



# Preemie Family



## NICU LIFE

### Superman TJ



Photo Credit: Baby Bella

**Gestation at Birth:**  
26 weeks, 5 Days

**Birth Weight:**  
1 lb. 15.3 oz.

**Days in the NICU:**  
78 Days

**Proudest Moment:**

The first time Superman TJ responded to my touch and the sound of my voice.

### PARENT TIP:

*Read to your baby daily!  
It fosters bonding with you  
and stimulates healthy brain  
development.*

#### SEE MORE:

Visit [www.preemieworld.com](http://www.preemieworld.com) late March to read a special update.

## 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** (Premie Shower), **Geoff Miller** (*little man* DVD) & **Sorry for Your Loss** (Premie Genius).

✓ **LIKED US YET?:** PremieWorld is doing another PremieWorld Facebook page contest. See page 2 of this newsletter for details!

✓ **DOWNLOAD FREE TOOLS:** From PremieWorld at <http://bit.ly/PremieFreebies> to use and pass onto other Premie Parents.

✓ **MARK YOUR CALENDARS:**

March 9-11, 2017: NPA's Annual Conference  
<http://www.nationalperinatal.org>

March 11, 2017: *Getting the Support You Need*  
<http://www.oley.org>

✓ **CONTACT US:**

- Have an event you want to share with our community?
- Have an organization or product we should know about?
- Know of a family or pro to highlight?
- *Email us at [connect@preemieworld.com](mailto:connect@preemieworld.com)*

## TOOLS AND RESOURCES FOR THE PREEMIE COMMUNITY

## TERM:

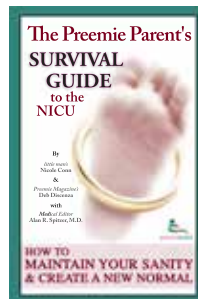
### *Cerebral Palsy (CP)*

**Cerebral Palsy (CP):** A muscle and coordination disorder caused by some form of neurological (brain) injury before, during, or after birth. There are several varieties of CP (*see the infographic in our Premie Freebie section on page 1*) and many are not obvious for a number of years. While this diagnosis can be devastating, it is important to note that there is extensive research on management of this disorder. Many people go on to have very productive lives with CP.

#### Questions to Ask the Doctor:

- Based on my child's unique situation, what are the chances of him/her having Cerebral Palsy?
- What type of therapies will we go home with from the NICU to help our child since CP is a common diagnosis with premature birth?

This excerpt is from  
*The Premie Parent's Guide  
to Survival in the NICU*  
on sale at  
[www.premieworld.com](http://www.premieworld.com)



## SUPPORT:

### *CP Daily Living* **CP DAILY LIVING**

JOURNAL & RESOURCES for Parents and Caregivers of Children with Cerebral Palsy

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)

## 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:

Premie 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 FAMILY ONLINE

### PREEMIE SUPPORT FORUM ON INSPIRE.COM

Connect with over 34,000 parents of preemies for FREE at <http://preemie.inspire.com> for the **Preemie Support Forum**. It is the largest and most active parent forum online, moderated by our own **Deb Discenza**.

*In the NICU/PICU:* 25 Weeker . . . 6 Weeks on Ventilator and Counting . . .

*In the NICU/PICU:* I Need Support

*In the NICU/PICU:* Ups and Downs

*At Home (Years 1-5):* Resources to Help Family Understand

*At Home (Years 1-5):* Sensory Brushing

### @PREEMIEWORLD @TWITTER.COM

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

### PREEMIEWORLD AT FACEBOOK.COM

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

### PREEMIEWORLD'S GROUP ON LINKEDIN

**#preemielove Note:** Geoff, 26 Weeker now 38!

**#preemielove Note:** Karla, 32 Weeker Born in 1982!

**#preemielove Note:** Patrick, 23 Weeker Now 30!

**#preemielove Note:** Kelly, 26 Weeker Born in 1984!

## GET SOCIAL WITH US!



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



- @PremieWorld



- [www.facebook.com/PremieWorld](http://www.facebook.com/PremieWorld)
- [Premie Parent's Survival Guide to the NICU](#)



- [www.instagram.com/premieworld](http://www.instagram.com/premieworld)



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## PREMIEWORLD'S "PREEMIE 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**

