



premiepro
support. educate. advocate.

Robynne R. Rembecki, MOT, OTR/L, CNT

NICU Occupational Therapist & Founder, Res-Q Wedge



Photo Credit: Richard M. Rembecki, MD PHD

Years Helping Premies: 29

Current Org: THR Presbyterian

Focus: Treating infant dysphagia and GER with the safest modalities in the NICU and in the home environment.

Pro Tip: You will continue to learn new NICU information daily regardless of how long you have been working with premies. Embrace your mentors, embrace new educational opportunities, stay on top of the latest research, and learn more about NICU topics you are not as familiar with to be the most effective therapist you can be!

IN THIS ISSUE:

Look for worldwide events

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

Interview with Robynne R. Rembecki

Robynne has worked with premies her entire career in the NICU to school and in the product arena.

Premie Genius: Juniper

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

Premie Organization: Child-Bright Network

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

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



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 at <http://bit.ly/PremieFreebies> and pass them onto Premie Parents in the unit's welcome packets.
- ✓ **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

SUPPORT: LITTLE ANGEL WINGS

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

PROGRAMS:

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/>

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.

More Support

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

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



ORG: CHILD-BRIGHT NETWORK

The **CHILD-BRIGHT Network** is an innovative network that aims to make the future brighter for infants, children, and youth with lifelong brain-based developmental disabilities and their families, including individuals with a diagnosis of a brain-based disorder (e.g. Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Fetal Alcohol Spectrum Disorder, Cerebral Palsy, intellectual or learning disabilities), and individuals at high risk for a brain-based disorder (e.g. preterm birth, congenital heart disease, genetic anomaly).

Research Projects of Interest to Families

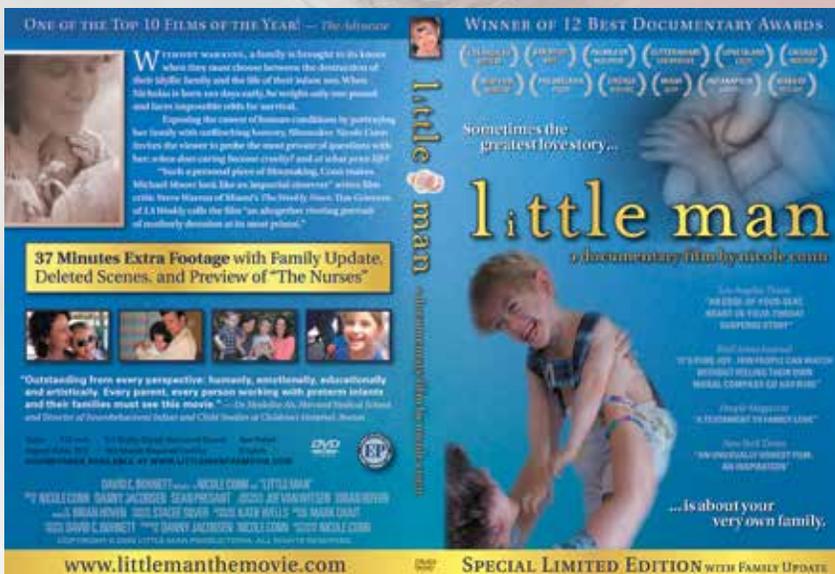
- **Parent-Centred Evidence-Based Care for Premature Graduates:** <http://preemie.us/PremieGrad>
- **BRIGHT Coaching: A Developmental Coach System to Empower Families of Preschoolers with Developmental Delays:** <http://preemie.us/CoachCB>
- **'READYorNOT' Moving Ahead with Transition of Care from Adolescence to Adulthood:** <http://preemie.us/CBAdulthood>



Year Established: 2016

Website: www.child-bright.ca

Location: The Research Institute of the McGill University Health Centre (RI-MUHC), Canada



"little man" is every preemie parent's story



www.littlemanthemovie.com

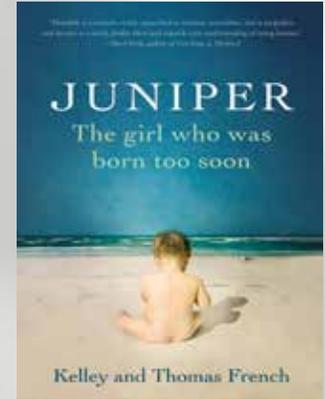
BOOK: JUNIPER (Kelley & Thomas French)

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.

SPEAKING UP, SPEAKING REAL LOUD

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>
Some tips:

- ☑ 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 & 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 Instagram

<http://preemie.us/PreemieInstagram>



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 It's a Premie Thing 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 to see 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>



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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

NIU SURVIVOR
PremieWorld.com

NAME: BABY DOE
DOB: 01/01/2006
WT: 500 GRAMS
GEST WEEK: 25.5

premieworld

JOIN THE CONVERSATION

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

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@ NICU Professionals
@ Early Intervention Professionals
@ Premie Parent Support Group
@ Leaders
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