



**premiepro**  
support. educate. advocate.



## PREEMIE BLACK HOLE

*recreating the PremieWorld*

I was the “Smiling Mom” in the NICU. You know, the one that looks like she has it together? She is fully showered, is pumping like a champ and appears to be handling everything just fine? Yeah, that was me. Even as the alarms went off, as the sepsis set in, even as major feeding issues caused all sorts of havoc heading toward discharge. At home each night was a different story as I would sit at my computer watching again and again the haunting video my father-in-law made of our daughter’s first hours in the NICU set to acapella music and cry hysterically. Becky came home and I thought all was fine but the black hole slowly covered me. When Becky hit 18 months old and I learned she qualified for Early Intervention services due to global delays, my ability to sleep was completely off. It was as if I were spiraling downward in a Premie Black Hole and struggled with what ultimately Postpartum Depression and PTSD. I spoke up, got help and got better. It turns out I was not alone in this per our latest survey report: <https://premie.us/PPDPTSDReport>

*We have a new survey - Premies & Breastfeeding:*

<https://premie.us/BreastFeedingSurvey>

*- Deb #celebratepreemies*

## IN THIS ISSUE:

### ***Premie Black Hole***

Deb Disenza talks about the black hole of Postpartum Depression and PTSD as a Premie Mom.

### ***Premie Genius: NICU Milestone Cards***

We highlight the latest Premie Genius product that is making a difference with premies everywhere.

### ***Premie Support: FSNCC***

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

*Look for worldwide events*

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



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

## TO DO LIST:

✓ **PremieWorld Tags.** Tag you are it, check out page 4 for a section all about [our Instagram followers](#).

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

✓ **2nd Int'l Conf Advances in Neonatal/Ped Nutrition**  
July 8-10, 2019 | Berlin, Germany  
<https://pediatricnutrition.pediatricsconferences.com/>

✓ **Int'l Conference on Pediatrics & Neonatology**  
June 25-26, 2019 | Amsterdam, Netherlands  
<http://pediatrics-congress.alliedacademies.com/>

## 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)!



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

## PREEMIE FREEBIE: PPD/PTSD SURVEY REPORT

PremieWorld 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 a summary report of our PPD/PTSD survey from June.** You can get it by going to the link below (and watch social media for parent quotes throughout the month):

***PPD/PTSD Survey Results:***  
<https://premie.us/PPDPTSDReport>

“ It took me to decide something was wrong and to get help. No one around me said a word. No doctors, no nurses, no social workers. No one even asked how I was doing. This went on for 18 months until I crashed. It was hell.

~ Deb Disenza, PremieWorld

”



# SUPPORT: FSNCC

“Family Support Network of Central Carolina (FSNCC) was founded in 1989 by a coalition of parents, medical professionals, and staff from community agencies serving children with special needs and their families. The organization’s mission is to provide support, education, and caring connections to those who have a child with special needs or who have experienced a NICU stay,” notes Executive Director Nancy Micca. Micca herself has a son with special needs who has greatly impacted and inspired her work within this organization.

Some of the services FSNCC provides includes:

- Parent Mentors
- Parent Groups
- Sibling Groups,
- Books for Babies Program
- Home Visitation Program

Year Established: 1989

Website: [www.fsncc.org](http://www.fsncc.org)

Outreach: Guilford County (Greensboro, NC) & Region

Executive Director: Nancy Micca



# ORG: BABIES WITH BOOKS

The future is bright for many preemies thanks to the selfless and generous work started in 2017 by then 15-year high school sophomore and Founder Benjamin Olshin in Portland, Oregon and his peers. Centered on the NICU at Randall Children’s Hospital, Olshin came into this due to family experience with the NICU. His mother is a neonatologist and his aunt was a 28-week preemie. Olshin notes, “While volunteering in middle school at a non-profit providing free books to low-income children, I learned about the importance of early literacy for school and social success and wondered whether this work could be extended to the NICU. I subsequently learned about research demonstrating that NICU babies, especially those cared for in single rooms, have higher rates of deficits in speech and language development. I also learned that reading, singing and talking with NICU babies appears to support these infants’ speech and language development, promote early literacy and support family bonding.”

For more information visit  
<https://www.babieswithbooks.org/>

Year Established: 2017

Fact: >150 families served since January 2018

Next: Extend the project across the hospital



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

WINNER OF 12 BEST DOCUMENTARY AWARDS

Without 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 100 days early, he weighs only one pound and faces impossible odds for survival.

Exposing the rawest of human 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: humanly, emotionally, educationally and artistically. Every parent, every person working with preterm infants and their families must see this movie.” — Dr. Heidi Lieke, 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.LITTLEMANMOVIE.COM](http://WWW.LITTLEMANMOVIE.COM)

DAVID C. BORNETT, NICOLE CONN, JOEL VAN WITSEN, BRIAN HOVEN, DANIEL JACOBSEN, SEAN PRESTANT, KATIE WELLS, MARK CHATT, BRIAN HOVEN, STRAZZ STUBER, NICOLE CONN, DAVID C. BORNETT

...is about your very own family.

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SPECIAL LIMITED EDITION WITH FAMILY UPDATE

“little man” is every  
preemie parent’s story



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



# EVERYtinyTHING: NICU MILESTONE CARDS

In recent years, special cards to celebrate the unique milestones of a NICU baby are in vogue. These are big moments for the NICU parent paparazzi set, desperate to have those special photo-worthy moments documented for baby books, for social media and for the baby-obsessed grandparent.

**EVERYtinyTHING**, a company to all things tiny babies has a unique set of NICU Milestone Cards that will be sure to delight parents, social media lovers and grandparents the world over. The 24-card set is full of cute, colorful graphics that are NICU friendly and gender-neutral and include messages around themes such as:

- Mom's/Dad's First Holding
- No More Feeding Tubes
- I'm Off the Ventilator Today
- Open Crib
- No More Phototherapy
- I'm Breathing on My Own Today
- and much much more . . .

For more information visit: [www.EverytinyThing.com](http://www.EverytinyThing.com)

ONE LUCKY Instagram winner that TAGS @PremieWorld in a post on Instagram AND is CURRENTLY IN THE NICU, will get a free set of these cards. Ends 7/15/19.



## WHEN YOU NEED HELP

Many a parent we know has worked through major trauma in the NICU only to believe that once they get the baby home they will be "fine." Postpartum Depression and PTSD affects both parents and it can hit hard at home. Signs you need to get help:

- ✓ **Withdrawing from Life.** You may not even realize that you are doing it, but slowly you pull away from everyone and everything you enjoyed in life. Even your baby.
- ✓ **Flashbacks.** It isn't just you. We all get them. Flashbacks to the beeping monitors, to your child getting really sick to the smell of the hospital soap to the doctor or nurse giving you bad news. The slightest thing can trigger bad memories.
- ✓ **Sleep Deprivation on Steroids.** Not sleeping (beyond the typical deprivation of having a baby at home) even though you are beyond exhausted? You deserve rest and you won't get it by ignoring this symptom.
- ✓ **Help Yourself = Help Your Baby.** Listen up, Moms and Dads: Therapy and medication is not something to be ashamed of or to feel you are being selfish. You have a child who needs you and research shows how these conditions can actually affect a preemie's developmental outcomes. Get to a doctor and get help. Your health, your relationships and your child depends on it.



## PREEMIE FAMILY ONLINE

### Inspire Premie Community:

Parents, Grandparents, Adults  
& High-Risk Pregnancies

Help your families connect with over 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.

<https://preemie.inspire.com>

PremieWorld on Twitter

<http://bit.ly/PremieTweets>

PremieWorld on Facebook

<http://preemie.us/PremieFB>

PremieWorld on Instagram

<http://preemie.us/PremieInstagram>



# HIGHLIGHTING @WRIGHTLJAMIE

Our latest preemie highlight: [@wrightlj Jamie](#)

"Meet Oliver Benjamin, he was born 5/22/19 at 32 weeks 6 days due to severe preeclampsia. He weighed 4lb 10oz, and was 16 inches long. Ollie stayed 29 days in the NICU and graduated on 6/19/19, which we now call his H(Ollie)day!" ❤️❤️❤️

## We Could Highlight YOUR PREEMIE

**Deadline:** Like, tag and include [@PremieWorld](#) in your Instagram update post by the 15th of the month.

**Who:** Premies in the NICU, Premie Angels, Post-NICU, Children, Teens, Adults.



## FEATURED PREEMIE PRIDE:

### Summer, Autumn, and Winter:

My triplets arrived unexpectedly at 28 weeks. They weighed between 2 and 3 pounds and stayed in NICU between 35 and 50 days. Multiple scares happened along the way including a heart operation at 4 months old for Summer. They are now 5 year old rambunctious girls. Their big sister, dad, and I are extremely lucky to have them here. Life with triplets is amazing! - Bree Rowe

We welcome your submissions for this section of Premie Pride, Premie Angel, and Premie Prayer at [PremieWorld.com](#)



## SNEAK PEEK

*In next month's issue.....*

### Premie World Tags

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

### Premie Genius

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

### And More!

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

<http://bit.ly/premie1>

## JOIN THE CONVERSATION

“When you help a family bond in the NICU, it lasts a lifetime.”

~ Deb Discenza, PremieWorld



[@PremieWorld](#)

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



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[@Early Intervention Professionals](#)

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"The story of our brand is the story of our family. We invite you to be part of it" -Yamile C. Jackson, PhD, PE, PMP




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



## Premie Tags

Honor the Journey

