



# Preemie Family

## Preemie Life

### Avery Ruth, Lily Anne & Zoe Rose Sorrells



Photo Credit: Sorrells Family

**Gestational Age at Birth:**  
25 weeks, 5 days

**Weight & Time in NICU:**

*Avery:* 1 lb., 4 oz.; 120 days

*Lily:* 1 lb., 6 oz.; 120 days

*Zoe:* 1 lb., 10 oz.; 291 days

**Proudest Moment (NICU):**

*Avery:* She was one month old when I was told I could hold her. I felt like a real mom, holding her baby.

*Lily:* When I got to help give Lily a sponge bath. She hated it, but I loved every second!

*Zoe:* Zoe was on the oscillator and conventional vent for 14 weeks. I walked into her room and did a double take when I heard the gurgling of the bubble CPAP instead of the hum of the vent.

*Coming Soon:* Check [www.PreemieWorld.com](http://www.PreemieWorld.com) to read about the Sorrells' triplets once home.

### Parent Tip:

*Never be afraid to ask a question and trust your instinct. God gave us intuition for a reason. Trust it no matter what.*

## Advocate: RSV Brief + Tips

The acronym RSV strikes fear into the hearts of preemie parents and professionals alike every cold/flu season. **The Institute for Patient Access** recently issued a policy brief on *Protecting Premature Infants from Infectious Diseases*. To read the brief go here: <http://preemie.us/RSVbrief> and PreemieWorld's tip sheet for keeping preemies #RSVfree is here: <http://bit.ly/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 another preemie symbol:**

*Preemie Dads are Powerful.* "Dads often feel neglected in the NICU environment, but our symbol says it all. The research is clear that fathers are a crucial part of

their baby's life in the NICU and at home," notes PreemieWorld's **Deb Discenza**. "I hope NICU Nurses will print out this graphic and put it on incubators worldwide to remind Dads of their special powers."

*Download it here & share with #preemiedads:*  
<http://preemie.us/PreemieDad>

## To Do List



**CONGRATS:** Pete Khuangsavanh is our winner for the *little man* DVD and our winner of the Alison Schleef book *A Giraffe Called Neo* is Twitter user [@MommyinSports](https://twitter.com/MommyinSports).



**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!**

*Support for Infant Loss*  
Preemies Today  
December 3, 2015  
McLean, VA  
[www.PreemiesToday.com](http://www.PreemiesToday.com)

*Preemie Playgroup*  
December 10, 2015  
Chantilly, VA  
[www.PreemiesToday.com](http://www.PreemiesToday.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*

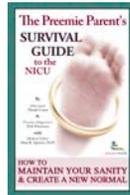
## FREE: Preemies Dads are Powerful

## 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.

### Questions to Ask the Doctor:

- What is being done by the team to protect my baby from RSV in the NICU?
- What should I do to protect my baby in the NICU?
- What should I do to protect my baby at home?
- What medications are available to help?



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: Nathan C. Splant Foundation

*Out of the Splant family's personal journey with premature birth, they formed the **Nathan C. Splant Foundation** to help other families.*

**Established:** 2007

**Outreach:** NW Indiana and the surrounding Chicagoland area

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

**Focus:** Providing parents with needed resources to help with the every day life changes that come with babies born too early and too small.

**Programs:** Grant giving, Racing for Babies event, Riding for Babies event and Prematurity Awareness Campaign.

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



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

**"Like" our FB page  
from 12/1/15 to 12/22/15 and you  
could win a copy of the award-  
winning *little man* DVD from  
PreemieWorld!**

<http://bit.ly/FBPreemie>

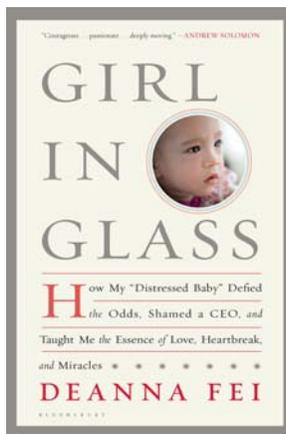
Parents & Professionals:  
Subscribe to our FREE newsletters  
today @ [www.PreemieWorld.com](http://www.PreemieWorld.com)

**The Details:**

**By:**  
Deanna Fei

**Available at:**  
[www.Amazon.com](http://www.Amazon.com)

**Cost:**  
\$26.00 USD

**Book: Girl in Glass**

Premie parents can relate to the world upending itself when a baby is born premature. But imagine ending up in the media spotlight over a CEO's crass comments about to your "distressed baby's" medical bills being the reason for AOL's employee benefits restructuring. Fei tells her family's side of the story from traumatic birth to NICU stay to homecoming and a CEO's poor excuse for the challenged bottom line. Every preemie parent as well as every special needs person challenged in the workplace will cheer aloud while reading this book.

*We're giving away this book!*  
*Follow us on Twitter by 12/22/15 to enter: <http://bit.ly/PremieTweets>*

**After the NICU:  
Playing the "Premie Card"**

*There are scenarios outside of the NICU where using the "Premie Card" totally applies. Consider pulling it out in these situations:*

- A well-meaning person at the doctor's office wants to get up close and personal with your infant . . . during RSV season.
- You see a friend at the grocery store as you are about to enter with your infant. The friend coos at your child and gets closer, cigarette in hand.
- The IEP team at school thinks your child is doing "great now" and wants to downgrade to a 504 plan thereby lessening services.

*What's your #preemiec card moment?*

**Premie Support Online****On the Premie Support Forum on INSPIRE:**

Connect with *almost 24,000 parents of preemies online for free* 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*.

RSV? Seizures? Apnea? – *In the NICU/PICU*

Alternative to Pediasure – *(Premies with Feeding Issues)*

Hello! Premie Born at 32 Weeks! – *Intro Your Very Important Premie (VIP)*

IVH Grade 4 – *At Home (Years 1-5)*

Micropremie Doing Good – *At School (Years 6-12)*

**On PremieWorld's Twitter Page:**

PremieWorld Supports Recommendations for Psychosocial Support of NICU Parents

**On PremieWorld's Facebook Page:**

Thoughts, Premie Parents? Challenges for Extreme Premies Can Last into Teens

**On PremieWorld's LinkedIN Group:**

STUDY: Probiotics May Not Shield 'Premies' From Serious Illness

STUDY: Vibration-based therapy can successfully treat apnea events in preterm infants

## 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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## Tip: Holiday Gifts for the Differently-Abled Child

*The gift-giving season is upon us and that can send many preemie parents running for shelter when trying to give out suggestions to well-meaning relatives. If your child has delays or is differently-abled, Deb Discenza has some suggestions for toys and more:*

**AblePlay from the National Lekotek Center ([www.ableplay.org](http://www.ableplay.org)):** This non-profit provides numerous services to help improve the lives of children with special needs through the utilization of toys and play. They offer play sessions, a toy lending library and more at numerous sites throughout the United States. And just in time for this holiday season, the organization has **AblePlay**, a site devoted to

rating and reviewing toys across the developmental abilities of a child. This site is an all-around winner and a must-have for the holiday shopping season.

**Toys 'R' Us Differently-Abled Toy Guide (<http://preemie.us/TRUdiffabled>):** Though focused on Toys 'R' Us stock, the listing helps families navigate potential toy offerings suitable for their child.

*What cool gifts did you find for your child? Tell us via Facebook/Twitter using #ablepreemie*