

# PREEMIES TODAY

## *Families Helping Families*

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### PREEMIE OF THE MONTH:

*This month's preemie is Jason Miller. Jason is just turning one and loves to get out and about with his big sister, Emily. Here is his story as told by his mom, Stephanie.*

We announced our second pregnancy on Thanksgiving of 2004 to our families. It was very exciting and was going to be a welcome addition to our family of three. We had a 3-year old daughter at the time. My due date was put at August 1st, 2005 but we were told that I would have a scheduled c-section on or around July 23rd, as my previous pregnancy ended in a c-section.

The pregnancy actually went pretty well. I exercised as much as I could and stayed busy chasing after our 3-year old daughter, Emily. All the ultrasounds came out normal and things progressed smoothly.

Around 18 weeks, I had an amnio and the results came back that the baby was fine and that it (we didn't find out the sex till later) was developing normally. However, the doctor found that I had placenta previa! He said to just continue with my normal check ups and to notify my OB immediately of any cramping or bleeding. Worst case scenario was that I would bleed and need a transfusion or have a hysterectomy.

In addition, right around mid-May on my 36th birthday, I tested positive for Gestational Diabetes which threw me for a loop. I was naïve and thought only overweight women were diagnosed with such a disease. But as I educated myself and spoken to other women who had been diagnosed, some of my worries were relieved. I began testing my blood daily.

Then during the week of June 12th I was feeling cramps and went into the hospital. I was on monitors for about three hours but there was no labor. It was more like Braxton Hicks contractions, so they sent me home. But the morning of Fathers Day I lost my mucous

plug, called my OB and she sent me to the hospital. I was monitored for 24 hours and told that upon getting home I was to remain on strict bed rest until the end of the pregnancy. I was shocked and scared. I was walking around angry and felt that this growth in my belly was just causing me all sorts of hardship. I wanted to enjoy this pregnancy but so far was having set backs right and left. I finally decided to call the doctor's office and



asked them to tell me the sex of my baby, perhaps it would help me bond with the baby in my belly.

At 1 a.m. on June 24th I awoke to use the bathroom and noticed that my bed was covered in blood. I panicked; we knew it was time. Our neighbor came over to stay with Emily while Al drove us to the hospital. Three hours later, Jason was born via c-section and then immediately taken to the NICU. Although his apgar scores were ok, he was having trouble breathing and had arrived almost 6 weeks early. He weighed in at 6 lbs 5 oz and was about 19" long.

The time we spent in the NICU was still the longest 8 days of our lives. I didn't get to hold Jason until a few hours after he was born and

could only hold him briefly. He had jaundice, was on oxygen and a CPAP. I wasn't allowed to nurse him till day 3 but thankfully for the few minutes I tried, he latched on. However after just a brief time, I had to put him back in the incubator. His bilirubin remained elevated and each day the neonatologist told us that we still couldn't take him home. He finally came off oxygen around day 3.

It wasn't till Sunday (48 hours later) that I realized no one had come to talk to me about "What to expect while the baby is in the NICU rather than in your room" re: emotions, fears, anxiety, health of baby, etc. By Monday evening I began to come off the high of having my baby, seeing my family, and having visitors. It sunk in that I still couldn't take Jason home. I felt very alone between my husband's visits (he had to be home with Emily). People stopped coming by the hospital including my extended family. I stayed there at night and most of the day in between cab rides home to see Al and Emily. Outside of the brief conversations I would have with the NICU nurses, I felt hopeless and alone, anxious and sad all at once. The hospital put me up in their maternity ward in a private room but I was always going down the hall in order to see my baby. It was surreal and unorthodox. And looking around I saw all the new moms with their babies in rooms right next to mine. There was no one to talk to except the NICU nurses and I already felt intimidated by them because I didn't want to take their precious time by asking so many questions. Eventually I was given a big folder that said "NICU Parents Information Packet".

I had walked into the NICU to see Jason and the world seemed to stand still. I looked around me and saw these new moms, like myself, standing in front of their tiny babies' incubators. Some were crying, others were speaking with the nurses and others stood like zombies peering at their tiny babies. Something was missing in this surreal setting.

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## Apraxia

Carrie is a 2-year old who is having behavioral outbursts, saying just 3-5 words, and is easily frustrated. She can follow one to two step directions but looks at her parents with a blank look when they try to get her to repeat words. She mostly points or pulls her parents to what she wants. Justin is a 4-year old whose speech is unclear and is unable to imitate words on demand or sing simple songs clearly. He can be clumsy on the playground and is a “picky” eater. These are examples of apraxic children.

Just what is apraxia/dyspraxia? Dyspraxia is a neurological disorder of motor coordination usually apparent in childhood that manifests as difficulty in thinking out, planning out, and executing planned movements or tasks. (Gale Encyclopedia of Neurological Disorders, 2005). It derives from the Greek word “praxis”, meaning “movement process”. Verbal dyspraxia is also known as developmental apraxia of speech and affects 6% of children ages 5 to 11. The cause of verbal apraxia is mostly unknown. What we do know, is that many children with apraxia do not usually start talking until age 2 or older. They are often silent as babies and toddlers, seldom babbling or cooing. They have difficulty discriminating between sounds and their own voices and do not “feel” the speech. They are unable to imitate speech and/or nonspeech sounds as their neurological system has not fully developed. Their speech may sound garbled or unclear.

Children with apraxia have limited expressive communication (actually saying words) but usually have an adequate understanding of language (receptive language). Dyslexia, learning disabilities and attention deficit disorder (ADD) often occur in children with apraxia. These children may also exhibit sensory integration dysfunction (SID) which is the brain’s inability to integrate certain information received from the body’s five basic sensory systems. This child may have difficulty differentiating between the sensory systems (e.g. detecting sight, sound, smell, tastes, temperatures,

pain and the position and movements of their body). The ongoing relationship between behavior and brain functioning is called sensory integration (SI). It is necessary to help the child organize and “calm” their body in order for them to generate speech.

Although children with verbal apraxia do not outgrow this disorder, they can develop clearer speech and language with appropriate intervention from a speech-language pathologist. They may also benefit from occupational and physical therapists who specialize in sensory integration. Findings from a neurodevelopmental evaluation may confirm a suspected diagnosis. Treatment programs that combine muscle movement, oral-motor therapy, speech sound production, and increasing expressive language skills often get the best results. Providing these children with undemanding and fun activities can lead to increased vocalizations. The focus should be to increase their ability to make ANY sounds. This can include animal sounds, laughter, coughing, kissing, or environmental sounds (car, airplane). Unstructured activities such as blowing bubbles or whistles, brushing teeth, singing repetitive songs (e.g. Old McDonald) or making silly faces/sounds in front of a mirror can lead to sounds, words, and expressions of joy in the ability to communicate!

### Resources:

Childhood Apraxia, Marshalla, P., 2002  
The Late Talker, What to Do If Your Child Isn’t Talking Yet,  
Dr Marilyn C. Agin  
[www.apraxia-kids.org](http://www.apraxia-kids.org)  
[www.healthline.com](http://www.healthline.com)  
[www.expresstrain.org](http://www.expresstrain.org)  
[www.kidsspeech.com](http://www.kidsspeech.com)

*This month’s contributor is Christina McAdams, SLP. She works as a Speech Language Pathologist in private practice and is the mom of two boys.*

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*continued from cover, Jason’s story*

Happiness, tears of joy, etc. All that stuff that is supposed to happen with a new baby. The connection to our newborns was sporadic and sometimes painful and scary. And knowing that immediately after giving birth, my physical self was going through a roller coaster ride of hormonal changes added to the stress.

The NICU nurses were amazing and acted as counselors in some respect reassuring me and the other parents that our babies would be okay and that their stay in NICU will only make them stronger. The care that they gave Jason was impeccable. And their sensitivity to my husband and me was unmatched.

Eventually after 8 long days in the NICU, with the last night being up in the PEDS ward, we were able to take Jason home with us. That was a great day and a relief. And although our experience with the NICU and our preemie was a different one and shorter than most, I still feel like a member of this special group of women that have been tested and made stronger through our experience with our preemies.

Jason is now 11 months old and a joy to be around. He’s got big blue eyes and a little bald head. But he is his sister’s pride and joy and our gift. He’s just about to turn 1, and we plan to celebrate with our friends and family not only his first year of life but also his fight to get into this world. He made his mark! And we love him.

## Local News:

*Announcements:*

### Call for Articles:

The Premies Today Newsletter is currently looking for contributors. If any of the following categories interest you, please contact us for more information.

#### *Premie of the Month*

Is your preemie over one year old and you want to have your story featured in our newsletter? Then submit your preemie story for Premie of the Month. Stories are typically written by parents and should be 800-1000 words. You also will need to include a recent photo of your preemie. To submit your story or to get more information, email Deborah at [deborah\\_leaf@yahoo.com](mailto:deborah_leaf@yahoo.com).

#### *Health Professionals*

Is there a topic that you think should be included in the Premies Today newsletter? Please submit your ideas and if you are available to write a short article about your topic. Contact Deborah at [deborah\\_leaf@yahoo.com](mailto:deborah_leaf@yahoo.com)

#### *Product/Book Reviews*

Is there a product that you can't live without or a book that helped you through the NICU? If there is a product or book that you would like to review for an upcoming newsletter, please contact Deborah at [deborah\\_leaf@yahoo.com](mailto:deborah_leaf@yahoo.com).

### June Family Outing

Please join us to celebrate Father's Day (one week late) at 10:30 on Saturday, June 24 at Kidwell Farms. It is located at 2709 West Ox Road, Herndon, Virginia. Kidwell Farm is a working farm sponsored by the Fairfax County Park Authority. Admission is free. So come and join the fun and see the new baby animals. There are picnic tables and some trees that provide shade. Please meet us near the playground and bring a dish to share. Following our lunch we will take a barnyard tour. Please RSVP to Mary Beth at [marybethhazeltrove@verizon.net](mailto:marybethhazeltrove@verizon.net)

### Support Groups:

#### *Take a Break*

Premies Today offers meal preparation assistance, babysitting, and other additional support options for preemie families in crisis. If you are in need of assistance or would like to volunteer to help others, please contact Sara at [sara@teamchae.com](mailto:sara@teamchae.com).

#### *"A Friend to Talk to"*

Our "Friend to Talk to" support line is up and running. Please feel free to give us a call and one of our preemie parent volunteers can offer you some much needed support. The support line telephone number is 703-552-0163, or toll free number at 1-888-712-3208.

#### *NICU Support Group*

INOVA Healthsource is continuing to offer a NICU Support group for NICU families at INOVA Fairfax. The meetings are held on the unit and vary month to month. The group is led by Lynn Kuba, RN and is a great opportunity to talk about your experience in the NICU. For more information contact INOVA Healthsource at 703-204-3366.

#### *Premies Today Online Chat*

Join us for our monthly online chats. This is a great outlet for new parents who still can't get out for our support groups. For more information contact Julie at [jkipers@lmi.org](mailto:jkipers@lmi.org)

#### *Local Support Groups*

Local support groups are going strong! On the 2nd and 4th Wednesdays at 7:30 pm we hold our local support group meetings. For more information email Deborah at [deborah\\_leaf@yahoo.com](mailto:deborah_leaf@yahoo.com).

#### *Yahoogroup!*

Come and join our yahoogroup and meet some of our wonderful parents where you can exchange information on preemie parenting. You can subscribe at <http://groups.yahoo.com/group/PremiesToday/>

## Helpful Resources:

The following are some helpful resources available by phone and online:

Prince William County Social Services:  
[www.co.prince-william.va.us/csb/programsandservices/](http://www.co.prince-william.va.us/csb/programsandservices/)

Fairfax County Department of Family Services:  
(703) 324-7500  
[www.co.fairfax.va.us/services/dfs/](http://www.co.fairfax.va.us/services/dfs/)

Social Security Administration:  
1-800-772-1213  
[www.ssa.org](http://www.ssa.org)

SIDS Mid-Atlantic  
(703) 933-9100  
[www.sidsma.org](http://www.sidsma.org)

March of Dimes  
1-800-326-BABY  
(703) 425-BABY (Metro DC)  
[www.marchofdimes.com](http://www.marchofdimes.com)

Sidelines National Support  
1-888-447-4754  
[www.sidelines.org](http://www.sidelines.org)

Early Intervention/ Infant Toddler Connection  
Fairfax County- (703) 246-7121  
Alexandria- (703) 838-5060  
Prince William- (703) 792-7879  
Calvert County- (410) 535-1955  
Arlington County- (703) 228-1630

WIC  
Manassas- (703) 792-4703  
Woodbridge- (703) 792-7319  
Springfield (703) 569-1031  
Mount Vernon (703) 660-7100  
Fairfax- (703) 246-7100

**For a list of online resources please go to:**  
**[www.PremiesToday.com](http://www.PremiesToday.com)**

### **Mission of Premies Today:**

*Premies Today is a 501(c)(3) nonprofit organization whose mission is to reach out and provide support to families of infants born prematurely beginning at birth and throughout childhood.*

*Vision: We will reduce the stress of caring for a child born prematurely by creating a network of families who offer help, comfort, and understanding to one another.*

*Values: We strive to promote compassion, inclusiveness, understanding and patience.*

**Membership/Subscription Information:**

We offer the Premies Today newsletter, family outings, parent support groups, preemie playgroups, and “A Friend to Talk To,” our call-in line for parents and families of preemies. Membership in our organization is free.

For a free subscription to the newsletter please email us at [premienewsletter@yahoo.com](mailto:premienewsletter@yahoo.com). If you would like to become a member of Premies Today please email us at [premiemembership@yahoo.com](mailto:premiemembership@yahoo.com). Our website is **[www.PremiesToday.com](http://www.PremiesToday.com)**

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Do you need to talk to someone who understands the preemie experience? If so, call the “Friend to Talk to” line at **1-888-712-3208**