



premieworld
support. educate. advocate.



PARENT STORIES TEACH

recreating the PremieWorld

PremieWorld continues to make changes for our community. More soon. :-). In the meantime:

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

#2 NICU Life. Our new survey is live - "NICU Life" - <https://premie.us/NICULifeSurvey>

#3 Instagram Live. I have started doing Instagram Live sessions with our community. We have had parents and pros from across the United States and at least 6 countries. Please follow PremieWorld on Instagram and join this international conversation!

- Deb #celebratepreemies

IN THIS ISSUE:

Parent Stories Teach

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

Premie Genius: Keepsie

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

Premie Support: Bryce's NICU Project

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.

Namaste for the NICU
February 16, 2019 | Cleveland, Ohio
<https://premie.us/NamasteNICU>

Team Hand to Hold Virtual 5k
February 17-28, 2019 | Virtual
<https://premie.us/H2H5k>

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 PREEMIE BIRTH 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 Premie Birth Survey in January. You can get it by going to the link below (and watch social media for parent quotes throughout the month):**

Premie Birth Survey Results
<https://premie.us/PremieBirthData>

“ I changed as person with my daughter's preemie birth. From such a traumatic experience, I was slowly reborn into Premie Mom, a fierce advocate for myself and my daughter. It was a powerful awakening mixed with tears and worries. ”
~ Deb Discenza, PremieWorld

EXCERPT: DEB'S TAKE ON THE NICU



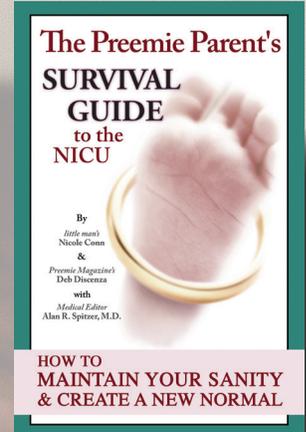
Deb's Take:

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. I always respond to any parent who emails me and asks for help. It's not that I feel like it's an obligation - it's what you give back because there was a mom, dad, or nurse who helped you that one day when you thought if you had to hear another piece of bad news you really were going to lose it. It may not seem like a big deal, but that person performed a random act of kindness in that moment when you needed another human being to treat you with tenderness because you were alone and lost.



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~ Deb Discenza, PremieWorld



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: BRYCE'S NICU PROJECT

Out of the sheer loneliness of a first Mother's Day in the NICU and the kindness of a stranger, came this generous non-profit organization.

When a nurse came and brought **Brittany Boet** a little scented hand sanitizer and holder and told her it was from a former NICU mom who too had spent a Mother's Day in the NICU, Brittany broke down. This gift stood out amongst the others because it came from the heart of another Mother who knew the brokenness of spending a Mother's Day in the NICU watching your baby fight for their life. When Mother's Day rolled around the following year, Brittany remembered the gift and told her husband Brian that they had to go to the NICU and give back. They knew how much the smallest gesture could make the biggest difference and how lonely the NICU was. And they determined that they would do whatever they could to help as many NICU families as possible to not feel that sting of loneliness. **Bryce's NICU Project** has gone from taking gifts and lunch to two hospitals on one holiday to 12 NICUs on 6 holidays in two states with more NICUs and states already lined up for 2019. Learn more at the organizational website (link below).

Year Established: 2015
Website: www.BrycesNICUProject.org
Outreach: U.S.: Texas, California, and Colorado



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 Glerason 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

DAVID C. BOHNETT DIRECTOR OF PHOTOGRAPHY NICOLE CONN WRITER "LITTLE MAN"
NICOLE CONN DANNY JACOBSEN SEAN PRESANTY JOE VAN WITSEN BRIAN HOVEN
BRIAN HOVEN STEVE SUDLER KATIE WELLS MARK CHATT
DAVID C. BOHNETT DIRECTOR OF PHOTOGRAPHY DANNY JACOBSEN NICOLE CONN WRITER NICOLE CONN
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...is about your very own family.

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"

www.littlemanthemovie.com SPECIAL LIMITED EDITION WITH FAMILY UPDATE

"little man" is every preemie parent's story



www.littlemanthemovie.com

KEEP SAFE, KEEP CLEAN: THE KEEPSIE

Some of the best products on the preemie parent market come from those that have been there. This is no different than with **Keepsie™ Designer/Owner/Preemie Mom Jennifer Melvin**. Parents on RSV lockdown and those venturing out to those germ-ridden follow-up appointments will feel much safer.

As Melvin attests, “The medical staff and families can be assured that the production details were and will never be compromised on- made with certified food grade safe material, no chemical additives and made in the USA. It is also designed with on the go and a baby’s life in mind- secure double snaps, air holes to eliminate moisture build up and aid in natural drying, a loop for paci clips and the space for it to remain attached to the plush animals or attachments it may have.”

The product is indeed sound and well designed. Parents will find this a must-have for the NICU and post-NICU life. Melvin has a soft spot for preemies not just her own. The company regularly gives back to the community, most recently in partnership with NICU support group **Silvie Bells** (www.SilvieBells.org) in the form of proceeds from each sale as well as donations of product to the care packages.

Keepsie™

KEEP SAFE. KEEP CLEAN.



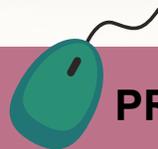
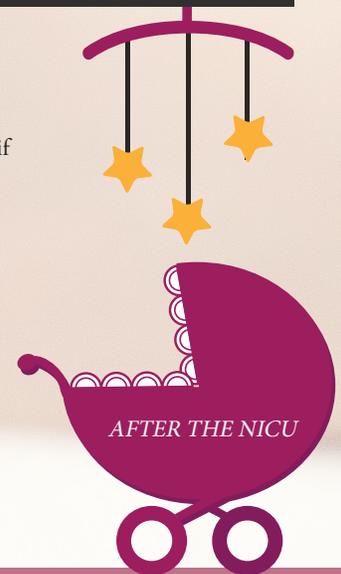
COOL: We're giving away two Keepsies to one new follower on Preemie World's Instagram page: <https://premie.us/PWInsta>

And congrats to Mary Johannigmeier, RN who won the January giveaway set of BEB Organic skincare for preemies!

STRUGGLE FEEDING SOLIDS

Are you heading toward or in the middle to attempting to feed your preemie solids yet? If you are already there, don't be shocked if there is a struggle. Feeding solids can be challenging for preemies and their families. Ask the pediatrician:

- My child is having trouble with solids. What are some strategies to get him/her engaged in trying again?
- My child chokes on solids. Is this a sign of a bigger concern? Could reflux (visible or silent) be a problem here?
- I have heard a lot about preemies and sensory processing disorder being a part of feeding. What do you suggest?
- What specialists should I reach out to for help if I think we need a specialist in toddler feeding?
- What are some good books and resources I should use for a selective eater like my child?
- Is there anything else I should know at this time?



PREEMIE FAMILY ONLINE

Inspire Preemie 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.

<http://premie.inspire.com>

PreemieWorld on Twitter

<http://bit.ly/PreemieTweets>

PreemieWorld on Facebook

<http://premie.us/PreemieFB>

PreemieWorld on LinkedIn

<http://bit.ly/PWLinkedIN>

HIGHLIGHTING @ARIANAE09

Our latest preemie highlight: Mikeala Joy (@arianae09):

Born 6-12-18 at 28 Weeks 1 day. She weighed 1lb. 10oz. and 12 inches long. Mikeala spent 199 days in the NICU before being discharged the week of Christmas! She is now 7 months old, 14lbs. and 24 inches long. She is our Hero! Our "Mighty Mikeala."



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 ANGEL:

Vivian: My dear baby girl was born at 28 weeks, weighing 800 grams. Instead of being the best day of my life, it was the scariest. My teeny baby thrived and grew stronger every day, right in front of my helpless eyes. Today, my one pound wonder is almost 5. She is the tallest kid in her preschool class.

-Jennifee Sutton

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....

Premie 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.

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/preemie1>

JOIN THE CONVERSATION

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

~ Deb Discenza, PremieWorld

f @PremieWorld
@Premie Parent's Survival Guide to the NICU

t @PremieWorld

in @PremieWorld
@NICU Professionals
@Early Intervention Professionals
@Premie Support Group Leaders
@Premie Parents

ig @PremieWorld