



# Preemie Professional



## PREEMIE PROFESSIONAL

### Jenné Johns, MPH

Author, *Once Upon a Preemie - A Book for Parents of Babies in the NICU*



Photo Credit: The Johns Family

**Years Helping Premies:** 3

**Focus:** Says, Author Jenné Johns, "I wrote *Once Upon a Preemie* to motivate, encourage, and inspire preemie parents while they are in the NICU and beside with their babies. I read to my son daily during our nearly three month NICU stay. These books were great, but none spoke to our unique NICU situation. *Once Upon a Preemie* Speaks directly to the NICU journey."

**Web:**

[www.OnceUponAPreemie.com](http://www.OnceUponAPreemie.com) +  
Facebook: [onceuponapreemie](https://www.facebook.com/onceuponapreemie); Instagram & Twitter: [#onceapreemie](https://www.instagram.com/onceapreemie)

### PROFESSIONAL TIP:

*Having the support and experience of other parents who have been in the same position is invaluable.*

## ADVOCATE: National CP Awareness Day

One of the common disabilities associated with premature birth is Cerebral Palsy (CP). **March 25, 2017** is **National CP Day** created by our friends at **Reaching for the Stars** (<http://www.reachingforthestars.org>) Awareness is key not only for community support but also for diagnosis and treatment of this multi-faceted disability. *Pssst! And check out our CP infographic below.*

## PREEMIE FREEBIE: Cerebral Palsy Infographic

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 freebie is a "**Cerebral Palsy**" infographic. "In honor of **National CP Awareness Day** on March 25th, it is important to provide a blueprint on what CP is for our preemie families and the many professionals surrounding

them," notes **Deb Discenza, Founder of PremieWorld**. "I hope it will be shared widely within the community."

**DOWNLOAD IT:**

<https://preemie.us/CerebralPalsyCP>

**MORE FREEBIES:**

<https://bit.ly/PremieFreebies>

## TO DO LIST:

- ✓ **CONGRATS!** **Robyn Teuchert** (Preemie Shower), **Geoff Miller** (*little man* DVD) & **Sorry for Your Loss** (Preemie 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:**  
**30th Annual Gravens Conference**  
March 1-4, 2017 Clearwater Beach, FL USA  
<http://preemie.us/Gravens2017>  
**NPA's Annual Conference**  
March 9-11, 2017, Atlanta, GA USA  
<http://nationalperinatal.org>
- ✓ **CONTACT US:**  
Have an event to share? A pro or an organization, or product to highlight? Tell us at: [connect@premieworld.com](mailto:connect@premieworld.com)

## TOOLS AND RESOURCES FOR THE PREEMIE COMMUNITY

## SUPPORT:



After her daughter **Maya** was born at 33 weeks and developed a 3-4 grade brain bleed, **Michele Shusterman** realized there was little in the way of resources for CP families. She created **CP Daily Living** and then **CP NOW**.

**Established:** 2011      **Outreach:** National

**Web:** [www.CPDailyLiving.com](http://www.CPDailyLiving.com)  
[www.cpnowfoundation.org](http://www.cpnowfoundation.org)

**Programs:** The site provides a blog with practical information and musings for the CP community. CP NOW also distributes the first parent-created diagnosis resource guide for the community.

**Cool:** The organization won a PCORI award to bring clinicians and patient advocates together to participate in a webinar and workshop. Please reach out: [www.cpresearch.net/research-cp-webinar-registration](http://www.cpresearch.net/research-cp-webinar-registration)

## ORGANIZATION:

### *Tiny Feet Foundation*

With the heartbreaking early birth and incredible loss of his son, **Rome Strong Turner**, father **Rick Turner** created the **Tiny Feet Foundation** to help support families with premature newborns and those who lose their babies pre-term. Today the organization continues the legacy of baby Rome with the leadership of four mothers of NICU babies.

**Established:**  
2012

Tiny Feet Foundation  
Supporting the NICU



**Website:** [www.tinyfeetfoundation.org](http://www.tinyfeetfoundation.org)

**Reach:** Families who have a child in the NICU at Sutter Children's Center in Sacramento, California which is the regional referral center for neonatal care for 27 counties and 50 hospitals.

#### **Program:**

The organization is having its **3rd Annual Fundraiser Event & Silent Auction** on **April 8, 2017**. Proceeds will provide basic support to families who have a children at the Sutter NICU in Sacramento. Learn more about this important event here: <http://tinyfeetfoundation.org/annual-fundraising-event.html>

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

LIKE US HERE:



<http://bit.ly/FBPreemie>

"Like" our FB page from **2/28/17** to **3/22/17** and you could win a copy of the award-winning *little man* DVD documentary from PremieWorld!



READ AND SUBSCRIBE:

Preemie parents and professionals are invited to subscribe to our **FREE** newsletters today @ [www.PremieWorld.com](http://www.PremieWorld.com)

## PREEMIE GENIUS:

### BOOK: *Once Upon a Preemie*



by Jenné Johns

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

For the multitudes of parents and grandparents sitting at bedside in the NICU, one of the worst things is to not be able to do what comes naturally: nurture the infant. Due to over-stimulation, illness and more, families sit by helpless. Reading is one of the few things that can truly continue that bond and stimulate the baby cognitively. A parent's soft voice is pure gold to that infant.

This is exactly Jenné Johns' reasoning behind creating *Once Upon A Preemie*, a book with inspirational words for baby and family. The rich colors and tones of the illustrations are soothing and yet playful. For families seeking to bond with their preemie in the NICU, to find some healing, this is your book.



#### WIN THIS ITEM!

Follow us on Twitter by 3/22/17 to enter: <http://bit.ly/PreemieTweets>



## AFTER THE NICU:

### *Cerebral Palsy Diagnosis*

With Cerebral Palsy (CP) being a huge concern with preemie parents, do not assume that your doctor will be the person to pick up on the most subtle of signs. You are the key person as you see everything and are the connecting point between professionals. Keep notes and share them with your team ongoing:

- Pediatrician
- Neurologist
- Early Intervention Therapist (PT, OT, Speech, etc.)
- Orthopedic Surgeon
- Developmental Pediatrician

And know that a second opinion is your right.

### SHARE YOUR TIPS:

Have a preemie with CP or at risk for it?

Tell us about it using the hash tag [#preemieworld](https://twitter.com/preemieworld)

## PREEMIE PROFESSIONAL ONLINE

### NICU PROFESSIONALS GROUP (LINKEDIN)

The Global Maternal & Neonatal Sepsis Initiative

Should We Be Doing More Rather than Less Car Seat Testing Prior to Discharge?

Is it Time to Say Goodbye to the Cow in the NICU?

Why Centralized Milk Prep & Milk Techs Improve Quality

### EARLY INTERVENTION PROFESSIONALS GROUP (LINKEDIN)

Unlimited Approved CEU Clinical Therapy Courses

ABA Early Neural Developmental Curriculum - Sign Up By 3/15/17 for special, low pricing!

Sensory & Learning Fun with Fake Snowballs!

### @PREEMIEWORLD @TWITTER.COM

**AMAZING:** Learn about #NICU Baby Silvie's Journey

**HELPFUL:** #preemie Parent Tips on Tube Feeding Post-#nicu in *Preemie Family*

### 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 34,000 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](mailto: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 HUGGIES**  
**in honor of their new Little Snugglers Nano Premie Diaper**  
**will be providing ONE NICU with:**  
**a DOZEN CASES of HUGGIES Diapers**

We will select one NICU from our "Premie Family for Professionals" list **by 3/22/17** at [www.bit.ly/PremieFam4Pros](http://www.bit.ly/PremieFam4Pros)

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

