



# Preemie Family

## Preemie Life

### *Ayla Capri Hall*



*Photo Credit: Hall Family*

**Gest. Age:**  
32 weeks

**Weight:**  
3 lbs, 2 oz.

**Time In NICU:**  
67 Days

**Proudest Moment (NICU):**  
When she was able to actually suck, swallow, and breathe while nursing without having a brady!

### Parent Tip:

*Kangaroo your baby as much as possible, but also allow yourself to take a break and leave the hospital.*

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

## Advocate: Pregnancy & Infant Loss Month

We as a community mourn alongside our fellow preemie parents who have lost a baby in pregnancy, at birth, in the NICU and beyond. October is **Pregnancy & Infant Loss Month** and we give thanks to organizations like **Share Pregnancy & Infant Loss Support**, **Zoe Rose Memorial Foundation**, **Now I lay Me Down to Sleep**, and **Still Standing Magazine**, for their ongoing efforts.

## Preemie Resource: Staying #RSVfree

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 "Staying #RSVfree." "You can never prepare enough for this season," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "Our handout provides some

nice tips not only for home but also for when you are also out and about such at the doctor's office. This is the list I would have wanted for those first few years."

**Get this month's freebie here and pass it on:**  
<http://bit.ly/RSVFREE> and look at our other freebies here: <http://bit.ly/PreemieFreebies>

## To Do List



**CONGRATS:** Congrats to **Emma Hostetter** on winning the little man DVD in our latest contest.



**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!**

*Monthly Preemie Playgroup*  
Preemies Today  
October 9, 2014  
[www.PreemiesToday.com](http://www.PreemiesToday.com)

*Four Before Their Time Book Launch*  
Graham's Foundation  
October 26, 2014  
Elverson, PA  
[www.grahamsfoundation.org](http://www.grahamsfoundation.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)

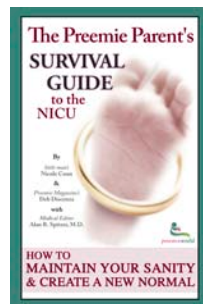
**Respiratory Syncytial Virus (RSV):** An illness initially resembling a modest cold in adults. It can be dangerous for newborns – and even worse for preemies – since it is highly contagious and complications from the virus can develop into a major respiratory infection. Many premature infants with Chronic 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)*

**HOW TO MAINTAIN YOUR SANITY & CREATE A NEW NORMAL**

## Support:



*From a little Gund Bear in Beth Maclin's son's incubator came the nickname "Little Bear" which now represents the organization to help preemie families around the world.*

**Year Established:** 2006

**Web:**

<http://thelittlebearfoundation.org>

**Outreach:** U.S., Canada & England

**Focus:** Supporting families with preemies as well as families going through a post-preemie pregnancy.

**Programs:** NICU Survival Kits for new preemie families, peer-to-peer support program, and mentor program.

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



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

**"Like" our FB page from 9/30/14 to 10/26/14 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:**  
Mighty Tykes

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



## Mighty Tykes' Infant & Child Weights

Mother and Inventor Isabella Yosuco created these innovative weights after her son was born with Down Syndrome and she learned he would be affected by hypotonia, low muscle tone, and weakness common in many other conditions including prematurity. These were created with input from OTs and PTs.

Soft and colorful, these weights are not only made in the U.S.A. but are also lead-free and also washable. They come in 1/8, 1/4 and 1/2 pound weights.

*COOL: One new @PreemieWorld Twitter follower during 9/30/14 - 10/26/14 could win a copy of this book! Go here: [www.twitter.com/preemieworld](http://www.twitter.com/preemieworld)*

*EXTRA COOL: Mighty Tykes is offering PreemieWorld readers a one-time discount code on their weight products: **PREEMIE14***

## After the NICU: Paying for Synagis (palivizumab)

*With RSV season just about here, there are many preemies preparing for Synagis injections. This effective monoclonal antibody is not cheap. Approved but need help paying for it? Consider contacting these organizations for help:*

- **Access 360:** Synagis Manufacturer Medimmune has a program that will help families needing assistance with the cost of the drug. Find out more here: [www.MyAccess360.com](http://www.MyAccess360.com)
- **Patient Access Network (PAN Foundation):** PAN is dedicated to providing help and hope to people with chronic or life-threatening illnesses for whom cost limits access to breakthrough medical treatments: [www.PANfoundation.org](http://www.PANfoundation.org)

## Preemie Support Online

### On the Preemie 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 **Preemie Support forum**. It is the largest and most active forum online, *moderated by PreemieWorld's own Deb Discenza*.

When did your preemies come home? – *in NICU/PICU*

Chronic Lung Disease, Failure to Thrive, G-Tube – *in Premies with Feeding Issues*

How are you coping with your preemies challenges? – *in At School, Years 6-12*

Update on 24-week Preemie – *in Preemie Hope*

### On PreemieWorld's Twitter Page:

RESEARCH: Lahav Group Study on Maternal Sounds Lowering Preterm Newborn Heartbeat – <http://ow.ly/BC65d>

### On PreemieWorld's Facebook Page:

PREEMIE UPDATE: Jackson Chance Meghie – <http://bit.ly/PreemieJackson>

### On PreemieWorld's LinkedIN Group:

COOL: Milestone Blog Post from Preemie Mom & Author Jennifer Degl – <http://ow.ly/BC544>

NEWS: NIH officials cleared of interfering in oversight of preemie study – <http://ow.ly/C1nyr>

## 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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## Q&A: What are the Top Myths Surrounding RSV?

*RSV season is less than a month away, so we are grateful to our friends at the Alliance for Patient Access (AfPA) for dispelling myths surrounding RSV.*

**1. RSV is a common cold. False!** While RSV may "look" like a common cold, in older adults and young infant, it can be life threatening. RSV is 10 times more deadly than the flu.

**2. RSV is spread through coughing. False!** RSV is spread through droplets and the live virus can live for hours on surfaces such as countertops. RSV is highly contagious and this is why good hand washing is so important to prevent the spread of RSV.

**3. There is a medication to help prevent RSV. True!** Synagis (also known as *palivizumab*) is a medication that can help prevent RSV. Babies at risk for RSV are given Synagis every month during RSV season (Oct-March in most places).

**4. My baby can only get RSV once a year. False!** After recovering from an RSV infection, your baby is still susceptible to getting it again if exposed, as we do not build immunity to this virus after getting it once. This is why babies who get Synagis need to have the injections monthly, because the antibody in the injection "wears off" in ~28days.

*Sign the Premie Petition: <http://bit.ly/PremiePetition>*