

PREEMIES TODAY

National Premie Families Support Network

Nickolas & Olivia: A Story of Hope

By Jenifer Klepesky

Nickolas and Olivia are twins who were born on February 25, 2006. They were born at 28 weeks gestation, weighing 2lbs., 12 ounces and 15 and 15.5 inches in length. They were so small and fragile at birth that I was afraid to touch them; I was afraid they would break. Their legs were so thin that their hospital leg bands could be moved up and down with ease. Once removed, I realized that their leg bands were so small that I could pass a quarter through them.

Nickolas is the oldest by one whole minute and was born at 1:30 pm. He was also the sicker of the two babies. His condition was critical and grave. He was born with an infection called Sepsis. He had a partially collapsed lung and a hole in his heart, too. As a result, Nickolas had a lot of breathing problems at birth. Both of them had Retinopathy of Prematurity (ROP) and we worried about their risk of becoming blind. They also required several blood and platelet transfusions.

At 11:15 pm the doctor came to my room. He began to tell me about how well Olivia was doing. I started to wonder why he started with her and did not seem to be saying anything about Nick. That is when he told me the bad news. He said that Nickolas was having severe problems breathing. The valve in his heart re-circulated carbon dioxide. It should have closed at birth, allowing the carbon dioxide to be released, but it did not. The doctor believed that he would need surgery to remove the defective valve. They were doing everything they could, but needed my permission to connect him to an oscillator.

The next morning the doctor returned to my room with yet more bad news. Nickolas also had a brain bleed. They were doing a test to see how bad it was. It could range anywhere from a Grade I to a Grade IV. We hoped for the best. Later that afternoon he returned to my room and informed me that my son had a Grade III brain bleed. I was mortified; I asked what that meant for my son. He explained how the bleed could affect our son. The best-case scenario was that he would be a slow learner and the worst was that he could be a paraplegic, never having use of his arms or legs.

A priest came to my room and asked if he could pray at my bedside. I am Catholic and I have a strong belief in the power



Nickolas and Olivia pictured in 2009 testing driving toy cars

of prayer and miracles, and I needed a miracle, badly! I explained to him what was going on and begged him to pray at their bedside. I was desperate. He offered to contact a Catholic priest to baptize the babies and I agreed. At 8:00 pm, my children were bap-

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PREEMIES TODAY

Preemies Today
P.O. Box 523525
Springfield, VA 22152

Founded:
March 2003

website:
PreemiesToday.org

e-mail:
info@preemiestoday.org

Preemies Today is a 501(c)3 non-profit organization whose mission is to provide outreach and support programs to families of infants born prematurely beginning at birth and throughout childhood.

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Calendar of Events

April

Wed., Apr 8, 2009, 7:30–9:30 pm
Parent Coffee
11858 Rockville Pike, Rockville, MD 20852

Wed., Apr 8, 2009, 7:30 - 9:30 pm
Parent Coffee
Barnes and Noble in Fair Lakes, VA

Sat., April 18, 2:00 - 4:30 p.m.
Expanding the Diets of Children with Sensory-Based Feeding Disorders
Speaker: Kelli Atangan, SLP
Holy Cross Hospital, Silver Spring, MD

May

Sat., May 2, 2:00 - 4:30 p.m.
Understanding Vision Development in the Preschool Child: Activities for Mind and Body
Speaker: Nancy Lewis, OD
Holy Cross Hospital

Wed., May 13, 2009, 7:30–9:30 pm EDT
Parent Coffee
11858 Rockville Pike, Rockville, MD or Barnes and Nobles Fair Lakes, VA

Sun., May 31, 1:00 - 3:00 pm
Braille Babies
Speaker: Kim Avila, M.A., COMS
City of Fairfax Meeting Room A/B
10360 North Street
Fairfax, VA 22030-2514
*E-mail info@preemiestoday.org for more information.

Please RSVP to events@preemiestoday.org or online through our Big Tent system.

march of dimes[®]
march for babies[®]

one day...
all babies will be born healthy.

the walk starts at marchforbabies.org/oneday

our national sponsors

Kmart CIGNA FARMERS FedEx Famous Footwear Liberty Tax Service Continental Airlines

Join the Preemies Today team as we walk together to help fight prematurity. Go to www.marchforbabies.org/preemiestoday. Please let us know if you are already registered to walk.

SPD: The Misdiagnosed Disorder

By Lucy Jane Miller, PhD, OTR



If your baby was born early, it will come as no surprise to learn that prematurity and other birth complications are prime suspects in the search for what causes Sensory Processing Disorder (SPD), the complex brain disorder that affects the way sensations are experienced and organized. It also won't come as a surprise that getting an accurate diagnosis of SPD or appropriate treatment can be a challenge.

Prenatal conditions and birth trauma occur in a much higher percentage among children with SPD than among typically developing children. In particular, health care providers have long observed that extremely premature babies (under 32 weeks of gestation) and infants with very low birth weight (less than 1,500 grams) are extremely likely to have sensory processing issues (e.g., sensitivity to light, noise, touch, taste, or movement; abnormal muscle tone; and/or delayed speech/language development are among the sensory challenges).

We don't know whether the higher incidence of sensory difficulties in early preemies is caused by the premature birth itself, by the lengthy hospitalization that typically follows, or by other factors. Those are subjects for future research. In the meantime, if your child was born very early or at any extremely low birth weight, he or she is more likely to experience "red flags" of SPD than other children.

And because SPD is not yet recognized in the Diagnostic and Statistical Manual (DSM), you may face a long road to an accurate diagnosis and appropriate treatment. Two misdiagnoses are especially common. Children with the subtype of Sensory Seeking/Craving are frequently misdiagnosed with Attention Deficit Disorder because of their quest for sensory input, which is mistaken for the hyperactivity of ADHD. Children with the Sensory Under-Responsivity subtype of SPD can be misdiagnosed with Asperger Syndrome or another autistic spectrum disorder

because poor awareness of sensory input, language delays, and motor difficulties can be mistaken for the impaired socialization, impaired communication, and stereotypical movement patterns that are hallmarks of ASD.

If your infant or child has more than a few red flags of SPD, you will want to become informed about the disorder as quickly and thoroughly as possible to avoid misdiagnosis of your child's symptoms. Learn all you can about Sensory Processing Disorder from the SPD Foundation web site or my book *Sensational Kids: Hope and Help for Children with Sensory Processing Disorder*, where you'll find more about research on the causes of SPD. Use the Foundation's Treatment Directory to find a service provider with expertise in SPD who can evaluate your child and, if indicated, provide appropriate treatment.

Unfortunately, your child's health care providers, teachers, and others may not know enough yet about SPD to recognize its symptoms and/or distinguish those symptoms from signs of other childhood developmental conditions. By educating yourself about the disorder, you take a crucial first step toward getting the assessment and intervention your "sensational" preemie may need. Believe in your intuitions and find health care providers who will listen and support you. Many are out there, but you might have to search for the "right" person.

Lucy Jane Miller is Founder and Executive Director of the SPD (Sensory Processing Disorder) Foundation and author of *Sensational Kids: hope and Help for Children with Sensory Processing Disorder (Perigee Books: 2006)*. More information about SPD is available at www.SPDFoundation.net.



PREEMIES TODAY

Presents

Understanding Developmental Delays and Child Development

A Lecture Series for Parents and Professionals

Holy Cross Hospital, First floor

1500 Forest Glen Road, Silver Spring, MD 20910

Saturday afternoons, 2:00 - 4:30 p.m.

April 18, 2009

Expanding the Diets of Children with Sensory-Based Feeding Disorders

Speaker: Kelli Atangan, SLP

Room: EDU 2&3

This lecture will focus on expanding the tastes and textures your child accepts in order to create a more well-balanced diet. It will cover assessment and intervention for children with sensory-based feeding disorders due to prematurity and early tube feedings. These children often have very limited diets and may avoid trying new foods because of how they look, feel or smell. They may also have other physical, developmental or behavioral challenges contributing to their restrictive diet. We will discuss how to select foods, transition to new foods, get your child motivated to try new foods, and reduce mealtime frustration.

May 2, 2009

Understanding Vision Development in the Preschool Child: Activities for Mind and Body

Speaker: Nancy Lewis, OD

Auditorium A&C

A hands-on discussion of vision and vision development. You will learn how to facilitate the development of those visual skills that are needed for success in the classroom and in life.

COST: Preemies Today Members FREE

We are asking for a suggested donation of \$25.00 per lecture for non-members.

Pre-registration is encouraged and would be appreciated. Questions? Call Preemies Today: 703-229-0835.

Preemies Today
P.O. Box 523525
Springfield, VA 22152

or e-mail events@preemiestoday.org

Directions:

Holy Cross Hospital is located conveniently off the Capital Beltway. Take exit 31A, Georgia Ave. Turn right (0.37 miles) on Forest Glen Road.

*Thank you to our speakers and to the families and professionals that attended the March lectures.

The Spring 2009 Lecture Series Continues



Kelli Atangan, SLP, is a pediatric Speech Language Pathologist who received her Masters degree from Gallaudet University in 2006. She has worked with children with feeding disorders in various settings including the NICU, acute care, acute rehabilitation, as well as outpatient therapy. She currently works at Building Blocks Therapy, a private practice in Falls Church, VA and Northwest DC.

Nancy Lewis, DO, has many years experiences in the the diagnosis and treatment of learning related visual disorders in children, adolescents, and adults. She is a graduate of American University and the New England College of Optometry. She has participated in an Externship at the Gesell Institute for Human Development and an Internship in Vision Therapy at the State University of New York. She is a past board member and advisor for Developmental Delay Resources (DDR), WISER Past-President, 1990-1992. She is presently in private practice with Dr. Paul A. Lewis.

The opinions expressed in the lectures are those of the presenters and may not necessarily reflect Preemies Today. We encourage all families to discuss new approaches with your child's healthcare team before beginning any new program or treatment.

Children's Health Insurance Program Reauthorization Act (CHIPRA)



Kathy Mingledorff, Founder of Premies Today, speaks on behalf of CHIPRA at a Congressional Press Conference in January of 2009

On February 4th, 2009, President Barak Obama signed the Children's Health Insurance Program Reauthorization Act (CHIPRA) better known as the State Children's Health Insurance Program (SCHIP) into law.

Important points to note regarding CHIPRA:

- It increases access to health care services to children.
- It extends and expands coverage for low-income and uninsured children.
- It qualifies children from families 300% above the FPL (which equals an income of \$66,150 in 2009 for a family of four).
- It adds 33 billion in federal funds to state health care programs by 2013.
- It provides coverage to over 6 million children who may otherwise be uninsured over the next four years.
- It simplifies enrollment.
- It allows dental coverage to all enrolled.
- It provides coverage to low-income legal immigrant children.
- It provides coverage to low-income pregnant women.

Resources:

Go to the Insure Kids Now website at www.insurekidsnow.gov to find out about your state's plan.

References:

1. Kaiser Family Foundation: Kaiser Commission on Medicaid and the Uninsured Key Facts, (2009, February) <http://www.kff.org/medicaid/upload/7863.pdf>
2. American Medical Association (2009, February), <http://www.ama-assn.org/ama1/pub/upload/mm/399/schip-chipra-hr2-summary.pdf>
3. CHIPRA 101: Overview of the CHIP Reauthorization Legislation (2009, March) <http://www.familiesusa.org/assets/pdfs/chipra/chipra-101-overview.pdf>

Send your comment on CHIPRA to:

http://www.whitehouse.gov/the_press_office/SCHIP_Public_Review/

Thank you to the March of Dimes and those that lobbied on behalf of this bill so that millions of children would have access to health care.

Paying for your Premie's Care:

1. Soon after the birth of your child, contact your health insurance company and find out what your plan pays for in regards to hospitalization.
2. If your child's birth weight is 1199 grams or less you are eligible for Medicaid and Supplemental Social Security Income (SSI).
3. If your child remains in the hospital for more than 30 calendar days, you are eligible for Institutional Medicare.
4. Before leaving the NICU plan for additional care that your child may need. If your child has a feeding tube, oxygen, or other breathing support you may need additional assistance. Talk to a social worker on how Medicaid Waivers may benefit your child or one of our parent to parent volunteers.
5. Once your baby is home it is important to understand your health insurance plan. Some specialists may be out-of-network. You may need to talk to your employer's Human Resource Department to receive in-network benefits.

Hope, continued from page 1

tized. During the baptism the nurse checked Nick's blood gas, it was still very bad. They did not know if he would make it through the night. An hour after the baptism, the blood gas was repeated and it had improved. The doctors and nurses



Olivia's hand pictured from her isolette in 2006

could not come up with an explanation. They said it was a miracle. I did not need an explanation; I already knew what did it. In my heart I believe, the baptism and the power of prayer saved their lives. Nickolas and Olivia were added to the "sick list" at my local parish and the congregation was asked to keep them in their prayers. After the baptism, Nickolas increasingly got better and never turned back. He even came home before his sister Olivia.

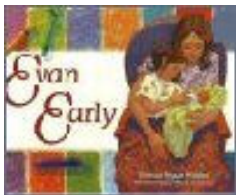
Two weeks after they were born, Nickolas was finally off of the oscillator. He was on continuous positive airway pressure (CPAP). Olivia was doing well, and then started becoming less active. Her nurse became concerned and notified the doctor. Olivia was diagnosed with necrotizing enterocolitis (NEC). She had to be placed on antibiotics for ten

days. Fortunately, it was caught early enough that Olivia was able to avoid surgery and got well. It was the longest ten days of my life. She increasingly got better and moved to nasal cannula and then a crib!! It was very exciting as she graduated to each stage.

Overall my children spent about 6 1/2 weeks in the NICU. They came home about six weeks before their due date which was amazing. In the beginning the doctors said to consider myself lucky if my children came home by their due date of May 17. Nickolas came home a few days before his sister. He was sent home on Reglan for reflux and on an apnea monitor. He was on the monitor and medication for about two months. The twins gained weight quickly and grew fast. They both received physical therapy for the first 2 1/2 years of their life. They were 18 months old when they took their first steps. They both started walking at the same exact time! Nickolas also needed speech therapy and tubes in his ears for fluid behind the ear drums.

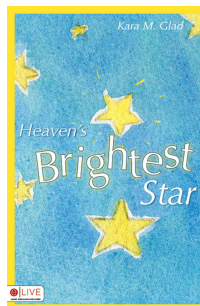
Today they are celebrating their 3rd birthday. It is an emotional day for me as I remember all too well three years ago today and the weeks that would follow. All the hope and prayers have paid off. They are two healthy and beautiful kids. They are entertaining and funny. I could not imagine life without them. Nicholas, despite his Grade III hemorrhage, runs, rides a tricycle, plays hockey, and he can skate circles around people! He also knows all of the Thomas trains by name. He is so smart and active; he is an absolute miracle! The twins are so different. Olivia is so bossy and Nick is so laid back. However, they both live life to the fullest. I love them both so much and they have given everyone they touch a greater appreciation of life itself.

Books for NICU Siblings



Evan Early by Rebecca Hogue Wojahn

Evan Early is an inspirational story about a little girl, Natalie, whose brother was born premature. It has beautiful illustrations and discusses the emotional ups and downs of the NICU in age appropriate terms. This book is best from children ages 3-7.



Heaven's Brightest Star by Kara M. Glad

Heaven's Brightest Star is a book about premature birth and loss. This difficult topic is written in easy to understand and age appropriate terms. Kara Glad, who lost her own son in the NICU, is able to find hope in the end through the eyes of the main character, Katie. The book is best for children ages 2 - adults.

March of Dimes.....www.marchofdimes.com

The March of Dimes offers a wealth of information about preterm labor and premature birth.

Social Security**Administration**.....www.ssa.gov

Many premature infants qualify for Social Security Disability regardless of income. Go to the above website to find your state's program.

State Children Health Insurance Program (SCHIP).....www.insurekidsnow.gov

All states have a health insurance program for uninsured families that meet the income gap. Go to your state's program.

Sidelines National**Support**....www.sidelines.org

Sidelines provides support for pregnant women on bedrest and those dealing with the after effects of bedrest.

Child Find

Preschool Child Find serves as a resource for preschool children and their families by providing therapy or educational services in the home or in various local elementary schools for children that qualify starting at age two through age five. This program is provided at no cost. If you suspect your child has a developmental delay, call now. It may take up to four months or longer to begin services.

Virginia

Alexandria (703) 824-6708

Arlington (703) 228-6042

Fairfax County

(703) 876-5244 Devonshire office,

(703) 446-2100 Lorton office

Falls Church City (703) 248-5655

Prince William County (703) 791-8857

Maryland

Montgomery County (301) 929-2222

Prince Georges County (301) 808-2719

Washington DC

(202) 727-8300

Social Services**Virginia**

Alexandria (703) 838-0700

Arlington (703) 228-1550

Fairfax County (703) 324-7500

Fauquier County (540)347-2316

Loudoun County (703)777-0353

Manassas City (703)361-8277

Manassas Park (703)335-8898

Prince William County (703)792-7500

Washington DC

Department of Human Services

(202) 671-4200

Maryland

Montgomery County (240) 777-1245

Prince George's County (301)909-7025

Early Intervention

This is a federally mandated program available in every state to screen and treat children under the age of three for developmental disabilities and delays. If you have any concerns about your preemie's development, contact your local office to have your child tested. Services are covered by most insurances and are billed on a sliding scale. Waiting lists may exist. Call as soon as possible.

Virginia**Infant and Toddler Connection**

Alexandria (703) 838-5060

Arlington County (703) 228-1630

Fairfax County/Falls Church (703) 246-7121

Loudoun County (703) 777-0561

Prince William (703) 792-7879

Washington, DC**Office of Infants and Toddlers With Disabilities**

(202) 727-8300

Maryland**Infant and Toddlers**

Montgomery County (240) 777-3997

Prince George's County (301) 265-8415

Don't Forget!

Wed., April 8, 2009, 7:30–9:30 pm
Parent Coffee
La Madeleine
11858 Rockville Pike,
Rockville, MD 20852

Wed., April 8, 2009, 7:30–9:30 pm
Parent Coffee
Barnes and Noble in Fair Lakes
Fairfax, VA 22033

Membership/Subscription Information:

We offer the Premies Today newsletter, parent lectures, family outings, parent support groups, preemie playgroups, and Parent-to-Parent support for parents and families of preemies. Membership in our organization is free.

For a free subscription to our newsletter and to join Premies Today visit our website at **www.PremiesToday.org** and click on "Join Us".

Are you interested in receiving future newsletters electronically?

Please e-mail us at info@premiestoday.org

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**PREEMIES
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P. O. Box 523525
Springfield, VA 22152

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