

# preemiefamily

support. educate. advocate.



## PREEMIE BRAINS

one issue at a time with PreemieWorld

Neuroplasticity. Just as an elderly patient can recover use of speech, movement and more in the case of stroke, so can a baby born early reach better outcomes. This is not magic, not a supplement, not a joke. Just as Olympians train like athletes so can a baby, a child and an adult struggling from debilitating conditions like Cerebral Palsy. It is time we gave baby brain science its due and stop telling parents that their baby is at risk for very poor outcomes based upon old data, small samples sizes and legal fine print. Karen Pape, MD's book, The Boy Who Could Run But Not Walk is a must-read for every parent, every pro.

2018: Giving preemies the tools to thrive, not just survive.

- Deb Discenza, Publisher & CEO



### IN THIS ISSUE:

Look for worldwide events https://preemieworld.com/events/

#### Preemie Brains

Deb Discenza gives insight into neuroplasticity, a concept surrounding the brain recovering from prematurity-related disabilities such as Cerebral Palsy. Not a cure, but it does make a huge difference.



Colson & Joe put out incredible care packages uniquely suited for NICU Mamas working on providing breast milk in the NICU.

### After the NICU: Questions for the Physical Therapist

After the NICU can be just as complicated as in the NICU. Read more from this excerpt of Deb Discenza and Nicole Conn's book, The Preemie Parent's Survival Guide to the NICU.



- **New Section.** Check out our new section, *Giving* From Your Heart, on p. 4.
- Freebies. Get free downloads from PreemieWorld at http://bit.ly/PreemieFreebies Have an idea for a freebie? Contact us and let us know.
- National Perinatal Association 39th Annual Conf March 14-16, 2018; Loma Linda, CA, United States http://nationalperinatal.org/2018 Agenda
- St. Patrick's Day Party for Preemies March 17, 2018; Bethlehem, PA, United States

### **CONNECT WITH US:**

Have an event you want to share with our community? Visit https://preemieworld.com or drop us a line at connect@preemieworld.com!



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@ www.instagram.com/preemieworld

### YOUR PREEMIE FREEBIE: PREEMIE BRAINS ARE FLEXIBLE

PreemieWorld 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 graphic about Preemie Brain Flexibility.

Print it out as a gift to that special person in your life. Or consider posting this on your social media and tag that dear family member, friend or pro.

To download this freebie, visit <a href="https://preemieworld.com">https://preemieworld.com</a>



I firmly believe preemie brains are flexible and with proper therapy children with Cerebral Palsy and other conditions can achieve more than we think. It is time to push back on old research and old assumptions and start again.

~ Deb Discenza, PreemieWorld



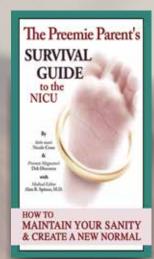
# PREEMIE TERMS IN THE NICU



### 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 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 prevention and management of this disorder. Many people go on to have productive lives with CP. An estimated 10-20% of preemies born under 1,000 grams at birth weight will develop CP. However babies born at less than 3.3 pounds (1,510 grams) still have a higher risk of CP than babies that are carried full-term. Roughly 8% to 15% of the under 1500 gram preemie population will develop some form of CP. These numbers are merely estimates as many children are not tracked after they leave the hospital. If you have any concerns about your infant, please talk to your child's doctor.





### Resources:

CP NOW: Advancing Neurorecovery - <a href="https://cpnowfoundation.org/">https://cpnowfoundation.org/</a>
CP Daily Living - <a href="http://cpdailyliving.com/">http://cpdailyliving.com/</a>

This excerpt is from The Preemie Parent's Guide to Survival in the NICU, Preemie World's widely circulated support book, on sale at <a href="https://preemieworld.com">https://preemieworld.com</a>. Get yours today!

# SUPPORT: OUR LITTLE PREEMIE

Our Little Preemie was born when founder Shatoya Lewis' daughter Zaria was born at 32 weeks gestation, weighing in at 3 lbs. 12 oz. and having a 31 day NICU stay. During Zaria's stay, Shatoya searched for success stories but had no luck. So she created an online community that provides parents with hope.

Visit https://www.instagram.com/ourlittlepreemie to join for FREE

#### Services

OLP provides Letters of Hope to parents in the Neonatal Intensive Care Unit (NICU). The details include a written letter from a previous NICU Mom and their graduate and a "before" and "after" photo of the graduate as well as encouraging words to the parents.



Established: 2017

Website: https://www.instagram.com/ourlittlepreemie Focus: All gestational ages - 21 weeks to 37 weeks. Outreach: Silver Spring, Maryland, United States



"little man" is every preemie parent's story



www.littlemanthemovie.com





One of the biggest struggles for preemie Moms is starting and keeping a strong breast milk supply for the baby until he/she can latch onto the breast. Thanks to **Colson & Joe** (<a href="www.ColsonJoe.com">www.ColsonJoe.com</a>), a company based out of Louisiana, Moms in the NICU have no further to look than the Colson & Joe website. The company provides "Premium Lactation Subscription Boxes" that as the company notes "contain innovative products, hand picked specialty items, and vital information to ease the process and enhance the bond between mom and baby during their breastfeeding/pumping journey. Our boxes feature a mixture of organic, natural, artisan, hand crafted, and uniquely useful goods." These lactation boxes are a one-stop shop for helping busy Moms keep breastfeeding going which benefits both Mom and baby. And family and friends looking to give a special gift should consider providing subscription to a Preemie Mom.

**Cool Facts:** Founders Mia and Jessica both had challenges with breastfeeding (with Jessica's happening during a NICU stay) so they get this from a variety of points of view. And a portion of the proceeds of every box sold is used to send free boxes to Moms in a NICU.



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PreemieWorld.com



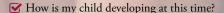
COLSON & JOE

One lucky winner will receive a single subscription box to try out! We'll select one NEW Instagram follower prior to 3/22/18. Enter to win by following us on Instagram at www.instagram.com/preemieworld.

Congrats to Everything Elijah, the winner of February's giveaway, a copy of Lily's Hope: A Preemie's Journey of Hope at www.LilysHopeFoundation.org

# **QUESTIONS FOR THE PT**

The following are some sample questions to ask a prospective Physical Therapist (PT) as listed in *The Preemie Parent's Survival Guide to the NICU* by Deb Discenza and Nicole Conn.



Is there anything extra I can do to help my child at home?

What types of therapies are you providing my child at this time and/or in the future?

☑ Is there anything else I should know at this time concerning my child's development now and in the future?



SURVIVAL



Find these questions and more in The Preemie Parent's Survival Guide to the NICU, available at www.PreemieWorld.com



# PREEMIE FAMILY ONLINE

### **Inspire Preemie Community:**

Parents, Grandparents, Adults & High-Risk Pregnancies

Help your families connect with over 42,000 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.

http://preemie.inspire.com

PreemieWorld on Twitter

http://bit.ly/PreemieTweets

PreemieWorld on Facebook

http://preemie.us/PreemieFB

Preemie World on LinkedIn http://bit.ly/PWLinkedIN

# **IEC SOCIETY: 2019 NEC SYMPOSIUM**

friends at the NEC Society have recently completed a very successful NEC Symposium in California. With that the organizais gearing up for its next symposium slated for June 2-5, 2019 at C.S. Mott's Children's Hospital in Ann Arbor, Michigan.

#### t the NEC Society:

ion: Through education, outreach, research, and cacy, we are committed to understanding necrotizing ocolitis and reducing its incidence.

Site: www.NECsociety.org



#### **Give From Your Heart**



Does your organization have a special event focused on helping preemies? Contact Us: <a href="mailto:connect@preemieworld.com">connect@preemieworld.com</a>

### **FEATURED PREEMIE PRIDE:**

My son Timothy (TJ) was born at 33 weeks 6 days and spent a month in the NICU. He is 9 months (7 months adjusted) and just graduated from physical therapy (he was in for hip dysplasia). He is meeting many of his milestones on time. Our son is a fighter.

- Anonymous

We welcome your submissions for this section of Preemie Pride, Preemie Angel, and Preemie Prayer at <u>PreemieWorld.com</u>



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### **SNEAK PEEK**

In next month's issue.....

#### New Item: Giving From the Heart

There is another special program where you can make a difference in the preemie community.

#### Preemie Genius

We are reviewing a new book focused on a very special preemie. Don't miss it!

#### And More!

Have you subscribed to Preemie Family yet? It's free! <a href="http://bit.ly/preemie1">http://bit.ly/preemie1</a>

# JOIN THE CONVERSATION

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

~ Deb Discenza, PreemieWorld





@ Preemie World

@ Preemie Parent's Survival Guide to the NICU



<u>@ Preemie World</u>



@ Preemie World

@ NICU Professionals

@ Early Intervention Professionals

@ Preemie Support Group Leaders

@ Preemie Parents



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