



# Preemie Family

## Preemie Life

### *Dylan Eli*



Photo Credit: L2 Family

**Gest. Age:**  
29 weeks

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

**Time In NICU:**  
101 Days

**Proudest Moment (NICU):**  
Breast-feeding . . . sounds simple enough but starting off with so many obstacles and then succeeding, it was amazing. He is still nursing at nearly 2 years old!

Coming Soon:  
Check [www.PreemieWorld.com](http://www.PreemieWorld.com) for Dylan's journey from preemie to now!

#### **Parent Tip:**

*Be there as much as possible, get to know your nurses AND doctors. Be part of the planning (especially if they do rounds). Do as much care as you can while visiting so you feel comfortable with it by the time you get home. And don't be afraid to ask . . . ANYTHING.*

## Advocate: Feeding Tube Awareness Week

Many preemies have a feeding tube during the NICU stay as they work toward eating orally. And many also go home on a feeding tube. **February 9-14 2014 is Feeding Tube Awareness Week** brought to you by the **Feeding Tube Awareness Foundation**. Learn more, and get great resources and inspiration by going to their website at: <http://www.feedingtubeawareness.com>

## Preemie Resource: Feeding Tube Awareness Foundation

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 the brochure for the "Feeding Tube Awareness Foundation."** "Feeding tubes are a way to feed our children," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "Yet parents of preemies are

stressed, isolated and have a ton of questions. This is where the FTAF works its magic connecting parents to one another and to resources." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. **Download it here now:** <http://bit.ly/TubeAware> **and check out more like this here:** <http://bit.ly/PreemieFreebies>

## To Do List



**CONGRATS:** [Jessica Guthrie of Eli's Hope](#) is the winner of the "little man" DVD; and [Maii Thompson](#) is the winner the book, *My Bubble Wrap Girl*.



**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!

**Fragile Beginnings Phone Group Call**  
JF&CS Boston  
First Tuesday of Each Month  
National Call  
<http://bit.ly/JFCScall>

**Power to Grow**  
Graham's Foundation  
February 20, 2014  
Toledo, OH  
<http://bit.ly/GFToledo>

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

*Tools and Resources  
for the Preemie Community*

## Term: Nasogastric Tube (NGT)

### **Nasogastric Tube (NGT):**

Made of soft plastic so that it doesn't hurt the baby, a tube that goes through the nose and passes through the esophagus into the stomach. The NG tube is used to take things out of the stomach and deliver food and medicine into the stomach. It is also used to check residuals. While it's not the greatest thing to look at and a bit discomfiting to the infant, they quickly



become used to it and it's very helpful in keeping your baby well nourished and hydrated.

### **Questions to Ask the Doctor:**

1. How long will my baby need this feeding tube?
2. Is there a medical issue relating to my child's need for a feeding tube?
3. What is being done by the team to help my baby learn to feed orally?
4. Are there feeding therapies the team is doing or that I can be doing to stimulate my child?
5. Is there anything else I should know about this?

*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 - please contact us at [connect@premieworld.com](mailto:connect@premieworld.com)*

## Support: Prematuridade



**Year Established:** April 2011

**Web:** [Prematuridade.com](http://Prematuridade.com)

**Outreach:** International

**Background:** Denise Centeno worked for 5 years as a nutritionist in her local NICU in Porto Alegre, south of Brazil. She quickly realized the importance and the lack of finding reliable information and connections in Brazil. And so [Prematuridade.com](http://Prematuridade.com) was born.

**Programs:** Information and resources for families, support program, participant in World Prematurity Day activities, partnered with EFCNI. Check the website for more info.

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



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

**"Like" our FB page  
from 2/3/14 to 2/26/14  
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.PremieWorld.com](http://www.PremieWorld.com)*



## Premie-Friendly Rattles

### The Details:

**By:**  
Magical Innovations

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



### The Genius:

Premie parents often liken their tiny infants to “warriors.” And what warrior couldn’t use a little strength training? Enter the Baby Barbells aka “Premie Rattles” by Magical Innovations.

Developed by a Physical Therapist, this colorful product weighs less than an ounce, is developmentally stimulating and is balanced so as to not twist the baby’s wrist. And *bonus*: it is dishwasher safe (top rack).

This is a must-have for NICUs, therapists and parents of premies and full-term babies.

*COOL: You could win 5 packages of the “4-pack” rattles and a 2-pack as well! Enter for your chance to win by signing up for Premie Family at <http://bit.ly/preemie1> or Premie Professional at <http://bit.ly/preemie2> from 2/3/14 - 2/26/14.*

## After the NICU: Feeding Tubes & People

*Premie Parents that are working with a feeding tube at home often encounter challenges with family and friends and others who don’t understand feeding challenges. Here are some tips to educating others:*

- Be clear and matter of fact that this is just the way your child is able to get nutrition while you work toward oral feedings.
- Give the feeding tube a fun nickname to lighten things.
- Keep your own emotions positive toward feeding tubes and others will emulate your behavior.
- Realize that you need people around you who support you. Let go of those who do not.

## Premie Support Online

### On the Premie Support Forum on INSPIRE:

Want to connect with *over 17,000 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:

“Severe Bottle Aversion”

“Delays and Insensitive Remarks”

“Need Advice”

### On PremieWorld’s Twitter Page:

“SMART: Physical Therapy Could Help with Premie Development – <http://ow.ly/sYUUC>”

### On PremieWorld’s Facebook Page:

“RESEARCH: Growth Factor Heals the Damage to Premie’s Brain – In Mice – <http://ow.ly/sYUst>”

### On PremieWorld’s LinkedIN Group:

“PremieWorld Founder Highlighted in Parenting Special Needs Magazine – <http://bit.ly/PSN4PW>”

“COOL: Special Update on the Resilient Premie Adelynn! – <http://bit.ly/PremieAdelynn>”

## 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*



Prolonged, effective, safe, and hands-free Kangaroo Care sessions. Guaranteed.



**kangaroozak.**



[www.nurturedbydesign.com](http://www.nurturedbydesign.com)



### Preemie Rattles

Developed by a Physical Therapist

[www.magicalinnovations.com](http://www.magicalinnovations.com)

(407) 230-4491



NICU Hope Beads



COMMEMORATE & SHARE

Your NICU journey through jewelry...



[facebook.com/NICUHopeBeads](http://facebook.com/NICUHopeBeads) | 979.635.0825

Interested in advertising? Contact us at [connect@preemieworld.com](mailto:connect@preemieworld.com)

## True or False: Myths About Feeding Tubes

*Premies in the NICU with serious feeding issues can often lead to the requirement of a feeding tube as they approach their discharge date. Unprepared, parents are full of questions and concerns about the long-term. Our friends at the Feeding Tube Awareness Foundation help us to dispel common myths.*

*You can't eat by mouth when you have a feeding tube.*  
**False.** Tube feeding can supplement what is eaten by mouth. As long as your child is allowed by her doctor to eat and drink, she can continue to do so after receiving a feeding tube. Oral eating should be encouraged as much as possible to maintain or develop oral eating skills.

*Tube feeding is forever.*

**It depends.** Some children have medical conditions that will require them to have feeding tubes their whole lives. But for many children, tube feeding is temporary. Children are able to wean off their feeding tubes once they are no longer medically necessary. It is often difficult to estimate how long a feeding tube will be needed, especially if the child's medical condition is not yet fully understood.



Visit our friends at the Feeding Tube Awareness Foundation at: [www.feedingtubeawareness.com](http://www.feedingtubeawareness.com)