



# Preemie Family

## Preemie Life

### *Derrick Henry & Dominick Merlyn Hanneman*



*Dominick (left) and Derrick (right)  
Photo Credit: Cari Hanneman*

**Gest. Age:**  
33 weeks and 5 days

**Weight:**  
Derrick - 5 lbs. 12 oz.  
Dominick - 3 lbs. 11 oz.

**Time In NICU:**  
Derrick went home after 30 days.  
Dominick passed away 22 days after birth due to Necrotizing Enterocolitis (NEC).

**Proudest Moment (NICU):**  
*Derrick:* Hearing he beat NEC and being able to Kangaroo him the next day.  
*Dominick:* Getting to kangaroo him and seeing him off oxygen and IV's before he got sick.

*Coming Soon:* Check [www.PreemieWorld.com](http://www.PreemieWorld.com) for Derrick and Dominick's journey.

#### Parent Tip:

*Do NOT be scared to ask questions. Dominick had a very smelly diaper that didn't seem normal and I was told otherwise. Do not be scared to ask various nurses their opinions or to ask a doctor for a second opinion. Do not settle and assume that because they are doctors that they have all of the right answers.*

## 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, 2014 is **Autism Awareness Day**. Learn more about this special day as well as month as well as through our friends at **Autism Speaks**: <http://bit.ly/1cVoKDK>

## Preemie Resource: <3 Preemies

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 a special logo, <3 Preemies.** "We want parents to celebrate their preemies," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "This logo will give them the chance to do that and to connect with

other preemie parents in a very special way. Tweet it, FB it, whatever you want. Love it and enjoy it!"

Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce.

**Download it here now:** <http://bit.ly/HeartPreemies>  
**and check out more like this here:**  
<http://bit.ly/PreemieFreebies>

## To Do List



**CONGRATS:** Kellie Hunt is the winner of the *little man* DVD and Crista Hopp has won a copy of *From Hope to Joy* by Jennifer Degl.



**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!**

*2014 Playdate with Purpose Challenge*  
Little Giraffe Foundation  
April, 2014  
<http://bit.ly/PreemiePlay>

*Young Child Conference & Expo*  
Los Ninos Services  
April 23-25, 2014  
New York, NY  
<http://www.YoungChildExpo.com>

Have an event to share? Email us:  
[connect@preemieworld.com](mailto:connect@preemieworld.com)

*Tools and Resources  
for the Preemie Community*

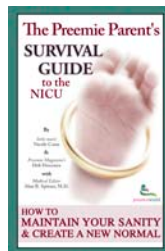
## Term: Ventilator (Vent)

### **Ventilator (Vent):**

The machine that breathes for your baby, the ventilator is the reason that so many premature babies can now actually survive. Premies born before 28 weeks will more than likely be put on a ventilator. Depending on medical challenges your baby has, they may be put on the ventilator at any gestational age if needed to help the baby breathe.



There are a wide variety of specialized ventilators with a veritable menagerie of settings to support the most critically damaged and underdeveloped lungs. Popular vent terms include: High Frequency Jet, Oscillator Vents, Intermittent Mandatory Ventilation (IMV) and Liquid Ventilation.



*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:

Prematurforeningen Mirakel



**Year Established:** 2013

**Web:** [www.prematurmirakel.se](http://www.prematurmirakel.se)

**Outreach:** National (Sweden)

**Background:** Pernilla Brown had twin girls at 28 weeks and lost one, Anna-Charlotta Hellner had twin boys at 25 weeks and one has cerebral palsy and other challenges. Together they work to make a difference for all preemie families before and after the hospital stay and also families that have lost a baby.

**Programs:** Annual holiday gifts to mothers on bed rest as well as weekly massages and more; funerals and clothing at no charge for babies that have passed away in hospitals in Gothenburg; Skype courses.

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



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

**"Like" our FB page  
 from 4/1/14 to 4/24/14  
 and you could win a copy of the  
 award-winning *little man* DVD  
 from PreemieWorld!**

<http://bit.ly/FBPreemie>

*Parents & Professionals:*  
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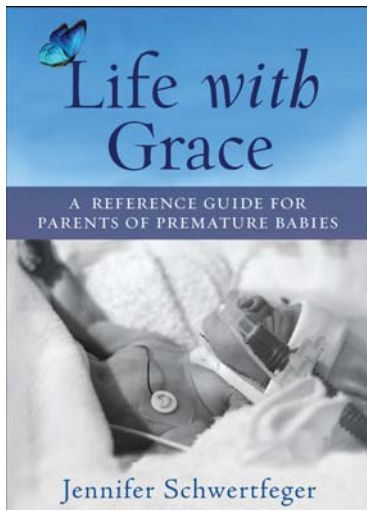


## BOOK: Life with Grace

### The Details:

**By:**  
Jennifer Schwertfeger

**Website:**  
<http://lifewithgracebook.com>



### The Genius:

With great honesty, author Jennifer Schwertfeger takes us through her 24-weeker Grace's miraculous 9-month NICU journey from troublesome pregnancy to birth to NICU to home and into the school years. This book is helpful to parents of premies at any stage in the journey as the author provides meaningful tips and definitions throughout. It is also a fabulous book for professionals to gain perspective on the preemie parent experience when working with a child with complex medical needs and a long-term NICU/PICU stay.

*COOL: 2 people could win a copy of this book! For your chance to win sign up for Premie Family (<http://bit.ly/preemie1>) or Premie Professional at <http://bit.ly/preemie2> from 4/1/14 - 4/24/14.*

## After the NICU: Resources for Trach Babies

*Having a preemie is isolating post-NICU, but it can be even moreso with a baby on medical equipment. Below are resources for families with a baby on a tracheostomy at home:*

- *Life with Grace* by Jennifer Schwertfeger  
<http://lifewithgracebook.com>
- Moms of Trach Babies  
(<http://bit.ly/TrachBabies>)
- Aaron's Tracheostomy Page  
([www.tracheostomy.com](http://www.tracheostomy.com))
- Global Tracheostomy Collaborative  
([www.globaltrach.org](http://www.globaltrach.org))
- Tracheostomies: The Complete Guide (<http://bit.ly/trachguide>)

## Premie Support Online

### On the Premie Support Forum on INSPIRE:

Want to connect with *over 18,000 other parents of premies online?* Check out the [www.Inspire.com](http://www.Inspire.com) **Premie Support forum**. It is the largest and most active forum online and *moderated by PremieWorld's own Deb Discenza*. The "rooms" range from "In the NICU" to "Going Home and Family" to "Growing Up and Education" along with more in-depth areas such as "Premies with CP," "Premies with Feeding Issues," and "Premie Tips." Check out some of our more recent topics:

"Micro-Premie Son Now Two Years Old"

"Researching a Feeding Program for 30-weeker Now 10-Year Old"

### On PremieWorld's Twitter Page:

"STUDY: Preterm Birth May Raise Child's Asthma Risk - <http://ow.ly/uPZQ1>"

### On PremieWorld's Facebook Page:

"What Do You Think of This Study/ Article? Should a Child's Gestation Be Put on their Record? - <http://ow.ly/uz7ql>"

### On PremieWorld's LinkedIN Group:

"Research - Rupture of Membranes"

"PREEMIE UPDATE for MARCH: Sofia - <http://bit.ly/PremieSofia>"

## 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: Top 3 Tips for Preparing & Going Home On a Trach

Jennifer Schwertfeger, *author of the new book, Life with Grace* ([www.lifewithgracebook.com](http://www.lifewithgracebook.com)), has some tips for parents considering a tracheostomy:

**1. Hindsight is 20/20.** Although we agonized over the decision of getting our daughter the trach, we could see it was the best decision the moment she came back from surgery. She was smiling, and breathing more comfortably. After seeing how happy Grace was, it was obvious that we had made a great decision.

**2. Ask tons of questions at the hospital.** Work with your social worker, ENT specialists, take a

CPR class, ask if they have a trach doll for practice. After your child goes through the trach surgery, make sure you stay overnight taking care of your child alone . . . with nurses there nearby to guide you. You will want to feel comfortable enough on your own, *before* going home.

**3. Preparation is Key at Home.** Have your home inspected before bringing your child home and a back-up plan for all emergencies in the home. And make sure you have a great connection with a home equipment company/supplier for all of your child's medical needs.