



# Preemie Professional

## Preemie Professional

**Carole Kenner, PhD, RN, NNP, FAAN**

*Executive Director of COINN & Dean/Prof at TCNJ*



Photo Credit: The College of New Jersey

**Org:** Council of International Neonatal Nurses (COINN); The College of New Jersey (The School of Nursing, Health and Exercise Science)

**Web:** [www.coinnurses.org](http://www.coinnurses.org)  
[www.tcnj.edu](http://www.tcnj.edu)

**Focus:** Dr. Kenner has an interest in raising the standard of neonatal nursing care and education with special interest in parent support, palliative care, and genetics.



### Professional Tip!

*Remember as a health professional walking into the NICU for the first time and how overwhelmed you felt. Imagine being the parent. You will be a better clinician.*

## Advocate: NICU Awareness Month

Do you work in a NICU or had a baby in the NICU? Not many people understand what a Neonatal Intensive Care Unit is and how it is important to honor the patients, the caregivers and the staff members of this special unit. **Project Sweet Peas** has created **Neonatal Intensive Care Awareness Month** for September. Check out more here, pass it on: <http://www.nicuawareness.org>

## To Do List



**CONGRATS:** Robert Reynolds, Sr. is the winner of our PreemieWorld Facebook page "like" contest for August. He 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 tools <http://bit.ly/PreemieFreebies> and pass them onto NICU Parents as part of your welcome packet.

MARK YOUR CALENDAR!



**NANN 30<sup>th</sup> Annual Educ Conference**  
National Assoc of Neonatal Nurses  
September 10-13, 2014  
Phoenix, AZ  
[www.nann.org](http://www.nann.org)

**National Neonatal Nurses Day**  
National Assoc of Neonatal Nurses  
September 15, 2014  
United States  
[www.nann.org](http://www.nann.org)

Have an event you want to share with our community? Contact us at: [connect@preemieworld.com](mailto:connect@preemieworld.com)

*Tools and Resources  
for the Preemie Community*

## Preemie Freebie: NICU Nurses' Day Note

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 "NICU Nurses' Day Note." "September 15<sup>th</sup> is known as Neonatal Nurses' Day," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "Preemie Parents are always looking for a way to say

'thank you' to their nurses' so we created this note to help them express their thanks." **Download it now:** <http://bit.ly/DearNurse> and check out more like this on our site here: <http://bit.ly/PreemieFreebies>

**COOL!** Like the PreemieWorld NICU Nurses' Day Facebook page here: <http://bit.ly/NICUNursesDay>

Support:

**Year Established:** 2000

**Web:** [www.fsnc.org](http://www.fsnc.org)

**Outreach:** Cone Health Women's Hospital and families in Guilford, Alamance, Caswell, Randolph, Rockingham counties (N. Carolina).

**Focus:** Providing support, education and caring connections to all NICU families via the Smart Start program.

**Programs:** Bedside support, weekly events, lending library, family resource room, Early Intervention Home Visitation Program, support groups, workshops, events for graduate families and also Elizabeth's Closet (baby supply warehouse) for families with financial challenges.

Org: Jackson Chance Foundation

Carrie and Terry Meghie *know intimately the importance of being able to spend time with your infant in the NICU. They feel strongly that their son, Jackson Chance, (who lived for 302 days with 2 of those days at home), had a happier and therefore a better quality of life thanks to their presence. Not every family is so lucky, and the Jackson Chance Foundation seeks to change that one NICU at a time.*

**Established:** 2012

**Type of Outreach:** Local (Chicago, Illinois)

**Website:** [www.jacksonchance.org](http://www.jacksonchance.org)

**Focus:** JCF in partnership with Ann & Robert H. Lurie Children's

Hospital of Chicago created the NICU Transportation Program which provides complimentary parking as well as transportation to all families, in each and every day their child is in the NICU.

**Save the Date:**

JCF has a 2<sup>nd</sup> Annual Playing It Forward Ping Pong Ball – read more in their flyer here:

<http://bit.ly/JCFPlayForward>

For sponsorship opportunities:

<http://bit.ly/JCFSponsor>



Jackson Chance Foundation  
[www.jacksonchance.org](http://www.jacksonchance.org)

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

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

**"Like" our FB page from 9/2/14 to 9/26/14 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](http://www.PreemieWorld.com)

**The Details:**

**By:**  
Firefly

**Website:**  
[www.fireflyfriends.com](http://www.fireflyfriends.com)



## Firefly Upsee

Thirty years ago, CEO James Leckey was fundraising for a charity event and went from florist to engineer after being inspired and motivated to develop postural support equipment for people with disabilities.

And with the creation of Firefly (an offshoot of the original Leckey Design, Ltd. company) and its Firefly Upsee product line, Leckey provides children with disabilities the ability to walk and move.

***NOTE:** Parents will want to discuss the potential of this device with their child's medical doctor and/or therapeutic professional in order to insure that the device is used properly for the child.*

## After the NICU: RSV & Synagis Preparation

*Parents are often behind the eight ball when getting ready for Respiratory Syncytial Virus season. Here are some quick reminders:*

- Talk to the doctor **now** about precautions needed this season.
- Call/Meet with the pediatrician or specialist's office now to work on a pre-approval of Synagis from insurance so as to not miss doses due to "red tape."
- Prepare family and friends now regarding visitation and more.
- Get those doctors appointments for the family done now to avoid unnecessary outings.
- Look at ways to get through isolation: books, videos, Skype chats with others, etc.....

## Premie Professional Online

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

RESEARCH: New Drug May Fight Serious Respiratory Virus in Infants- <http://ow.ly/AC2Yx>

RESEARCH: Fat from Human Breast Milk Enhances Premie Development - <http://ow.ly/Axd2J>

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

RESEARCH: Premature Baby's Shrill Cry May Be A Sign of Something Deeper - <http://ow.ly/AxeYV>

COOL: Developmental Music Therapy Class for Babies Creates Good Vibes: <http://ow.ly/Axc4p>

### **Premie World (www.Twitter.com):**

PREEMIE UPDATE: Micah and Zachary - <http://bit.ly/PremieMZ>

### **BE THE COOL PRO: Tell Your Families about the "Premie Network" on Inspire.com:**

Deb Discenza of PremieWorld moderates this global network of *over 19,000 parents* from NICU to home to school. [www.inspire.com/preemie](http://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](mailto:connect@preemieworld.com)*

### Get "Social" With Us!



[www.PremieWorld.com](http://www.PremieWorld.com)  
[www.LittleMantheMovie.com](http://www.LittleMantheMovie.com)



@PremieWorld



- PremieWorld
- Premie Parent's Survival Guide to the NICU



PremieWorld



Check out other LinkedIN groups we moderate:

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

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## CHANGES: AAP Revises Synagis Guidelines

In early August the Academy of Pediatrics (AAP) released its latest Red Book guidelines for Synagis, a monoclonal antibody given monthly by injection to help in prevention of RSV in high-risk infants such as premature babies. In short, the changes reduce dosing to only 28-weeker preemies (they have to be born prior to 29 weeks) and the lower gestational ages for only one season based upon specific criteria.

While PremieWorld appreciates the AAP's focus on reducing costs to the patient, there are concerns that these guidelines are based upon studies that have small population numbers, that do not have realistic

costs involved related to hospitalization and post-discharge needs with RSV and therefore does not properly represent all premature infants properly.

If there were to be a full impartial and non-political study of this issue that showed Synagis is not useful to specific populations as listed in the latest set of guidelines, then PremieWorld would fully support it. However, our requests have been ignored.

Parents and professionals concerned about this issue and in doing the best by premature infants for the long-term are welcome to sign our petition and pass it on at: <http://bit.ly/PremiePetition>