



# Preemie Family

## Preemie Life

### *Novali (Nova) Caelyn Reichard*



Photo Credit: Tyler Reichard

**Gest. Age:**  
32 weeks, 3 days

**Weight:**  
3 lbs. 4.6 oz.

**Time In NICU:**  
28 days

**Proudest Moment (NICU):**  
The first time I held her and she held her own body temp (the first official time I held her she dropped to 91 degrees.

#### Parent Tip:

*I know it is hard but try to take time for you.*

*Your health is important for your baby.*

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

## Advocate: National Handwashing Awareness Week

December aptly includes **National Handwashing Awareness Week** December 7 - 13, 2014. With RSV, cold and flu season in full swing, make sure to alert friends, family, and colleagues to this simple but effective way to prevent transmission of germs. Learn more here at the "Henry the Hand" website full of information and resources: <http://bit.ly/HenrytheHand>

## Preemie Resource: Holidays with Premies

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 "Holidays with Premies."** "Holidays are really tough for preemie families," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "Whether they are in the NICU

or at home on lockdown it is important to help them find ways to celebrate the season - Preemie Style!" Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce.

**Download it here now:**

<http://bit.ly/PreemieHolidays> and **check out more like this here:** <http://bit.ly/PreemieFreebies>

*Follow us on FB, Twitter & LinkedIn!*

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## To Do List



**CONGRATS:** [Rhiley Ethridge](#) is the winner of the *little man* DVD contest and [Pebbles of Hope](#) is the winner of *The Baby Signing Book* by Sara Bingham 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!**

*Amazon Wish List for the Holidays*  
Little Giraffe Foundation  
November & December 2014  
United States  
<http://bit.ly/LGFWishlist>

*Monthly Preemie Playgroup*  
Premies Today  
December 11, 2014  
Wings to Fly Therapy Center  
[www.PremiesToday.com](http://www.PremiesToday.com)

*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: Seizure

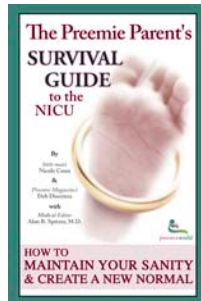
## Support: Lily's Hope

### **Seizure:**

When the brain cannot control certain electrical activity. There are many different types of seizures, including those caused by a disrupted nervous system, fevers, birth defects, and oxygen deficits. These can be as extreme as huge physical convulsions or as mild as minor physical disturbances. While over 50% of seizures are unidentifiable, there are many medications that they can give your baby to help

resolve and decrease the seizure activity.

**Nicole's Take:** We didn't even realize Nicholas had what we now refer to as an "undiagnosed seizure disorder," until well after we were home. And then we discovered he simply could not function when we tried to remove his Phenobarbital and Clonapin. But with both of these medications, whatever seizure disorder he is experiencing is kept under control.



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)



*Out of their own experience with premature birth, Jen Driscoll and her husband created Lily's Hope Foundation to make the NICU stay and discharge easier for families.*

**Year Established:** 2013

**Outreach:** National

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

**Programs:** Care packages that are customized for the family's specific needs either in the NICU or at home.

**Events:** Lily's Loop, upcoming golf outing and a 5K run.

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



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

**"Like" our FB page  
from 12/2/14 to 12/26/14 and you  
could win a copy of the award-  
winning *little man* DVD from  
PreemieWorld!**

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*Parents & Professionals:*  
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today @ [www.PreemieWorld.com](http://www.PreemieWorld.com)



## NICU Art Crib Cards

### The Details:

**By:**  
EVERYtinyTHING

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



EVERYtinyTHING

Infant incubators are often decorated with family photos to blankets to sibling drawings. But not every parent is able to pull something together. Enter EVERYtinyTHING with the perfect baby shower gift.

EVERYtinyTHING has come up with a set of classy and NICU friendly art work. Full of inspirational sayings and premie-friendly graphics, each two-sided piece will bring a smile to both NICU staffer and parent. With solid lamination, they are up to the task for regular sanitizing.

**COOL:** One new "PremieWorld for Pros" subscriber working at a NICU will be selected for a chance to win a set of these NICU Art Crib Cards.

## After the NICU:

*After World Prematurity Day/Month*

*With World Prematurity Day behind us, parents of premies can collectively attest to the following:*

- Prematurity does not end with the NICU. It is lifelong and one that pops up time and again.
- It is normal to be concerned about the "other shoe dropping."
- Never accept no for an answer when advocating for your child. Get assistance, get facts behind you and *do not give up*. Be that *squeaky wheel* and *keep pushing*. You are an expert!
- Prematurity is not about a day or a month each year, but a lifetime. And society has a lot more work to do to help these children and their families.

## Premie Support Online

### On the Premie Support Forum on INSPIRE:

Connect with *over 20,000 other parents of premies 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*.

Thankful for Fellow Premie Parents – *Open Discussion*

Cannot Gain Weight – *at Home (Years 1-5)*

Anyone else seeing concerning behavioral issues with their premie? – *at Home (Years 1-5)*

Premie Speech Delay– *Premie Tips*

Premies ARE Rockstars! – *in Open Discussion*

### On PremieWorld's Twitter Page:

LOVE: Thankfulness – Premie Parent Style by Author Jen Degl – <http://ow.ly/EZAWs>

### On PremieWorld's Facebook Page:

PREEMIE UPDATE: Margarita – <http://bit.ly/PremieMargarita>

### On PremieWorld's LinkedIN Group:

GREAT READ: The Micro-Premie Experience – <http://ow.ly/Ekxk7>

STUDY: Early, Small Babies May Be More Prone to Adult Hip Trouble – <http://ow.ly/EhR1E>

## 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

*Tools and Resources  
for the Premie Community*



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### Premie Rattles

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## PETITION: *New RSV Petition Citing Research Discrepancies*

*With the recent stressors surrounding the new Synagis (palivizumab) guidelines, professionals have launched a new petition to the AAP citing research discrepancies. Authors Ram Yogev, Lenny Krilov, Lenny Weiner and Jaime Fergie created this under the name Physicans and Other Professionals Urging Logical Approach to RSV (POPULAR). We asked Ram Yogev for a summary of this petition.*

### *What is the essence of this petition?*

As a group of healthcare professionals involved in the RSV prevention trials and caring for these infants, we believe that the most recent recommendations from the COID for increasing restriction of palivizumab use

in prematures (i.e. only for prematures with gestational age <29 weeks) merit further discussion and analysis as the data used to develop the recommendations seem to be incomplete or misinterpreted. Discussions with the AAP have been unsuccessful. We also found at least one agency that supposedly supported the new recommendations but in reality did not. Many of our healthcare colleagues support our request to re-evaluate the recommendations.

### *How can people find the petition?*

At <http://bit.ly/popularRSV> - if you sign it, please make sure to pass it on to others online or by email.