



premiepro
support. educate. advocate.



THEY ARE STILL PARENTS

one issue at a time with PremieWorld

Angel Parents are Still Parents. The premie 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 premie 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*



Above: The Premie Angel Certificate is highlighted in this month's "Premie Freebie," below and on PremieWorld's website.

IN THIS ISSUE:

Look for worldwide events

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

They are Still Parents

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

Premie Genius: Caring For Your Baby in the Neonatal Unit

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

Premie Organization: amiamusica

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



www.OnceUponaPremie.com

TO DO LIST:

- New - PremieWorld Tags.** Tag you are it, check out page 4 for a section all about **YOU**.
- Freebies.** Get free downloads from PremieWorld at <http://bit.ly/PremieFreebies> Have an idea for a freebie? Contact us and let us know.
- Bereaved Parents Awareness Month**
July 1-31, 2018 | Worldwide
<http://bereavedparentsawarenessmonth.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!

 @ www.facebook.com/PremieWorld

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 @ [PremieWorld](https://www.linkedin.com/company/premieworld)

 @ www.instagram.com/premieworld

PREEMIE FREEBIE: PREEMIE ANGEL CERTIFICATE

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 **Premie Angel Certificate**.

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

Get this at Premie 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, PremieWorld





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.

The NICU Family Symposium

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."



Website: www.NICUFamilyAlliance.org
Established: 2016
Focus: "One Stop Shop" for Support
Outreach: International

Visit www.NICUFamilyAlliance.org
for more info

ORG: AMIAMUSICA

Amiamusica was founded in Zurich, Switzerland in 2017. It was created with and for parents of preterm infants and aims at promoting the use of music for empowering parents and premature or newborn children by sharing experiences, gathering and disseminating knowledge, and enhancing skills and participation.



Executive Director Friederike Haslbeck notes, "We are interested in sharing experiences with music and premature birth. We are keen to hear from other parents what they experience, recommend and want to ask."

Check These Out: Amiamusica has a new lullaby book from parents for parents of preterm infants and it may be viewed and/or purchased here: <https://amiamusica.ch/wiegenlieder/> The organization also has a blog that they invite you to contribute to, comment on and read at: <https://amiamusica.ch/>

Year Established: 2017
Website: <https://amiamusica.ch/>
Outreach: International
Location: Zurich, Switzerland

Visit <https://amiamusica.ch/> for more info

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 Grerson 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. HeidiLise Ab, 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 Region Coding • English
SOUNDTRACK AVAILABLE AT WWW.LITTLEMANMOVIE.COM

DAVID C. BOHNETT • NICOLE CONN • "LITTLE MAN"
NICOLE CONN • DANNY JACOBSEN • SEAN PRESANT • JOE VAN WITSEN • BRIAN HOVEN
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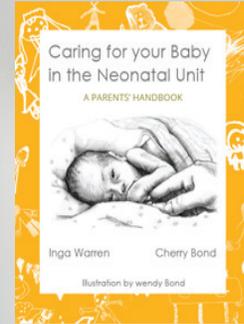
www.littlemanthemovie.com

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*



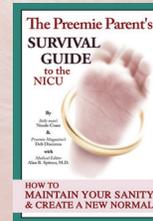
One lucky winner will receive a FREE copy of this book! We'll select one NEW Instagram follower prior to 7/22/18. Enter to win by following us on Instagram at www.Instagram.com/PreemieWorld

Congrats to @CourtsPreemieFoundation the winner of June's giveaway, a copy of Stuck in Bed (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 Preemie Parent's Survival Guide to the NICU, available at www.PreemieWorld.com



PREEMIE FAMILY ONLINE

Inspire Preemie 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 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>

NEW: PREEMIEWORLD TAGS

Preemie Parents on Social Media - this is for you! Tag @PremieWorld 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 @PremieWorld in your post by the 15th of each month.

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

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



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 "mom-ma"! He's my fighter!

- Anonymous



We welcome your submissions for this section of Preemie Pride, Preemie Angel, and Preemie Prayer at PremieWorld.com



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Premie Tags
Honor the Journey




SNEAK PEEK

In next month's issue....

New Section: Preemie World 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.

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 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, PremieWorld

f [@PremieWorld](https://twitter.com/PremieWorld)
[@Premie Parent's Survival Guide to the NICU](https://twitter.com/PremieParentSurvivalGuide)

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[@NICU Professionals](https://twitter.com/NICUProfessionals)
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[@Premie Support Group Leaders](https://twitter.com/PremieSupportGroupLeaders)
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