

Preemie Family



NICU LIFE

Superman TJ



Photo Credit: Baby Bella

PARENT TIP:

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

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.

SEE MORE:

Visit <u>www.preemieworld.com</u> *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*.

TO DO LIST:

CONGRATS!: Robyn Teuchert (Preemie Shower), Geoff Miller (little man DVD) & Sorry for Your Loss (Preemie Genius).

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

DOWNLOAD FREE TOOLS: From PreemieWorld at http://bit.ly/PreemieFreebies to use and pass onto other Preemie 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

TOOLS AND RESOURCES
FOR THE PREEMIE COMMUNITY

PREEMIE FREEBIE: Cerebral Palsy Infographic

PreemieWorld provides a number of free handouts to be used in the NICU and beyond in its <u>"Freebies"</u> 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 PreemieWorld**. "I hope it will be shared widely within the community."

DOWNLOAD IT:

https://preemie.us/CerebralPalsyCP

MORE FREEBIES:

https://bit.ly/PreemieFreebies

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 Preemie 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 Preemie Parent's Guide
to Survival in the NICU
on sale at
www.preemieworld.com

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: <u>www.CPDailyLiving.com</u> 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

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

The Preemie Parent's

SURVIVAL

GUIDE

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 PreemieWorld!



READ AND SUBSCRIBE:

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

PREEMIE GENIUS:

BOOK: Once Upon a Preemie



by Jenné Johns www.OnceUponAPreemie.com

For the multitudes of parents and grandparents sitting at beside 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!





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

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!



- www.preemieworld.com
- ${\color{gray}\bullet} \, \underline{www.littlemanthemovie.com}$

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- www.facebook.com/PreemieWorld
- Preemie Parent's Survival Guide to the NICU



www.instagram.com/preemieworld



- PreemieWorld
- NICU Professionals
- Early Intervention Professionals
- <u>Preemie Parent Support Group</u> Leaders
- Preemie Parents







Interested in advertising? Contact us at connect@preemieworld.com

PREEMIEWORLD'S "PREEMIE SHOWER"

PreemieWorld continues its monthly **Preemie 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 Preemie Diaper
will be providing ONE NICU with:
a DOZEN CASES of HUGGIES Diapers

We will select <u>one NICU</u> from our "Preemie Family for Professionals" list

by 3/22/17 at www.bit.ly/PreemieFam4Pros

NICUs: What do YOU want for a Preemie Shower?

Tell us using the hash tag #preemieshower







