



premiefamily
support. educate. advocate.

PREEMIE ADVOCACY

fighting for your preemie for the long-term benefit

When I had my daughter Becky at 30 weeks almost 14 years ago, I automatically assumed the NICU staff knew more about her needs than I did.

With each day of my daughter's NICU stay, I gained confidence in her care. This did not come easily at all. I struggled with first-time mother doubts, huge amounts of guilt and quite frankly, fear. I had no idea what lay ahead for my daughter.

I struggled with learning the medical terms, with handling medical equipment and follow-up appointments at home all wondering aloud what this meant for my daughter's long-term outcome. You see, there was something that my brain kept telling me that no one else knew: that I was the expert of my child, that I had a gut instinct that was steering me in the right direction.

Read Becky's story and hear how PremieWorld is tackling preemie outcomes:

IN THIS ISSUE:

Premie Shower

We have a special preemie shower this month to celebrate preemies in the NICU with loving and supportive words from author Jenné Johns.

Premie Genius: Juniper

A tale about preemie Juniper by award winning writers and Juniper's parents, Kelley and Thomas French.

After the NICU: Speaking Up, Speaking Real Loud

The squeaky wheel has nothing on a concerned preemie parent. Speaking up and loudly is important.

Look for worldwide events

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



TO DO LIST:

- ✓ **PremieStory:** Each month we release a new PremieStory. Find out when it goes live from our Premie E-News list: <http://premie.us/PremieNews>
- ✓ **Freebies from PremieWorld:** find them at <http://bit.ly/PremieFreebies> and share them with other parents you know.
- ✓ **Oley Foundation Regional Meeting**
July 5-8, 2017, Old Greenwich, CT, USA
<http://www.oley.org>
- ✓ **3rd Int'l Neonatology Assoc. Conf (INAC)**
July 7-9, 2017, Lyon, France
<http://www.worldneonatology.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!

 @ www.facebook.com/PremieWorld

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

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

 @ www.instagram.com/premieworld

PREEMIE FREEBIE: NICU NUTRITIONIST BADGES

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 freebies celebrate NICU Nutritionists.

Please make sure to forward this edition to your NICU nutrition team members as well as feeding specialists.

To download this freebie, visit <https://premieworld.com>

“ NICU Nutritionists are a key part of the NICU team in that they provide infants with the optimal nutrients to help them grow and to thrive and, ultimately, to go home. They are real heroes in the NICU environment.

~ Deb Discenza, PremieWorld





TERM: DEVELOPMENTAL DELAY

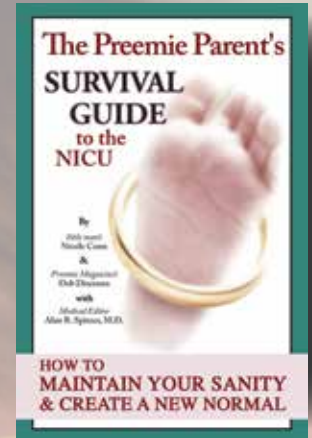
Developmental Delay

Babies are expected to reach certain milestones (i.e. walking and talking) within a predictable amount of time. Premies, due to their early birth and subsequent medical challenges, may take longer to reach those milestones. May Premies receive occupational therapy and/or physical therapy to deal with all the various issues of being born too early: the stress it puts on the muscles, the stiffness in the bodies of infants that are on the vent for any length of time, etc. This therapy is very important for your baby. If your baby is vented, ask your nurse to get an occupational therapist (OT)/physical therapist (PT) consultation.

Other Tips:

- ✔ Ask to have the OT/PT session scheduled for when you are able to be there.
- ✔ Talk to the OT/PT about ways you can bond with your baby, help with development now and going home.
- ✔ Ask the doctor now about plans for referrals for therapy after the NICU.
- ✔ At discharge, if your baby does not qualify for Early Intervention, ask what other local resources are available to help you.

*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: LITTLE ANGEL WINGS

Little Angel Wings helps bereaved families who have experienced the loss of a baby/child at any age/gestation.

PROGRAMS:

Care Packages. The organization provides comfort care packages to bereaved families in the United Kingdom. These include a knitted hat, booties/mittens, a tealight candle, poem and a special letter.

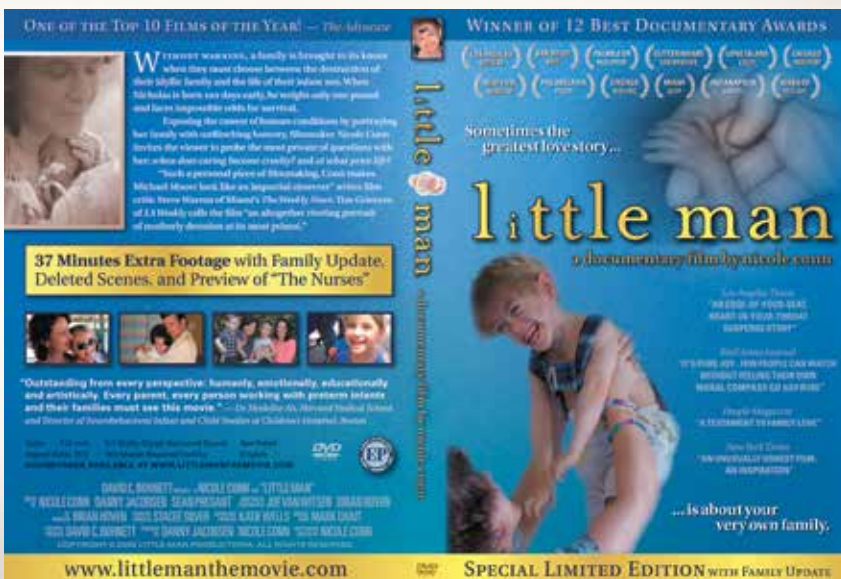
Online Support & Remembrances. Little Angel Wings provides support on its Facebook page and maintains regular remembrances and candle lightings for 15 October annually (Pregnancy and Infant Loss Remembrance Day) as well Christmas and other holidays.

And More. The group also makes personalised graphics for families as well as open albums.

Visit <http://www.littleangelwings.btck.co.uk/> for more info



Website: <http://www.littleangelwings.btck.co.uk/>
Focus: Any family that has lost a baby/child.
Based: Huddersfield, United Kingdom
FB Page: <https://www.facebook.com/littleangelwings06/>



*"little man" is every
preemie parent's story*



www.littlemanthemovie.com

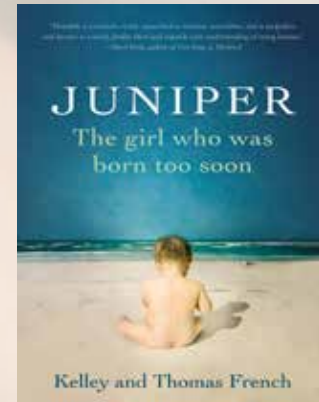
BOOK: JUNIPER (Kelley & Thomas French)

Award-winning powerwriting couple Kelley and Thomas French have taken the preemie parent and NICU experience and owned it fully. Sparing no blushes they tell the story of how their 23-weeker daughter, Juniper, came to be and of the family's daily struggles in the NICU and in life outside the NICU. Every page is filled with raw honesty that any parent can relate to in this experience, from the struggles with relationships, to the tough discussions with doctors at bedside to the horrific noise of the breast pump endlessly mocking Kelley. This book should be required reading of every parent of a micro-preemie in the NICU as well as that of every labor and delivery team member and neonatology team member. Learn more about this book at the website: <http://juniperbook.com/>



“ Crazy questions flashed through my mind. Should we prepare a birth announcement? What would we name her? If she died, would we get a birth certificate? Would there be a funeral? Would we get a box of ashes, and if so, what size box? Was she aware of us? Did she recognize me like I recognized her? Was she afraid? Did she wonder where I had gone? If she ever got out of this box, would she know I was her mother? ”

~ Kelley French, *Juniper*



One lucky winner will receive a FREE copy of this book! We'll select one NEW Twitter follower prior to 7/22/17. Enter to win by following us on Twitter at www.twitter.com/premieworld.

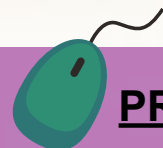
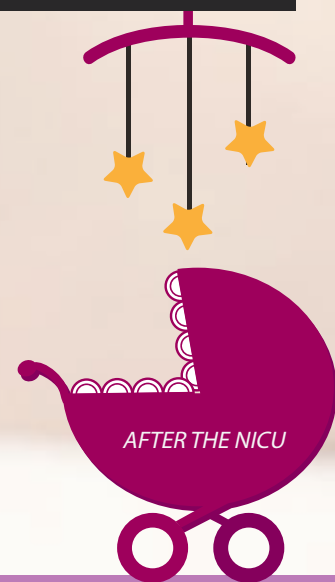
WOO HOO!: For July, Tyla Cousins won the Flora Tummys Probiotic Sprinkles.

AFTER THE NICU: SPEAKING UP

When it comes to your preemie's development, you are the key person to get things moving on evaluations, on appointments, on therapy and long-term progress. **Learn about Deb's story on why advocacy is so important:** <http://preemie.us/PreemieFight>

- ☑ Be consistent at pediatrician appointments about your baby's delays. Make sure they are documented.
- ☑ Being the nice parent is not always what is best for your child. Don't be rude, but speak up and loudly if need be.
- ☑ Contact your local Early Intervention program to get your child evaluated. If you are already in EI, call the coordinator if you feel that things are not going in the right direction. *Don't wait.*
- ☑ Know that you are the expert of your child. Trust your expertise of your child and get help now.

Struggling with milestones? Reach out to 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 almost 37,000 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 LinkedIn
<http://bit.ly/PWLinkedIN>

ONCE UPON A PREEMIE



PreemieWorld continues its monthly Premie Shower! Do you know a deserving NICU in need? Enter to win a Premie Shower for the NICU of your choice. Each month, PremieWorld picks one NICU to receive donated items such as blankets, toys, and diapers to help brighten the days of preemie parents and the professionals who treat their children.

Our friends at Once Upon a Premie www.OnceUponAPremie.com will be helping us provide a dozen children's books to one NICU! To enter, a professional from a NICU must sign up as a new subscriber on our "Premie Family for Pros" list by 7/22/17.

Enter to win at <http://bit.ly/PremieFam4Pros> Or tell us what you'd like us to include in a future shower at [#preemieshower](https://twitter.com/preemieshower)

June's Winner: Bobby Bellflower @ Regional One Health NICU!

FEATURED PREEMIE PRAYER:

I pray that you shield and protect Zaria as she grows and develops in the hospital. Wrap your arms around her and give her strength to thrive so she can come home to her family. Amen.

~ Anonymous



Submit your Premie Pride, Premie Angel & Premie Prayers at our site at <https://PremieWorld.com>

SNEAK PEEK

In next month's issue.....

New Premie Shower

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

Premie Genius

We have a new app to review for Breastfeeding Awareness Month!

And More!

Have you subscribed to Premie Family yet? It's free!

<http://bit.ly/preemie1>



Prolonged, effective, safe, and hands-free Kangaroo Care sessions. Guaranteed.



www.nurturedbydesign.com



Go to www.OnceUponAPremie.com to get reading

"Reading is one of the few things that can help bond and stimulate a baby cognitively. A parent's soft voice is pure gold."





Premie Tags
Honor the Journey




JOIN THE CONVERSATION

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

f @ www.facebook.com/PremieWorld
@ Premie Parent's Survival Guide to the NICU

t @ PremieWorld

in @ PremieWorld
@ NICU Professionals
@ Early Intervention Professionals
@ Premie Parent Support Group
@ Leaders
@ Premie Parents

ig @ www.instagram.com/premieworld