

PREEMIES TODAY

National Premie Families Support Network

Batter Up! A Boy Born at 31 Weeks Swings His Way into the World

By Charlene Fronczek

I met my husband, Joe, in 2002 and we were married in 2004. Eight weeks into our marriage we became pregnant. Although surprised, we were excited about the prospect of becoming parents and looked forward to welcoming a child into our lives.

At 34 years old and an insulin-dependent diabetic, I knew that a pregnancy could be tough and that I'd be considered high risk. I was referred to a team of specialists and immediately started scheduling weekly appointments. My medical team was impressed with my blood sugar, which was under tight control. All of the initial blood work and the first ultrasound came back perfectly normal. I felt great and never experienced any morning sickness. At around 11 weeks along, I began spotting. This really threw me off guard as I thought my diabetes was the only thing that might cause pregnancy related complications. Spotting was not a problem related to diabetes. I rushed to the doctor and they confirmed that everything looked fine and I was sent home with instructions to get some rest and relax.

Throughout the next few months the spotting would come and go and despite a battery of tests including several ultrasounds, the placenta looked great and the baby didn't show any signs of being in danger. The cause of bleeding couldn't be determined. On one hand this was a comfort to me, but in the back of my mind I couldn't help being a little worried. The worry totally faded at six months, when the bleeding completely stopped. My check-ups continued to go well and my diabetes remained under tight control. I even got clearance to go on a family vacation to Myrtle Beach. I eagerly started packing for vacation and looked forward to my last trimester of pregnancy.

Things suddenly changed and my world was shaken on the evening of August 29, 2005, just two days prior to leaving for the beach. I came home from work, ate dinner, and rested on my bed watching the news. This was my usual routine and I was feeling fine. At approximately 8 p.m., I noticed that I was leaking some fluid. Since I wasn't in any pain, I wasn't overly concerned and decided to wait until my husband got home and then decide what we should do. The leaking stopped after that one episode and since I continued to feel okay we got ready for bed and decided to



Andy, pictured above, loves baseball and the Pirates.

contact the doctor in the morning just to be safe.

Suddenly, at 2:30 a.m., the leaking started up again so we called the doctor. She suggested that I meet her at the hospital as a precaution. I felt fine and wasn't in any pain, but didn't want to defy medical advice so we agreed to meet her. Looking back I was pretty naïve as I didn't even take an overnight bag with me. I was sure we'd be returning home within a few hours. As I attempted to step out of the

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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

January

Parent Support Meeting

Wed., January 14, 7:30 p.m.
Barnes and Noble, Fairfax, VA
RSVP to events@preemiestoday.org

Parent Support Meeting

Wed., January 14, 7:30 p.m.
La Madeleine
Rockville Pike
Rockville, MD
RSVP to events@preemiestoday.org

New → **Telephone Support Group with Cathy Rodrigues, LCSW and Life Mentor Coach along with special guest JoAnn Kennedy, OTR/L**

Fri., January 16, 1 p.m. EST
Parenting and Discipline: Understanding the Impact of Sensory Development
RSVP to events@preemiestoday.org.
Call-in-number is 712-423-1620 and the access code is 612931#

February

Parent Support Meeting

Wed., February 11, 7:30 p.m.
Barnes and Noble, Fairfax, VA
RSVP to events@preemiestoday.org

Parent Support Meeting

Wed., February 11, 7:30 p.m.
La Madeleine
Rockville Pike
Rockville, MD
RSVP to events@preemiestoday.org

Dance for Hope--Dance-a-Thon

Fri., February 13, 2009, 5:00 p.m.
To Raise Money and Awareness for the March of Dimes
George Mason University-Dewberry Hall
Fairfax, VA

*Organized by the Alpha Phi Omega Co-ed Service Fraternity.
Families and children of Preemies Today are invited to participate and raise awareness.
RSVP to events@preemiestoday.org.



Program Updates:

Special Note:

Preemies Today would like to offer a warm welcome to our new board members : Heather Hall, Judy Bender, and Betty Connal. Thank you for your committment to being a part of our team.

At the same time, our board also bids farewell to Susan Boucher, Heather Abondi, and Malou Gemeniano. We thank you all for the wonderful contributions you have made to this organization and the preemie community.

Next month: We are excited to share more about our new members of the board and the changing structure of the Preemies Today organization.

car at the hospital, my water broke. This time I was sure as it was literally a flood! My OB/GYN confirmed that it was amniotic fluid and admitted me to the hospital. I continued to feel fine and was not experiencing any pain. A fetal monitor showed that the amniotic fluid level was very low and the baby's heart rate was showing signs of distress. At this point, I still had not idea that delivery was imminent. I believed that we were safe in the hospital and they would fix whatever was wrong and I'd go on to experience the last trimester of my pregnancy. It wasn't until alarm bells started going off and a team of nurses ran into the room that my husband and I became worried. An oxygen tube was inserted into my nose and I received my first of two shots of betamethasone to rapidly mature my baby's lungs. The doctor informed us that I would deliver via emergency C-section and they were working on scheduling space for me.

My journey into the preemie world had begun and it didn't matter that I wasn't prepared.

As I was being wheeled to the operating room things suddenly hit me like a ton of bricks and I broke down in tears. This was a defining moment for me, one which I will never forget. My journey into the preemie world had begun and it didn't matter that I wasn't prepared. My beautiful baby boy, Andrew Jerome, was born at 31.5 weeks gestation weighing 3 pounds and was 16 inches long. Undoubtedly he was the smallest baby I'd ever seen. Andrew was whisked away to the NICU where he would spend the next several weeks. It was extremely difficult leaving the hospital without my baby, but I knew he was getting the care he needed.

As parents, we dealt with many preemie challenges: a few days on the ventilator, difficulty sucking, feeding tubes, high bilirubin levels, low birth weight, apnea, reflux, and low muscle tone. Andy came home on a heart monitor, weekly physical therapy, regular visits to the pulmonologist, and we started a round of synagis shots and subsequent hibernation to keep him healthy and lower his risk for **RSV** and pneumonia. Andy also developed a **hemangioma** on his upper lip. At 8 months old, he underwent surgery in Los Angeles, the only place that agreed to do the risky procedure, to remove the benign tumor. At 22 months he was diagnosed with mild sensory processing disorder and receptive language delay for which we started weekly occupational therapy.

Today, Andy is a happy, healthy 3-year-old who loves sports and collects baseball and football cards. He's full of energy and has a zest for life. We have continued with

weekly occupational therapy and Andy attends preschool five mornings per week as part of a **non-categorical preschool** class that integrates a therapy-based educational program. Despite a rough beginning, Andy continues to thrive and we count our blessing every day. The preemie experience has made us more flexible and has taught us to sit back and savor the simple things life has to offer.

Preemie Quick Facts:

Betamethasone--a steroid given to a woman experiencing premature labor to aid in maturing her unborn baby's lungs and reduces the chances of respiratory distress in a premature infant. ¹

Hemangioma--is a benign (non-cancerous) tumor that is similar to a birthmark. Hemangiomas will begin growing soon after birth and continue growing until 6-12 months of age and then will begin to reduce in size. Most of the time hemangiomas are left untreated unless they are suspected to interfere with eating, breathing, or other vital organs. Hemangiomas are commonly present in 25% of low birth weight babies and most disappear on their own. ²

Low Muscle Tone--a neurological reaction that the muscle has to stimulus. Children with low tone may have poor posture, body awareness, feeding issues, and coordination problems compared to a child with normal tone. Evaluation and treatment can be done by a physical or occupational therapist. ³

Non-Categorical Preschool--children with a variety of developmental delays benefit from special education and related services in a classroom setting. Having a variety of students with different strengths and needs can be mutually beneficial for all students. ⁴

RSV --(respiratory syncytial virus) is a virus that begins with cold-like symptoms but then can result in a lower respiratory infection, lung inflammation, wheezing, difficulty breathing and pneumonia. ⁵

1. Meriter Health Services (n.d.) Parting Your Premature Baby--Commonly Used Medications. Retrieved January 3, 2009, from <http://www.meriter.com/living/preemie/meds.htm>

2. Children's Hospital Boston (n.d.) My Child Has a Hemangioma. Retrieved January 3, 2009, from <http://www.childrenshospital.org/az/Site998/mainpageS998P0.html>

3. Dobkins, Leslie, OTR/L, SIPT-C (n.d.). Could My Child Have Low Muscle Tone? Retrieved January 3, 2009, from <http://www.omill.org/articles/LowMuscleTone.html>

4. Fairfax County Public School (2008, May) Child Find: Frequently Asked Questions. <http://www.fcps.edu/ss/preschool/childfind/faqs.htm>

5. Mzingo, Tracy A. (2008, winter) Healthy Children: When it is More Than a Cold. <http://www.aap.org/healthychildren/08winter/HC-winter08-rsv.pdf>

Improving Your Child's Visual-Motor Integration Skills

by Carl Gabbard of Texas A&M University and Tatiana Bobbio of State University of Campinas, Brazil



istockphoto.com/Rohit Sethi

A view of research concerning premature and low birth weight infants shows that some may be at-risk to have deficits in fine- and visual-motor integration in later years. These deficits may contribute to an array of developmental impairments evident by school age. For example, difficulty with

handwriting, printing skills, copying, cutting, and visual-tracking that underscores several play activities. Problems such as these are typically more obvious by 3 years of age. However, most experts would agree that the earlier the intervention, the better the chances of improvement.

What is visual-motor integration?

It is defined as the degree to which visual perception and limb movements, in this case finger - hand actions, are well coordinated. Assessment involves the extent to which a person can integrate their visual and motor abilities. Related to this is fine-motor function - the developmental status of finger / hand movements. Although the use of visual information may play a role in these tasks, assessment focuses on motor actions.

Recommended Activities.

Remember, the focus of these actions are use of eyes and hands / fingers working together. The general recommendation is to use age appropriate materials and activities. Nonetheless, in many situations you will need to "back-up" and work up to and perhaps beyond your child's age.

INFANTS

Crib toy activity: overhead mobiles (colorful and moving), especially those that afford grasping

Soft grasping rings, shapes

Provide rattles and teething rings to reach, grasp, and shake

Pop bubbles by reaching, poking, and clapping (also for older children)

Stacking objects: Legos, cups, small containers

Building towers with small toy cubes

Developmental Milestones

The following list examines a few milestones depicting when 75% of children accomplish the task. However, please keep in mind that our objective should be to help your child get to the next level, regardless of how he or she compares with others.

Infants

Grasp objects (rattle size)	3.5 months
Reach with some accuracy	5 months
Place object in a cup	12.5 months
Scribbles	15 months

Preschoolers

Build tower of cubes (small blocks)	3 years
Handles small fork and spoon	3 years
Cuts with scissors	3 years
Copy circle and crosses	3.5 years
Laces shoes	4 years

School Age

Copy square	5 years
Colors within the lines	5 years
Prints fairly well	6 years
Catch a ball	6-7 years

3-YEARS AND UP

Drawing / writing – use big then small pencils / crayons; chalk on a board and driveway

Art activities – finger painting

Stringing objects - use string / shoe laces: beads, colored macaroni, cereal such as Cheerios and Fruit Loops

Sorting - shapes, cards, buttons (by size, color), coins

Continued on page 5

3 Years and Up, continued

Cutting with scissors

Computer and board games: moving the computer mouse to targets and objects is an excellent activity

Puzzles: large, then smaller pieces

Peg board games

Playing catch--use soft colorful balls of various sizes

Tying shoe -- laces, ribbons

Hand / Finger strength:

Squeeze Play-Doh or real dough (finger / hand strength)

Open and close ziplock bags and jars

Pinching - clothespins, clips, snaps, velcro

Zipper and snap toys

Widely used and effective professional assessments include:

Posture and Fine Motor Assessment of Infants: ages 2- to 12 months

Peabody Developmental Motor Scales, Second Edition (PDMS-2): Fine-Motor section ages birth to 5 years

The Beery-Buktenica Developmental Test of Visual-Motor Integration: ages 2 and up

To learn more about various professional assessments, please go to www.pearsonassessments.com.

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Tatiana Bobbio, MS, teaches pediatric physical therapy and is currently a Visiting Scholar at Texas &M University

.....
? If you suspect a problem, ask your doctor, medical professional (usually a physical therapist), or school diagnostician to perform an assessment.
.....

Please cut out and post in your home to help keep your child healthy.

By Cathy Rodrigues, LCSW



Will you wash your hands for my baby?

Babies born prematurely or who have heart problems and lung issues are at greater risk to be hospitalized from a cold. **RSV(respiratory syncytial virus)** is a virus that begins with cold-like symptoms but then can result in a lower respiratory infection, lung inflammation, wheezing, difficulty breathing and pneumonia. RSV, the most common cause of bronchiolitis, can result in long term negative effects on the ability for a newborn or infant to breathe easily.

A baby becomes infected by coming in contact with another infected person or with the secretions from an infected person. An infant usually acquires the infection from contact with an older family member who may have only mild, cold-like symptoms.

When someone is infected, extra precautions need to be taken by washing hands often and preventing the spread of infectious secretions on tissues and objects. RSV is spread by direct or close physical contact, which includes touching or kissing an infected person, or contact with a contaminated surface.

The American Academy of Pediatrics says to take the following precautions:

- Make sure everyone washes their hands before touching your baby.
- Keep your baby away from anyone who has a cold, fever or runny nose.
- Keep your baby away from crowded areas like shopping malls.
- Keep your baby away from tobacco smoke. Parents should not expose their infants and young children to secondhand tobacco smoke, which increases the risk of and complications from severe viral respiratory infections.

So if I ask you to wash your hands, it's nothing personal. I ask everyone to keep my baby healthy!

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Fairfax Neonatal Associates (FNA) Neurodevelopmental Research Studies

By Ida Sue Barton, PH.D., ABPP-CN

Improving the care of preterm babies is a central concern of FNA physicians and staff at Inova Fairfax Hospital for Children's NICU. It is important to learn more about the intellectual, behavioral and academic outcomes of NICU "graduates". This information is useful to help the physicians better understand which, or what combination, of the many different care practices and treatments provided in the NICU will result in the best possible developmental outcomes for the preterm child.

Neurodevelopmental research studies began three years ago at the IFHC NICU. The first studies were of those born weighing less than 1000 grams (2 lbs. 3 oz.), who were then 6 years old. These studies have already provided important information about the intelligence, academic achievement, attention, judgment and reasoning, language, memory, motor skill, and emotional function of these children. Data is also being collected on a comparison group of term-born, normal birth weight children who were born at IFHC.

The success of these studies of children at 6 years old led to decisions to 1) continue testing each birth group of preterm children as they turn 6 years old, and 2) expand our studies to include 3 year old children who weighed less than 1000 grams at birth. We also are testing 3 year old term-born controls and children who were born at 34 - 36 weeks gestational age.

There is very little detailed information in medical journals about the outcomes of these early born young children. However, we do know that the preterm baby is at risk for later intellectual and cognitive problems. Studies such those we are conducting are expected to help us understand which medical, family, and behavioral factors will either improve or possibly worsen a child's functioning, in order to arrive at an understanding of how best to have the most optimal outcomes.

Our research is being conducted on an ongoing basis. If you think your preterm child may be eligible to be included

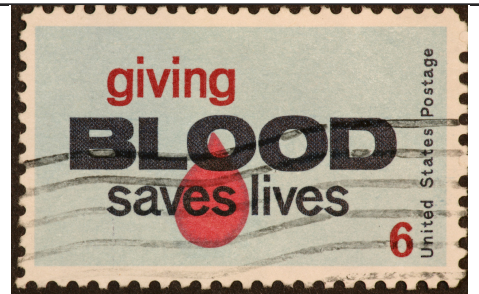
These studies have already provided important information about the intelligence, academic achievement, attention, judgment and reasoning, language, memory, motor skill, and emotional function of these children.

in these studies, or if you have a child who was not preterm and who is either 3 or 6 years old and can be a control subject, we would like to hear from you. We will provide you with a summary of your child's intellectual test results at no cost to thank you for your participation in these studies.

You can reach us at 703-289-1400, ext. 2416. We look forward to hearing from you and to continuing these important studies.

Ida Sue Baron, Ph.D., ABPP-CN
Director of Neuropsychology
Department of Pediatrics
Inova Fairfax Hospital for Children
Falls Church, VA 22042

Save the Date:
Give Blood
February 14, 2009



Many of our children benefited from blood transfusions. Join us as we give back to the community.

info@premiestoday.org

Helpful Resources Websites and Numbers

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

Membership/Subscription Information:

We offer the Preemies Today newsletter, family outings, parent support groups, preemie play-groups, and a Parent-to-Parent telephone line for parents and families of preemies. Membership in our organization is free.

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

Don't Forget!

**Telephone Support Group with
Cathy Rodrigues, LCSW and
Life Mentor Coach along with special guest JoAnn
Kennedy, OTR/L**

Fri., January 16, 1 p.m. EST

Parenting and Discipline: Understanding the Impact of Sensory Development

This newsletter was funded by donations and contributions made to Preemies Today. This material is for informational purposes only and does not constitute medical advice. The opinions expressed in this material are those of the author(s) and do not necessarily reflect the views of Preemies Today.

**PREEMIES
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