



premiepro
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/NICU-life>. 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 Disenza 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/>

✓ **36th Annual Advances in Care Conference 2019**
March 26-30, 2019 | Snowbird, Utah, United States
<http://paclac.org/advances-in-care-conference/>

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](#)



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@ 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 Disenza, PremieWorld

SUPPORT: HELPING LITTLE HANDS



Like so many support groups in the preemie 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. Western Australia is enormous so we began talking about how we could support other families going through the NICU. A passing smile and nod with another family in the our nursery turned into a friendship. We worked out they had been having the same discussions so we put our minds together and helping little hands was born."

helping little hands' services include "Dinner's Ready" program, "Nutritious Nibbles", a massage, well-being events, travel support and home support services while the baby is in the NICU. They're currently fundraising to install cameras in the NICU. Check their page and donate: <https://www.mycase.com.au/charity/23730/helpinglittlehands>

Year Established: 2017
Website: www.HelpingLittleHands.org
Outreach: Western Australia
Founder: Kate Crassweller; Joanne and Scott Beedie

helping
little hands
supporting families of premature babies

ORG: TWENTY-FIVE AND FOUR

Twenty-Five and Four was created in honor of our son, W, who was born at 25 weeks and 4 days," notes Founder Amanda Huhta. "He was just 1 pound 12 ounces and spent 110 days in the NICU before we were able to bring him home. W is a remarkable little boy with more spirit in him than anyone we've ever met. Nothing will stop his fighting personality and we are blessed to be his parents! When we were in the NICU, I couldn't find any micro-preemie clothes small enough for W. The few I did find were so expensive. I enlisted my mom to see if she would be able to make something small enough for him to wear. Of course, she had a doll size shirt in the mail within a day!

Huhta continues, "Twenty-Five and Four was created when I realized that I wasn't the only one who was torn apart that I wasn't able to dress my baby. At Twenty-Five and Four, we strive to make quality shirts for the tiniest of babies. We want parents of these micro-miracles to be able to experience the joy of being able to put a shirt on your baby! 100% of donations are used to make sure every baby has a shirt that fits. We want to make sure every parent gets the joy of dressing their little ones, no matter how small!"

For more information visit www.TwentyFiveandFour.org



Twenty-Five and Four
Giving diaper shirts to NICU families

www.twentyfiveandfour.org

Year Established: 2017
Outreach: International
Site: www.TwentyFiveandFour.org

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. Hellel Abi, 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 Regional Coding English
SOUNDTRACK AVAILABLE AT WWW.LITTLEMANMOVIE.COM

DAVID C. BARNETT DIRECTOR OF PHOTOGRAPHY NICOLE CONN WRITER/DIRECTOR
NICOLE CONN DANNY JACOBSEN SEAN PRESTANT EDITOR JOHAN WITSEN BRIAN HOVEN
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...is about your very own family.

www.littlemanthemovie.com

SPECIAL LIMITED EDITION WITH FAMILY UPDATE

"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.



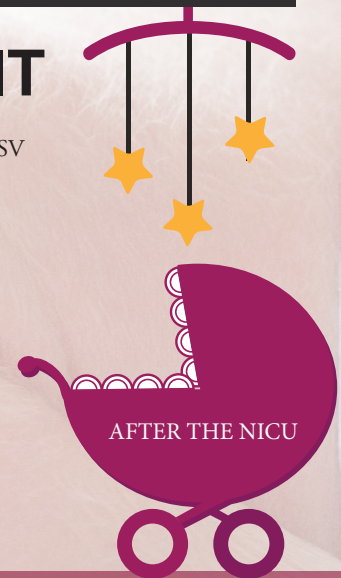
For more information visit <https://www.facebook.com/IslandAngelGownsbytrisha/>
GRATITUDE: We are donating 12 Angel Island Gowns and Bereavement kits to a local NICU.

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 Instagram

<http://preemie.us/PremieInstagram>

HIGHLIGHTING @SHANNAGRAYY

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

*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 PREMIE 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 PREMIE 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 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



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Premie Tags
Honor the Journey

