



premiepro
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:

Look for worldwide events

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

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.



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.

Brain Monitoring/Neuroprotection in Newborn February 7-9, 2019 | Clearwater, Florida, USA <https://premie.us/COINNneuro>

NEO: The Conference for Neonatology 2019 February 21-23, 2019 | Louisiana, United States <http://www.neoconference.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

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

SUPPORT: BRYCE'S NICU PROJECT



It all started with a Mother's Day gift from a former NICU Mom. Founders **Brittany and Brian Boet** were in the NICU with their firstborn, Bryce. Brittany spent her first Mother's Day in the NICU and looking back realized that every day in the NICU was hard but that particular holiday was 10 times harder. Her family did their best to cheer her up by giving her gifts and support but when a nurse came and brought her 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.

Giving Back. When Mother's Day rolled around the following year, Brittany remembered the gift and told 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. They determined that they would do whatever they could to help as many NICU families as possible to not feel that sting of loneliness. After fundraising with family and friends for two years, the Boets were able to provide two NICUs with gifts, lunch and support. Upon hearing that they had 11 NICUs in their city, they realized that many other families were in great need of this type of support. That year they established their organization as a 501(c)(3) non-profit. **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
Founders: Brittany and Brian Boet



ORG: MIRACLE EAR FOUNDATION

The **Miracle-Ear Foundation**® serves and supports children and adults who have a hearing loss. Our **Gift of Sound** program provides hearing aids and hearing support services to families or individuals who have incomes that are significantly limited, who are unable to afford the costs of quality hearing instruments, and who have exhausted all possible resources for their hearing health. Hearing challenges are unique, every application for service and support are considered on an individual basis. This private nonprofit organization is the philanthropic arm of Miracle-Ear. Originally this organization was founded to support only low-income children with hearing loss, but has now expanded to also help adults. Undetected hearing loss in children can delay speech and language, affecting social and emotional growth as well as academic achievement. Our goal is to give the Gift of Sound to enhance lives and empower children and adults to succeed.



Year Established: 1990
Outreach: National, available in areas where there is a Miracle-Ear store.

For more information visit www.Miracle-EarFoundation.org

ONE OF THE TOP 10 FILMS OF THE YEAR! — *The Advocate*

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"

WINNER OF 12 BEST DOCUMENTARY AWARDS

Los Angeles Times: "AN EDGE-OF-YOUR-SEAT, HEART-IN-YOUR-THROAT SUSPENSE STORY"

Will 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"

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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 a two Keepsies to one new follower on PreemieWorld's Instagram page: <https://preemie.us/PWInsta>

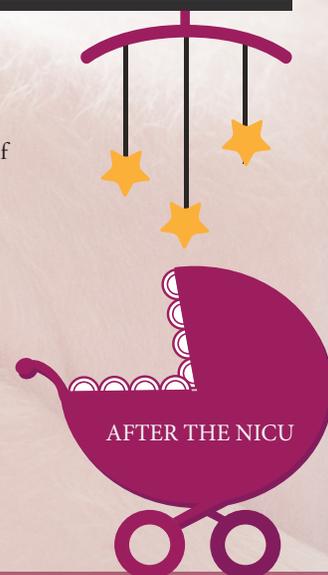
And congrats to Mary Johannigmeier, RN who won the January giveaway set of BEB Organic skincare for preemies!



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://preemie.inspire.com>

PreemieWorld on Twitter

<http://bit.ly/PreemieTweets>

PreemieWorld on Facebook

<http://preemie.us/PreemieFB>

PreemieWorld on Instagram

<http://preemie.us/PreemieInstagram>

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 PRIDE:

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



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Premie Tags
Honor the Journey

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

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 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

f @PremieWorld
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t @PremieWorld

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@Early Intervention Professionals
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