



# preemiefamily

## support. educate. advocate.



## THEY ARE STILL PARENTS

*one issue at a time with PreemieWorld*

**Angel Parents are Still Parents.** The preemie community is close-knit despite being full of families with a variety of challenges and of every type of background. Regardless of gestational age, disabilities, medical conditions, we are all one family. This also includes Angel Families - families who have lost a preemie either in a multiple or singleton pregnancy and/or birth/infancy. A loss does not make a parent any less of a parent than that of one that got to walk out the doors of the NICU with their "graduate." **Angel Parents matter. They are still parents.** As July is Bereaved Parents Awareness Month join me in taking time to reach out to an angel family and check in and talk about their child - by name so they can continue the memory and legacy of this very special family member. - **Deb Discenza**

## IN THIS ISSUE:

### ***They are Still Parents***

Deb Discenza recognizes Angel Parents in honor of Bereaved Parents Awareness Month.

*Look for worldwide events*

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

### ***Preemie Genius: Caring For Your Baby in the Neonatal Unit***

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

### ***Preemie Support: NICU Family Alliance***

A non-profit that is making a difference in the field of prematurity and neonatology.

## PREEMIE FREEBIE: PREEMIE ANGEL CERTIFICATE

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 a **Preemie Angel Certificate**.

This freebie is an important tool for labor and delivery, postpartum, NICU and post-NICU professionals.

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



**In solidarity with Bereaved Parents Awareness Month, we stand and recognize angel parents as just that . . . parents. They deserve respect, empathy and kindness. Their grief does not just go away with time. They lost a child.**

~ Deb Discenza, PreemieWorld



[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.

### Bereaved Parents Awareness Month

- July 1-31, 2018 | Worldwide  
<http://bereavedparentsawarnessmonth.info>

### Hot Topics in Pediatrics

- July 26-28 2018, Lake Buena Vista, Florida, USA  
<http://www.HotTopicsinPediatrics.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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# TERM: INTUBATION



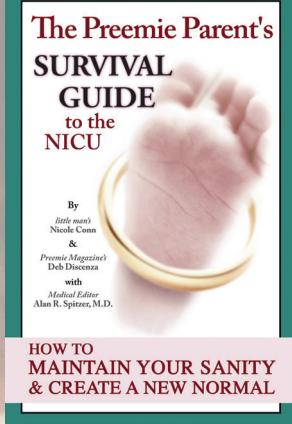
## Intubation:

When your baby has a tube inserted into his throat and is put on the ventilator. Of all of the contraptions in the hospital, this one is one of the most difficult to deal with: while it provides your baby with the ability to breathe, it is also the one thing that keeps you from seeing your baby's beautiful face. Additionally it can, at times, be terribly painful for both the infant and parent. Many hospitals have a standard practice of managing this pain by keeping the vented infants on low doses of pain medication. Intubation also comes with inherent risks. First and foremost, a foreign body is in your baby's lungs. This increases the chance of infection. Moreover, when infants begin to wriggle around they can accidentally extubate themselves.

## Questions for the Doctor

- My child's intubation - how long do you think he/she will need to be on the ventilator?
- What is the plan for the intubation duration?
- What if the tube accidentally comes out (extubates)?
- Is there anything else I should know at this time about this matter and any longterm effects on my child?

*This excerpt is from **The Preemie Parent's Guide to Survival in the NICU**, PreemieWorld's widely circulated support book, on sale at <https://preemieworld.com>. Get yours today!*



# SUPPORT: NICU FAMILY ALLIANCE

Having twins in the NICU for 56 days wasn't **Lisa Beauchamp**'s biggest battle, that came later. It was only after she got them home, did she realize the overwhelming task of managing their developmental needs. It was a full-time job between follow-up visits, doctor's appointments, emails, phone calls, speech therapy, physical therapy, more appointments, more phone calls and all that while her babies were on medication every 3 hours. She needed help and so **NICU Family Alliance** was born.

Notes Lisa, "The organization's mission is to provide families with the resources they need to thrive. By partnering directly with healthcare providers, insurance companies, family counselors, other organizations, and agencies we can connect parents directly with the resources they need. We are a "one-stop shop" for educational materials, Wellness Workshops, support groups, financial counseling, grief counseling, and other affiliated services. From these partnerships, came the **NICU Family Symposium** which launched in 2017. The event provided both parents and professionals the opportunity to listen, learn and interact with one another. It was also a surprise to hear from honored guest, Congressman Ami Beri, that he too was a NICU Dad. The symposium was a huge success and now with the help and support from volunteers and partnerships, the NICU Family Alliance is proudly making a positive impact on the NICU community."



Visit  
[www.NICUFamilyAlliance.org](http://www.NICUFamilyAlliance.org)  
for more info

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. Exposed to the harsh realities of 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 Hellesta Als, 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 DVD VIDEO ESRB PARENTAL ADVISORY

**SOUNDTRACK AVAILABLE AT [WWW.LITTLEMANTHEMOVIE.COM](http://WWW.LITTLEMANTHEMOVIE.COM)**

DAVID C. BOHNETT PRODUCED BY NICOLE CONN AND DANNY JACOBSEN WRITTEN BY DAVID C. BOHNETT AND DANNY JACOBSEN STARRING SEAN PRESTANTO, JOE VAN WITSEN, BRIAN HOVEN, BRADLEY COOPER, STACEY SILVER, KATE WELLS, MARK CHATZ, DAVID C. BOHNETT AND DANNY JACOBSEN DIRECTED BY NICOLE CONN PRODUCED BY DAVID C. BOHNETT AND DANNY JACOBSEN WRITTEN AND DIRECTED BY NICOLE CONN © 2008 LITTLE MAN PRODUCTIONS. ALL RIGHTS RESERVED.

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**SPECIAL LIMITED EDITION WITH FAMILY UPDATE**

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 ENDLESSLY HEART-SEIZE 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.

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



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

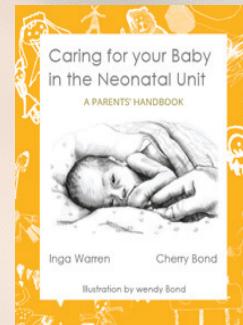
## BOOK: CARING FOR YOUR BABY IN THE NEONATAL UNIT

**Caring for Your Baby in the Neonatal Unit** by neonatal developmental gurus **Inga Warren** and **Cherry Bond** is a book parents will want to check out and NICU professionals will want to have on hand for families in their NICU library. With practical tips throughout the book's sections welcoming parents, taking them through the baby's journey in the NICU care to getting to know their infant, to practical baby care to a very unique and useful chapter on development in the preterm infant and newborn, parents will feel supported. An important note - all of the drawings in the book are premature babies thereby being very sensitive to parents' needs to see a picture that reminds them of their own child in the NICU. Add in soothing touches of color and a loving yet respectful tone and this book is a winner.

**The importance of parents in the neonatal unit cannot be overestimated. You will soon know your baby better than anyone else. The loving care that only parents can give will last your baby for the rest of his life.**

~ *Caring for Your Baby in the Neonatal Unit*

**One lucky winner will receive a FREE copy of this book! We'll select one NEW Instagram follower prior to 7/22/18. Enter to win by following us on Instagram at [www.Instagram.com/PremieWorld](http://www.Instagram.com/PremieWorld)**

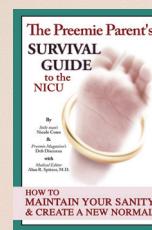


Congrats to @CourtsPremieFoundation the winner of June's giveaway, a copy of *Stuck in Bed* ([www.StuckInBedBook.com](http://www.StuckInBedBook.com))

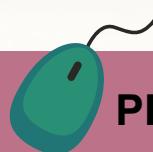
## Q'S ABOUT FEEDING ISSUES

Struggled with feeding in the NICU and realize that this has continued at home ongoing? Yup - been there and done that. Many parents struggle with picky eaters post-NICU. Be vocal with the pediatrician with these questions:

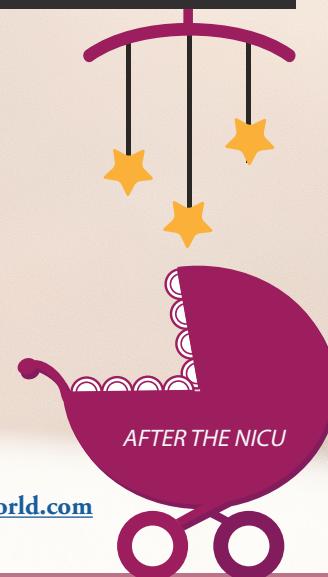
- My child was premature and I know feeding issues are a challenge. What options are there?
- Are there specialists for feeding help? Who are they and what do they do?
- What is the process to getting referred for specialist assistance? What is "Failure to Thrive"?
- What else do you suggest that we try before moving toward a specialist?



Find these questions and more in *The Premie Parent's Survival Guide to the NICU*, available at [www.PremieWorld.com](http://www.PremieWorld.com)



## PREMIE FAMILY ONLINE



### Inspire Premie Community:

Parents, Grandparents, Adults  
& High-Risk Pregnancies

Help your families connect over 45,000 parents of preemies worldwide! This close-knit forum is moderated by our own **Deb Disenza**.

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/PremieTweets>

PreemieWorld on Facebook

<http://preemie.us/PremieFB>

PreemieWorld on LinkedIn

<http://bit.ly/PWLinkedIn>

# NEW: PREEMIEWORLD TAGS

Preemie Parents on Social Media - this is for you! Tag @PreemieWorld on any of our social media pages with an update on your preemie (NICU, Preemie Angels, infant, toddler, child, teen, adult) and each month we will pick one preemie's post to highlight in future editions.

## Details:

**Deadline:** Like and tag @PreemieWorld in your post by the 15th of each month.

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

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

## FEATURED PREEMIE PRIDE:

AJ was born at 30 weeks weighing 2lbs 3oz. Now 9 months actual! Crawling, trying to stand up on his own, teething, and he says "hey" "yeah" and "momma"? He's my fighter!

- 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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NICU SURVIVOR  
PreemieWorld.com

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

Preemie Tags  
Honor the Journey

[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 want to 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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