



# Preemie Professional

## Preemie Professional

### *Ram Yogev, MD*

Director, Pediatric, Adolescent and Maternal HIV Infection at Ann & Robert Lurie Children's Hospital of Chicago; Susan B. DePree Founders' Board Professor in Pediatric, Northwestern University Feinberg School of Medicine



Photo Credit: Ann & Robert H. Lurie Children's Hospital of Chicago

#### Web:

[www.luriechildrens.org](http://www.luriechildrens.org)

#### Years in Pediatrics

37 - Pediatric Infectious Disease  
40 - Pediatrics

#### Focus:

RSV Prophylaxis, vaccines, and treatment.

#### Advocacy:

Dr. Yogev, part of POPULAR (Physicians and Other Professionals Urging Logical Approach to RSV) has launched this petition:

<http://bit.ly/popularRSV>

### Professional Tip!

*Pediatricians owe their patients the best care possible and to make sure that their voices will be heard.*

## 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>

*Follow us on FB, Twitter & LinkedIn!*

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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> and pass them onto NICU Parents as part of your welcome packet.

#### MARK YOUR CALENDAR!



*Specialty Review in Neonatology*  
MEDNAX  
February 17-22, 2015  
Orlando, FL  
[www.specialtyreview.com](http://www.specialtyreview.com)

*NEO: The Conference for Neonatology*  
Pediatrics  
February 19-22, 2015  
Orlando, FL  
[www.neoconference.com](http://www.neoconference.com)

*Have an event you want to share with our community? Contact us at:*  
[connect@preemieworld.com](mailto:connect@preemieworld.com)

*Tools and Resources  
for the Preemie Community*

## 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](http://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).

## Org: Dandy-Walker Alliance, Inc.

*A father of a premie takes on Dandy-Walker Syndrome.*

**Website:**

[www.Dandy-Walker.org](http://www.Dandy-Walker.org)

**Year Established:** 2006

**Outreach:** International

**Focus:** Individuals and families affected by Dandy-Walker Syndrome, the most common malformation of the hindbrain region.

**Background:** Founder Eric Cole's son Ryan was born in May 2005, 12 weeks premature weighing 1 lb. 15 oz. and spent 156 days in the NICU. After the NICU, Eric launched the online repository that was the beginning of the Dandy-Walker Alliance, Inc.

**Programs:**

*Patient Registry:* This global registry helps to understand the health issues experienced by individuals.

2014: Funded the largest whole exome sequencing research projects of Dandy-Walker samples ever conducted globally to advance knowledge genetically and more.

2015: Expansion into creating a multi-institutional data and genetic repository and increase funding to researchers studying to researchers studying the mechanism underlying Dandy-Walker Syndrome.



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



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

**"Like" our FB page from 2/3/15 to 2/26/15 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.PreemieWorld.com](http://www.PreemieWorld.com)

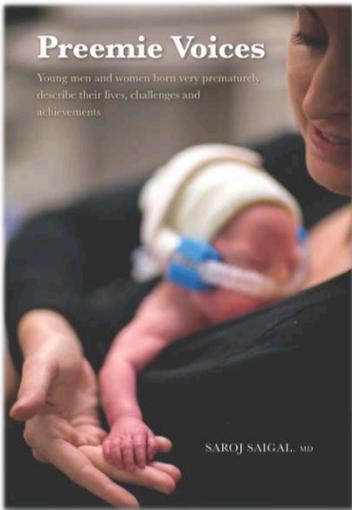


## Preemie Voices

### The Details:

**By:**  
Saroj Saigal, MD

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



*Preemie 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](http://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](http://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 Professional Online

### NICU Professionals Group: (www.Linkedin.com)

Potential Dangers of single-rooms in the NICU

STUDY: More Extreme Preemies Are Surviving

RSV & BLACK INFANTS: Physicians Urge RSV Protection for Black Infants

RESEARCH: Breakthrough in premature baby study

Caffeine and Its Impact on Neonatal Morbidities

### Early Intervention Professionals Group: (www.Linkedin.com)

The easy way to fix a front lisp

Picky Eaters in Preschool: 7 Tips for Teachers

**Follow us on FB, Twitter & LinkedIn!**

### Premie World (www.Twitter.com):

SPECIAL PREEMIE UPDATE: Grayson Kapferer

ARTICLE: Legacy implements 'kangaroo care' for premature babies'

### BE THE COOL PRO: Tell Your Families about the "Premie Network" on Inspire.com:

Deb Discenza of PremieWorld moderates this global network of *almost 21,000* parents from NICU to home to school. [www.inspire.com/preemie](http://www.inspire.com/preemie)

Check out these groups and more by referring to the "Get 'Social' With Us" on page 4 for more information. Have news or research to share with us? [connect@preemieworld.com](mailto:connect@preemieworld.com)

## 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
- Little Man the Movie

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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.

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.