

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

Our Premie of the Month is Mia Marie Cannon. Mia turned 2 years old last month and proves that preemies can be born without any major medical problems.

Oh, What a Special Delivery!

Mia entered this world two months early on February 26, 2004 at 32 weeks gestation via emergency C-section.

After a fairly uneventful 7 months of pregnancy (other than being a Rh-Negative Mom and borderline hypertension), I went to a routine OB/GYN check up on Monday, February 23. At that time, I was told that there didn't seem to be enough amniotic fluid and that Mia might have to be born a little earlier than her estimated April delivery date. The perinatologist didn't seem too worried. However, he scheduled me for two steroid shots (Betamethasone)...just as a precaution...and asked that I come back on Thursday of that same week for a follow-up. I proceeded with steroid shot #1 on Tuesday, and steroid shot #2 on Wednesday.

I took off from work the entire day on Thursday to first go to the follow-up visit and also to run as many errands as possible (i.e., post office, cleaners, grocery store, oil change for car, etc.). However, that Thursday morning follow-up appointment changed my life, totally.

At that follow-up appointment on Thursday, during a sonogram, it was discovered that there still was not enough fluid and also that the baby's heartbeat seemed to have slowed down dramatically since Monday's visit. After a few minutes and a second opinion/consultation with another doctor, it was decided that Baby Mia need to be delivered immediately. The doctors advised me that there was no need to go absolutely anywhere because they would walk with me right down the hallway to the labor & delivery section at INOVA Alexandria Hospital. (My doctor's office was actually located inside the

hospital building).

I said, "Hey, no way. I have lots to do today. I don't even have my labor & delivery bag with me." In so many words, the doctors said "you will survive without your bag." They then asked if I wanted to call someone. I said "Yes, my husband!"

My husband was not in his office, so I had to leave him a voicemail and the message said, "Hey Babes, don't be alarmed, but I'm going to have the baby today! Call me back on my cell phone." When my husband called me



back, he was shocked he said he was walking around in circles in his office confused. This totally caught us both off guard. Needless to say, he left his office immediately to be with me.

Six hours later, Mia Marie Cannon was born weighing only 2 pounds, 8 ounces, 13.5 inches long, via emergency C-section in the breech position. Actually Mia was screaming/crying while her head was still lodged in my stomach and her butt was being pulled out first. Her APGAR scores were 7 and 9. We were told that Mia she was breathing on her own and that her lungs seemed mature. However, she did not have one ounce of fat under her skin. She was literally all skin and bones—no fatty layer whatsoever. So regul-

ating her body temperature was of serious concern. We were also told during my c-section recovery period that if Mia was not delivered that day, she would not have survived another 24-hours in-Utero. As I said at the beginning of this article, Oh, What a "Special Delivery!"

Luckily, Mia was born without any major health problems although my labor & delivery report indicated that I had PIH (Pregnancy Induced Hypertension with a blood pressure that peaked at 174/140), severe IUGR (severe IntraUterine Growth Restriction), severe oligohydramnios (too little amniotic fluid), poor biophysical profile, and anemia of prematurity.

The entire NICU staff at the INOVA Alexandria Hospital were truly amazed at how little assistance Mia needed. Mia did not need any oxygen, nor did she have any major "preemie" issues to be concerned about. While in the NICU, Mia was gavage fed for only one day and was given Bilirubin phototherapy for jaundice for 4 days. Mia was then released to go home after 24 days (3 weeks) (weighing at that time 4 pounds, 1 ounce). Once released, Mia was given Zantac and Reglan to take for her mild GERD, nutritional support of Neosure formula (for extra calories/weight gain) to be taken with breast-milk, Polyvisol w/ iron (vitamins), and an eye ointment for conjunctivitis. She also had to come home with the State law mandated apnea monitor/equipment.

Today, Mia is a happy and healthy "big girl" weighing 21 pounds and is 31 inches tall. She loves to sing and dance and brush her teeth. Although she's an extremely picky eater (like her Dad), her favorite foods are broccoli and green beans. Unfortunately, she hates all fruit (unless it's in a juice format) and refuses to drink milk from a cup.

As you can imagine, we are extremely delighted with our Special Delivery!

Focus of the Month:

The terms high or low tone are familiar to many parents of premature infants, but what is tone? This question is asked repeatedly by parents and students, and seems to be a recurring topic among therapists. Medical professionals use this term to describe many conditions that infants born prematurely face, from generalized motor delay, drooling and, feeding difficulties, to poor postural alignments. It is even sometimes considered the culprit for speech/language delays, poor focus/attention, or academic difficulties.

There is a wide range of normal tone and an average adult may have “high tone” or “low tone”. A baby who was born prematurely may have been given a diagnosis of high or low tone. Likewise, a preschooler or kindergartner with no known medical problems, but who is delayed in running, jumping, or hopping, may be given the label of high or low tone. The questions always asked by parents is, “what is tone and when is this ‘tone’ something to worry about?”

WHAT IS TONE?

Although there is debate in the medical community over the exact definition of tone, in this discussion we will use the following neurodevelopmental definition of tone:

Tone is the overall state of muscles that is high enough to maintain an upright posture against gravity (upright sitting, good standing posture), but is low enough to allow us to move in and out of positions (walking, running, jumping).

Another term often used interchangeably with low tone is hypotonia. Hypotonia usually refers to reduced muscle tone that often is associated with genetic conditions such as Down Syndrome or Prader Willi. When hypotonia is associated with these conditions, a clear pattern emerges and these conditions are readily diagnosed at birth through chromosomal testing. Many premature infants undergo repeated neurological tests such as MRI's, CATscans, and ultrasounds. If, by the corrected age of two years, significant gross motor delays in crawling and walking are still evident, a child may be given a diagnosis of cerebral palsy. This diagnosis also carries with it a clinical diagnosis of hypotonia (low tone) or hypertonia (high tone) and is neurological in nature. Cerebral palsy, as with

What is Tone?

genetic conditions, is easy to understand and visualize.

Most children who eventually need intervention are given a label of generalized hypotonia without any other medical diagnosis. Parents of premature infants have been told that they can expect different movement styles from their babies and toddlers. For example, premature infants may have stiffer movements and postures. Or, they may have more floppy postures. These movement differences are usually temporary but they may still affect how quickly a baby may learn new motor skills such as reaching, rolling, or sitting. Every parent of a premature or high risk infant should make sure that developmental milestones in the first 18 months are assessed by a physician or by a physical therapist. Early intervention is important in order for the correct movement patterns to be introduced. Examples of correct, early movement patterns would be rolling without hyperextension of the head and neck; or, crawling on hands and knees and not “bottom scooting”.

DOES MY CHILD HAVE LOW TONE?

If your child is now walking, there are specific CHARACTERISTICS that are typically displayed in children with hypotonia:

1. Decreased strength.
2. Decreased endurance
3. Delayed motor skill development
4. Poor posture
5. “Loose” joints and ligament laxity
6. Poor attention, poor focus, hyperactivity

The aforementioned characteristics may manifest in the following way and may require further evaluation if present at age three or older:

- sits in a “W” style position (hips rotated inward, knees touching, lower leg out to the sides)
- stands with excessively rounded shoulders, “sway back”, weak abdominal muscles
- has markedly flat feet
- walks on his/her toes (this is never normal at any age!)
- seems clumsy or falls frequently
- has trouble going up and down steps reciprocally and without the use of an adult's hand
- has trouble running, jumping, hopping, kicking or catching a ball
- drools

- has difficulty chewing certain textured foods
- seems weaker than other children of the same age
- holds a crayon with a very weak and immature pattern
- has difficulty sitting still even for short periods of time
- has difficulty following directions
- is afraid to be on swings, slides or other playground equipment
- is unsafe on playground equipment

SUMMARY:

We can all put ourselves in a category of high or low tone and still be considered within normal limits. Some examples of normal high tone would be the average person who always sits erect, has more tightness around their joints, and tends to move more quickly and with more energy. The normal low tone person is the person who has more overall flexibility. They may slouch, may be able to sit in a W sit position, or may always prop their head up with their hand when doing desk work. Typically they have more ligament laxity. Is one type of tone better than another? The answer is no. We have high tone basketball players and runners; low tone gymnasts and skaters. Built upon their individual muscle tone is strength and the ability to demonstrate skill in movement. This high or low tone is not abnormal and there is no neurological or medical reason for the difference. This normal high or low tone can be attributed to genetics, ethnic differences, environmental differences, and/or cultural biases.

Differences in tone only become a problem when, as stated in our initial definition, it interferes with the ability to hold ourselves up against gravity and does not allow us to move through positions efficiently and with the least amount of energy.

If you have questions about whether your child's overall tone is impacting on his/her motor or cognitive development, talk to your pediatrician. Your concerns can be easily addressed through a physical, occupational, or speech evaluation.

This month's contributor is Suzan C. Syron, PT, Pediatric Clinical Specialist, NDT certified. She is the owner of the Children's Therapy Center in Northern Virginia.

Local News:

Announcements:

Preemies Today Annual Celebration and Silent Auction

This year's celebration will take place on May 21, 2006* at the Sully Government Center in Chantilly, VA. Come and enjoy our VIP area (for the Very Important Preemies), great food, and make your bid on some exciting auction items. Proceeds from the Silent auction will help support our programs such as our NICU Welcome Home bags. We will also be donating 20% of the proceeds to a NICU in New Orleans affected by Hurricane Katrina. If you would like to help volunteer at the event or if you have an auction item you would like to donate please contact Deborah Leaf at deborah_leaf@yahoo.com.

*Please note that we have moved our Annual Celebration from March to May due to RSV season.

Fairfax County Transitions Fair

The Infant Toddler Connection, the Fairfax County early intervention office, is offering a Transition Fair on March 11, 2006 from 9:00-11:00 am at the Fairfax County Government Center, Alexandria. The February Fair was cancelled due to inclement weather. The Transition Fair will provide families the opportunity to meet with different groups or organizations that can help your child once he or she has transitioned out of the early intervention program. Please RSVP to Paula Gorman at 703-246-5313 or paula.gorman@fairfaxcounty.gov.

March of Dimes, Walk America

Please help the March of Dimes continue to save the lives of babies born prematurely by participating in Walk America 2006. Join the Preemies Today team by contacting Susan at susan.salguero@inova.com.

Times and Places of this Year's Walk:

Leesburg, VA, <i>Ida Lee Park</i>	4/30/06
Manassas, VA, <i>Loy Harris Pavilion</i>	4/23/06
Reston, VA, <i>Lake Fairfax Park</i>	4/23/06
Springfield, VA, <i>Lake Ancocotink Park</i>	4/23/06

Warrenton, VA, <i>Airlie Center</i>	4/30/06
Washington, DC, <i>Sylvan Theatre</i>	5/01/06

(*Washington Monument grounds*)

Support Groups:

Take a Break

Preemies 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.

"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.

Preemies Today Online Chat

Join us every 1st and 3rd Thursday of every month at 8:30 pm for an online chat. For more information contact Julie at 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 preemiestoday@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/>

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/

Fairfax County Department of Family Services:

(703) 324-7500
www.co.fairfax.va.us/services/dfs/

Social Security Administration:

1-800-772-1213
www.ssa.org

SIDS Mid-Atlantic

(703) 933-9100
www.sidsma.org

March of Dimes

1-800-326-BABY
(703) 425-BABY (Metro DC)
www.marchofdimes.com

Sidelines National Support

1-888-447-4754
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.PreemiesToday.com

Misson 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.

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.

To subscribe to the newsletter please email us at premienewsletter@yahoo.com. If you would like to become a member of Premies Today please email us at premiemembership@yahoo.com. Our website is **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**