



Preemie Professional

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Photo Credit: www.Kernicterus.org

Professional Tip!

First, risk assessment for KI is not just about a number, it's also about the risk factor. In addition to the TSB, consider the other risk factors such as acidosis, infection, hypoalbuminemia, hemolysis, and look for signs of encephalopathy. Second, when a baby with hyperbilirubinemia is in need of surgery don't forget to continue phototherapy.

Organizations:

- Kansas City Kernicterus Center
- University of Missouri-Kansas City
- University of Kansas Medical Center

Preemie Focus: The KCKC is devoted to studying the effects of moderate to severe hyperbilirubinemia resulting in KI and BIND. Information gathered at the center is focused on preventing bilirubin neurotoxicity in premature and term infants as well as treatments for KI and BIND.

Advocate: NIDCAP Needs You!

With her research to help reduce neonatal stressors in the NICU and the creation of the NIDCAP Federation International training program, Dr. Heidi Als has made a difference for preemie families worldwide. Yet AAP's journal *Pediatrics* printed an article that is misleading and serves to discredit NIDCAP. **Please sign & pass on this petition:** <http://bit.ly/NIDCAP>

To Do List



Deadline Approaching: 30 April 2013 is the end of the "For the Love of Babies" campaign by Hand to Hold (www.HandtoHold.org)



Professionals, sign up your organization to receive Preemie Family to distribute to your families: <http://bit.ly/PreemieFam4Pros>



Download PreemieWorld's FREE tools <http://bit.ly/PreemieFreebies> and pass them onto NICU Parents as part of your welcome packet.

MARK YOUR CALENDAR!



Fragile Beginnings Support Call
JF & CS Boston
April 9, 2013 NOON - 1 p.m. ET
Worldwide
<http://bit.ly/FragileBeginnings>

8th Annual Golf Tournament
Katelyn Hall Foundation
April 22, 2013
Washington, DC area
<http://ow.ly/i9Nlw>

Have an event to share? Email us details at connect@preemieworld.com

*Tools and Resources
for the Preemie Community*

Preemie Resource: Risk Factors & Need for Help

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 is "Risk Factors & Need for Help."** "In reviewing the Love & Logic (www.LoveandLogic.com) series, I realized how preemie parents are at a real disadvantage," comments Deb Discenza, co-Founder of

PreemieWorld, LLC. "With the focus on the child's needs, setting limits takes a back seat. This tool gives you clues of when to seek help." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. **So go download it here now:** <http://bit.ly/RiskFactor> **And check out many more here:** <http://bit.ly/PreemieFreebies>

Support: *Dallas Premie Parents***Founder:**

Jacqueline Neyland, BSW

Year Established: 2011**Web:**www.DallasPremieParents.blogspot.com

Focus: Providing support to families of NICU babies in the Dallas/Ft. Worth, TX region through in-person support and handmade gifts.

Programs: NICU get-togethers, holiday events, resources. Coming is a mentor program, antepartum support program, postpartum support and specialized NICU support.

Org: *Parents of Infants & Children with Kernicterus (PICK)*

Premies parents are quite familiar with jaundice as they watch their baby bathe in the incubator's "bili lights" during the stay. For those that do not get the proper treatment, Kernicterus can create life-long damage and even death. PICK was formed to help raise awareness and support families that have been affected.

Website: www.PICKonline.org

Founding: Media coverage in September 2000, following the testimony of Susan Sheridan (PICK co-founder) at an Agency for Healthcare Quality & Research summit on patient safety, facilitated the networking of seven moms of children with kernicterus. These moms quickly realized that their children's injuries were not as rare as the

medical and public health communities estimated. PICK mobilized rapidly to create awareness about kernicterus and strategies for preventing this easily preventable patient injury.

Programs:

- Research for prevention & cure
- Family support
- Uniting families & data gather
- Lobbying for studies and screening
- Collaborating with researchers
- Support Groups in US/Brazil
- Social Media awareness

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

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

**"Like" our FB page
from 4/1/13 to 4/26/13
and you could win a copy of the
award-winning *little man* DVD
from PreemieWorld!**

<http://bit.ly/FBPreemie>

*Parents & Professionals:
Subscribe to our FREE newsletters today @
www.PreemieWorld.com*

Preemie Genius: Parenting Children w/Spec Med Needs

The Details:

Name:

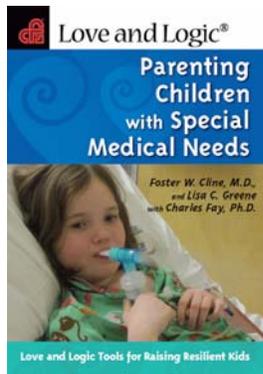
Parenting Children with Special Medical Needs

By:

Love and Logic Institute, Inc.

The Website:

www.loveandlogic.com



The Genius:

Parenting a child without needs is challenging. But when you add in special needs (medical, developmental, behavioral and more) parents are often at a loss how to bring up their child to be confident and self-sufficient in terms of life but especially in terms of the daily treatments and therapies that are needed in childhood and even into adulthood. Love and Logic's special series on special medical needs provides solid tips to get there. *And it works.*

COOL:

We are giving away two books and a DVD in the "Parenting Children with Special Medical Needs." The winners will be selected from the new subscribers to *Preemie Family* 4/1/13 - 4/26/13. <http://bit.ly/preemie1>

After the NICU: Asking for Help

In the early days and months of a NICU stay and even at discharge time, families are scrambling to tackle urgent matters at the hospital alongside maintaining demands of home, work and more.

If someone offers help – ask him/her to set up and coordinate a "team list" for the family needs for meals, childcare, etc. These sites take the work out of coordinating:

- CaringBridge - <http://caringbridge.org>
- Lotsa Helping Hands - <http://bit.ly/HelpingH>
- Sign Up Genius - <http://bit.ly/XiLmVp>

Preemie Professional Online

NICU Professionals Group: **(www.Linkedin.com)**

"ARTICLE: Pain drug may prevent preemie lung damage - <http://ow.ly/jhq9P>"

"STUDY: NICU Understaffing Leads to Higher Infection Rates - <http://ow.ly/jhqq7>"

Early Intervention Professionals Group: **(www.Linkedin.com)**

"Help a special education student in DC access needed iPad apps - <http://goo.gl/Rxqk5>"

"How autism can cost families millions"

"The Movement of Imperfection"

Preemie World (www.Twitter.com):

"Special Preemie Update from our latest issue of 'Preemie Family': Henry Joseph Anicker - <http://bit.ly/HenryAnicker>"

"ARTICLE: Omega-3 DHA May Prevent Earliest Premies - <http://ow.ly/jhpR0>"

"ARTICLE: Amniotic fluid 'may heal premature gut' - <http://ow.ly/jp93o>"

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

Get "Social" With Us!



www.PreemieWorld.com
www.LittleMantheMovie.com



@ PreemieWorld



- PreemieWorld
- Preemie Parent's Survival Guide to the NICU



PreemieWorld



Check out other LinkedIN groups we moderate:

- NICU Professionals
- Early Intervention Professionals
- Preemie Parent Support Group Leaders
- Preemie Parents
- Little Man the Movie

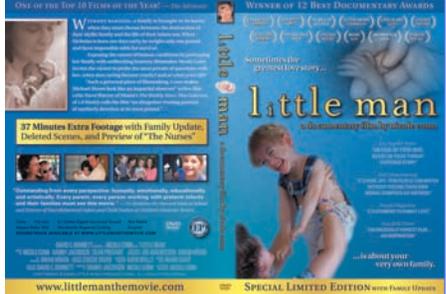
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Parent Tips for Pros: Participating in "For the Love of Babies"

Hand to Hold, a national NICU parent support program has launched its "For the Love of Babies" campaign happening now until 30 April 2013. Public Awareness Director, Amy Carr gives us the background on this event:

Q: How did this special fundraiser come about?
For the Love of Babies is a 100-day fundraising and awareness campaign designed to help not only raise awareness of the challenges associated with a baby's hospital stay and infant loss, but also to fund Hand to Hold's efforts to expand parent support, education and resources to NICU families across the country.

Q: Can a NICU participate? And any prizes?
A: Yes, an individual hospital or NICU can set up a personal fundraising page. Participants who raise a total of \$1,000 or more by April 30, 2013 may gift an annual subscription to Hand to Hold's new NICU Resource Library to the hospital of their choice. (They may also purchase an annual subscription for their NICU at any time). Those who raise a total of \$500 or more in the campaign are entered into a random drawing in May for an Apple iPad Mini.

Q: Where do families go to sign up?
A: <http://donate.handtohold.org/forthelove>