



premieworldfamily

support. educate. advocate.

EXCLUSIVE HUMAN MILK AWARENESS

It's time to know your options

As the Mom of a preemie born at 30 weeks in 2003 I know all too well the importance of an exclusive human milk diet. I totally get it. But *reality check*: not every baby can get breastmilk from Mom as was the case with my daughter because she had a weak suck. However, I was able to pump, and pump I did.

At one point the NICU fortified my daughter's feedings to give her extra calories for growth. Unfortunately that was done with traditional bovine fortifier which lacked the benefits of my milk and was given to Becky *without my knowledge or even my permission*.

Learn from me and ask your team about what is being fed to your baby and ask that you provide permission before cow-based fortifier is added to your baby's diet. As important as any medical procedure or intervention, you have the right to be informed about the nutrition of your baby. In preemies less than 1,250 grams (roughly 2.7 pounds), human milk is quite literally "medicine."

~ Deb, Publisher & CEO, PremieWorld

IN THIS ISSUE:

Exclusive Human Milk Awareness

This special edition is just for you. Learn all about what an exclusive human milk diet can do for your preemie in the NICU.

Know Your Preemie's Nutritional Rights

Ask questions, be informed. Be proactive and vocal about what your baby should and should not be fed in the NICU.

Tools, Resources, and Valuable Links

We're here to help you make informed decisions.

See advice from the NCfIH:

<http://premie.us/EHMDVideo>



TO DO LIST:

- ✓ Understand the research on **babies born under 1,250 grams and why they should receive only human milk** until their GI System is ready for foreign substances.
- ✓ **Talk to your team** about your baby's nutritional needs and hospital policy on formula for VLBW babies.
- ✓ Be aware that whether you breastfeed or use human donor milk, **a fortifier will need to be added to support adequate growth**.
- ✓ **Know there are two types of fortifiers available**: one made from cow's milk, called 'human milk fortifier,' and one made from true human milk. This can be very confusing. **Ask your professional to clarify and make sure you request the fortifier made from human milk.**

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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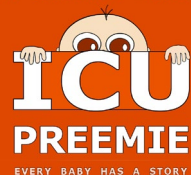
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PREMIE GENIUS: A FREE COMPREHENSIVE NICU PARENT APP

Peek a Boo



Every parent in the NICU is searching for information as they navigate the NICU journey. Peekaboo ICU has brought it all together in one amazing free mobile APP. Parents can customize and track their preemie's individual growth and development.

Watch this short video on YouTube: <https://www.youtube.com/watch?v=sP-NFzdw0bc>

Download the APP at <https://play.google.com> or <https://itunes.apple.com/>



INFOGRAPHIC

NCfIH National Coalition
for Infant Health
Protecting Access for Premature Infants through Age Two

Why PREMATURE INFANTS Need Access to an EXCLUSIVE HUMAN MILK DIET



In the United States, more than **1 IN 10 BABIES ARE BORN PREMATURE**. Very low birthweight babies are born severely premature, weighing less than 1,250 grams.



What does a 100% human milk diet consist of? It is Mother's Milk, or pasteurized milk from a screened and qualified donor plus supplemental human milk-based fortifier to provide added calories and nutrients required for adequate growth.

The National Coalition for Infant Health (NCfIH) is a collaborative of professional, parent, clinical, community health and family support organizations focused on improving the lives of premature infants and their families.

As a key priority, the Coalition advocates for access to human milk and human milk-based fortifiers for very low birth weight preemies.

"An exclusive human milk diet can shield preemies from necrotizing enterocolitis, or NEC, a potentially life-threatening intestinal condition," says Dr. Mitchell Goldstein, Medical Director.

"The most common and serious intestinal disease you will hear about as a parent of a preemie is necrotizing enterocolitis," he says.

Necrotizing enterocolitis happens when tissue in the small or large intestine is injured or begins to die off. This causes the intestine to become inflamed or, in rare cases, develop a hole (perforation). Many of these babies require immediate surgical intervention and often don't survive.



Mitchell Goldstein, MD

*Prof. of Pediatrics, Division of Neonatology
Loma Linda University Children's Hospital*

*Medical Director, National Coalition
for Infant Health*

While the exact cause of NEC is unknown, experts believe that different factors play a role in its development. These include too little blood flow to the intestine as a result of a difficult delivery, heavy growth of bacteria in the intestinal wall, and the use of cows-milk formula or fortifier before baby's digestive system is mature.

In fact, studies show a 77% reduction in NEC in 1,250 gram babies who received an exclusively human milk diet.

But it's not just about NEC! Evidence also supports that an exclusive human milk diet has additional benefits beyond the reduction in NEC including reducing the use of total parenteral nutrition (TPN), the number of days in the hospital, complications with bronchopulmonary dysplasia, retinopathy, feeding intolerance, sepsis, and an increase in overall growth.

There is a clear distinction between cow or "bovine" fortifiers and exclusive human milk fortifiers and we urge parents to be informed and work with their healthcare team on this vital issue.

“The American Academy of Pediatrics recommends the use of human milk for all preterm infants for the first six months of life, whether Mother's own milk or pasteurized donor human milk when Mom's own is unavailable.”

~ Section on Breastfeeding
Pediatrics, Vol. 129 No. 3, March 2012

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Visit <https://hubs.ly/H08G-1w0> to download this infographic in English or Spanish

BE PROACTIVE, KNOW YOUR PREEMIE'S RIGHTS

Express your desire for an exclusive human milk diet with your healthcare team:

- ☒ Request lactation support if you choose to breastfeed
- ☒ Ask if the hospital has or can provide your baby access to human donor milk and human milk-based fortifier. If not, ask how you and your healthcare team can work together to obtain it for your baby

Actionable steps you can take as a parent of a 1,250 gram (or less) preemie:

- ☒ Consider providing consent only for human donor milk and human milk-based fortifier (no formula or cow-based products of any kind)
- ☒ Download the letter of medical necessity in the tools section and have your provider send it to your insurance carrier
- ☒ Present the clinical evidence provided in the tool section to your healthcare team
- ☒ Contact your hospital administrator



PREEMIE STORY: A MOM WHO GAVE BACK



About 14 weeks before my due date, I was diagnosed with gestational diabetes and had some bleeding and cramps. It was my first pregnancy, so I tried not to worry. But I started having contractions one night and woke up with more bleeding, so I went to see the doctor. I learned I was having my baby that day. I was in such a state of shock, I didn't want to believe we were going to the NICU! My husband and I were just staring at each other, crying. There was a 90% chance of our son living, which was good to hear, but we were very scared.

Mason was born 14 weeks premature on February 25th, 2016, at the exact time I was born, 4:17 p.m. He weighed 2 lbs 2 oz. (just under 1,000 grams). You always think that when you have a baby, you'll be able to hold them, but they immediately took

him to the station with a million nurses around him. We didn't hear him cry. I stared at them for what felt like a long time until they said, "He's okay."

Mason was too premature to breastfeed, so I started pumping, knowing how important it is for preemies to get all that nutrition. After the first two weeks, they began fortifying my milk with a human milk-based fortifier for the extra nutrition he needed. Mason went back and forth between two hospitals' NICUs for several months, and I was there with him every day. I asked a lot of questions, and kept a notebook and a blog, which helped me deal with my emotions while also keeping our family and friends up-to-date.

When we brought him home on June 14th, we were unprepared and scared. I was still unable to breastfeed. In early September, he finally latched on one time after weeks of trying. But the doctor encouraged us to continue pumping and using the fortifier to ensure Mason was getting the right nutrition. We were having a rough time, but we kept trying. All this pumping meant I had a lot of excess milk. So I became a donor. I think it's great that donor milk helps preemies - I saw how important human milk-based fortifier was to my own son while he was in the NICU. I decided to do the same for other preemies.

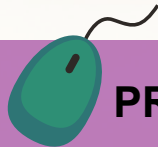
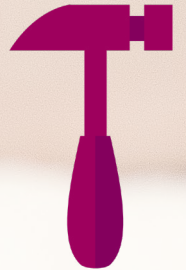


NUTRITION TOOLS AND RESOURCES

We have taken the premie universe and boiled it down into some very useful tools just for you. With links, with support and more, grab a bottle of water and hydrate, rest and check them out below:

- ✓ Clinical evidence behind the benefits of an exclusive human milk diet: <https://premieworld.com/wp-content/uploads/Clinical-Studies.zip>
- ✓ NCIH Video & Infographic: <http://preemie.us/EHMDVideo> ; <https://hubs.ly/H08G-1w0>
- ✓ Hand To Hold's PDF: <http://handtohold.wpengine.netdna-cdn.com/wp-content/uploads/2017/01/Nurturing-and-Nutrition-short-version-for-website-FINAL.pdf>
- ✓ Peekaboo ICU APP: <http://www.peekabooicu.com/app/>
- ✓ Sample Letter of Medical Necessity: <https://premieworld.com/human-milk>

Also make sure to check out Premie World's extensive freebies section online at <https://premieworld.com>



PREEMIE FAMILY ONLINE

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

Help your families connect with almost 40,000 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>

PremieWorld on Twitter

<http://bit.ly/PremieTweets>

PremieWorld on Facebook

<http://preemie.us/PremieFB>

PremieWorld on Instagram

<https://www.instagram.com/premieworld>

IT'S ABOUT WHAT'S IMPORTANT:



The Morgan Leary Vaughan Fund

Human Milk is for Humans, Cow's Milk is for Cows

We talked to Stephanie Vaughan, Co-Founder and President of The Morgan Leary Vaughan Fund, about why an exclusive human milk diet is so crucial for very low birth weight babies.

"In my opinion, 'breastfeeding' can be a polarizing term," she said. "My twin sons were born at 28 weeks gestation, after which I exclusively pumped for 4 ½ months. I was fortunate to produce an ample supply of milk. However, my husband and I decided early on that feeding at the breast was not something that we wanted either baby to attempt. What premature babies need is access to an exclusive human milk diet to reduce NEC and so much more. The nutritional benefits can be provided in many ways: feeding at the breast, expressed mother's milk, donor milk, the addition of a human milk-based fortifier, or any combination thereof."

The Morgan Leary Vaughan Fund (Morgan's Fund) is an all-volunteer, public charity dedicated to Necrotizing Enterocolitis (NEC). Its mission is to promote public awareness about NEC and the potentially devastating effects it can have on preemies and their families, and to advance research to prevent, diagnose, treat, and ultimately, cure NEC.



Check out the "Speaking of NEC" Podcast Series:

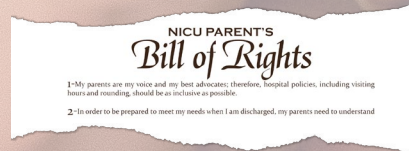
<http://www.morgansfund.org/category/podcast>

See more at <http://www.morgansfund.org>



Find a Premie Parent Alliance member support organization in your area at:

www.premieparentalliance.org



Premie Parents have rights in the NICU. Learn yours by downloading the Premie Parent Alliance Bill of Rights here:

<http://www.premieparentalliance.org/bill-of-rights/>

NICU NURTURING + NUTRITION

Hand to Hold: Fragile Babies, Strong Support

HUMAN MILK FORTIFICATION

Your premature baby has extraordinary nutritional needs as they are continuing the vital work of developing all of their body organs, particularly their brain. Their body systems are very fragile and human milk is as important as any other medication they receive. The American Academy of Pediatrics recommends human milk fortification for all infants less than 1500 grams or 3 pounds 5 ounces. And for those very low birth weight babies less than 1,250 grams (roughly 2.5 pounds), it is vital for parents to understand that there are two types of fortifiers available. Optimally, these very small preemies need a fortifier that is 100% human milk-based rather than non-human milk-based. As the best advocate for your baby, it is important for you to discuss these options with your NICU care team.

Hand to Hold, a national organization with a support network that stretches across the United States, has a wonderful resource to help you learn about nutrition choices, *NICU Nurturing and Nutrition*.

Download it for free at: <https://premieworld.com/human-milk>

This resource contains honest information for parents who want to give their babies the best start in life.

Go to <http://handtohold.org/> for peer support and other resources

JOIN THE CONVERSATION ON NUTRITION

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

~ Deb Discenza, PremieWorld



@ www.facebook.com/PremieWorld

@ *Premie Parent's Survival Guide to the NICU*



@ *PremieWorld*



@ *PremieWorld*

@ *NICU Professionals*

@ *Early Intervention Professionals*

@ *Premie Parent Support Group Leaders*

@ *Premie Parents*



@ www.instagram.com/premieworld



Dear Premie Parent,

Congratulations on your bab(ies)! As a mother of preterm triplets, I can relate to the mix of emotions that seem to hit at the same time. Feeling joyful yet worried as you watch your child/ren's journey through the Neonatal Intensive Care Unit (NICU) is a very normal response to this experience. This is also your journey, too, one that you need not walk alone.

We have long known that breast milk is the "liquid gold" of nutrition for newborns, and it is critically important, as a collective voice for NICU parents, that our PPA members are well equipped to advocate for an exclusive human milk diet on behalf of the families we serve.

I founded the Premie Parent Alliance (www.PremieParentAlliance.org) as a way of unifying the many parent-led organizations that support parents like you around the United States.

Our members provide an array of resources, educational materials and services, any of which are available no matter where you live. Take a moment and browse our website to find one of these incredible organizations near you. And while you are at it also check out our Premie Parent Bill of Rights, too. It belongs to all who walk this journey.

Wishing you a smooth ride through the NICU, discharge and onto home.

Keira Sorrells, Founder & President
Premie Parent Alliance
www.PremieParentAlliance.org