



premiepro
support. educate. advocate.



MY FIERCE ADVOCATE

one issue at a time with PremieWorld

“Your speaking up could make a difference for you but especially for those coming after you.” I said this last week to my preemie, Becky, 15 and a freshman in high school. As a student with disabilities as well as gifts that puts her in the “twice exceptional” category. Unfortunately while special education professionals are aware there is such a category they have yet to figure out how to support a child like Becky. Despite having an Individualized Education Plan (IEP), she is equal parts bored and frustrated in her high level classes and we are currently discussing a dual enrollment between high school and college to keep her stimulated. As this is occurring, a local advocate pushing legislation related to this asked me to speak before the school board and I plan to do it. However, I also encouraged Becky to speak up as well. After all, her words are going to have a greater impact than mine. Despite the challenges, despite any anxiety she might have, she agreed wholeheartedly. I couldn’t be more proud of my daughter. It is so important to have our children learn to speak up, too.

- Deb #celebratepreemies

IN THIS ISSUE:

Look for worldwide events

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

My Fierce Advocate

Deb Discenza talks about the importance of encouraging our preemies to advocate for themselves and for others.

Premie Genius: Developmental Care News

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

Premie Support: Sister Friend Up

A group that is making a difference in the field of prematurity and neonatology.



www.OnceUponaPremie.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.
- Pediatric Ophthalmology & Optometry Conf**
December 10-11, 2018 | Dubai UAE
<https://pediatrics.ophtalmologyconferences.com/>
- 12th World Pediatric Congress**
December 10-12, 2018 | Abu Dhabi UAE
<https://pediatrics-congress.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: PREEMIE FACEBOOK FRAME

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 special holiday gift to you our readers. It is a Facebook Frame that is preemie-focused just for you! Click the link below:

Premie Facebook Frame: <https://premie.us/PremieFrame>

“ It is important to #celebratepreemies and be proud of their warrior-like status in the NICU and beyond. Share that story and your preemie’s beauty with our special holiday gift. ”

~ Deb Discenza, PremieWorld

SUPPORT: SISTER FRIEND UP



Founder Heather Tanner's story will resonate with many a preemie parent as she eloquently recounts the creation of **Sister Friend Up**:

*It all started with a hello and a hug. On a particularly hard day, two families would be forever changed. Very early in the morning, one month into living life in the NICU, my son was taken into surgery, again. It being a small hospital, the closest waiting room was just outside the unit. Another mother I'd seen leaving the NICU earlier. Slowly approached me in the waiting room. She had a very soft smile and introduced herself. After a short discussion, we realized that we shared the same name. But the similarities didn't stop there. Our boys were having the same surgery, by the same surgeon, on the same day. We shared a hug and an understanding as well as exchanging our phone numbers that day. As the time in the NICU wore on, I would check in on her and she would check in on me. Six weeks after surgery, my son was discharged from the hospital. I wondered how the other Heather was doing so I friended her on Facebook. Four and a half months after leaving the NICU, I found myself in a desperate situation. Something was horribly wrong with my son, Colton. Doctors dismissed my concern as being anxiety of a first-time parent or being hyper-vigilant. Not knowing where else to turn I called my NICU friend. We sat on the phone for hours and counseled (Sistered) each other. Finally, we formed a plan of action to get my son the care he needed at Cincinnati Children's Hospital. This act of Sistering one another became the basis and foundation for what would later become **Sister Friend Up**. Sistering for us is the process of forming and supporting meaningful relationships among women, who have been affected by someone who is medically fragile. We encourage, support and educate, these families as well as advocate about topics relevant to them.*

Year Established: 2016
Website: <https://www.facebook.com/sisterfriendup/>
Outreach: United States
Founder: Heather Tanner, MSA, BSBA



ORG: KNOX BLOCKS FOUNDATION

On December 20th, 2016 **Mark and Elisha Palmer's 3.5 month old son Knox** went down for a nap and never woke up. His death was SIDS. "Wanting to do whatever we could so that no other parent had to feel a loss like this," notes Elisha Palmer, "We began the **Knox Blocks Foundation** which provides Owlet Smart Socks to infants in need. The Owlet monitors the infants heart rate and oxygen levels and notifies parents if those levels are abnormal thereby giving parents the right information at the right time. With each Owlet we give we provide families with a little peace of mind and a piece of Knox."



The organization provides Owlet monitors for free and by your buying one directly through Knox Blocks, the Owlet company will "Match us 3 to 1 by for the remainder of the year. So with a \$300 donation we can provide an Owlet to you and that also allows us to provide 3 monitors to families that are in need and cannot afford them," says Elisha.

For more information visit www.KnoxBlocks.org

Year Established: 2017
Website: www.knoxblocks.org
Location: Iowa, United States
Outreach: National

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 Grerson 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. Heloise 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 Widescreen Region Coding English
SOUNDTRACK AVAILABLE AT WWW.LITTLEMANMOVIE.COM

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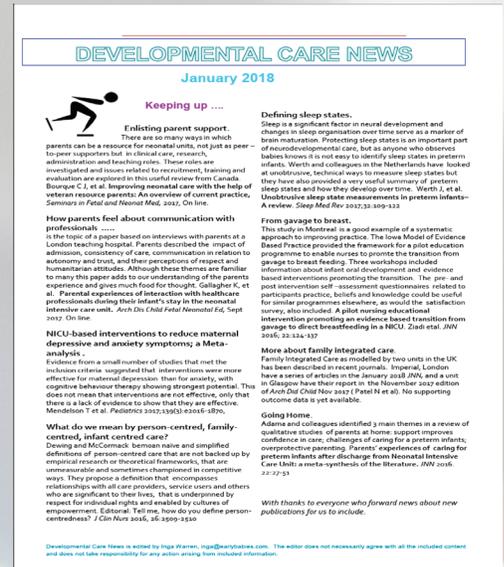
NEWSLETTER: DEVELOPMENTAL CARE NEWS

Developmental Care News is a free monthly newsletter created and distributed by the Early Babies website (www.EarlyBabies.com). The site is run by authors **Inga Warren** and **Cherry Bond**, known for their book *Caring for Your Baby in the Neonatal Unit*.

Each edition catches up the subscriber on the latest news and research in the developmental community. Also included is a calendar of dates for trainings and other relevant meetings. This item is useful not only for the professional sector but also the parent community as well.

Subscribing is required to receive each edition ongoing. Simply visit the Early Babies website (www.EarlyBabies.com) and click on the subscribe button.

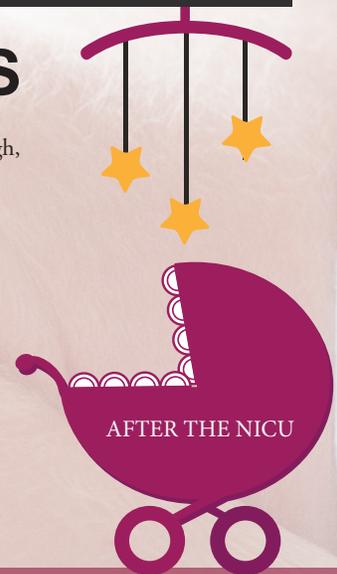
Congrats to Terri Lynn Major-Kincade, MD, the winner of November's giveaway, the book Dad Pad Neonatal (<https://thedadpad.co.uk/neonatal/>)!



COMEBACKS ON PREEMIE COMMENTS

Even in the NICU you had this, right? Bizarre comments from people, nosy questions? Yup. It doesn't end with the NICU though, it only gets even more odd. How do you cope? How do you handle these folks and maintain your sanity? We have some tips.

- Stay silent and stare. Look at them like they grew three heads. Hopefully one of those new heads has common sense!
- To the know-it-all about babies, respond, "You do know a lot. But I am the expert of my child." Then change topics.
- To the really rude question or comment - laugh and say, "You really didn't mean that did you?" Then change topics.
- When they are not getting the point that you are irritated, annoyed, pissed off, angry, ready to throttle them: stay silent, turn and walk away.



PREEMIE FAMILY ONLINE

Inspire Premie 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>

PremieWorld on Twitter

<http://bit.ly/PremieTweets>

PremieWorld on Facebook

<http://preemie.us/PremieFB>

PremieWorld on Instagram

<http://preemie.us/PremieInstagram>

PW TAGS: @mizzt_kikimaya

Our latest preemie highlight: Lovely Solikha Maya, 27 weeker and her incredible mother (@mizzt_kikimaya):

This is my 27 weeker Solikha Maya. She was born weighing 1lb 15oz, she spent 98 days in the NICU, had stage 3 ROP, Jaundice & a PDA. Each November, I am always flooded with memories of our NICU journey. 4 years later I feel like I can finally breathe. World Prematurity Month and Day is a time of reflection. That first glance of your tiny frame, yearning to hold you in my arms. I had no fear 'til that moment I saw you laying there lifeless and we couldn't do anything to comfort you. Your tiny frame and translucent skin, the tubes and wires that covered your features were so heartbreaking. You continued to breathe and fight the moment you took your first breath! I feel the sadness and heartbreak dissipate. I know this is the healing part. I am amazed by those feelings. I never thought I would get there. Stay strong my fellow preemie parents!



We Could Highlight Your Preemie in Our Newsletters & Online!

Deadline: Like, tag & include @PremieWorld in your update post by the 15th of the month.

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

Networks: Twitter (@PremieWorld), Facebook (PremieWorld, The Preemie Parent's Survival Guide to the NICU, NICU Nurses' Day, Preemie Study), Instagram (@PremieWorld).

FEATURED PREEMIE PRAYER:

Leah-Lee:

I pray for Leah-Lee to have a healthy life and that every negative thing said over her life to be broken in Jesus name . Amen.

- Anonymous



We welcome your submissions for this section of Preemie Pride, Preemie Angel, and Preemie Prayer at PremieWorld.com

SNEAK PEEK

In next month's issue.....

Preemie 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.

Preemie Genius

We are reviewing a new item of interest to parents of premies and pros. Don't miss it!

And More!

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JOIN THE CONVERSATION

“ Always remember, you know what is best for your child! ”
~ Deb Discenza, PremieWorld

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Premie Tags

Honor the Journey