



Preemie Family

Preemie Life

Alejandro de Jesus Fernandez-Khonyongwa



Photo Credit: Jesus Fernandez-Munoz

Gestational Age:

24 weeks

Weight:

645 grams

Days in the NICU:

5.5 months + re-hospitalized for 6 weeks for retinal surgery and RSV

Proudest Moment in the NICU:

Holding Alejandro for the first time and finally feeling like a mother – his mother. Priceless!

Coming Soon!:

Check www.PreemieWorld.com for an update on Alejandro now!

Parent Tip:

Trust your gut – if something doesn't sound or look right, it probably isn't. Speak up and use your voice which are the first steps towards a lifelong journey of advocacy for you and your child.

Advocate: World Braille Day

The 4th of January 2013 is World Braille Day due to it being the birthday of Louis Braille who invented this code in 1821. In our community of preemie parents we have many families affected by blindness due to Retinopathy of Prematurity (ROP). Braille is used worldwide. To learn more about the individual behind it go here to find out more: <http://bit.ly/BrailleDay>

Preemie Resource: Positive Preemie Breastfeeding Tips

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 "Positive Preemie Breastfeeding Tips."** "The biggest frustration I hear about from moms is regarding breastfeeding," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "The NICU is so isolating

and moms need to know that it important to ask for help with this and to stick up for themselves and their baby." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. **So go download it here now:** <http://bit.ly/PreemieBF> **And check out more like this here:** <http://bit.ly/PreemieFreebies>

To Do List



Wishing all families a Happy New Year full of hope and peaceful new beginnings. May you and your family thrive in 2013!



CONGRATS to LAURA EFINGER for winning the latest contest. She will receive the book, *Ryan and the Green Monsters*



Download PreemieWorld's FREE tools <http://bit.ly/PreemieFreebies> to use and to pass onto others.



MARK YOUR CALENDAR!

The Power to Grow
Graham's Foundation
January 18, 2013
New York, NY
<http://bit.ly/Power2GrowNY>

The Power to Grow
Graham's Foundation
January 31, 2013
Toledo, OH
<http://bit.ly/Power2GrowOH>

Have an event to share? Email us with the name, date, location and website link at connect@preemie-world.com

*Tools and Resources
for the Preemie Community*

Term: Occupational Therapist

Support: TTMF

Occupational Therapist (OT):

A specialist trained to deal with the myriad of stages of development from a muscular and neurological standpoint. They will also analyze the effects of being born prematurely on the development of your baby's gross and fine motor skills.

Questions to ask the OT during the NICU stay or at home during Early Intervention sessions and beyond:

- At this time, how is my child's muscle tone?
- At this time, is there anything that concerns you about my child's overall development?
- Is there anything that I can do to help my child's needs in this area?
- Is there anything else I should know at this point or in the future to help my baby's development?



www.ttmf.org

Year Established: 2004

Focus: Fairfield County, Connecticut

Web: www.ttmf.org

Note: All volunteers have experienced the birth of a premature baby. Most materials and programs are bilingual in English and Spanish.

Programs: In-hospital/community-based parent mentoring, in-hospital family resource rooms and libraries, welcome and home care packages, bereavement support and resource supply bag, emergency financial and equipment assistance, NICU enhancement program, online community and after NICU resources.



*This excerpt is from **The Premie Parent's Guide to Survival to the NICU** on sale at www.PremieWorld.com*

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



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

"Like" our page from 1/3/13 to 1/28/13 and you could win a copy of the award-winning *little man* DVD from PreemieWorld!

PreemieWorld's page is here:

<http://bit.ly/FBPreemie>

Preemie Genius: It's A Preemie Thing

The Details:

Name: It's a Preemie Thing

By: Julie Howard

Est: 2010

The Website:

www.ItsAPreemieThing.com



The Focus:

Shirts for the entire preemie community of babies, toddlers, children and their adult counterparts.

The Genius:

Sassy sayings that help to lighten the preemie experience and bring a community of NICU families together.

Sample Sayings: "02 . . . it's not just for old people," or "Got sanitizer?," or "NICU nurses hold the future in the palm of their hands."

COOL: **Subscribe to Preemie Family or Preemie Professional 1/1/- 1/28/13 and you could win a "foot-prints" t-shirt (size preemie to 6T) for your child.**



After the NICU: Handling Winter Appointments

With RSV terrorizing preemie parents throughout the winter, it makes those all-important doctor and specialist appointments a necessary evil. How does a parent of a preemie cope?

Get A Room! Upon check-in ask if you could be put into an exam room immediately.

Schedule Next Appointments from Home. Avoid getting caught up in the appointment set-up line by leaving directly and calling in later to set up the next visit.

Paying the Co-Pay By Befriending the Office Manager. See if the Office Manager could assist by grabbing your payment from your exam room and maybe he/she will also consider setting up the next appointment too!

Preemie Support Online

On the Preemie Support Forum on INSPIRE:

Want to connect with over 13,000 other parents of preemies online? Check out the www.Inspire.com Preemie Support forum. It is the largest and most active forum online and *moderated by PreemieWorld's own Deb Discenza*. The forum has "rooms" that range from "In the NICU" to "Going Home and Family" to "Growing Up and Education" and more. Check out some of our topics:

"26 Week Preterm Baby"

"Growth"

"Help - Go Home with a Feeding Tube?"

On PreemieWorld's Twitter Page:

"Keeping Marriage Strong: A Preemie Mom Copes Just After the NICU - <http://ow.ly/g6Z9S> "

"PREEMIE REALITY: The Struggles of RSV Season - <http://ow.ly/gd9bs> "

On PreemieWorld's Facebook Page:

"COOL: Deb's 'Preemie Pulse' guest post on the 'Preemie Coalition' blog - <http://ow.ly/fYNXf>

On PreemieWorld's LinkedIN Group:

"PREEMIE ARTICLE: One Mom's Journey from One of our www.Inspire.com Preemie Support forum Moms - <http://ow.ly/fZl4r> "

Get "Social" With Us!



www.PremieWorld.com
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
- Little Man the Movie

*Tools and Resources
for the Premie Community*




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Q&A w/ Deb Discenza of PremieWorld: *Life As a Premie Parent*

Q: In your experience, what are the biggest obstacles for parents in the NICU?

A: Three obstacles: 1. Connecting with their child, 2. Working with the staff and 3. Trying to handle the rest of life during the chaos.

Q: What are the biggest obstacles after the NICU?

A: Three obstacles *just to begin with*: 1. Trying protect their child from not only the public but also during doctor's appointments and curiosity-seeking friends and family members, 2. Juggling all of the follow-up appointments, developmental exercises, medical equipment vendors and more along with the "normal" newborn matters, and 3. Longterm

concerns for their child not only medically but developmentally and educationally.

Q: What is the best piece of advice for family and friends in helping the premie family?

A: They need to realize that the parents have been through a tough time in the NICU and that translates over into that baby's health and developmental progress going forward out of the NICU. Listen to what the parents have to say, empathize, and follow their requests. They have been trained by the NICU.

See PremieWorld at www.PremieWorld.com