



# Preemie Family

## Preemie Life

### *Jackson Chance Meghie*



Photo Credit: Carrie Meghie

#### **Parent Tip:**

*Enjoy the moments. Make the NICU your home and the hospital team your extended family.*

**Gest. Age:** 30 weeks, 6 days

**Weight:** 3 lb. 11oz.

**Time In NICU:**  
300 Days (and 2 days home)



Jackson Chance Foundation  
www.jacksonchance.org

#### **Proudest Moment (NICU):**

The joy Jackson brought to people. He deeply touched so many during his life and continues to do so with his legacy through the Jackson Chance Foundation.

Coming Soon:  
Check [www.PreemieWorld.com](http://www.PreemieWorld.com) to read Jackson's full journey.

## 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>

## 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>

## 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> to use and to pass onto others.



#### **MARK YOUR CALENDAR!**

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

*Preemie Power Photo & Essay Contest*  
Hand to Hold  
September 29, 2014 (nominations open)  
[www.handtohold.org](http://www.handtohold.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*

## Term: Respiratory Syncytial Virus (RSV)

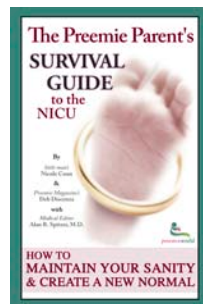
**Respiratory Syncytial Virus (RSV):** An illness initially resembling a modest cold in adults. It can be dangerous for newborns – and even worse for preemies – since it is highly contagious and complications from the virus can develop into a major respiratory infection. Many premature infants with Chronic Lung Disease will be eligible for Synagis injections on an annual basis during cold and flu season.



### **Sign the Preemie Petition!**

*The Preemie Petition was launched by PreemieWorld in mid-2014 to push back against upcoming restrictions to the Synagis guidelines. To learn more about the guideline changes, see page 4 of this newsletter. And join over **6,300 parents and professionals globally** who have already signed our petition and pass it on:*

<http://bit.ly/PreemiePetition>



*This excerpt is from The Preemie Parent's Guide to Survival in the NICU on sale at [www.PreemieWorld.com](http://www.PreemieWorld.com)*

*\*\*We do bulk orders for hospitals\*\**

*[connect@preemieworld.com](mailto:connect@preemieworld.com)*

## 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.

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## 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 Support Online

### On the Premie Support Forum on INSPIRE:

Connect with *over 19,000 other parents of preemies online* at [www.Inspire.com/preemie](http://www.Inspire.com/preemie) for the **Premie Support forum**. It is the largest and most active forum online, *moderated by PremieWorld's own Deb Discenza*. Whether you are in the NICU, just home or working through the school years, we have discussions you won't want to miss.

"34 week preemie – 6 months actual today. Weight?!" – *in 33-36 week preemies*

"When do you talk to your children about the month and day they were born?" – *in At Home (years 1-5)*"

### On PremieWorld's Twitter Page:

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

### On PremieWorld's Facebook Page:

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

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

### On PremieWorld's LinkedIN Group:

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

## 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

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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>