

Preemie Professional

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Silke Mader

Chairwoman, European Foundation for Care of Newborn Infants



Organization:

European Foundation for Care of Newborn Infants (EFCNI)

Years in the Field:

16

Focus:

Expertise in advocacy for preterm infants and their families as well as raising awareness for the needs of the tiniest babies in our society.

Professional Tip:

All relevant stakeholders in the area surrounding "prematurity" should work together, as that is much more efficient, as in the end **Facebook:** it is all about improving our children's health.

Website:

www.EFCNI.org

https://www.facebook.com/efcni

Advocate: Kangaroo Care Awareness

Kangaroo Care is used in NICUs worldwide, but yet many NICUs have yet to adopt this simple practice as a routine way to help preemies. Help us celebrate the 4th International Kangaroo Care Awareness Day on May 15, 2015. Learn more with this downloadable newsletter from our friends at Nurtured by Design (home of the Zaky): http://conta.cc/1cw9Fcj

To Do List



CONGRATS: Karen Wahlin, MFT gets the Bentley's Preemie Blessing and Jennifer Hunter receives a copy of the little man DVD.



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



Download PreemieWorld's FREE and pass them onto NICU Parents as part of your welcome packet.

MARK YOUR CALENDAR!



Neonatal Pharmacology **Contemporary Forums** May 14-16, 2015 Scottsdale, AZ

Spanish Society of Perinatal Medicine 2015 May 20-22, 2015 Seville, Spain

Have an event you want to share with our community? Contact us at:

Tools and Resources for the Preemie Community

Preemie Resource: Parents of Preemies Day Logos

PreemieWorld provides a number of free handouts to be used in the NICU and beyond in its "Freebies For You" section of the website.

This month's freebie surrounds "Parents of Preemies Day" powered by Graham's Foundation. We are including three different types of logos to be used by parents and professionals alike online.



Download them here:

General: http://preemie.us/PPDLogo

Parent: http://preemie.us/PPDProudParent Support: http://preemie.us/PPDSupporter

Support: Little Miracles



With the NICU stay of her son, Harry, Cirsty de Gruchy-Wilson wanted to make sure all families were supported with practical gifts and emotional support.

Year Established: April 2014

Outreach: National (to the only SCBU on island of Jersey, Channel Islands in the United Kingdom).

Web: www.littlemiraclesjersey.co.uk

Programs: Supplies a "Hug in a Box" for families that has practical items for the SCBU stays and provides emotional support upon entry to the SCBU. *Connect on Facebook and Twitter to keep updated.*

Org: Milky Mums

After working through breastfeeding in the NICU herself, Carmen Gould and a group of volunteers are on a mission to make things easier for other Mums.

Website:

www.milkymums.org.au

Blog:

https://milkymums.wordpress.com

Year Established: 2014

Outreach: Australia (National)

Focus: Mothers with babies in the Neonatal Intensive Care Unit (NICU)

Background: "Milky Mums was established by me after I had my son at 26 weeks," says founder Carmen Gould. "He came home

after 138 days in the NICU but during that time I realised that more resources and emotional support were needed for mothers breastfeeding and expressing for babies in the Neonatal Intensive Care Unit."

Programs:

- Donation of hand-free pumping bras to NICUs around Australia
- Sharing of stories from mothers who have breastfed or expressed for babies in the neonatal intensive care unit via our blog
- Loan pool of breast pumps direct to mothers (in development, contact for info)



PreemieWorld: "Like" Us On Facebook & You Could Win!



Visit PreemieWorld's FB page at: http://bit.ly/FBPreemie

"Like" our FB page from 4/28/15 to 5/22/15 and you could win a copy of the awardwinning *little man* DVD from PreemieWorld!

http://bit.ly/FBPreemie

<u>Parents & Professionals:</u> Subscribe to our FREE newsletters today @ www.PreemieWorld.com



The Details:

Name:

Complex Child Magazine

Year Established: 2008

Focus: Children with complex medical issues and disabilities

Website:

www.complexchild.com

Facebook:

www.facebook.com/ComplexChild



Complex Child Magazine

Having had a child with complex medical needs herself, editor Susan Agrawal understands the unique needs of parents in similar circumstances. When she and other experienced parents were busy answering the same questions and giving practical tips again and again, Complex Child Magazine was created to give a home to their enduring wisdom. For parents of preemies as well as professionals, this body of information is incredibly useful in that it goes across medical specialties and also delves into practical matters such as insurance, taxes, advocacy and more. This magazine is at the top of our list of resources for NICU discharge paperwork for parents.

After the NICU: Sibling Rivalry at Home

When your preemie is home, older siblings are likely to have a mixture of excitement and even frustration. How to keep things cool:

- Give siblings a special job to help out with the baby that is appropriate for their age and skill level.
- Praise them on all *positive* interactions with the baby.
- When the baby is napping or sleeping, take a bit of time to snuggle with siblings and to even let them talk about their concerns if they are at an age where they can express them.
- When possible, take siblings out one at a time on their own for a special trip to the grocery store, the pharmacy, etc. so you two can talk. Maybe even grab a special snack just for you two.

Preemie Professional Online

NICU Professionals Group: (www.LinkedIN.com)

RESEARCH: Premature babies more sensitive to parenting style than full-term kids

SMART: What Parents Can Do to Help Preemies

<u>Early Intervention Professionals Group:</u> (www.LinkedIN.com)

Is direct instruction that answer for teaching struggling readers?

How to test for muscle leg length discrepancy in toddlers?

Can a three-year old special learner play the piano?

Preemie World (www.Twitter.com):

THOUGHTS? Are NICU Antibiotics Overused?

BE THE SMART PRO: Tell Your Families about the "Preemie Network" on Inspire.com:

Deb Discenza of PreemieWorld moderates this FREE global network of *almost* **22,000** *parents* from NICU to home to school. www.inspire.com/preemie

Check out these groups and more by referring to the "Get 'Social' With Us" on page 4 for more information. Have news or research to share with us? connect@preemieworld.com









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

Tip: Preemie Parents are Part of the Team (Part II)

They say hindsight is 20/20 and that is so true. Deb Discenza, Publisher at PreemieWorld, in this second installment (you can find the first installment here), gives insight into what she believes Preemie Parents in the NICU right now should know for sure:

Know that as a parent YOU ARE part of the NICU team. As I took in the sight of my 30-weeker preemie girl hooked up a lot of medical equipment and clearly in distress, I had no clue how to soothe her. My first inclination was to try and hold her but the barriers of the incubator and the equipment left me impotent to do anything. I assumed the staff members were the

ones in charge and I as the parent was simply a bystander. A nurse showed me how to a temperature check and later a diaper change, but honestly it did little to help and I simply continued pumping breast milk.

It was when I first saw the power of my first session of **Kangaroo Care** that I realized my importance to this odd NICU equation. I *was* part of the team. I made a difference.

You are part of the NICU equation. You matter. You count. You have say and you have the ability to speak up.

#preemieparentpower