



premieworldfamily
support. educate. advocate.



NICU LIFE, UNVEILED

recreating the PremieWorld

PremieWorld is working heavily behind the scenes - more coming soon! In the meantime:

#1 NICU Life Survey Summary. We launched our second survey and had a lot of interesting findings. Check out the summary in our Freebie section or here: <https://premie.us/NICULife> And follow us on Twitter, Facebook, LinkedIn or Instagram because we will highlight specific quotes not included in the summary.

#2 Discharge Day Survey. Our new survey is live - <https://premie.us/DischargeDaySurvey>

#3 Instagram Live. Our Instagram Live sessions continue to gain great interest from the parent and professional communities. We would love to have you join in on the conversation!

- Deb #celebratepreemies

IN THIS ISSUE:

NICU Life, Unveiled

Deb Discenza talks about exciting developments ahead for PremieWorld and its community of parents, pros and more.

Premie Genius: Island Angel Gowns by Trisha

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

Premie Support: helping little hands

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

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.

✓ **Intrauterine Growth Restriction-IUGR Awareness**
March 13, 2019 | Worldwide
<https://m.facebook.com/IUGRAwareness/>

✓ **St. Patrick's Day Party for Premies**
March 15, 2019 | Bethlehem, Pennsylvania, USA
<https://premie.us/StPattysPremies>

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

PREEMIE FREEBIE: RESULTS OF NICU LIFE SURVEY

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 the NICU Life survey from February.** You can get it by going to the link below (and watch social media for parent quotes throughout the month):

NICU Life Survey Results
<https://premie.us/NICULife>

“ The day-to-day NICU Life was controlled chaos between going back to work a week after the birth, visiting in the afternoons, pumping every 2 hours, updating family and friends and collapsing into bed for a 5-hour sleep each night. ”

~ Deb Discenza, PremieWorld

ADVOCATING FOR YOURSELF



Excerpt:

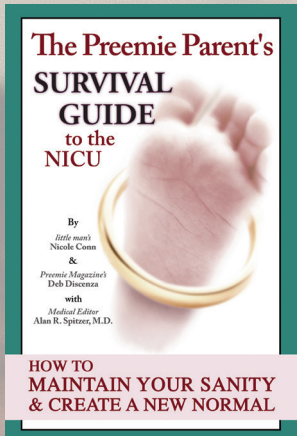
The sooner you realize that taking care of yourself will help your child, the better off you will be. This is not to suggest that you become a pain-in-the-butt parent that no one wants to work with, but it is important that the medical staff know that you are a force to be reckoned with. You are not to be “handled” - the hospital should understand that you are taking your job as advocate seriously. You are aware that this is a medicine about which you know nothing. You only want what is best for your child, but you also expect to be kept well-informed of all important changes in your child’s medical status. You expect to be treated as a member of the team.

“

As the doctors realize that they can rely on you to be a level-headed person trying to do what is best for your newborn, they will soon respect you and want your involvement. Indeed, some may turn to you for your input.

~ The Premie Parent's Survival Guide to the NICU.

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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: HELPING LITTLE HANDS

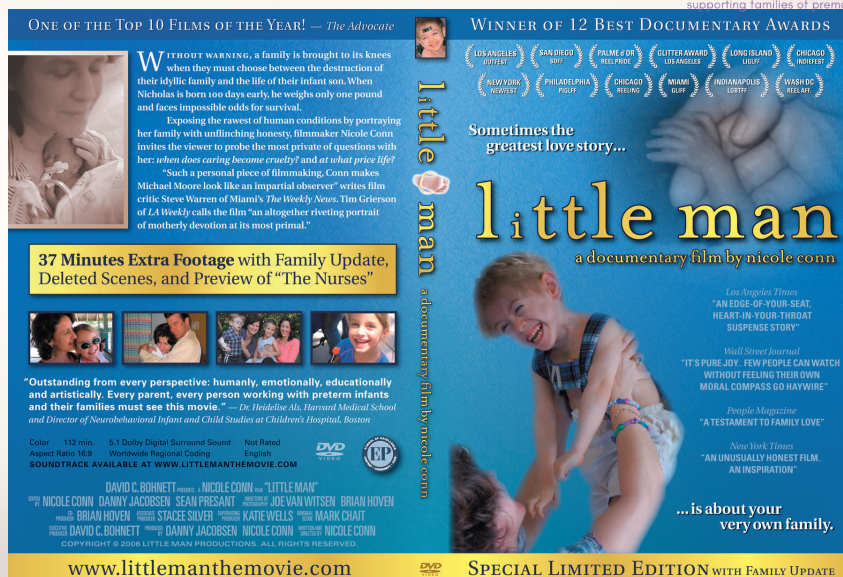
Like so many support groups in the premie community, their beginnings have a personal experience at the core. For Founder Kate Crassweller, this story begins with her twins: “In March 2016, our identical twin boys – James and Fraser – were born exactly 3 months early at 26+6. Our first days in the NICU were a blur of beeps and buzzes until four days in when both our boys became very ill. It was Easter; everything was closed and our families were away so we existed on the contents of the hospital vending machine. We had two sick babies in hospital and one confused two-year-old at home. We spent weeks traveling between the boys’ incubators and our daughter’s bed trying to spend time with everyone. After 3.5 weeks James died. After 3.5 weeks I finally got my first cuddle with Fraser. One hundred and twenty-three days after James and Fraser were born we got to take Fraser home. For over 4 months we juggled NICU life with the needs of our toddler, Evie. We got through it by celebrating milestones (at home and in hospital) -- by baking kilo cakes and painting pictures and because we had support from family, from friends and from all of the incredible NICU staff. But not everyone is as fortunate to have support. From that “helping little hands” was born.” Help them get cameras installed in their NICU: <https://www.mycase.com.au/charity/23730/helpinglittlehands>

Year Established: 2017

Website: www.HelpingLittleHands.org

Outreach: Western Australia

helping
little hands
supporting families of premature babies



“little man” is every
preemie parent's story



www.littlemanthemovie.com

ISLAND ANGEL GOWNS BY TRISHA

"After two of my friends suffered losses and with the babies being so small and not having something nice to dress them in, I knew that I could help," notes **Island Angel Gowns by Trisha & NICU Support** Founder **Trisha Morris**. Having been sewing since she was 11 years old, she created beautiful works of art for these families. Seeing the impact made an impression on Morris. "When I reached out to my local hospitals I was informed that so many of them had nothing on hand. So I started up right away and got to work on getting wedding dress donations." Morris provides all services for free including NICU care packages (for Mom and baby), bereavement care packages (for moms who suffer a loss), angel gowns with a clay casting and an angel wing heart pin for parents to keep, doula/SB Doula in training, inclusion jewelry made with Ash, Hair, breast milk and more, and emotional support.

These Angel Gown Kits are beautifully crafted with each detail thought out with care and respect for the baby and the bereaved family. Every NICU should have these kits on hand to provide lasting dignity to a family that is struggling to come to grips with the loss of their baby. It is done with love. Island Angel Gowns by Trisha deserves 10 Premie Genius awards for what they are doing for the families.



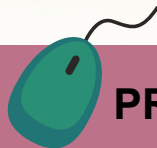
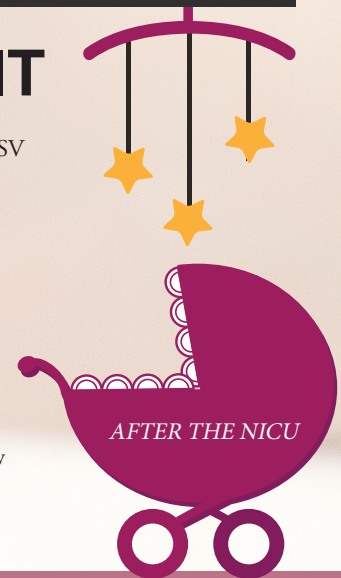
For more information visit <https://www.facebook.com/IslandAngelGownsbytrisha/>
GRATITUDE: We are donating 12 Angel Island Gowns and Bereavement kits to a local NICU.

And congrats to Alexandria Nunn who won the February giveaway set of The Keepsie pacifier holders perfect for preemies!

PEOPLE WHO JUST DON'T GET IT

So you are home from the NICU and people start telling you, "It's over, relax." They make a grab for your baby despite it being RSV season or there is a discussion around delays and things get heated. What do you say? Some ideas:

- ☑ "Having a premie changed me forever. You do not know what this is like so telling me to relax is not going to help."
- ☑ "Want to help? Respect boundaries and give me space to advocate for my child. I have a right to worry."
- ☑ "Prematurity leaves its mark on the babies and the families . . . for life. That is just reality. Please respect this."
- ☑ "What I have been through was life-altering. There is no going back. I am working on moving forward."
- ☑ "I have had professionals tell me they didn't realize the trauma of a premature birth until they experienced it. So know this is not an easy situation for me. I have changed as a person."



PREEMIE FAMILY ONLINE

Inspire Premie Community:

*Parents, Grandparents, Adults
& High-Risk Pregnancies*

Help your families connect 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>

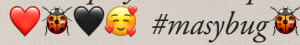
PremieWorld on LinkedIn

<http://bit.ly/PWLinkedIn>

HIGHLIGHTING @SHANNAGRAYY

Our latest preemie highlight: Masy Faith Gray (@shannagrayy):

*Couldn't get her to wake up for me
at all this morning to take a bottle,
so, I played dress up.*



We Could Highlight YOUR PREEMIE in Our Newsletters & Online!

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

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

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



FEATURED PREEMIE PRIDE:

Addelyn:

My preemie warrior Addelyn just turned one she was born at 33 weeks due to severe preeclampsia and IUGR she was 2 lbs. 10 oz. She is forever my miracle girl!

- Samantha Weidner

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.....

PremieWorld 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.

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

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

~ Deb Discenza, PremieWorld



@ [PremieWorld](#)

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



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@ [NICU Professionals](#)

@ [Early Intervention Professionals](#)

@ [Premie Support Group Leaders](#)

@ [Premie Parents](#)



@ [PremieWorld](#)

"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



Premie Tags
Honor the Journey

