

# PREEMIES TODAY

## *Families Helping Families*

### PREEMIE OF THE MONTH:

*This month's preemie is Abigail Ablondi. Abigail is a miracle baby in many ways and one day might just be the next Mrs. Maryland, just like her mom! Here is her story as told by her mom, Heather.*

After my husband and I got married, we decided to try to start our family right away. After a year of trying, we sought help from a fertility specialist and a year later we had finally conceived our first baby. All throughout that second year of trying, I remember saying, "If I could just get pregnant, I know everything will be fine." I could not have been more wrong.

At about 21 weeks gestation, my husband left for an overseas business trip that would have him out of the country for 4 weeks. I can remember counting down the days until he would return on March 19, 2006. I had no idea that that date would take on significance for a much different reason.

The morning of March 19th finally arrived and I spent the day preparing a nice meal and getting the house ready for him to come home. I checked his flight status and found out that it was delayed by two hours, so I decided to take a nap to make time go by faster. When I woke up from my nap, something was very wrong. While sleeping, my water had broken. I called the doctor and was told to go to Reston Hospital immediately.

Once at Reston, I realized the severity of my situation. I was placed on complete bedrest, given numerous IVs (they had a difficult time getting one in place), and connected to all the traditional monitors. I will never forget the look of panic on my husband's face when he arrived and I told him what had happened. It was definitely not the reunion we had anticipated.

After having mild contractions throughout the night, I was told that I would need to be transferred to another hospital because the NICU at Reston was not able to care for a 25 weeker. Thankfully, they were able to take me at Inova Fairfax where I spent the next two and a half weeks on bedrest. Once there, I was given terbutaline to stop my contractions and monitored for infection constantly.



On April 4 at 6 pm, my contractions started again and they were not able to stop them. I was taken to labor and delivery and prepped for a normal vaginal delivery. Several hours later, Abigail's heart rate started to skyrocket and my temperature started to climb. These were both signs that infection was setting in and they decided to do an emergency c-section right away.

Abigail was born at 11:44 pm on April 4th. She cried when she came out, but was immediately intubated. I got to see her before they rushed her to the NICU. Her face was severely bruised and her eyes were swollen to the size of golf balls from the lack of amniotic fluid, but to me she

was the most beautiful baby I had ever seen.

Several hours after being born she decided to extubate herself and was placed on CPAP. We were thrilled that she seemed to be doing so well. I did not realize that we were in our "honeymoon" period. At around 10 am the next morning, she took a severe turn for the worse and was placed on the oscillator at 100% oxygen. We were told that the next 72 hours were crucial and that we needed to prepare ourselves for the fact that she may not make it.

Well, our daughter has been a fighter from the beginning. She amazed the doctors when she was taken off the oscillator five days later and moved to the CPAP and then twelve hours later to a nasal cannula. Throughout her 89 day NICU stay, we moved back and forth between the two. There were times when I was convinced that I would be sending her off to school on a CPAP.

Abigail also suffered from a mild Level 1 IVH, had numerous transfusions, was treated for severe jaundice, had several infection scares, had an open PDA (that closed on it's own) and a heart murmur that was caused by her ASD valve. She was also treated for reflux and when she was able to eat from a bottle she needed thickened feeds due to aspiration.

Her main problem all throughout her stay continued to be her lungs. We were told that even though she was born at 28 weeks, her lungs were more like those of a 25 week baby. She was finally given an inhaled steroid treatment and we saw immediate results. It was a wonder drug for her and she was able to come off the CPAP within days of starting the treatment. When she was finally weaned down to just

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**Mission of Preemies Today:**

*Preemies 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.*

**What We Do**

We offer local in-person support to families of preemies in the extended Washington DC metropolitan area. We provide on-line support to families of preemies located across the country and internationally. Preemies Today is made up mostly of parents of children born prematurely. We network with other parents groups, healthcare providers, therapists, and people providing community resources to obtain information for our members.

**Our Programs**

Monthly Newsletter

Parent support groups

Online Chats

Premie Play groups

Family Outings

Premie Care Packages for NICU families

“Take a Break” program for families in need

“Friend to Talk To” support hotline

Resource Brochures

Online Yahoo group

*You are cordially invited to the  
Preemies Today Annual Celebration*

*June 9, 2007*

*3pm - 6pm*

*The Physician's Conference Center  
Inova Fairfax Hospital*

Many factors may affect successful nursing for any baby. If the baby is nursing well, the position, utensil (breast or bottle) and flow rate will not matter. The baby has the oral motor skill to accommodate what ever position, utensil or flow rate is present. However, premature infants may have difficulty adjusting to changes in position, utensils or flow rates. Premature infants have all of the muscles needed for the face and mouth, but the muscles may need stimulation to be able to move efficiently. A premature baby may fatigue easily during feeding. While in the hospital, you, the lactation consultant and the therapists worked to help your baby to begin nursing, using whatever assistance was needed (Haberman bottles, preemie nipples, supplemental nursing system, support to the jaw and cheeks). Now that your baby is home, it may be difficult to keep the momentum going to increase the amount per feeding, reduce the time needed to feed and to move toward breast feeding. If your baby is still on oxygen and has a nasogastric tube, your baby may not yet be stable enough to move to oral intake. The focus of treatment is to move your baby to more stable health.

#### Body Position

If your baby is now healthy and stable and you are ready to work to improve feeding, several areas must be addressed: position of the body, position of the head and neck, and oral motor control. Many premature babies fatigue as they move against gravity during nursing, whether at the breast or with a bottle. The baby tires easily as he or she moves the lips, cheeks, jaw and tongue against gravity. In order to compensate for muscle weakness, the baby may hyperextend the head and neck (arching the body backward), or lock the tongue against the roof of the mouth, or clamp the jaw closed. All of these patterns make feeding more challenging for the caregiver and for the baby.

To minimize work against gravity during nursing and reduce fatigue (lazy baby, sleepy baby, the nibbler), make certain that the baby is held in an inclined sidelying position, whether during breast feeding or bottle feeding. If using a football hold, still maintain the baby on his or her side. In inclined sidelying, the baby is positioned with the shoulder over shoulder and hip over hip, trunk straight and

shoulders higher than hips Support the legs in a flexed position (bent at the knees and hips) to avoid the baby hyperextending (going stiff and arching) the body.

Inclined sidelying position enhances the front to back movement of the rib cage during breathing, making breathing less effortful as compared to sitting. Also in this position, there is less gravity load (pressure) on the lower jaw as compared to sitting or reclined positions. In sidelying, gravity works through the jaw joint like a hinge on a gate, making jaw movement easier. Each nutritive suck should have a rhythmical up and down jaw movement at a rate of one per second. If jaw movement is reduced and only forward back tongue movement is present, the suck will be less efficient for drawing the fluid into the mouth.

In sidelying, if there is too much flow from the nipple, the excess fluid will pool in the lower cheek, or come out of the mouth, while if positioned reclined in arms or with the chin lifted, the fluid would collect in the pharynx (back of the throat) or would move into the air way where choking could occur. In inclined sidelying, the tongue is not pulled forward, as it may be in a sitting position when the jaw is open. If the baby is positioned in inclined sidelying, the tongue will not be pulled to the back of the mouth, as may occur in a slightly reclined position of the body or if the chin is tilted up. Gravity helps to maintain the tongue in a more neutral position in the mouth when the body is in a sidelying position. This makes the tongue movement for sucking (movement of the middle of the tongue to the roof of the mouth) more efficient and less effortful for the baby. If positioned in inclined sidelying, the tongue will not lock on the roof of the mouth, making insertion of the nipple easier.

If using a bottle, an easy way to place the baby in sidelying is to first position the baby in the caregiver's arm, as the caregiver would typically do, then the caregiver leans back into a semi-reclined position, so the baby is now in sidelying on the caregiver's chest.

#### Head and Neck Position

Head and neck position can also help your baby to move more efficiently during suck-

ing. Provide support for the head so that the back of the neck is elongated, with a slight flexion (chin slightly down position) of the head during nursing. This position is similar to the way we move our head when nodding the head to mean "yes." The neck is straight and the chin is positioned slightly down. If the baby lifts the chin, this may activate a pattern of jaw clamping. Helping the head to stay slightly flexed also enhances the jaw movement needed for efficient sucking. For a baby who fatigues easily, when the chin is farther away from the neck there is less stability (support) for jaw movement during sucking. By maintaining the head and neck in the position described (elongation through the back of the neck with slight flexion of the chin), less direct support is needed at the front of the jaw, allowing for better up and down jaw movement which needed for an efficient suck. In inclined sidelying, gravity can help to support the alignment of the head and neck for the baby, rather than the baby working so hard against gravity when nursing.

#### Oral Motor Control

Giving an infant commands such as, "Don't bite," or "Swallow," is not age appropriate and is not effective. Another ineffective technique still promoted by some is to stroke down the front of the throat to enhance swallowing. This does not help to improve swallowing for several reasons. First of all, the pressure is on the front of the throat, where the trachea (wind pipe) is located. One cannot touch the esophagus (food tube) from the outside because it is positioned between the spine at the back of the neck and the trachea at the front of the neck. That means that stimulation is given to the one place (the wind pipe) that fluid should definitely not enter. Also, the direction of the stroke is downward. In order to swallow, the cartilage must move upward. So stroking the front of the throat does not help with swallowing.

Oral motor control may be more difficult for babies who fatigue easily. Providing different positions or utensils can help to compensate for poor control. When using a bottle such as the Haberman or Infamil Mead Johnson Cleft Palate Nurser, the caregiver can pace the presentation of the fluid by giving a small pressure to the utensil every three seconds. If using a bottle with an assisted flow or with a fast flow, positioning in inclined sidelying is

# PREEMIES TODAY

## *4<sup>th</sup> Annual Celebration and Silent Auction*

**June 9, 2007, 3:00-6:00 p.m.**

**INOVA Fairfax Hospital Physician's Conference  
Center**

*Located to the right of the Woman's and Children's Center*

- *Free Admittance*
- *Meet and network with other preemie parents*
- *Dinner by Outback Steakhouse*
- *Children's Activities*
  - *Sense Abilities for Kids*
  - *Music from Miss Roberta*
  - *Face Painting*
- *Free Children's Raffle*
- *Goody Bags for kids*
- *Incredible Silent Auction deals*
- *Parent Resource Tables*

*Highlighted Silent Auction Prizes Walt Disney passes; McLaren stroller – Techno XLR; weekend at the Omni Hotel, NC; A flower pot autographed by the Governor of VA; NICU Journals, Top Golf, Spa Certificates, Arena Stage, Air Duct Cleaning Service, Private Tour of the National Zoo, Dinner Done, Circustickets, wine and many more!*

*Preemies Today is a nonprofit organization supporting preemie families  
For more information contact: [elainenoto@preemiestoday.org](mailto:elainenoto@preemiestoday.org) or 703-552-0163*

## Preemie of the Month Update: Madison Hazelgrove



*"Just hanging out!"*

Madison Leigh was born a little over 5 years ago weighing 1 lb 14 ounces. She is now a beautiful little girl who enjoys being a kid. She is in her third year of special education preschool and will be entering Kindergarten in a regular classroom with special education support this fall. She has been identified with a learning disability due to working memory processing deficit and visual processing deficit. She is also finishing her first year of ballet/tap dance which she has enjoyed. She also enjoys playing with the neighborhood kids, swimming, and going to school.

Madison has had a few complications due to her prematurity. Madison developed hydrocephalus due to a severe brain bleed and required a shunt when she was two months old. She recently had it replaced for the first time which apparently is pretty good as revisions and replacements to shunts can occur often in patients. It only took her a couple of days to get back on her feet and playing again with her little sister, Lexi. We have also had our fair share of OT and PT sessions that continue to help Madison.

I know I am Madison's dad and can be a bit partial, but there are just some people that you just can feel that they are destined for great things, and I firmly believe Madison is one of those people. She has a great spirit and loves life. She mentions wanting to be a doctor or a fireman, or a police officer when she grows up. You can really see that she wants to help others.

*Douglas Hazelgrove is the proud father of Madison and Lexi and works in IT.*

### Preemies Today Program Update: Preemie Care Kits

*by Elaine Noto*

We are excited to announce that our Preemie Care Kit program is expanding! We currently distribute the Kits to NICU's at Reston and Fair Oaks and in June will begin delivering them to Georgetown hospital.

These Kits respond to some of the needs experienced by families of premature infants who are in the NICU. Each Preemies Today canvas tote bag includes a Sudden Infant Death Syndrome (SIDS) endorsed Halo Sleep Sack, Preemies Today magnet with hotline number and website, educational literature from the SIDS Foundation, the March of Dimes and information about the Early Intervention Programs. A Preemies Today Membership Packet and a handy bottle of Hand Sanitizer is also included.

By the end of this summer we will also be adding a NICU Journal and an RSV-Free Zone door hanger; just in time for RSV season, along with tips on how to keep your little one safe this winter!

As always our goal is to provide support and information to our families. We constantly are looking for ways to improve our Programs and would be grateful to receive feedback about our Preemie Care Kit Program. Maybe you've seen a brochure that we don't provide, but you know would help other families. Please email your thoughts to me at [elainenoto@preemiestoday.org](mailto:elainenoto@preemiestoday.org).

*I want especially to thank The March of Dimes, ExxonMobil Favorite Charities Campaign and LMI who have provided generous support to help us continue to develop and supply these Kits to our families.*

### Preemies Today Support Programs:

*"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.

*Take a Break*

Preemies Today offers meal preparation assistance and additional support for preemie families in crisis. If you are in need of assistance or would

like to volunteer to help others, please contact Susan at [susan.boucher@starpower.net](mailto:susan.boucher@starpower.net).

*Preemies 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 every 2nd Wednesday 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/PreemiesToday/>

## Local News:

### Preemies Today Celebrates Father's Day

Preemies Today will be sending Father's Day cards to all our local area NICUs.

Preemies Today members will also be manning tables at several local NICUs on June 16 in honor of Father's Day. We will have coffee and other treats to honor dads celebrating with their NICU babies. Moms are welcome to partake in the goodies as well! For more information, or to volunteer to help out please contact Susan Boucher at [susan.boucher@preemiestoday.org](mailto:susan.boucher@preemiestoday.org)

### Ethics Course Needs Volunteers

Uniformed Services University provides a one day Ethics Course for their third year medical students. On this day parents are invited to speak to medical students in small groups to share their NICU stories and experiences. This day has a lasting impression on each of these students and is worthwhile for all parents as well.

When: 28 August 2007, Tuesday

Where: Uniformed Services University, Bethesda, Maryland

Time: 11:30 luncheon; Course participation 1pm - 4pm

RSVP: Kathy Vestermark/703-264-0674 or [vestermarkx8@cox.net](mailto:vestermarkx8@cox.net)

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*continued from cover, Abigail's Story*

the low-flow cannula, I could see the light at the end of the tunnel.

Abigail came home on June 29, 2006 – her due date. We had oxygen, monitors and lots of medications, but that didn't matter. All that mattered was that we had our angel home with us. She has been absolutely thriving ever since. She has "graduated" from all her preemie doctors and is growing and developing on schedule for her adjusted age. We realize how blessed we are for this outcome and never

take for granted all of the "could have beens".

Abigail has a smile that will brighten anyone's day. She loves to meet new people and makes new friends wherever she goes. One of her favorite things to do is watch Disney's High School Musical or American Idol. She is fascinated by singing and will dance along with the music. She even dances to the music in the grocery store while sitting in the shopping cart. She is a very happy and good-

natured child who brings us immense joy everyday.

Right now, Abigail is the center of our world, but that is all going to change soon. We were very surprised to find out that she is going to be a big sister in November. I can only hope that this next little girl turns out as special as our Abigail. I just pray that she stays inside until much closer to her due date and not want to do everything like her big sister.

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*continued from page 3, Nursing considerations*

important to avoid excess fluid collecting in the back of the throat.

Another area of focus is to improve minimal competencies for the muscles for the face, using interventions that do not require the infant to follow commands, as infants use reflexive patterns. The muscles may need assisted stretch to provide stimulation to be able to move efficiently.

Poor oral motor control is often present for premature babies. The movements needed for efficient and effective sucking require durational control and durational strength. Many babies fatigue after only one or two sucking movements, and then must rest before activating a sucking pattern again. Often these babies try to stabilize with the jaw by clamping on the nipple when the muscles fatigue. There are specific assisted movements for the muscles of the face that are appropriate for an infant. For a list of therapists trained in these interventions, see the web site [www.beckmanoralmotor.com](http://www.beckmanoralmotor.com)

Clinical observation by a number of professionals indicate that durational jaw movement

of 10 to 15 seconds of jaw movement is helpful for a more organized sucking pattern, whatever utensil is used. That movement is timed to be one per second for 10 to 15 seconds of duration. A trained therapist can assist in the assessment and appropriate treatment for the baby who fatigues easily, has significant loss of fluid, has a noisy suck, has a poor latch, clamps on the nipple or has poor weight gain. When oral motor difficulties are identified and treated early, additional problems can be avoided.

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*Debra Beckman, MS, CCC-SLP has worked in the field of communicative disorders since 1975, specializing in motor speech disorders. She has worked in a*

*variety of settings, including schools, hospitals, universities, trauma centers, homebound, foster homes, group homes, Intermediate Care Facilities for the Mentally Retarded (ICF-MRs), nursing homes and large residential facilities. As a self-employed consultant, she has co-authored training materials for the states of Florida, Oklahoma and Wyoming, which are presently used in a number of states. She has served as a court appointed witness and as a resource content expert for seven federal court cases, regarding services for the developmentally disabled. Ms. Beckman has presented at numerous local, state, national and international conferences, and has published articles in professional books, journals, monographs; and in Exceptional Parent magazine. She has been awarded a United States patent for a therapeutic oral probe. She has developed the E-Z spoon and Tri Chew teether. Ms. Beckman has been recognized by her peers and her community for outstanding clinical achievement.*

## **Helpful Resources:**

### **National Resources**

#### **Social Security Administration:**

1-800-772-1213

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

*Many premature infants qualify for Social Security Disability, regardless of parents income. Ask your NICU social worker or contact the SSA to see if your child qualifies.*

#### **The State Children's Health Insurance Program (SCHIP)**

<http://www.insurekidsnow.gov/>

*All states have a health insurance plan for uninsured children under the age of nineteen whose families meet the income cap. Go to the above website to find your state's program.*

#### **March of Dimes**

1-800-326-BABY

[www.marchofdimes.com](http://www.marchofdimes.com)

*The March of Dimes has a wealth of information about preterm labor and premature birth. It is also a great place to start in looking for support in your area.*

#### **Sidelines National Support**

1-888-447-4754

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

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

#### **SIDS Mid-Atlantic**

(703) 933-9100

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

*Look here for information on how to prevent Sudden Infant Death Syndrome.*

### **Metro Washington, DC Resources**

#### **Social Services- Virginia**

Alexandria- (703) 838-0700

Arlington County - (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

#### **Social Services, Maryland**

Montgomery County- (240) 777-1245

Prince George's County- (301) 909-7025

#### **Social Services, Washington, DC**

Department of Human Services- (202) 671-4200

#### **Early Intervention/ Infant Toddler Connection**

*This is a federally mandated program available in every state to screen and treat children under the age of 3 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.*

#### **Virginia**

Alexandria- (703) 838-5060

Arlington County- (703) 228-1630

Fairfax County/Falls Church City- (703) 246-7121

Loudoun County- (703)-777-0561

Prince William- (703) 792-7879

**Washington, DC-** (202)727-8300

#### **Maryland**

Montgomery County- (240) 777-3997

Prince George's County-(301) 265-8415

#### **WIC**

*Provides food, nutrition counseling, and access to health services to low-income women, infants, and children under the Special Supplemental Nutrition Program for Women, Infants, and Children, popularly known as WIC.*

#### **Virginia**

Manassas- (703) 792-4703

Woodbridge- (703) 792-7319

Springfield (703) 569-1031

Mount Vernon (703) 660-7100

Fairfax- (703) 246-7100

**Washington, DC-** (202) 645-5662

#### **Maryland**

Montgomery County- (301) 762-9426

Prince George's County- (301)856-9600

**For a more complete listing of resources please go to:  
[www.PremiesToday.org](http://www.PremiesToday.org)**

**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 our newsletter and to join Premies Today please email us at [info@premiesto-day.org](mailto:info@premiesto-day.org) or you may go to our website at [www.PremiesToday.org](http://www.PremiesToday.org) and click on "Join us."

**In this Issue:**

Preemie of the Month:  
Abigail Ablondi

Focus on:  
Breastfeeding

**Fourth Annual Celebration  
and Silent Auction  
Saturday, June 9**

This newsletter was funded by a Community Grant from the March of Dimes. This material is for information 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 the March of Dimes.

**PREEMIES  
TODAY**

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

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**