



# Preemie Family

## Preemie Life

### *Charlie Allene Wood*



Photo Credit: Kali Adams

**Gestational Age at Birth:**  
26 weeks

**Weight:**  
790 grams (~ 1 lb. 12 oz.)

**Time In NICU:**  
89 days

**Proudest Moment (NICU):**  
I am told she screamed the entire way down to the NICU after the delivery.

#### **Parent Tip:**

*Softly read, sing, and talk to your baby. Even if you can't hold him or her just yet.*

#### Coming Soon:

*Check [www.PreemieWorld.com](http://www.PreemieWorld.com) to read how Charlie is doing now.*

## Advocate: World Autism Day

Preemies are at high-risk for a variety of developmental disabilities and parents need resources to be solid advocates. With that in mind April 2, 2015 is **Autism Awareness Day**. Learn more about this special day as well as month as well as through our friends at **Autism Speaks**: <http://preemie.us/ASDday>

## To Do List



**CONGRATS:** *Sunny Dean* has won the *little man* DVD and *@woodra* is our winner for Andy Male's book, *Go Premies!*



**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!**

*Tournament of Hope*  
Lily's Hope Foundation  
April 17, 2015  
Coopersburg, PA  
[www.lilyshopefoundation.org](http://www.lilyshopefoundation.org)

*Celebration of Miracles*  
The Tiny Miracles Foundation  
April 24, 2015  
Darien, CT  
[www.ttmf.org](http://www.ttmf.org)

*Have an event you want to share with our community?*

*Contact us at:*

*Tools and Resources for the Preemie Community*

## Preemie Resource: Health Record

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 "Health Record." "Going from appointment to appointment can leave you frazzled on paperwork," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "We created this

freebie to help caregivers save time on form completion and more." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce.

**Download it here:** <http://preemie.us/preemiehealth> and **check others here:** <http://bit.ly/PreemieFreebies>

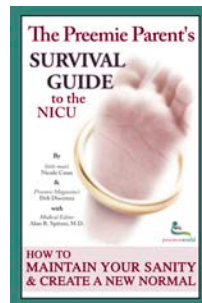
## Term: Therapy

**Therapy:** Anything being done to treat your baby for any condition. Most commonly, therapy is used to help stimulate your baby's body to heal itself and catch-up in developmental milestones. You may find that your baby's NICU has therapists on staff to help with this and/or that your baby will be prescribed a variety of therapies to receive



once home. All of it is helpful and will make a difference for your baby down the road.

**Some Types of Therapy:** Occupational Therapy, Physical Therapy, Speech Therapy, Vision Therapy, Music Therapy, Feeding Specialists.



*This excerpt is from*  
**The Premie Parent's Guide to Survival in the NICU** on sale at  
[www.PremieWorld.com](http://www.PremieWorld.com)  
 \*\*We do bulk orders for hospitals\*\*  
[connect@preemieworld.com](mailto:connect@preemieworld.com)

## Support: His Middle Name



*With the very early birth of their son, the Lubins "didn't have a leg to stand on" and created their own community.*

**Year Established:** 2011

**Outreach:** International

**Web:** [www.hismiddlename.com](http://www.hismiddlename.com)

**Background:** The Lubins started the organization organically from friends and family locally and then grew from there with a strong online presence.

**Programs:** The family is very connected to the March of Dimes with speaking engagements, a March for Babies walking team and more:  
<http://preemie.us/HisMiddleName>

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



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

**"Like" our FB page from 3/31/15 to 4/26/15 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.PremieWorld.com](http://www.PremieWorld.com)



## Book: Bentley's Premie Blessing

## After the NICU: The Premie Binder

### The Details:

#### **Written By:**

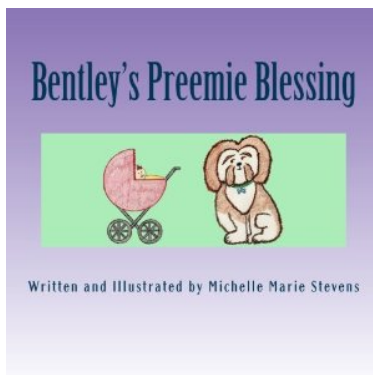
Michelle Marie Stevens

#### **Illustrated By:**

Michelle Marie Stevens

#### **Website:**

[www.premie blessings.com](http://www.premie blessings.com)



*Bentley's Premie Blessing* is the perfect gift for the new preemie family in the NICU, especially ones with siblings at home trying to adjust to the radical change in their routine.

Written from a family pet dog's perspective, the narrative is perfect for reading to a baby as well as to a new sibling trying to understand why Mom and/or Dad are not at home as usual.

With clear and friendly illustrations, this is a book that will also be a welcome addition to the baby's book library at home.

**COOL:** We're giving away a copy of this very book to one new PremieWorld Twitter follower 3/31/15- 4/26/15 - [www.twitter.com/premie world](http://www.twitter.com/premie world)

*Going to an appointment? Save time and effort by creating a "Premie Binder" ahead of time. Include:*

- Discharge Paperwork
- Completed "Health Record" (see our "freebie" on p.1 free to download from our website).
- Pediatrician paperwork regarding growth statistics over time.
- Specialist paperwork regarding instructions for tests, treatments, as well as test results.
- Information for your local pharmacy and your mail order pharmacy.
- Your child's insurance card and other related paperwork.
- Therapy evaluations and reports
- Education plans for childcare, educational settings and more.

## Premie Support Online

### On the Premie Support Forum on INSPIRE:

Connect with *over 21,000 other 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*.

Bacterial Meningitis – *In the NICU/PICU*

Premie Plasticity – *Premie Hope*

Did Speech Therapy Services Help Your IUGR Toddler Eat Better? – *At home (years 1-5)*

Global Developmental Delay – *At home (years 1-5)*

Breastfeeding or Exclusive Pumping for 27 Weeker- *Premie Tips*

### On PremieWorld's Twitter Page:

Tough Topics in the #premie world: What do you think of this article on #preemies #bigbiz and #donormilk in the NICU? – <http://ow.ly/KTTtu>

### On PremieWorld's Facebook Page:

SPECIAL: Premie Update on Sam, a 26 weeker – <http://premie.us/PremieSam>

To Delay or Not Delay – That is the Question – Premies Being Held Back? <http://ow.ly/KphnQ>

### On PremieWorld's LinkedIN Group:

Delayed-Onset PTSD Can Happen to Premie Parents and Mothers Who Experienced a Traumatic Birth

## 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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## Tips: Premie Parents are Powerful (Part I)

*They say hindsight is 20/20 and that is so true. Deb Discenza, Publisher at PremieWorld, gives insight into what she believes Premie Parents in the NICU right now should know for sure:*

*Know that a premie parent's love is medicine.* After having my daughter at 30-weeks gestation and later staring into her incubator in the NICU, I felt so lost, so useless as a parent. Nothing felt natural to me in those first few days and weeks. What did I know? I figured the medical staff knew more than I did. I wondered if it would matter at all if I was by her side in the NICU during the stay. What I know now is that the gentle lullabies I sang to my daughter while holding her,

the Kangaroo Care sessions we did, the books I read to her – they *all* were a form of medicine as well. I helped to soothe her, as did my husband. Relieving her stress in the NICU chaos gave her the ability to rest and to sleep, which in turn helped her to grow and to thrive. That “medicine” continued at home where we worked through numerous developmental delays and took on a lot of therapies over the years. Yet it all came down to a moment this past week when my thriving 11.5 year old said, “Mom, thank you for all you do for me. You do a lot and I love you.” Love is the most powerful medicine of all.

**#preemieparentpower**