

# Preemie Family

## Preemie Life

#### Isaac Nathaniel Lalunio



Photo Credit: Lalunio Family

**Gestational Age at Birth:** 25 weeks

Weight at Birth: 1lb. 4oz.

**Time in the NICU:** 10 months and 22 days

Proudest Moment (NICU): I got to do Kangaroo Care with Isaac and saw him look up at me.

### Parent Tip:

Be involved in your child's day-to-day care and ask lots of questions.

#### Blog:

www.isaacsjourneyblog.net

<u>Coming Soon:</u> Check <u>www.PreemieWorld.com</u> to learn more about Isaac's journey.

## Advocate: Cerebral Palsy Awareness

Many preemies in our community have Cerebral Palsy and continue to show the public their amazing capabilities despite having CP. March, 2016 is National Cerebral Palsy Awareness Month in the United States. Learn more, and get great knowledge, resources, and information at the Where There's Hope website: <a href="https://www.cpinfo.org">www.cpinfo.org</a>

#### To Do List



CONGRATS: Allison Porter won our *little man* DVD and Kathy White won the "Music for Preemies CD!



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.lv/freemieFreebies to use and to pass onto others.



#### **MARK YOUR CALENDAR!**

Plunge for Preemies
Project Sweet Peas
March 12, 2016
Warwick, Rhode Island USA

Young Child Expo & Conference April 13-15-2016 New York, NY www.youngchildexpo.com

Have an event you want to share with our community? Contact us at: connect@preamieworld.com

Tools and Resources for the Preemie Community

## Preemie Resource: Neos are Lifesavers

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** "**Neos are Lifesavers.**" "Let's face it, Neonatologists save lives every day," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "I cannot imagine a bigger weight on a medical professional's shoulders

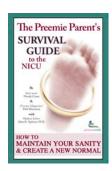
than that of saving the life of an infant. So we wanted to celebrate them in a fun and yet powerful way." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. So go download it here now: <a href="http://bit.ly/NeoLifesavers">http://bit.ly/NeoLifesavers</a> And check more freebies right here: <a href="http://bit.ly/PreemieFreebies">http://bit.ly/PreemieFreebies</a>

## Term: Muscle Tone Definitions

**Hypertonia:** High or tight muscle tone. It is quite common for infants on ventilators to exhibit tight muscle tone, as it is very hard on their little bodies to be stuck in a certain position endlessly. If untreated, this can lead to dysfunction of the muscle or deformity. Ask your doctors or nurses for an occupational therapy consultation.



Hypotonia: Commonly referred to as "floppy," means low muscle tone. This may occasionally be a sign of early cerebral palsy and is treated with physical therapy. In many babies, however, it may be only a reflection of the fact that they are very ill and it will improve over time.



This excerpt is from The Preemie Parent's Guide to Survival in the NICU on sale at www.PreemieWorld.com \*\*We do bulk orders for hospitals\*\*

#### Support: Little Big Souls International

Fueled by the loss of her niece, Chief Mrs. Yvonne Igweh LLB.B.L MPhil (Cantab) was determined to give other pre-term babies a fighting chance.

Established: 2009

Outreach: International/Global advocating platform, operationally throughout Africa and the U.K.; Co-Founder of World Prematurity Day.

#### Social Media:

Web: www.littlebigsouls.com FB: LittleBigSoulsUKUSAFRICA

Twitter: @littlebigsoulsl

**Programs:** Every Breath Counts Advocacy campaign, Equipment Donation Program, Parental Support, Sponsor a Preemie Program, Walk for Babies, NICU Support and Medical Conferences, and World Prematurity Events.



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



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

"Like" our FB page from 3/1/16 to 3/22/16 and you could win a copy of the awardwinning little man DVD from PreemieWorld!

## http://bit.ly/FBPreemie

Parents & Professionals: Subscribe to our FREE newsletters today @ www.PreemieWorld.com



#### The Details:

By:

Leanne Sawyer

Available at:

http://preemie.us/lsawyer

Cost:

\$22.87 USD



## <u>tiny steps - My First Year</u> Record Book

Preemie parents can collectively relate to the frustration of filling out mass-market baby books given to them by well-meaning family members or friends. In a nutshell, those books have no sense of the preemie experience. This is where *tiny steps – My First Year Record Book* is perfectly suited to the NICU family and especially to the preemie family. With easy-to-complete pages for data and inserting pictures, the book marks this event with sensitivity and respect. It even has a place for parents to express their feelings during specific moments. Grandparents, family and friends, this is an ideal keepsake for preemies and their families!

We're giving away this book! Follow us on Twitter by 3/22/16 to enter: <a href="http://bit.ly/PreemieTweets">http://bit.ly/PreemieTweets</a>

## After the NICU: Early Intervention is Key

Preemies, whether 23 weeks or 33 weeks, the research is clear that the earlier you identify and address delays, the better the outcome. Why?

- Your baby lost time in the womb and spent that time in an incubator or hospital crib.
- Your baby may have medical or developmental diagnoses that could affect development and the sooner these are addressed, the better he/she will do in the longterm.
- Early Intervention can give you extra needed developmental support that your pediatrician cannot.

Tell us how your preemie is doing in - #preemietherapy

## Preemie Support Online

#### On the Preemie Support Forum on INSPIRE:

Connect with *over* **25,000** *parents of preemies for free* at <a href="https://www.inspire.com/groups/preemie">https://www.inspire.com/groups/preemie</a> for the *Preemie Support forum*. It is the largest and most active forum online, *moderated by our own Deb Discenza*.

27 Week Preemie CLD, Doctors Suggest Trach – *In the NICU/PICU* 

FTM to 32 weeker, Retractions Okay? - *Introduce Your Very Important Preemie* 

Vaccinating a Micro-Preemie - Preemie Tips

IUGR and Speech Delay – At Home (Years 1-5)

Standing Device - Preemie Hope

#### On PreemieWorld's Twitter Page:

PREEMIE UPDATE: Twins Claire & Mary

#### On PreemieWorld's Facebook Page:

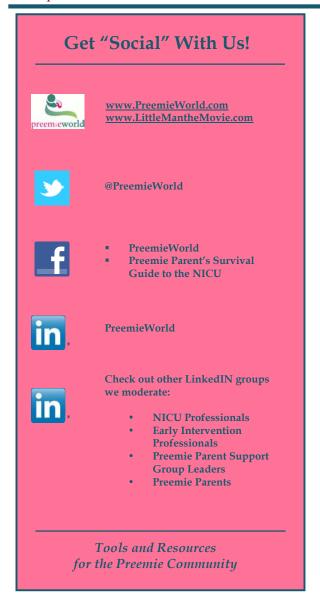
SCARY: Evidence of RSV Spread by Aerosol

#### On PreemieWorld's LinkedIN Group:

STUDY: Risk of Preemie Birth May Rise for Depressed Parents-to-Be

RESEARCH: Extremely Small Preemies May Face Bullying, Mental Health Risks

PROMISING: Two Drugs May Help Improve IQ and Brain Development in Preemies









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## Preemie Parent Words: Parent Instinct Pays Off

Deb Discenza gives insight into the winding trail of getting answers developmentally and more.

I had doctors and nurses crowing at my daughter Becky's strength and resilience in the NICU. "She's doing great," they said. *I believed them*. Even through our rollercoaster ride, Becky was strong. At discharge, the NICU OT told me, "There will be delays but she's doing well." *I believed her, too.* 

But at home, as I was sifted through the paperwork and made appointments, my gut instinct told me otherwise. *Something is not right*. So I signed Becky up a monitoring through our local Health Department and the NICU's follow-up clinic. Within months the teams

now talked about ways to help with the increasing delays. But otherwise, I was told, she was doing well. *Something is not right* – this mental mantra continued inside me. Fast forward to Becky at 18 months old and qualifying for Early Intervention: it dawned on me that *I was the expert of my child*. So I spoke up, I took my daughter to specialists and therapists and more. By 12 years old we addressed developmental diagnoses from autism, to ADHD, to feeding issues, sensory issues to motor coordination issues to very mild Cerebral Palsy. She is doing well *-now*. *Trust your preemie parent instinct*.

What has your #preemieinstinct told you?