



premieworldfamily

support. educate. advocate.



PTSD AFFECTS US ALL

one issue at a time with PremieWorld

Post Traumatic Stress Disorder (PTSD). Many of us know it as the disorder affecting the military during and after deployment to a war zone. What you may not realize is that PTSD affects anyone that is suffering any type of trauma. For a preemie parent that could be a traumatic birth, the NICU, watching your child struggle and more. That sets up *both* parents (yes, Mom and Dad) for PTSD. And this challenge does not come with the NICU alone. It can pop up after discharge and even years later. Think that your PTSD doesn't negatively affect your child? *It does in terms of developmental milestones.* So know that in getting yourself help it is the healthiest thing you could do for both you and your preemie. I know, *I have been there myself.* In recognition of PTSD Awareness Month, check out our freebie.



2018:

Giving preemies the tools to *thrive*,
... not just survive.

IN THIS ISSUE:

Look for worldwide events

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

PTSD Affects Everyone in the Family

Deb Discenza talks about the realities of PTSD and the longterm effects on preemie families.

Premie Genius: Stuck in Bed

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

Premie Support: Love for Lily

A non-profit that is making a difference in the field of prematurity and neonatology.

YOUR PREEMIE FREEBIE: PTSD AWARENESS BADGE

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 are Premie Parent PTSD Badges for Mom and Dad.

We invite all parents affected by Post-Traumatic Stress Disorder to reach out to our featured support groups for additional assistance.

Get this at Premie Freebies at <https://premieworld.com>



In solidarity with PTSD Awareness Month, we recognized the struggle that parents of preemies endure in the NICU, at home and for years to come due to PTSD. Getting help is key for your ability to help your child.

~ Deb Discenza, PremieWorld



www.OnceUponAPremie.com

TO DO LIST:

- New Section.** Check out our new section, *Giving From Your Heart*, on p. 4.
- Freebies.** Get free downloads from PremieWorld at <http://bit.ly/PremieFreebies> Have an idea for a freebie? Contact us and let us know.
- Pints for Premies**
- June 4, 2018, Minneapolis, Minnesota, USA www.neonatalfoundation.org
- Speaking of NEC: Unplugged**
- June 11, 2018, Cromwell, Connecticut, USA www.MorgansFund.org

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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TERM: EXTUBATION

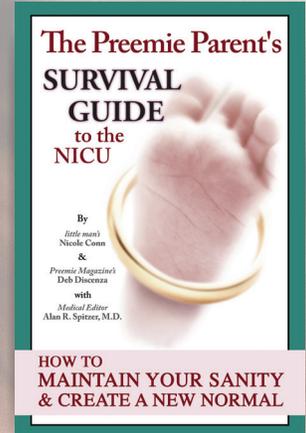
Extubation:

Extubation is one of your greatest milestones for you and your baby - that is if it's planned. Many of these babies routinely extubate themselves - accidentally. They pull out the tube - probably because it doesn't feel good in there. Sometimes they are actually ready to breathe on their own, and know better than we do that it's time. Other times they accidentally get their hands stuck in the way and fling it out because the tape on their faces has come loose.

Questions for the Doctor

- My child's extubation - was it planned or unplanned?
- How did my child do with the extubation? Is the vent still needed?
- If the tube is still needed, how did the re-intubation go?
- Do you have any idea when my child can be properly weaned from the vent at this point (if re-intubation is done)?

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: LOVE FOR LILY

After their daughter Lily was born at 24 weeks gestation but too soon to survive, the Cahoon family celebrated the first Mother's Day afterward by launching **Love for Lily**. The organization is now in its 6th year. "She taught us more about love in her short life than we ever thought possible and now her story lives on in our hearts and the world that we do through Love for Lily," notes mother **Sahra Cahoon**.



The Mission

Love for Lily's mission statement is to "Support families in the Neonatal Intensive Care Unit (NICU) to thrive during their stay and at home.

Website: www.lfnicu.org
Established: 2012
Focus: Emotional Support, Essentials Bags, Meals
Outreach: Denver, Colorado Area & Beyond

Visit www.lfnicu.org for more info

Offerings

- NICU Love: In-Unit facilitated support groups: teaching coping skills and providing community.
- Essentials Bags: Items that can provide a little comfort and ease the burden of life in the NICU.
- Grants for insured families who spend 4 weeks or more in the NICU to help obtain therapies that support the well being of their child(ren).
- Lasting Love: Post-NICU Group for moms to come together for one year after discharge.

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 Glerason 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. HeidiLise 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

DAVID C. BOHNETT DIRECTOR OF PHOTOGRAPHY NICOLE CONN EDITOR "LITTLE MAN"
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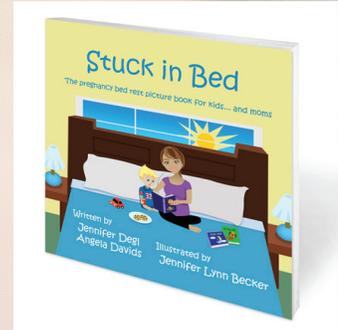
BOOK: STUCK IN BED



Bed-rest during a difficult pregnancy is tough whether in the hospital or at home. Add in children who are used to having a daily routine with Mom and this can create a lot of difficult moments for everyone involved. This is where the sheer genius of authors Jennifer Degl of Speaking from Moms and Babies (www.SpeakingfromMomsandbabies.com) and Angel Davids of Keep 'Em Cookin (www.KeepEmCookin.com) results in a book that will help bed-rest mothers everywhere: *Stuck in Bed*. Every single page provides a challenge from the child's point of view as well as the mother's idea on how to combat each one. In addition, on each page is a special tip to further explain the difficulty further for parents so they can continue to navigate similar questions ongoing. Add in a back section to write letters to the child and the future baby and you have a perfect item for every high-risk pregnancy unit in hospitals worldwide.

“We have great news,” my parents said
“Come over here and sit on the bed.”
“We’re having a baby,” my Mommy said.
I got so excited that my face turned RED!

~ *Stuck in Bed*



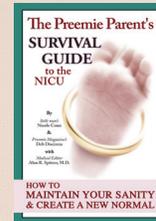
One lucky winner will receive a FREE copy of this book! We'll select one NEW Instagram follower prior to 6/22/18. Enter to win by following us on Instagram at www.Instagram.com/PreemieWorld

Congrats to @miraculousmalcolm, the winner of May's giveaway, a copy of Nicole Brady's book DREAMWISP (<https://www.dreamwisbook.com/>)

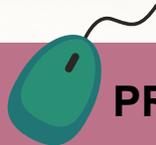
Q'S ABOUT GERD/REFLUX RESOLVING

Once you are out of the NICU and equipment has started to shed, parents immediately think about shedding medications, too. Some questions to ask at the well-check appointments:

- Based on today's exam, when can we look to shedding the reflux medication?
- When it is time to wean off the medication, how is that done?
- Are there any residual issues I should be aware of after the medication is weaned?
- Could you please update my child's other doctors with the results of today's exam and our discussion?



Find these questions and more in The Preemie Parent's Survival Guide to the NICU, available at www.PreemieWorld.com



PREEMIE FAMILY ONLINE

Inspire Preemie Community:

Parents, Grandparents, Adults
& High-Risk Pregnancies

Help your families connect over 44,000 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>

Give From Your Heart



PINTS FOR PREEMIES

This month's **Give From Your Heart** celebrates the **2nd Annual Pints for Preemies** event held by the international organization, **Minnesota Neonatal Foundation**.

Details:

What: Pints for Preemies

Where: Surly Brewing Co., 520 Malcolm Avenue, SE, Scheid Hall, 2nd Floor, Minneapolis, Minnesota, U.S.A.

Date: Monday, June 4, 2018, 6 - 9 p.m.

Tickets: Purchase tickets at www.neonatalfoundation.org



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



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



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SNEAK PEEK

In next month's issue....

New Item: Give From Your Heart

There is another special program where you can make a difference in the preemie community.

Preemie Genius

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

And More!

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

JOIN THE CONVERSATION

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

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NICU Hope Beads

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Premie Tags

Honor the Journey