

Preemie Family



PREEMIE LIFE

Samuel Grant Lundgren & Jacob Paul Lundgren



Photo Credit: Trissica Rogers, RN

PARENT TIP:

If you anticipate a lengthy NICU stay, get a primary nurse.

Gestational Age at Birth: 24 weeks, 3 days

Weight at Birth: Samuel: 1 lb. 6 oz. *lacob*: 1 lb. 14 oz.

Time in NICU: Samuel: 143 days Jacob: 123 days

Proudest Moment: Both boys being stable enough to have kangaroo care together.

SEE MORE:

Go to <u>www.preemieworld.com</u> *late September* to read a special update.

ADVOCATE: NICU Nurses Day

Every year on 15 September, the preemie community celebrates NICU Nurses worldwide for **NICU Nurses Day**. Tell us your favorite NICU Nurse Story during the month of September on our NICU Nurse Day Facebook page: https://facebook.com/NICUNursesDay and make sure to use the special hashtag #preemienurses in your post.

TO DO LIST:

☑ CONGRATS!: Cynthia Brooks (Preemie Shower), Crystal Sherman (little man DVD) & Herts Milk Bank (Preemie Genius).

LIKED US YET?: PreemieWorld is doing another PreemieWorld Facebook page contest. See page 2 of this newsletter for details!

DOWNLOAD FREE TOOLS: From PreemieWorld at http://bit.ly/PreemieFreebies to use and pass onto other Preemie Parents.

MARK YOUR CALENDARS:

September 10, 2016: Lily's Loop Family Fun Runhttp://www.lilyshopefoundation.org

September 10, 2016: Christmas in the City http://www.thegiftoflife27.org

☑CONTACT US:

- Have an event you want to share with our community?
- Have an organization or product we should know about?
- Know of a family or pro to highlight?
- Email us at connect@preemieworld.com

TOOLS AND RESOURCES
FOR THE PREEMIE COMMUNITY

PREEMIE FREEBIE: Celebrating NICU Nurses

PreemieWorld provides a number of free handouts to be used in the NICU and beyond in its <u>"Freebies For You"</u> section of the website. This month's freebie is **Preemie Nurses are Part of the Family**. "With September celebrating NICU Nurses, we wanted to do our part to help the preemie community join the party," comments **Deb Discenza**, **Founder of PreemieWorld**. "NICU Nurses have a unique patient relationship because of their love of the babies and their

strong connection to the families. I know I am not alone in counting our NICU Nurses as part of the family."

DOWNLOAD IT:

http://preemie.us/PreemieNurses

MORE FREEBIES:

http://bit.ly/PreemieFreebies

TERM:

Brain Bleed

Brain Bleed (IVH or Intraventricular Hemorrhage): The blood vessels in your baby's brain can bleed rather easily, even when the infant is moving in some cases. There are generally 4 levels of brain bleeds (from 1 to 4). Grade 4 is the most serious and can be the source of seizures, blindness and severe retardataion. The doctors normally scan for brain bleeds within the first 24 hours (the most critical), then after three days, and then after one week. The chances of a brain bleed one week are dramatically decreased. Often they will do a final brain bleed check at week six.

Ouestions to Ask the Doctor:

What stage is the bleed? What can be done medically or what can I do to help at this point? What are the longterm outcomes

for this stage of a brain bleed?

This excerpt is from
The Preemie Parent's Guide
to Survival in the NICU
on sale at
www.preemieworld.com

Pediatric Hydrocephalus Foundation, Inc.

SUPPORT:

TOUNDATION

When **Kimberly Illions** son **Cole** was diagnosed in utero with **Hydrocephalus** in 2005, the family volunteered with an organization that ended up not using the donations properly. So they created the **Pediatric Hydrocephalus Foundation, Inc.**

Established: 2009

Outreach: National & Worldwide

Website: www.HydrocephalusKids.org

Cool: The organization is 100% volunteer-run and has zero office space. 100% of the donations goes to education, support and research. They hold an annual free conference in Washington, DC to advocate on Capitol Hill for more funding from NIH and to raise awareness.

PREEMIEWORLD: "LIKE US" ON FACEBOOK & YOU COULD WIN!

The Preemie Parent's SURVIVAL

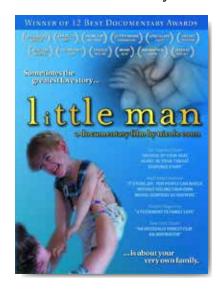
GUIDE

LIKE US HERE:



http://bit.ly/FBPreemie

"Like" our FB page from **8/30/16 to 9/22/16** and you could win a copy of the award-winning *little man* DVD documentary from PreemieWorld!



READ AND SUBSCRIBE:

Preemie parents and professionals are invited to subscribe to our FREE newsletters today @ www.PreemieWorld.com

PREEMIE GENIUS:

The Boy Who Could Run But Not Walk



by Karen Pape, MD www.karenpapemd.com

Every parent of a preemie that is told their baby has a brain bleed or brain injury of some type is left feeling crushing anxiety over their child's future. To add to this no concrete suggestions are given on what can be done to help their child other than "wait and see."

Enter Neonatologist and Neuroscientist **Karen Pape**, **MD** who brings with her solid scientific evidence that the injured infant brain can recover. The book is solid

in detail, has endless stories of patients that went from bad to amazing changes all based on science and common sense.

This book should be required reading for parents and pros alike.

WIN THIS BOOK!

Follow us on Twitter by 9/22/16 to enter: http://bit.ly/PreemieTweets



THE BOY

who

RUN BUT NOT WALK

COULD

KAREN PAPE, MD

AFTER THE NICU:

Brain Injury Hope

If your baby had a brain bleed in the NICU, you are not alone in worrying about your child's future despite not having concrete evidence about outcomes.

The reality is that early brain injury and resulting conditions like Cerebral Palsy are undergoing a vast renaissance thanks to the theory surrounding Baby Brain Neuroplasticity. *There is hope.*

Does that mean that every therapy program out there is to be trusted? Not necessarily. Make sure you have researched the credentials of the therapy program as well as the professionals guiding it. Get lots of references and call them all. And most important - what does your gut instinct tell you about this program?

SHARE YOUR TIPS:

How have you been proactive with your child's developmental monitoring?

Use the hash tag #preemieparentexpert

PREEMIE FAMILY ONLINE

PREEMIE SUPPORT FORUM ON INSPIRE.COM

Connect with over 29,000 parents of preemies for FREE at http://www.inspire.com/groups/preemie for the Preemie Support Forum. It is the largest and most active forum online, moderated by our own Deb Discenza.

In the NICU/PICU: Bilateral Grade 4 IVH

At Home, Years 1-5: RSV Season - What Does It Really Mean?

Preemie Tips: Life After Premature Twins

Open Discussion: "Parents are usually right about these things."

@PREEMIEWORLD @TWITTER.COM

PREEMIE UPDATE: Dylan & Hayden

PREEMIEWORLD AT FACEBOOK.COM

COOL: A Preemie, Now an Adult, Thanks NICU Nurses

PREEMIEWORLD'S GROUP ON LINKEDIN

HELPFUL: Step-by-Step Breastfeeding Guide for Premature Babies

RESOURCE: Vaccines for Children - Information for Parents & Caregivers

GET SOCIAL WITH US!



- www.preemieworld.com
- ${\color{gray}\bullet} \, \underline{www.littlemanthemovie.com}$

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- www.facebook.com/PreemieWorld
- Preemie Parent's Survival Guide to the NICU



owww.instagram.com/preemieworld



- PreemieWorld
- NICU Professionals
- Early Intervention Professionals
- <u>Preemie Parent Support Group</u> Leaders
- Preemie Parents







Interested in advertising? Contact us at connect@preemieworld.com

PREEMIEWORLD'S "PREEMIE SHOWER"

PreemieWorld has launched a monthly **Preemie Shower!** Each month we will be picking *one NICU* to receive donated items.

September's product is the **Snuza Hero Portable Baby Monitor.** Learn more at <u>www.snuza.com</u>

Snuza will be donating
12 Snuza Hero Sets to ONE lucky NICU!

We will select <u>one NICU</u> from our "Preemie Family for Professionals" list **by 9/22/16** at www.bit.ly/PreemieFam4Pros

NICUs: What do YOU want for a Preemie Shower?

Tell us using the hashtag #preemieshower

