



premiepro
support. educate. advocate.



POST-DISCHARGE LIFE

recreating the PremieWorld

"She is doing great!" said the pediatrician. "And don't worry about her being early, my son was early too. She'll be fine." This was 24 hours after Becky's discharge from the NICU and we were exhausted and stressed. We were also feeling the magnitude of our daughter's premature birth in the lightness of our child while reconciling that with the extreme weight of her portable oxygen tank and monitor.

Less than 5 days later we were in the Pulmonologist's office for an emergency appointment due to our daughter's monitor alarms increasing and her sleeping through feedings. She was admitted to the hospital that afternoon for feeding challenges and a solid dip in her weight. This was not normal and we knew it. Like, us, parents weighed in our post-discharge survey: <https://premie.us/PostNICUReport>

We have a new survey - Living in a Non-Premie World:
<https://premie.us/NonPremieWorldSurv>

- Deb #celebratepreemies

IN THIS ISSUE:

Post-Discharge Life

Deb Disenza talks about the stress of post-discharge life and all that goes with it.

Premie Genius: Twin to Twin

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

Premie Support: Care for Families

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

Look for worldwide events

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



www.KeytoCP.com

TO DO LIST:

✓ **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.

✓ **Young Child Conference & Expo**
April 30- May 3, 2019 | New York, NY, United States
<https://youngchildexpo.com/>

✓ **Kangaroo Care Awareness Day**
May 15, 2019 | Worldwide
<https://kangaroo.care/>

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: POST-DISCHARGE SURVEY SUMMARY

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 summary report of the Post-Discharge Day survey from April.** You can get it by going to the link below (and watch social media for parent quotes throughout the month):

Discharge Survey Results:
<https://premie.us/PostNICUReport>

“ We cocooned ourselves at home with our daughter, venturing out with her only when absolutely necessary for those follow-up appointments. Anyone that came to the house got quizzed, got demands for hand-washing and more. ”

~ Deb Disenza, PremieWorld



SUPPORT: CARE FOR FAMILIES

What started as a purely altruistic goal of one young woman quickly turned into a very personal mission help others. Founder Chercara Thompson started the New Zealand charity **Care for Families** as a young woman working through homeschooling. Later married and attempting to start a family she soon found herself seeing firsthand the challenges families of babies go through in the NICU, SCBU, and NNU.

She notes, "At 16, I started Care for Families for families with children aged newborn to 5 years old. Then I saw a big need in my community. We quickly grew from there until at age 18 my husband and I had our first miracle baby born prematurely. From there we branched into doing our prem packs.

The prem packs are made with true understanding of the challenges for families. Thompson continues, "Nine years on and after having 3 miracle prems amongst multiple losses of our own, the prem packs have become the main part of what we do and my passion and empathy goes beyond just sending a pack out. Each one is genuinely packed with love, care and careful attention and made specifically for each of the families."

Care for Families provides packs for full-term, for prem and for bereavement families.

Year Established: 2010
Website: <http://www.careforfamiliestrust.org/>
Outreach: New Zealand
Founders: Chercara Thompson



ORG: HUDSON DAVID McNEEL FOUNDATION

The **Hudson David McNeel Foundation** was created shortly after **Heather McNeel** gave birth to their son Hudson just shy of 25 weeks after waking up in aggressive labor. Born that afternoon weighing 650 grams, Hudson was transferred to the **University of Washington Medical Center's NICU in Seattle**. Notes Heather McNeel, "Hudson underwent many tests and fought a very tough fight, but unfortunately the odds were not in his favor. Due to the profound care that he received, we were able to spend precious time with him before his passing. This experience changed our lives forever and opened our eyes to prematurity and it's severe impact on the world. It quickly became our mission to share Hudson's life, to raise awareness and to help give others, like him, a fighting chance." From there the Foundation was born and creates a lasting legacy for Hudson in the form of numerous beneficiaries in the UWMC NICU in terms of equipment, training, medical supplies and many other initiatives.

For more information visit www.hudsonmcneel.org

Year Established: 2011
Outreach: UWMC NICU, serving a 5 state region
Site: www.hudsonmcneel.org



HUDSON DAVID McNEEL
FOUNDATION

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 Grierson 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. Hedelee 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 Regional Coding English
SOUNDTRACK AVAILABLE AT WWW.LITTLEMANMOVIE.COM

DAVID C. BARNETT DIRECTOR OF PHOTOGRAPHY NICOLE CONN EDITOR "LITTLE MAN"
NICOLE CONN DANNY JACOBSEN SEAN PRESANTY EXECUTIVE PRODUCERS JOEL VAN WITSEN BRIAN HOVEN
EXECUTIVE PRODUCERS BRIAN HOVEN PRODUCED BY STACEY SILVER PRODUCED BY KATIE WELLS PRODUCED BY MARK CHATT
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SPECIAL LIMITED EDITION WITH FAMILY UPDATE

"little man" is every
preemie parent's story



www.littlemanthemovie.com

BOOK: TWIN TO TWIN

Twin to Twin is the riveting parenting memoir of **Crystal Duffy** that takes readers on a journey through her high-risk twin pregnancy and terrifying diagnosis to in-utero treatment of **Twin to Twin Transfusion Syndrome (TTTS)**.

Throughout her prolonged antepartum stay, Crystal shares an uninhibited divulgence of her fears and heart-rending experiences while drawing upon her spirituality, her newfound connections with medical staff and support from her family. With this support system, she finds the courage to advocate for her babies and draw strength during her preemie twins' stay in the NICU.

Twin to Twin is an appropriate tool to help families understand TTTS while putting it all together in a charming, authentic and witty way. It is also an excellent aid for anyone in the field of maternal-fetal medicine to help provide insight to the emotional rollercoaster families diagnosed with TTTS experience. It is a story that provides hope even in the most dire of circumstances.

For more information visit:

<https://crystalduffy.net/books/twin-to-twin/overview/>

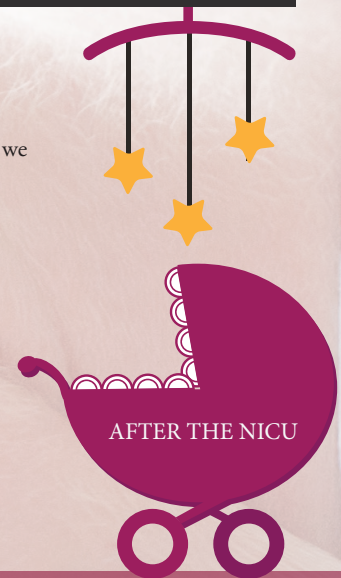
and CONGRATS to Rachel Murphy, one of our new Instagram followers - she won the book "Small But Mighty" - <https://small-but-mighty.org/>



TWIN TALKING POINTS

Twins and all multiples get a lot of attention from the public. And a lot of *really inappropriate touching*. Its hard to be *that parent*, we know. But remember some clear points when dealing with nosy people:

- ☒ Your children are not a zoo exhibit. They are human and they need and deserve space. You are their protector.
- ☒ Your role as parent means that you have to be loud and clear at times to tell people to back off touching them.
- ☒ You appreciate commiserating with others about joys and challenges of multiples, but this need not be a full saga of reality-show proportions. Fake a dirty diaper or another type of baby emergency and get the heck out of there.
- ☒ Comments about your fertility or children's special needs - stop and stare. Don't say a word. Your look says it all and then quickly leave. Nosy people with insulting behavior deserve nothing more than that.
- ☒ Repeat the above as necessary for a refresher!



PREEMIE FAMILY ONLINE

Inspire Preemie Community:

*Parents, Grandparents, Adults
& High-Risk Pregnancies*

Help your families connect with 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.

<https://preemie.inspire.com>

PreemieWorld on Twitter

<http://bit.ly/PreemieTweets>

PreemieWorld on Facebook

<http://preemie.us/PreemieFB>

PreemieWorld on Instagram

<http://preemie.us/PreemieInstagram>

HIGHLIGHTING @minii but mighty

Our latest preemie highlight:
@minii but mighty:

We made it 🙌❤️❤️

#home #59days

#nicugraduate

#premiestrong

#mywarriorprincess

We Could Highlight YOUR PREEMIE.

Deadline: Like, tag and include [@PremieWorld](#) in your Instagram update post by the 15th of the month.

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



FEATURED PREEMIE PRIDE:

Amelia Jayne -

My Christmas Day miracle was born weighing just one pound 6 ounces at 24 weeks and two days! She had a 12% survival chance but she fought and proved that she is meant to be here, other than a few scars and a repair to her heart she is getting ready to become a teenager. - Ailsa Pollard

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!

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, PremieWorld



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@ [Premie Parent's Survival Guide to the NICU](#)



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@ [NICU Professionals](#)

@ [Early Intervention Professionals](#)

@ [Premie Support Group Leaders](#)

@ [Premie Parents](#)



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"The story of our brand is the story of our family.
We invite you to be part of it" -Yamile C. Jackson, PhD, PE, PMP



Preemie Tags

Honor the Journey

