



premiepro
support. educate. advocate.

INTERVIEW with BETSY PILON



President, Hope for HIE

Name: Betsy Pilon, President

Years Helping Premies: Hope for HIE was founded as a support group in 2010. In 2013, it was organized into a formal 501c3 organization, serving families worldwide with awareness, education and support for Hypoxic Ischemic Encephalopathy (HIE) across all causes and outcomes.

Focus: HIE occurs mainly in term infants, but can occur in preemies.

Professional Tip: Families who have peer-to-peer support from the beginning of a diagnosis feel more empowered in their parenting.

IN THIS ISSUE:

Interview with Betsy Pilon

As the president of Hope for HIE, Betsy Pilon tells us a bit about this very special organization.

Premie Genius: MyMilkID App

With it being Breastfeeding Awareness Month, we review a set of apps devoted to keeping breast milk safe.

Premie Organization: The Patrick Palin Foundation

A non-profit brings light, love and needed resources to NICU families.

Look for worldwide events

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



www.OnceUponaPremie.com

TO DO LIST:

- ✓ Check out our **Premie Wall Pages** on our website - <https://premieworld.com> and submit your pride, prayer, and/or angel today!
- ✓ **Premie Freebies:** From PremieWorld at <http://bit.ly/PremieFreebies> and pass them onto Premie Parents in their welcome packets.
- ✓ **Fragile Infant Feeding Institute (FIFI)** August 21-25, 2017, Clearwater, Florida, USA <http://www.cme.hsc.usf.edu/fifi10/>
- ✓ **2nd Int'l Symposium on the Fetal Brain** August 24-25, 2017, Washington, DC, USA <http://www.fetalbrainsymposium.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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YOUR PREMIE FREEBIE: EVERY DROP COUNTS

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: **Liquid Gold: Every Drop Counts.**

With it being Breastfeeding Awareness Month, PremieWorld joins in the celebration with a message meant to encourage mothers and celebrate each drop of milk.

To download this freebie, visit <http://bit.ly/PremieFreebies>

“ Premie Moms worldwide struggle with breastfeeding and with breastpumping. Just trying to do this deserves love and support and yes, celebration. **Every drop counts. Every single drop.** ”

~ Deb Discenza, PremieWorld

SUPPORT: DORIS MOLLEL FOUNDATION

In Tanzania, where around 213,000 babies are born prematurely annually, with 9,000 of them will end up dying from complications of their preterm birth. The **Doris Mollel Foundation** seeks to raise public awareness of premature birth and it envisions a “barrier-free, inclusive, diverse world that values each individual and their voice” and where “all people with disabilities as well as preterm infants enjoy the power of equal rights and opportunities, dignity, choice, independence and freedom from abuse, neglect and discrimination.”



Established: February 2015
Website: www.dorismollel.com
Focus: Promote public awareness about prematurity.
Outreach: Tanzania, Africa

PROGRAMS:

Outreach Via Media

The organization reaches out through the various media outlets in Tanzania to spread awareness around prematurity and to spread hope for those who were born prematurely. The organization does this surrounding its various activities including World Prematurity Day and a charity walk.

Programs & Activities

Ramadan basket donations in Bagamoyo, Zanzibar and Tanga; launch of a premature equipped ward at Sekoutore Hospital - Mwanza; celebrating and recognition of Kangaroo Care Awareness Day with media outreach and the donation of 20 dresses for mothers who are in the preemie ward in Temeke Hospital Dar-es Salaam; Workshop on prematurity prevention and lifesaving to train nurses across all regions in Tanzania as well as an equipment donation; organizing a special cleaning project for preemie wards in recognition of International Women’s Day along with the donation of equipment; large equipment donation to various hospitals throughout Tanzania through Vodacom; blood drives, donation of books, uniforms and blankets to Hadzabe primary school students.

Visit <http://dorismollel.com> for more info

ORG: THE PATRICK PALIN FOUNDATION, INC.

After losing their precious son Patrick in the NICU at 25 days old, the Palin family formed a foundation to keep Patrick’s memory alive while supporting other families who find themselves in the same stressful situation as them. They support families in the NICU as well as those families that experience the loss of an infant.

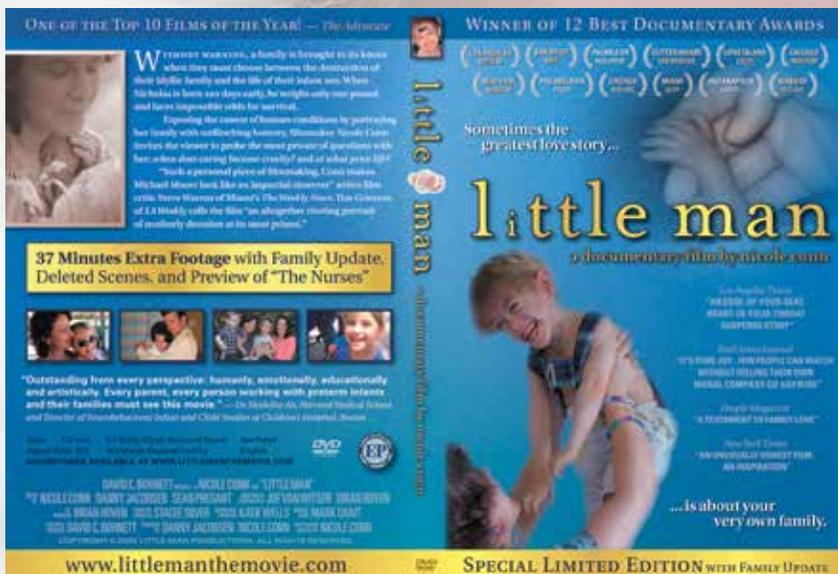


Programs for Preemie Families

NICU Family Support Package; NICU Family Memory Package, Sweethearts (fabric hearts worn on the parent’s skin to absorb their scent and to be left with the baby when they cannot be there); NICU Family Relief Basket; Legacy Gifts (sending a family of loss a plan in memory of their baby such as a rose bush); Sibling Packages; Precious Baby Blankets (blankets donated to hospitals to use when presenting stillborn babies to their parents for that difficult time they are saying hello and goodbye.

Visit <http://www.thepatrickpalinfoundation.org> for more info

Year Established: 2015
Website: www.thepatrickpalinfoundation.org
Focus: To support families with a baby in the NICU and those who experience the death of an infant.
Outreach: Hospitals in Massachusetts but also directly to families anywhere in the United States.



“little man” is every preemie parent’s story



www.littlemanthemovie.com

MYMilkID APPS SAVE PARENTS & PROS

Breast milk management in the NICU just got easier and safer for both parents and pros thanks to MYMilkID.

MYMilkID has come out with not one but two slick apps (MYMilkID for parents and MYMilkID Pro for hospital team members/daycare pros) to properly manage breast milk so that there are no mix-ups and easy electronic communication can happen between the various parties. Mom starts the tracking process at home with unique auto-generated labels for each vial that can be printed at home or at the hospital or even be ordered through the app (for a fee). After depositing the marked vial at the hospital she can then follow each vial of milk from receipt by the hospital to use for the baby and also knowing when the milk is expired for use. Alternately, providers have their side of the tracking as well which includes the option for it to be integrated into the hospital electronic medical record. Once the baby is home, daycare providers can continue the same process in their facility. MYMilkID has done an incredible job thinking out thought out the entire process in each setting and boiling it down into down to easy-to-navigate buttons on the apps. For the busy Mom and the busy pro, this allows for the ultimate safety for the baby.



MYMilkID is the first all mobile breast milk management tool designed specifically for busy Moms.



~ MYMilkID



MYMilkID (Pro)

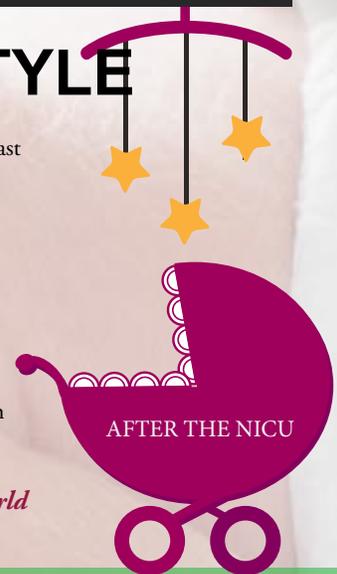
PARENTS - download the free app off AppStore or on Google play. PROVIDERS (hospitals and daycare pros), your free app is also on these platforms with an Android version coming soon.

BREASTFEEDING GOALS, PREEMIE-STYLE

When one thinks about breastfeeding goals, there is this sense that milk will come in and that you will feed that baby from the breast without a problem for months or years. But with the preemie mom, life is different and sometimes goals need to be tweaked.

- ✓ Focus on the moment - attempt pumping for a day, attempt a practice breastfeeding session when the baby is ready.
- ✓ Think about pumping for a week and attempt more breastfeeding practice sessions guided by a lactation consultant.
- ✓ Try pumping for one month and plan a breastfeeding practice for each day when the baby is well enough to do so.
- ✓ And Know that being a mother first is most important and is not based on breastfeeding. Do what you think you can and know that guilt has no place in the NICU or post-NICU. *You are doing an amazing job just by trying, period.*

Struggle with pumping and/or breastfeeding in the NICU? Tell us on social media with the hash tag #premieworld



PREEMIE FAMILY ONLINE

Inspire Preemie Community- Parents, Grandparents, Adults and High-Risk Pregnancies

Help your families connect with **over 38,000 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>



PREEMIE SHOWER: LANSINOH

PreemieWorld continues its monthly Preemie Shower! This edition, our friends at Lansinoh www.Lansinoh.com will be donating **50 Lansinoh Starter Sets** to a single NICU that includes everything mom needs to successfully start and continue breastfeeding. This set is perfect for a new mom and will help her to address common breastfeeding challenges. Includes best-selling Lansinoh® HPA® Lanolin, recommended by lactation consultants and doctors in the USA. Also includes best-selling Lansinoh® Nursing Pads, Therapearl® 3-in-1 Breast Therapy packs, and Latch Assist™ Nipple Everter. **To enter, a professional from a NICU must sign up as a new subscriber on our “Preemie Family for Pros” list by 8/22/17. Enter: <http://bit.ly/PreemieFam4Pros>**

On social media, tell us what you'd like in a future shower at [#preemieshower](https://twitter.com/preemieshower) And congrats to July's Preemie Shower winner: **Adriana Park!**



FEATURED PREEMIE PRIDE:

So strong, awesome and doing great from the start - my 33 weeker.

- KeyaraMarie



We welcome your submissions for this section of Preemie Pride, Preemie Angel, and Preemie Prayer at <https://PreemieWorld.com>



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Preemie 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....

New Preemie Shower

We are gearing up for a new Preemie Shower for one lucky NICU. Will it be yours?

Preemie Genius

We are reviewing a new preemie children's book. Don't miss it!

And More!

Have you subscribed to Preemie Family yet? It's free!
<http://bit.ly/preemie1>

JOIN THE CONVERSATION

“ You are the expert of your child, period. ”
~ Deb Discenza, PreemieWorld

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