



preemiepro
support. educate. advocate.



POST-DISCHARGE LIFE

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://preemie.us/NonPremieWorld>

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

- Deb #celebratepreemies

IN THIS ISSUE:

Look for worldwide events

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

Premie Alien Family

Deb Disenza 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.



www.KeytoCP.com

TO DO LIST:

✓ **PremieWorld Tags.** Tag you are it, check out page 4 for a section all about [our Instagram followers](#).

✓ **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://preemie.us/NECSymp2019>

✓ **18th Annual World Congress on Neonatology**
June 14-15, 2019 | Montreal Canada
<https://neonatal.conferenceseries.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!



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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://preemie.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 Disenza, PremieWorld

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.

Year Established: 2017

Website: www.EarlyBirdFoundation.com

Outreach: Lexington, Kentucky USA + Region

Founders: Ashton Tackett and Lyndsey Lewis



Early Bird Foundation, Inc.
Peer Support for NICU Families

ORG: ASSOCIAZIONE CUORE DI MAGLIA

With an army of volunteers knitting soft hats, shoes, dudu and covers ASSOCIAZIONE CUORE DI MAGLIA focuses on bringing humanity to the hospitalization of tiny babies in the Italian wards of the Neonatal Intensive Care Unit. "Cuore di Maglia" is an idea born to remedy a mistake. A shoe that was too small that was followed by the search for a "Cinderella" to which it could fit. It is as the organization states, "A simple gesture to bring a semblance of normality and hope that, has been proven, has positive effects on the newborn, on his mother and on his father. The controls in place for production are very strict, respecting the measures of the premature babies and performing scrupulously the models prepared specifically and without seams, with fine yarns such as cotton and merino wool, which maintain body temperature, are hypoallergenic and extremely soft." Within its first 10 years, the organization has donated over 6,000 blankets and about 8,000 kits of caps and shoes.

For more information visit
<https://cuoredimaglia.wordpress.com>

Year Established: 2008

Outreach: Italy

Site: <https://cuoredimaglia.wordpress.com/>



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 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 Worldwide Regional Coding English
SOUNDTRACK AVAILABLE AT WWW.LITTLEMANMOVIE.COM

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www.littlemanthemovie.com

SPECIAL LIMITED EDITION WITH FAMILY UPDATE

"little man" is every
preemie parent's story



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 PREEMIE 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
- ✓ **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
- ✓ **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/>

AFTER THE NICU



PREEMIE FAMILY ONLINE

Inspire Preemie Community:

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

Help your families connect with over 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>

PreemieWorld on Twitter

<http://bit.ly/PreemieTweets>

PreemieWorld on Facebook

<http://preemie.us/PreemieFB>

PreemieWorld on Instagram

<http://preemie.us/PreemieInstagram>

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 breathe/suck/swallow thing down we're golden!

- Megan Paulsen



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 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

“When you help a family bond in the NICU, it lasts a lifetime.”

~ Deb Discenza, PremieWorld



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



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Premie Tags
Honor the Journey

