



premiepro  
support. educate. advocate.



## DISCHARGE DAY

*recreating the PremieWorld*

**"I am really nervous about bringing her home - I don't feel ready yet," I said as Nurse Donna completed the final touches on my daughters discharge from the NICU.**

I was shaking with nerves, thinking that I was suddenly being handed my infant on oxygen and a monitor and a bunch of medications and feeling more like a poorly trained nurse than a mother. "You will be fine. You know what to do," she replied. As we headed home, I continued to shake. The feelings got better over time as I gained confidence in myself, but we had major hiccups that rattled me in those first few weeks and months. This was not normal and I knew it. Our Discharge Survey spoke volumes: <https://premie.us/PremieDischarge>

Tune in on an upcoming [Instagram Live](#) to hear about our family's discharge day.

*We have a new survey - Post-Discharge Life:*  
<https://premie.us/PostNICUSurvey>

- Deb #celebratepreemies

## IN THIS ISSUE:

*Look for worldwide events*

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

### *Discharge Day*

Deb Disenza talks about the stress of discharge day and all of those conflicting emotions.

### *Premie Genius: Small But Mighty*

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

### *Premie Support: Red de Apoyo a Papás de Prematuros*

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



[www.KeytoCP.com](http://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.

✓ **NPA 2019 - Improving Access to Perinatal Care**  
April 3-5, 2019 | Providence, RI, United States  
<http://nationalperinatal.org/2019Conference>

✓ **The Pediatric Academic Societies (PAS) Meeting**  
April 24-May 1, 2019 | Baltimore, MD, United States  
<https://2019-pas-meeting.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](mailto:connect@premieworld.com)!



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## PREEMIE FREEBIE: 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 Discharge Day survey from March.** 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/PremieDischarge>

“ Though we had been slowly preparing for discharge day for weeks, the shock of the actual day came quickly and abruptly and we did not feel totally prepared. Our daughter didn't seem truly ready yet. We were happy, but really scared. ”

~ Deb Disenza, PremieWorld

# SUPPORT: RED DE APOYO A PAPÁS DE PREMATUROS



**Out of** Danny Schwank's personal experience, Red de Apoyo a Papás de Prematuros (RAPP) was born. "In our 35-day journey with our 32-week preemie, Lukas, we experienced fear, love, hope, sadness all in a single day. During that time, we made friends, cried with them and shared each other's happiness. From that experience another mother, Paola Cofiño, and I started to think, 'How we can do more to help others in our situation?'"

**Building Red de Apoyo a Papás de Prematuros (RAPP).** "2017 was our planning year and in the meantime, we were supporting other families from our NICU," notes Schwank. "In 2018 we started our Facebook page [RAPP \(Red de Apoyo a Papás de Prematuros\)](https://www.facebook.com/RAPPGT/). Currently, we are providing the utmost support in our private hospitals and extending our knowledge and resources with parents from public hospitals as well. In 2018 we supported more than 29 families! We have a small mentoring group of 7 mothers and 2 fathers, but we are always searching for more families and information to prepare ourselves better to support whomever needs us."

**Support In Person But Also Online.** The group goes beyond in-person support to helping others virtually through RAPP's social media channels, as well as having private one-on-one conversations if families prefer it. "We have a Facebook and Instagram page where we post related information, terminology and articles. We also post a highlighted preemie story every 15 days."

**Coming Up.** Says Schwank, "For 2019 we are fundraising to give away NICU packages that will include hand sanitizer, cream, some snacks, a notepad and pen."

**Year Established:** 2018  
**Website:** <https://www.facebook.com/RAPPGT/>  
**Outreach:** Guatemala City  
**Founders:** Danny Schwank and Paola Cofiño



## ORG: NEWBORN FOUNDATION

"The Newborn Foundation was launched after the co-founder's baby, Eve, was diagnosed with a critical congenital heart defect at two days old," comments team member Maclaren Johnson. "Eve was able to survive because of early detection in the hospital and access to life-saving treatment. Now, because of Eve, all 4 million newborns in the U.S. are being screened with pulse oximetry."

Johnson continues, "Newborns with a congenital heart defect can appear healthy at first, the pulse oximeter screening can identify heart abnormalities before any signs are shown. The noninvasive pulse oximeter uses a "little red beam of light" to read both the amount of oxygen in the blood and pulse rate. And the pulse oximeter sensor is placed on the newborn's toe and then provides a reading that indicates if the newborn passes or fails the screening test."

*For more information visit [www.NewbornFoundation.org](http://www.NewbornFoundation.org)*

**Year Established:** 2010  
**Outreach:** International  
**Site:** [www.NewbornFoundation.org](http://www.NewbornFoundation.org)



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. Heidi Lieke, 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 Worldwide Regional Coding English  
SOUNDTRACK AVAILABLE AT [WWW.LITTLEMANMOVIE.COM](http://WWW.LITTLEMANMOVIE.COM)

DAVID C. BARNETT, NICOLE CONN, "LITTLE MAN"  
NICOLE CONN, DANNY JACOBSEN, SEAN PRESANT, JOEL VAN WITSEN, BRIAN HOVEN  
BRIAN HOVEN, STACEY SILVER, KATIE WELLS, MARK CHATT  
DAVID C. BARNETT, DANNY JACOBSEN, NICOLE CONN

...is about your very own family.

[www.littlemanthemovie.com](http://www.littlemanthemovie.com)

SPECIAL LIMITED EDITION WITH FAMILY UPDATE

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



[www.littlemanthemovie.com](http://www.littlemanthemovie.com)

## BOOK: SMALL BUT MIGHTY



The Neonatal Intensive Care Unit (NICU), is a great equalizer for all premie parents that endure it. Regardless of gestational age at birth, a premie parent is a premie parent. They all work through many of the same exact emotions and worries. They fear their baby might not make it. They also fear that the bond with their baby is broken while they wait days, weeks, and even months before that first hold.

No one understands this pain like that of the medical team members surrounding the families, especially those in the nursing spectrum. Enter ***Small But Mighty*** author **Alyssa Veech, NNP**, a Neonatal Nurse Practitioner from at Sisters of Charity Hospital and faculty member at the University of Buffalo. Her passion for families in the NICU is evident with every word of this book.

Traveling through the premie journey in the NICU, Veech lovingly brings us through the moment by moment stay of the NICU all the way into discharge. With words that gently speak of the challenges of tiny babies, she also uplifts them as strong fighters. And with a very diverse set of parents illustrated throughout the book, every premie parent in the NICU will read these words aloud with pride. This book should be on the baby registry list for all premie parents and a shoe-in buy by all grandparents.



For more information visit <https://small-but-mighty.org/>

**COOL! We are giving away a copy of this book to a new  
(by 15th of the month!) Instagram Follower at <https://www.instagram.com/premieworld/>**

## ALL OF THAT PAPERWORK

You get home and breathe a sigh of relief. No more hospital visits, no more running back and forth -yay! But wait - *oh no*, lots of follow-up appointments and *yeesh - paperwork!* What do you do to tame that paperwork? Some tips:

- ☑ Either buy a binder or a set of folders (new or used, doesn't matter) as your organizer.
- ☑ Divide the binder and/or label the folders into sections such as NICU, Insurance, Pediatrician, Cardiologist, etc.
- ☑ When you get paperwork, put it in where it should live and at the top so you have most current info on top.
- ☑ Make sure all notes from the doctors, therapists, etc. go into this for safe-keeping.
- ☑ Put this organizer in a safe place away from prying eyes and little hands.



## PREMIE 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.

<https://premie.inspire.com>

*PremieWorld on Twitter*

<http://bit.ly/PremieTweets>

*PremieWorld on Facebook*

<http://premie.us/PremieFB>

*PremieWorld on Instagram*

<http://premie.us/PremieInstagram>

# HIGHLIGHTING @LULULENNYN

Our latest preemie highlight: Lennyn (@lululennyn):

*Welcome to the world little Lennyn!  
#family #nicubaby #prayers #lenijanée  
#followourpage #parenting #babylove*

We Could Highlight YOUR PREMIE in Our Newsletters & Online!

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

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

**Networks:** Twitter (@PremieWorld), Facebook (PremieWorld, The Premie Parent's

Survival Guide to the NICU, NICU Nurses' Day, Premie Study), Instagram (@PremieWorld).

## FEATURED PREMIE PRIDE:

*Sofia Angelina Vercesi, was born at 24 weeks in 2009. Weighing just 681 grams. Sofia was given little hope of survival. The future painted was an incredibly grim one. Then, our beautiful determined little fighter decided she was not giving up that easily, despite facing multiple life threatening complications. She fought each battle like a miniature caped crusader, became the star of her own book and is now about to turn 10. - Becky Meechan*

We welcome your submissions for this section of Premie Pride, Premie Angel, and Premie Prayer at [PremieWorld.com](http://PremieWorld.com)



## SNEAK PEEK

*In next month's issue.....*

### PremieWorld Tags

Tag us and we're in! But it is really all about you, Social Media Follower! We share the love right back to you.

### Premie 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 Premie Family yet? It's free!

<http://bit.ly/premie1>

## JOIN THE CONVERSATION

“ Always remember, you know what is best for your child! ”

~ Deb Discenza, PremieWorld



@ [PremieWorld](https://www.facebook.com/PremieWorld)

@ [Premie Parent's Survival Guide to the NICU](https://www.facebook.com/PremieParentSurvivalGuide)



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

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@ [Early Intervention Professionals](https://www.linkedin.com/company/EarlyInterventionProfessionals)

@ [Premie Support Group Leaders](https://www.linkedin.com/company/PremieSupportGroupLeaders)

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