Project**, a non-profit based outside of Louisville (New Albany, Indiana, USA). "We exist to mobilize communities to offer support to families that are welcoming new children into their home while facing difficult circumstances. This could be a family that has a complicated pregnancy and are facing extended stays in the NICU, families with children born with special needs, adoptions, financial difficulties, etc.," says volunteer **Barb Andres**. "In June of 2017 one of our best friends delivered a little boy with Down Syndrome," Andres continues. "She had a difficult pregnancy and was too emotional to work on a nursery. As she was in the hospital recovering, our group of friends surprised her with an extreme makeover Nursery edition! We spent the weekend completely building and designing her dream nursery - with the help of all of her friends and family. We documented the whole thing on Facebook and people could watch from afar and jump in to help when they could. It was amazing - and we saw what can happen when people come together to support someone in a real tangible way."

*Check out more of their stories and projects at [www.TheNurseryProject.org](http://www.TheNurseryProject.org)*

**Year Established:** 2018

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

**Outreach:** Regional - primarily southern Indiana right outside of Louisville (New Albany, Indiana, USA).



ONE OF THE TOP 10 FILMS OF THE YEAR! — *The Advocate*

**W**ITHOUT WARNING, a family is brought to its knees when they must choose between the destruction of their idyllic family and the life of their infant son. When Nicholas is born ten days early, he weighs only one pound and faces impossible odds for survival.

Exposing the harsh realities of preterm conditions by portraying her family with unflinching honesty, filmmaker Nicole Conn invites the viewer to probe the most private of questions with her: *when does caring become cruelty? and at what price life?*

"Such a personal piece of filmmaking, Conn makes Michael Moore look like an impartial observer," writes film critic Steve Warren of Miami's *The Weekly News*. Tim Grierson of *LA Weekly* calls the film "an altogether riveting portrait of motherly devotion at its most primal."

**37 Minutes Extra Footage with Family Update, Deleted Scenes, and Preview of "The Nurses"**

**Outstanding from every perspective: humanely, emotionally, educationally and artistically. Every parent, every person working with preterm infants and their families must see this movie.** — *De Hellebrekers, Harvard Medical School and Director of Neurobehavioral Infant and Child Studies at Children's Hospital, Boston*

Color 112 min. 5.1 Dolby Digital Surround Sound Not Rated  
Aspect Ratio 16:9 Worldwide Regional Coding English  
SOUNDTRACK AVAILABLE AT [WWW.LITTLEMANTHEMOVIE.COM](http://WWW.LITTLEMANTHEMOVIE.COM)

**DAVID C. BOHNETT** PRODUCED BY **NICOLE CONN** WRITTEN & DIRECTED BY **NICOLE CONN** AS "LITTLE MAN"  
WITH **DAVID C. BOHNETT**, **DANNY JACOBSEN**, **SEAN PRESENT**, **JOE VAN WITSEN**, **BRIAN HOVEN**,  
**PRODUCED BY** **BRIAN HOVEN** **PRODUCTION DESIGNER** **STACEY SILVER** **EDITOR** **KATE WELLS** **PROPS** **MARK CHAT**  
**PROPS** **DAVID C. BOHNETT** **PROPS** **DANNY JACOBSEN** **PROPS** **NICOLE CONN** **PROPS** **NICOLE CONN**  
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[www.littlemanthemovie.com](http://www.littlemanthemovie.com)

**WINNER OF 12 BEST DOCUMENTARY AWARDS**

(LOS ANGELES) (SAN DIEGO) (PALM BEACH) (GLITTER AWARD) (LONG ISLAND) (CHICAGO)  
(NEW YORK) (PHILADELPHIA) (CHICAGO) (MIAMI) (INDIANAPOLIS) (WASH DC)

Sometimes the greatest love story...

**little man**  
a documentary film by nicole conn

*Los Angeles Times*  
"AN END-TO-END, HEART-IN-YOUR-SOFA SUSPENSE STORY"  
*Wall Street Journal*  
"IT'S PURE JOY. FEW PEOPLE CAN WATCH WITHOUT FEELING THEIR OWN MORAL COMPASS GO HAYWIRE"  
*People Magazine*  
"A TESTAMENT TO FAMILY LOVE"  
*New York Times*  
"AN UNUSUALLY HONEST FILM. AN INSPIRATION"

...is about your very own family.

**SPECIAL LIMITED EDITION WITH FAMILY UPDATE**

*"little man" is every preemie parent's story*



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

## BOOK: OUR ONLY TIME

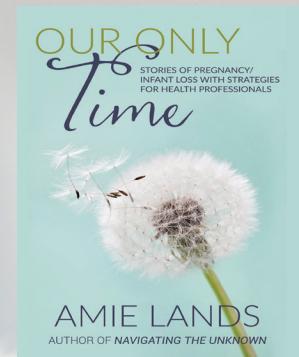
Our Only Time: Stories of Pregnancy/Infant Loss with Strategies for Health Professionals by Amie Lands is an important book that is useful for both preemie families as well as preemie professionals. With incredible wisdom woven into stories by grieving mothers themselves and then the author's focus on strategies for health professionals, the book is important to read from cover to cover.

This is one book that every single OB/GYN, NICU, PICU and pediatrics staff member will want to have as required reading upon hire and again throughout their tenure at the hospital. Every professional has something to learn from this book on how to help families navigate this extremely tough time in their lives. It is well passed the time that we honored a baby's death with the same care and due diligence we would the average patient in the unit.

**“ All losses, no matter gestation or age of baby, are worthy of validation. Validate all losses.”**

~ Our Only Time

*One winner will receive a FREE copy of this book.  
We'll select one NEW Instagram follower prior to 10/22/18. Enter to win by  
following us on Instagram at [www.Instagram.com/PremieWorld](http://www.Instagram.com/PremieWorld)*



Congrats to Laura Gold the winner of September's giveaway, a copy of Candy Campbell's Good Things Come in Small Packages ([www.CandyCampbell.com](http://www.CandyCampbell.com))

## Q'S TO THE PEDIATRICIAN ABOUT RSV

Respiratory Syncytial Virus (RSV) strikes fear in every preemie parent in the NICU but especially at discharge time and at home. The public is largely ignorant about RSV so make sure you talk to your pediatrician as the season starts.

- Should my child be on full or partial house lock down this cold/flu/RSV season?
- How do I handle doctor's appointments during this time? I worry the waiting room is dangerous for my child.
- What are the symptoms I should watch for in terms of a cold, flu, and RSV?
- If I suspect any of these illnesses, and it is after hours, how should I handle the situation? Stay home and handle it as best I can on my own? Call your office and page you? Take my child to the nearest Emergency Room? At what point should I be prepared to call for an ambulance?



## PREEMIE FAMILY ONLINE

### Inspire Preemie Community:

Parents, Grandparents, Adults  
& High-Risk Pregnancies

Help your families connect almost 46,000 parents of preemies worldwide! This close-knit forum is moderated by our own Deb Discenza.

The community connects families in the NICU, at home, into the school years, adult preemies and women with high-risk pregnancies.

<http://preemie.inspire.com>

PreemieWorld on Twitter

<http://bit.ly/PreemieTweets>

PreemieWorld on Facebook

<http://preemie.us/PreemieFB>

PreemieWorld on Instagram

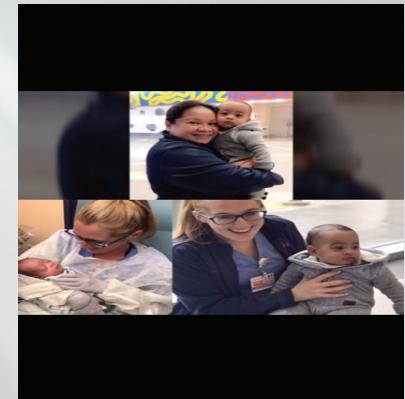
<http://preemie.us/PreemieInstagram>



# PW TAGS: PREEMIE NOAH

Our latest preemie highlight amazing Noah ([@tamayonoah](#)):

Happy Neonatal Nurses Day . . . I can't ever thank enough these nurses that for 3 months were like family. Not only took care of Noah but of course in many ways took care of me. I know I wouldn't have been able to even learn the things I was taught. Or care for Noah the way they did. Thank you @jpresss @deidrehopern @deedeepickles\_ and the many others that were there for my family. It takes a big heart to care for these souls!



## We Could Highlight Your Preemie in Our Newsletters & Online!

**Deadline:** Like, tag & include @PreemieWorld in your update post by the 15th of the month.

**Who:** Preemies in the NICU, Preemie Angels, Post-NICU, Children, Teens, Adults.

**Networks:** Twitter (@PreemieWorld), Facebook (PreemieWorld, The Preemie Parent's Survival Guide to the NICU, NICU Nurses' Day, Preemie Study), Instagram (@PreemieWorld).

## FEATURED PREEMIE ANGEL:

### Royal Newson:

Dear Lord, Please look over my sweet baby boy. I realize Royal J. was ill and was better off in Heaven and not here suffering. Momma loves you RJ and you will always be in my heart. ~ Anonymous

We welcome your submissions for this section of Preemie Pride, Preemie Angel, and Preemie Prayer at [PreemieWorld.com](https://PreemieWorld.com)



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**Preemie Tags**  
Honor the Journey

NAME: BABY DOE  
DOB: 01/01/2006  
WT: 500 GRAMS  
GEST WEEK: 25.5

[preemie-world.com](http://preemie-world.com)

## SNEAK PEEK

In next month's issue....

### New Section: PreemieWorld Tags

Tag us and we're it! But it is really all about you, Social Media Follower! We share the love right back to you.

### Preemie Genius

We are reviewing a new item of interest to parents of preemies and pros. Don't miss it!

### And More!

Have you subscribed to Preemie Family yet? It's free!

<http://bit.ly/preemie1>

## JOIN THE CONVERSATION

Always remember, you know what is best for your child!

~ Deb Discenza, PreemieWorld



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@ [Preemie Parent's Survival Guide to the NICU](#)



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