



premieworld  
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](http://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](mailto:connect@premieworld.com)!

f @ [www.facebook.com/PremieWorld](http://www.facebook.com/PremieWorld)

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

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

ig @ [www.instagram.com/premieworld](http://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



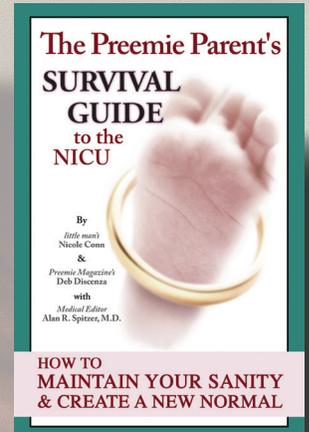
### Excerpt:

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.



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.mycause.com.au/charity/23730/helpinglittlehands>

Year Established: 2017  
Website: [www.HelpingLittleHands.org](http://www.HelpingLittleHands.org)  
Outreach: Western Australia



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. Helaine 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 Widescreen Region Coding English  
SOUNDTRACK AVAILABLE AT [WWW.LITTLEMANMOVIE.COM](http://WWW.LITTLEMANMOVIE.COM)

DAVID C. BOHNETT DIRECTOR OF PHOTOGRAPHY NICOLE CONN WRITER/DIRECTOR “LITTLE MAN”  
NICOLE CONN DANNY JACOBSEN SEAN PRESENTANT JOE VAN WITSEN BRIAN HOVEN  
BRIAN HOVEN STACY SUDLER KATIE WELLS MARK CHATT  
DAVID C. BOHNETT DANNY JACOBSEN NICOLE CONN  
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Los Angeles Times  
“AN EDGE-OF-YOUR-SEAT, HEART-IN-YOUR-THROAT 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.

www.littlemanthemovie.com

SPECIAL LIMITED EDITION WITH FAMILY UPDATE

“little man” is every premie parent’s story



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



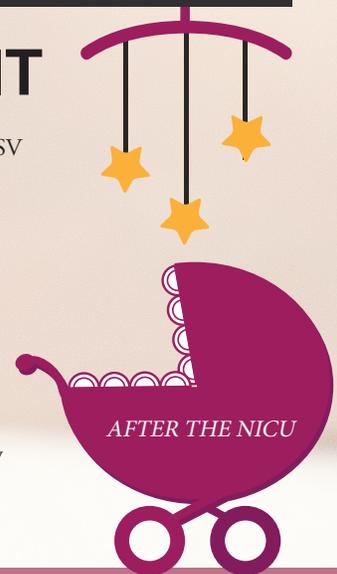
For more information visit <https://www.facebook.com/IslandAngelGownsbytrisha/>  
**GRATITUDE: We are donating 12 Angel Island Gowns and Bereavement kits to a local NICU.**

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

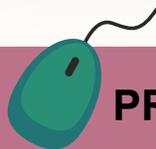
## PEOPLE WHO JUST DON'T GET IT

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.”



AFTER THE NICU



## 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://premie.inspire.com>

*PremieWorld on Twitter*

<http://bit.ly/PremieTweets>

*PremieWorld on Facebook*

<http://premie.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.*

❤️🐛💚🥰 #masybug🐛



**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 Preemie Pride, Preemie Angel, and Preemie Prayer at [PremieWorld.com](http://PremieWorld.com)



**Something SPECIAL is coming soon.....**

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

## SNEAK PEEK

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

### Preemie World 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 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 ”



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



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@ [Premie Parents](https://www.linkedin.com/company/PremieParents)



@ [PremieWorld](https://www.instagram.com/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




A brand by Nurtured by Design

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



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

*Preemie Tags*  
*Honor the Journey*