



Preemie Professional



PREEMIE PROFESSIONAL

Stacey Skrysak

President, Co-Founder of Triple Heart Foundation



Photo Credit: Skrysak Family

PROFESSIONAL TIP:

The smallest acts of kindness and care mean so much to NICU families. As a parent who spent 4 months in the NICU and lost one child (at two months) I will forever remember the little moments that made our experience better. From taking pictures of our babies to making signs for their big milestones, these kind gestures go a long way.

Years Helping Premies:

3

Focus:

Providing comfort to NICU families through delivering new children's books for bedside reading.

Website:

www.tripleheartfoundation.com

Inspiration for the Charity:

The organization was created to honor their triplets born in 2013 at 22 weeks and 6 days. Abby passed away shortly after birth; Parker at two months old. It was a NICU nurse who mentioned the benefits of reading to the babies. Those were the seeds of the organization.

ADVOCATE: World Braille Day

January 4th, 2017 is World Braille Day due to it being the birthday of Louis Braille who invented this code in 1821. In our community of preemie parents we have many families affected by blindness due to **Retinopathy of Prematurity (ROP)**. Braille is used worldwide. To learn more about the individual behind it, go here to find out more: <http://bit.ly/BrailleDay>

PREEMIE FREEBIE: VIPreemie (VIP) Badges

PremieWorld provides a number of free handouts to be used in the NICU and beyond in its "[Freebies](#)" section of the website.

This month's freebies are **VIPreemie (VIP) Badges**. "Parents and grandparents are so stressed that the baby is in the NICU that the celebration tends to go by the wayside," comments **Deb Discenza, Founder of PremieWorld**. "Our

VIPreemie badges give them a simple chance to show off their preemie pride to the world." :-)

DOWNLOAD IT:

<http://bit.ly/PremieFreebies>

MORE FREEBIES:

<http://bit.ly/PremieFreebies>

TO DO LIST:

- ✓ **CONGRATS!** **Bobby Bellflower** (Premie Shower), **Aldy Serrano** (*little man* DVD) & **Nicolas Bamat** (Premie Genius).
- ✓ **LIKED US YET?:** PremieWorld is doing another PremieWorld Facebook page contest. See page 2 of this newsletter for details!
- ✓ **DOWNLOAD FREE TOOLS:** Free from PremieWorld at <http://bit.ly/PremieFreebies> and pass them onto Premie Parents in their welcome packets.
- ✓ **MARK YOUR CALENDARS:**
 - Swiss Society of Neonatology Annual Mtg.** January 10, 2017 in Zurich, Switzerland <http://www.swiss-paediatrics.org>
 - NICU Consortium Ed Meeting & Webinar** January 25, 2017, Denver CO & Online <http://www.specialkids-specialcare.org>
- ✓ **CONTACT US:** Have an event to share? A pro or an organization, or product to highlight? Tell us at: connect@premieworld.com

TOOLS AND RESOURCES FOR THE PREEMIE COMMUNITY

SUPPORT:

Will's Way Foundation



WILL'S WAY FOUNDATION

After the premature birth of their son Will and during his 5-month stay in the NICU, Scott Bolick and Brittany Lothe saw firsthand the challenges that come with having a sick child in the hospital. Their foundation seeks to change that.

Established: 2014

Outreach: Northern California

Web: www.willswayfoundation.us

Programs: Providing crucial and effective support to low-income families through support grants and research. To date the organization has provided over 700 support grants including meals, transportation and lodging. And now they are partnering with UCSF on a research project to advance family integrated care in the U.S.

ORGANIZATION:

Triple Heart Foundation

Ryan and Stacey Skrysak created Triple Heart Foundation in honor of their premature triplets - Peyton, Parker and Abby who were born in 2013 at 22 weeks and 6 days. With the death of two of the triplets, their daughter Peyton survived and is today a happy and healthy 3-year old. During the NICU stay a nurse suggested the helpless parents read to their children. Those were the early seeds of **The Triple Heart Foundation**.

Established: 2016

Reach: Regional Illinois/National

Website: www.tripleheartfoundation.com



Programs:

The organization donates new children's books to NICU families. But with a recent grant the organization is now developing care packages that include books, handmade crochet hats and blankets by volunteers. The organization is seeking extra volunteers to meet the demand. Contact them at the website for more information.

Need a Care Package? Contact the organization at their website via the "Contact Us" form.

PREMIEWORLD: "LIKE US" ON FACEBOOK & YOU COULD WIN!

LIKE US HERE:



<http://bit.ly/FBPreemie>

"Like" our FB page from 1/3/17 to 1/22/17 and you could win a copy of the award-winning *little man* DVD documentary from PreemieWorld!



READ AND SUBSCRIBE:

Preemie parents and professionals are invited to subscribe to our **FREE** newsletters today @ www.PremieWorld.com

PREEMIE GENIUS:

RES-Q Wedge



by CR Enterprises, LLC
www.ResQWedge.com

If there is one thing most preemie parents “get” is acid reflux. Reflux wreaks havoc with feeding, with sleeping, with growth and especially with that all-important “tummy-time” and “head-molding” requirement for development. Enter the ResQWedge to the rescue!

The ResQWedge is a medical device used by NICUs and rehab facilities to provide a 35-45 degree angle for supine resting and 30-degree angle for prone positioning. It is now available for sale to patient families directly. A solid, well-made product, the ResQWedge’s genius is in its quality and its simplicity to keep the baby up at a safe and appropriate angle for relief and continued progress



WIN THIS ITEM!

Follow us on Twitter by 1/22/17 to enter: <http://bit.ly/PreemieTweets>



AFTER THE NICU:

When it is Time to Change Doctors

Not every doctor is going to be a perfect fit for your child. Start the new year off assessing how your post-NICU team (pediatrician, specialists, therapists) is helping or hindering your child, such as:

- The professional is not well-versed in prematurity and its short-term and long-term effects.
- The professional seems to brush off your ongoing concerns about your child.
- The professional is not considering other ideas in terms of treatment, despite being shown credible literature.
- The professional is not a good personality fit with what you need.

SHARE YOUR TIPS:

Have you had to change doctors post-NICU? Tell us about it using the hash tag [#preemiedocs](https://twitter.com/preemie/docs)

PREEMIE PROFESSIONAL ONLINE

NICU PROFESSIONALS GROUP (LINKEDIN)

The Power of Human Touch

Is there Such a Thing as Too Much Protein for Preterm Infants?

STUDY: ‘Kangaroo Mother Care’ May Improve Premies Lives into Adulthood

EARLY INTERVENTION PROFESSIONALS GROUP (LINKEDIN)

Here’s a Free Resource to Help Pediatric OT, PT & SLP Clinics Reach their Practice Growth Goals in 2017

A NEW App that Will Have Your Students Talking!

Empowering Carryover is One of the Cornerstones of Therapy

@PREEMIEWORLD @TWITTER.COM

STUDY: Babies Born Early More Likely to Be Short

STUDY: Mothers of Premies More Likely to Suffer Depression for Up to Eight Years

BE THE SMART PRO FOR FAMILIES

Tell your families about the **Preemie Support Forum** on Inspire.com! Our own **Deb Discenza** moderates this **FREE global network of over 32,000 parents from NICU to school to adulthood.** Visit us at <https://preemie.inspire.com>

FIND OUT HOW TO JOIN THESE GROUPS

Refer to “Get Social with Us” on page 4 for more information. Share news and research with us at connect@preemieworld.com.

GET SOCIAL WITH US!



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PREMIEWORLD'S "PREMIE SHOWER"

PremieWorld continues its monthly **Premie Shower!** Each month we will be picking *one* NICU to receive donated items.

Our friends at Little Lotus will be providing ONE NICU with: a set of their Little Lotus Swaddle Blankets

We will select one NICU from our "Premie Family for Professionals" list **by 1/22/17** at www.bit.ly/PremieFam4Pros

NICUs: What do YOU want for a Premie Shower? Tell us using the hash tag **#premieshower**

