



premiefamily
support. educate. advocate.

HELPING PREEMIES THRIVE

one issue at a time with PremieWorld

It is a brand new year. And with that we plan to tackle many of the issues that have plagued the premie community ongoing without a lot of success. It is time to rise, it is time to be heard. It is time to push the needle, to provide our much-needed input on the issues affecting our children growing up and the beautiful premie angels with wings.

Keep an eye on this space and on our website. We'll be getting the word out about our efforts to make changes through these channels. Our goal is to have your voice heard. *Your voice counts.*

2018: Giving preemies the tools to thrive, not just survive.

- Deb Discenza, Publisher & CEO



IN THIS ISSUE:

Look for worldwide events

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

2018: Helping Premies Thrive

Deb Discenza's urgent message for 2018: it is time to help preemies for the longterm and what you can do about it.

Premie Genius: Lulla Doll

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

Premie Organization: ST.AN.DE

Mental Health advocacy takes on a new focus, check out what this organization is doing to make changes and refer your families.



www.OnceUponaPremie.com

TO DO LIST:

- New Section.** Check out our new section, *Giving From Your Heart*, on p. 4.
- Freebies.** Get free downloads from PremieWorld at <http://bit.ly/PremieFreebies> Have an idea for a freebie? Contact us and let us know.
- Support for Infant Loss**
- January 4, 2018; McLean, Virginia, USA
<http://www.premiestoday.com>
- Monthly Premie Playgroup**
- January 11, 2018; Chantilly, Virginia, USA
<http://www.premiestoday.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

 @ [PremieWorld](https://twitter.com/PremieWorld)

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

 @ www.instagram.com/premieworld

YOUR PREEMIE FREEBIE: ANGELS REMEMBERED

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 **Premie Angels - Always Remembered**.

This graphic will help remind all angel parents that they are not alone. Consider posting this on your social media and tag that dear family member or friend.

To download this freebie, visit <https://premieworld.com>

“ Many parents have just come through another holiday season quietly mourning while putting on a fake smile for the world. They deserve to know that their babies are always loved, always remembered. *Always.* ”

~ Deb Discenza, PremieWorld

A QUICK REALITY CHECK: THE NICU



A Quick Reality Check

Before jumping in, realize that being in the NICU is akin to being in a war. Once you are stuck in a fox-hole together, neither race, nor age nor socio-economic status matters compared to getting out of that fox-hole alive.

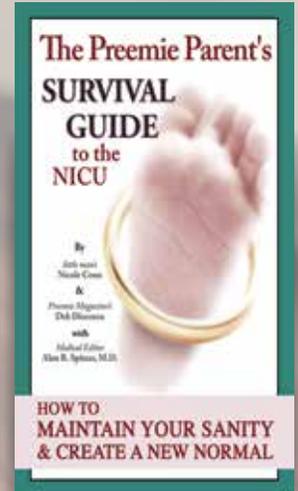
The NICU is a great equalizer. A parent is a parent is a parent. And parents who have kids who face medical challenges do not see anything other than their infant getting well. Certainly there are parents who behave badly, but the true mettle of people comes out in these life and death situations and most people are good at their core. Parents just want their kids to get well and to leave the hospital. You end up spending a lot of time in the hospital with these people and the staff members attending to you and their needs, and you can't find a kinder, warmer second family than the parents and staff in the NICU.

Also note that here the people cut right through the small talk and banter. There's no time for light exchanges of pleasantries - you're eager to talk about what matters and get to the heart of things, often sharing parts of yourself and family dynamic with perfect strangers. But you're not strangers because we're all in this together.

Deb's Take

I always think about the NICU sort of like being a special member of a club. When you meet another NICU parent, it's like meeting a fellow veteran with whom you've gone through the bloody battle together. There's a wonderful shorthand to your language and they get it.

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



SUPPORT: PROJECT PREMIE

Inspired by an article on author Kelley French's journey with her micro-preemie daughter (check it out here: <http://premie.us/PremieJ>) Brianna Stoohs created the Project Premie.



Established: 2017
Website: <https://projectpremie.wixsite.com/info>
Focus: Supporting families of premies of any kind.
Outreach: Northern NJ/NY Area, USA

Project Origins

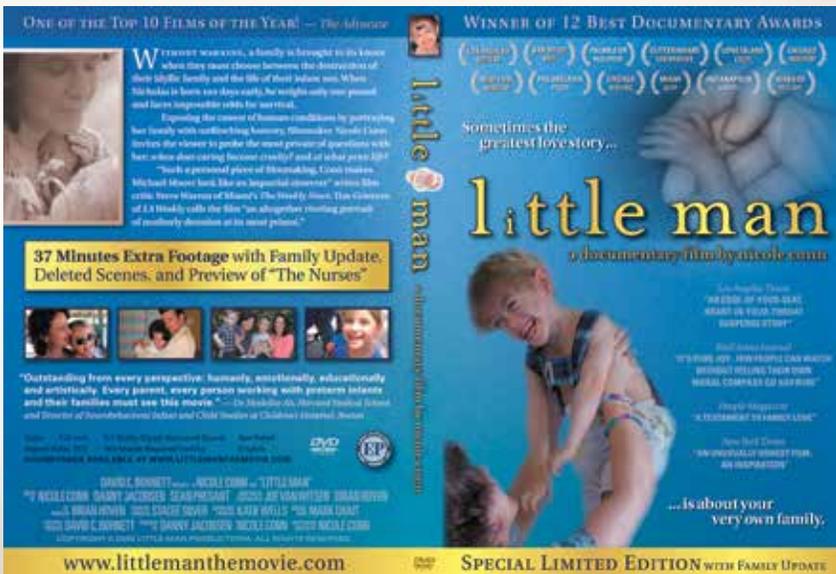
Brianna Stoohs started Project Premie after reading about author Kelley French's daughter's journey in the NICU as a micro-preemie. And so she started the organization as a part of the Community Problem Solving Program in her area. She realized that "preemie births affect a large amount of people and that they can sometimes be particularly emotionally taxing."

Visit <https://projectpremie.wixsite.com/info> for more info

Donate at: <http://gofundme.com/projectpremie>

Projects

As premies have trouble regulating their body temperature, Project Premie aims to provide items such as blankets and beanie hats to premature babies in the region. They are also working on providing care packages for the families for emotional support and partnering with local hospitals to "create communal areas for families to easily access items for daily needs that they may have forgotten."



"little man" is every preemie parent's story



www.littlemanthemovie.com

LULLA DOLL



Kangaroo Mother Care (KMC) has proven to increase the growth, weight gain and overall well-being of preemies due to the fact that they can truly relax and get solid sleep on the chest of Mom and/or Dad. Cuddling too provides strong stress-relief for preemies as they work through the NICU days and when they are at home. But what about when they are in the hospital and no one is available to help them soothe?

It is easy to see why the Lulla Doll is so appealing, as the product is soft, pleasing and accessible. It also has a device inserted into it to re-create the sounds of a real life heartbeat and of a person breathing. NICUs with babies on heart monitors will find this not only a way to help the baby lower cortisol levels but also to provide a sense of comfort for families having to leave their baby at the hospital each day and night.

“There can be many reasons why parents can’t keep their little ones close. . . .serious reasons like illness and hospitalization of parents and babies. Indeed, the idea of the Lulla doll was born when my friend had her baby girl prematurely and had to leave her alone in the hospital every night for two weeks. That really struck a chord with me and it was then that I decided to bring the Lulla doll to life.”

~ Eyrún, Founder of Roro

One lucky winner will receive a Lulla Doll! We'll select one NEW Instagram follower prior to 1/22/18. Enter to win by following us on Instagram at www.instagram.com/premieworld.

Congrats to Brianna Stoohs, the winner of December's giveaway, a the book 95 Days in the NICU by Avie Banks!

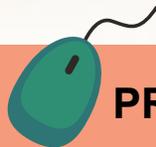


NEW YEAR, NEW QUESTIONS

With a new year, it is time to renew the diligence with which parents should be asking the pediatrician direct questions regarding their preemie's health and developmental outlook. Always know you have the right to ask for a referral to a specialist. Questions:

- Based upon the health issues in the NICU, how is my child doing now? And the long-term outlook?
- Based upon my child's gestation, what areas of concern are you watching now? The status of each?
- What do you know about the long-term outlook for a preemie of my child's gestation? If not, then who can help me?
- Are there specialists medically and/or developmentally that you think could be of help right now? If yes, who?

Need forms for appointments to log questions and answers? Check out our freebies at www.PremieWorld.com



PREMIE FAMILY ONLINE

Inspire Premie Community- Parents, Grandparents, Adults and High-Risk Pregnancies

Help your families connect with over 41,000 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>

PremieWorld on Twitter

<http://bit.ly/PremieTweets>

PremieWorld on Facebook

<http://preemie.us/PremieFB>

PremieWorld on LinkedIn

<http://bit.ly/PWLinkedIN>



SPEAKING OF NEC: UNPLUGGED

Give From Your Heart

PreemieWorld is honored to bring you special events that will serve to help others in the form of education, in terms of help where needed and more. Mark your calendar and [#givefromyourheart](#)

Our friends at **The Morgan Leary Vaughan Fund** (www.MorgansFund.org) have a one-day regional conference, "Speaking of NEC: Unplugged," focused on "identifying practical solutions for reducing the devastating effects of Necrotizing Enterocolitis (NEC) on premature infants and their families. The event, happening in the Greater Hartford, Connecticut area is set for 11 June 2018. The conference will include topics such as the parent's perspective, current data on NEC, impact of NEC on local communities, the clinical socio-economic burden of NEC and the inclusion of an exclusive human milk diet as the standard of care and more.



*Does your organization have a special event focused on helping preemies?
Tell us about it at connect@premieworld.com*

FEATURED PREEMIE PRIDE:

My son Timothy (TJ) was born at 33 weeks 6 days and spent a month in the NICU. He is 9 months (7 months adjusted) and just graduated from physical therapy (he was in for hip dysplasia). He is meeting many of his milestones on time. Our son is a fighter. - Anonymous



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



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www.nurturedbydesign.com

SNEAK PEEK

In next month's issue.....

New Item: Giving From the Heart

There is another special event coming where you can make a difference in the preemie community.

Preemie Genius

We are reviewing a new book focused on a very special preemie. Don't miss it!

And More!

Have you subscribed to Preemie Family yet? It's free!
<http://bit.ly/preemie1>

JOIN THE CONVERSATION

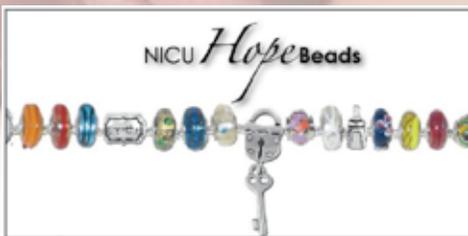
“ Always remember, you know what is best for your child! ”
~ Deb Discenza, PreemieWorld

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NICU Hope Beads

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Your NICU journey through jewelry...

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Preemie Tags

Honor the Journey




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