



Preemie Family

Preemie Life

Sophia King



Photo Credit: Stacy King

Gest. Age:
24 weeks

Weight:
1 lbs. 9 oz.

Time In NICU:
103 days

Proudest Moment (NICU):
From day one she came out kicking with so much fight for life and still has that desire to live.

Coming Soon: Check www.PreemieWorld.com to read how Sophia is doing now.

Parent Tip:

Learn as much as you can in the NICU and document it all with photos and journals. Never be afraid to ask for help.

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 feeding tubes. **February 8-14 2015 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.feedingtubeawarenessweek.org>

Preemie Resource: Milestone Log

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 "Milestone Log." "Seeing the pediatrician for check-ups can require some prep by preemie parents," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "We created this

milestone log for them to keep on their fridge and complete between check-ups. Then all they have to do is bring the completed paperwork in with them." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce.

Download it here: <http://bit.ly/milestonelog> and **check out more here:** <http://bit.ly/PreemieFreebies>

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To Do List



CONGRATS: Cassie Fulton is our winner of the *little man DVD!*



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!

Project: Cameron's Story Bookraiser
Project: Cameron's Story
February 16, 2015
Barnes and Noble, Saratoga, NY
www.projectcameronstory.com

4th Pediatric Feeding Conference: It Takes a Village
Feeding Matters
February 28, 2015
Phoenix, AZ
www.feedingmatters.org

Have an event you want to share with our community?

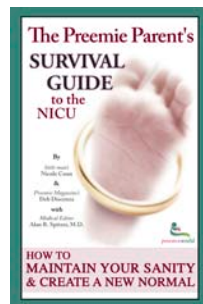
*Tools and Resources
for the Preemie Community*

Term: Developmental Delay

Developmental Delay: Babies are expected to reach certain milestones (i.e. walking and talking) within a predictable amount of time. Premies, due to their early birth and subsequent medical challenges may take longer to reach those milestones. Many premies receive occupational therapy and/or physical therapy to deal with all of the various issues of being born too early – the stress it puts on the muscles, the stiffness in the bodies of infants



that are on the vent for any length of time, etc. This therapy is very important for your baby. If your baby is on the ventilator, ask your nurse to get an occupational therapy (OT)/physical therapist (PT) consultation. Some infants receive therapy early on after discharge, others do not require it and the parents can take a “wait and see” approach. Your pediatrician can guide you through this and may refer you to your area’s Early Intervention Program.



This excerpt is from
**The Premie Parent's
Guide to Survival in the
NICU** on sale at
www.PremieWorld.com
**We do bulk orders for
hospitals**
connect@premieworld.com

Support:

Parents of Premies Association



Parents of Premies Association
Association des parents d'enfants prématurés

After experiencing a lack of resources and isolation after the birth of her premie, Nicole Lyons created the Parents of Premies Association.

Year Established: 2014

Outreach: Ottawa, Canada

Web: www.popottawa.org

Programs: *Presents for Premies* (package of helpful items for the stay); *Caiden's Library* (a book library for parents to read to their child); support groups, events, advocacy (local meal services to give discounts to parents and house cleaners to cater to parents in the NICU or newly home from the NICU).

PreemieWorld: “Like” Us On Facebook & You Could Win!



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

“Like” our FB page
from 2/3/15 to 2/26/15 and you
could win a copy of the award-
winning *little man* DVD from
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Premie Voices

The Details:

By:
Saroj Saigal, MD

Website:
www.saigalpreemievoices.com



Premie Voices is like looking into a crystal ball and seeing the future. Told in the voices of 41 former micro-preemies now in their 30s, each talks about their lives and give intimate details surrounding their challenges as well as their achievements.

This book is a treasure trove of insight, historical data and more for the parent and the professional alike. It also surprises in ways the reader would not expect. *A must-read for all.*

COOL: Check out a special video that accompanies the book at Dr. Saigal's website. Dr. Saigal offers special book pricing on the site as well at \$25 + S&H, too: www.saigalpreemievoices.com

DOUBLE COOL: We're giving away a copy of the book to one new PremieWorld Twitter follower 2/3/15 - 2/26/15 - www.twitter.com/preemieworld

After the NICU:

Approaching the Pediatrician on Delays

While many pediatricians will take a "wait and see" approach to your child's development, it is okay to disagree. How to prep for that discussion at check-up time:

- Bring a developmental log – we have developed a great one for you: <http://bit.ly/milestonelog>
- Bring other observations – grandparents, teachers, child care, but make sure you get it in writing.
- Proactive vs. Reactive: Be clear to the doctor that you are an expert of your child and that you are connected in the preemie parent community where the proactive approach is always stressed over the reactive approach. *Research shows this approach is always better.*

Premie Support Online

On the Premie Support Forum on INSPIRE:

Connect with *almost 21,000* other parents of preemies online at www.Inspire.com/preemie for the *Premie Support forum*. It is the largest and most active forum online, *moderated by PremieWorld's own Deb Discenza*.

Great App – *Premie Tips*

Chronic Lung Disease and Not Gaining Weight – *Premies with Feeding Issues*

So Soon . . . – *at My journal*

My addition to the preemie hope stories– *Premie Hope*

My Miracle Baby – *in Premie Angels*

On PremieWorld's Twitter Page:

SPECIAL PREEMIE UPDATE: Grayson Kapferer

Could Premature Birth Affect Adult Relationships, Self-Esteem?

On PremieWorld's Facebook Page:

STUDY: More Extreme Premies are Surviving

On PremieWorld's LinkedIN Group:

RSV: A Respiratory Virus that Can Send Infants and Kids to the Hospital

RESEARCH: Low Vitamin D Linked to Risk of Preterm Birth

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

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Q & A: Advice for Parents & Pros Regarding Premies

Saroj Saigal, MD, FRCP (C), Professor Emerita Pediatrics at McMaster University and Pediatrician in their Neonatal Follow-Up Program has written Premie Voices, (review p.3) which details the outcomes of very premature infants now, in their 30s, in their own writing. We asked her for advice . . .

What would you like for parents to know?

Infants respond remarkably to being at home and thrive on parental interaction. At school, the incidence of learning problems is 2-3 times more common in very premature infants compared to infants born at term. As they grow older, some children may face math difficulties, and a higher proportion will require special education assistance.

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However the majority of premature infants graduate from high school, and many even go onto post-secondary education. Learning difficulties in premature infants are challenging, both for the children and their parents. Encouragement and a positive attitude are essential.

What would you like professionals to know?

Until recently, not much was known about how very premature children fared in their roles and responsibilities as young adults. We now know that despite the earlier development lags and disabilities, the majority of very premature children are very resilient, and function surprisingly better than we had expected.

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