



premieworld  
support. educate. advocate.



## PREEMIE ALIEN FAMILY

*recreating the PremieWorld*

It was like we had landed on a new planet upon NICU discharge. Instead of seeing family and friends as people I admired, I only saw people with germs all over them. Surfaces of my lovely home suddenly had me jumping to clean *everything*. I had hand sanitizer pumps at every sink in the house as well as in each diaper “station” we set up on each floor of our home. And one at the front door for good measure to make it clear that *we meant business*.

Anyone coming into the house was scrutinized and asked to wash their hands. This included the visiting nurse, the health department professionals who were there at our request to monitor our daughter’s development. We had become aliens in a germ-filled world and we didn’t care what other people thought. As it turned out, we weren’t alone. Check out our latest community survey summary on this subject: <https://premie.us/NonPremieWorld>

*We have a new survey - PPD & PTSD:*  
<https://premie.us/PPDPTSDsurvey>

- Deb #celebratepreemies

## IN THIS ISSUE:

### *Premie Alien Family*

Deb Discenza talks about becoming “aliens” in a world full of people with “germs all over them.”

### *Premie Genius: Calming Diaper Rash Cream*

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

### *Premie Support: Early Bird Foundation*

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:

- 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.
- NEC Symposium**  
June 2-5, 2019 | Ann Arbor, Michigan, United States  
<https://premie.us/NECSymp2019>
- ‘Tinis for Premies by Graham’s Foundation**  
June 19, 2019 | Perrysburg, Ohio, United States  
<https://premie.us/Tinis4Premies2019>

## 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)!

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

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

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

 @ [www.instagram.com/premieworld](https://www.instagram.com/premieworld)

## PREEMIE FREEBIE: LIVING IN A NON-PREEMIE WORLD

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 Living in a Non-Premie World survey from May.** You can get it by going to the link below (and watch social media for parent quotes throughout the month):

*Living in a Non-Premie World Results:*  
<https://premie.us/NonPremieWorld>

“ I really noticed that my “Address Book” of people I relied upon for help changed with this experience. Suddenly I was leaning on fellow preemie parents near and far for advice rather than family and close friends. They really had my back. ”  
~ Deb Discenza, PremieWorld



# A SPECIAL NOTE FOR DADS

## Excerpt:

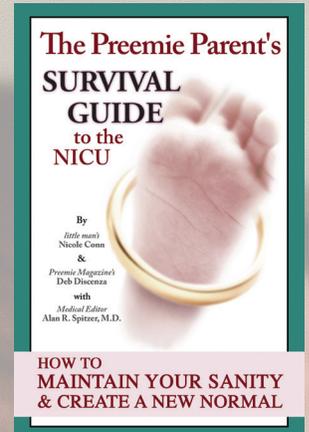
Dads definitely tend to get the short end of the stick when it comes to all things NICU. While the mother often feels left out of the parenting experience, the dads feel completely ignored and end up dealing with so much of the outside world chaos instead. While we know the NICUs don't intend to make this occur, it does. Dads, hear us loud and clear: you are very important to the well-being of mom and baby during this time so come to the NICU whenever humanly possible.



**Dads, hear us loud and clear: you are very important to the well-being of mom and baby during this time so come to the NICU whenever humanly possible.**



*-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: EARLY BIRD FOUNDATION, INC.

Having endured the extreme isolation that comes with a stay in the Neonatal Intensive Care Unit (NICU) founders Ashton Tackett and Lyndsey Lewis saw a lack of peer support in the three NICU facilities where they live in Lexington, Kentucky. And so **Early Bird Foundation, Inc. was born.** The organization's focus is on families who have experienced a NICU stay of any length, in the past, currently or those with high risk pregnancies likely to experience a NICU stay in the future. Support includes:

- Monthly peer-led NICU family support group meetings and dinner at the local Ronald McDonald house for past, present and future NICU families.
- Hospital visits and follow-ups for individual families including those currently in the NICU or on antepartum bed rest. Each family is provided with a NICU care package that includes NICU related storybooks, a premie outfit, snacks, a gift card and hand sanitizer or lotion.
- Fill Your Cup Initiative provides each of the three local NICUs with NICU Mom water bottles with a tag including an encouragement to focus on self-care during this time and an invitation to the support group.
- Craft Night which creates hand-crafted unique bassinet name cards to the local hospitals as keepsakes for the families.
- NICU Family of the Month highlight on the organization's website and on social media to spread awareness of the challenges of NICU families.

For more information visit <https://www.EarlyBirdFoundation.com>



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

WINNER OF 12 BEST DOCUMENTARY AWARDS

**little man** documentary film by nicole conn

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"

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"

...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)

## CALMING DIAPER RASH CREAM

Baby products are assumed to be safe and are regulated like everything else, right? *Think again.* BEAUTYCOUNTER Founder and CEO **Gregg Renfrow** was "...Surprised when I learned that when it comes to the personal care industry, that's simply not the case. Companies are allowed to use harmful ingredients and make their own judgments about safety. And so I started BEAUTYCOUNTER, a company devoted to progress. Here you'll find a wealth of empowering information about ways we can all make the world healthier, along with safer products you can trust. Because we all deserve better. Our vision is bold; real answers are never timid. Help us put truth back in beauty."

In addition to adult-oriented skin care that includes washes, make-up, a men's care line and more, the company has a specific baby care line that includes a baby-wash, baby oil and a product that every preemie parent will find of interest - Calming Diaper Rash Cream. While the products are more expensive, you do get a product that has been "rigorously tested" by the company and "prohibit the use of 1,500 harmful or questionable ingredients."

*For more information visit:*  
<https://www.BEAUTYCOUNTER.com>

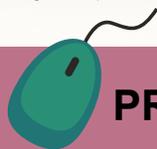
*ONE LUCKY new Instagram winner will get a free bottle of the BEAUTYCOUNTER Calming Diaper Rash Cream. Ends 6/15/19.*



## FINDING YOUR PREMIE TRIBE

One of the hardest things when you leave the NICU? Connection with others that know what you are going through. Consider reaching out to a preemie support group - there are many online and in-person. Some suggestions for your search:

- ✓ **National Perinatal Association's Family Advocacy Network.** Learn more at <http://nationalperinatal.org>
- ✓ **Preemie Parent Alliance.** This group focuses on the combined parent voice and PreemieWorld is a founding member. Check out their members, many of which are support groups, at [www.PreemieParentAlliance.org](http://www.PreemieParentAlliance.org)
- ✓ **European Foundation for the Care of Newborn Infants (EFCNI).** This group does a lot of advocacy in the preemie space and has groups across the globe join them in speaking out about preemie family rights and more. Their website lists the organizations involved in their efforts at [www.efcni.org](http://www.efcni.org)
- ✓ **National Premmie Foundation.** This organization has a membership of support groups helping to provide families with information and support during their journey of prematurity. <http://prembaby.org.au/>



## PREMIE FAMILY ONLINE

### ***Inspire Preemie Community:***

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

Help your families connect with over 46,000 parents of premies 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 premies and women with high-risk pregnancies.

<https://preemie.inspire.com>

*PreemieWorld on Twitter*

<http://bit.ly/PreemieTweets>

*PreemieWorld on Facebook*

<http://preemie.us/PreemieFB>

*PreemieWorld on LinkedIn*

<http://bit.ly/PWLinkedIN>

# HIGHLIGHTING @ELITECONCEPTSCANADA

Our latest preemie highlight: [@eliteconceptscanada](#)

Meet Emma, a former 26-weeker that just turned 9 months old and loves her father! ❤️❤️❤️

When your micro preemie turns 8 months old and wants to play in her new toy but her legs are too little but u have a few bits of scrap in the shop and this client doesn't care about the finish [@premieworld](#)  
#micropreemie #preemie #8monthsold #preemieproblems #preemiedad #preemieparent #26weeker #nicusurvivor #tinybuttoough #daddyslittlegirl #woodwork #woodworker #pine #notmyfinestwork #shedoesnotcare #quickndirtyproject



We Could Highlight YOUR PREEMIE.

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

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

## FEATURED PREEMIE PRIDE:

Amelia Louise -

Today Amelia officially took more of her feeding by mouth than by her ng tube! She took 40 of her 60 mLs!! She was born the day after Christmas at 30 weeks gestation and is making strides! Once we get this breathesuck/swallow thing down we're golden!

- Megan Paulsen



We welcome your submissions for this section of Preemie Pride, Premie Angel, and Premie Prayer at [PremieWorld.com](#)

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

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

“ Premie Parents, remember YOU are the expert of your child. Trust your gut. ”

~ Deb Discenza, PremieWorld



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



[@PremieWorld](#)



[@PremieWorld](#)  
[@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

**The Zaky**  
A brand by Nurtured by Design  
[www.TheZaky.com](http://www.TheZaky.com)

*Premie Tags*  
Honor the Journey

00001  
NICU SURVIVOR  
PremieWorld.com

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