

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

This month's preemies is Bailey Hooper. It was a long road to pregnancy with Bailey, but he could not wait to make an appearance. Here is his story as told by mom, Lori.

I was the mother of 2 boys and very busy. I had recently started a small company and my husband and I had just bought out our very first home. Having a third child was the farthest thought from my mind. My oldest son was in 1st grade and my youngest was just 3 years old. Then I met a new friend, one of the mother's on my son's baseball team. She and I became close friends as the months went on. She had three kids and she was pregnant. As time went on, I found myself pondering the thought of adding another to our family as well. My husband and I discussed this and we decided it was time. And so began the ride.

I had no idea what was in store but naively, I just thought we would get pregnant after a few tries. I had not had any trouble conceiving my first two boys and thought it would be the same with the third. Weeks turned into months and nothing was happening. So, I went to the local library and borrowed about 15 books regarding "getting pregnant, natural family planning, secondary infertility...etc..." and I began researching infertility online. I soon became consumed. Then finally, after over a year of trying I got a positive pregnancy test. I took 3 early pregnancy tests that day and they were all positive. I was over the moon! Unfortunately my joy was short lived. I woke up a few days later to bleeding and cramping. I had a natural miscarriage that same day. The following day began a series of HCG blood testing as the DR's would follow my levels back down to zero. This took weeks and I was devastated. But, I never gave up. I started seeing an infertility specialist shortly after

this and under went extensive testing. Every test came back normal, which was sometimes harder to take than if they had actually found a cause. I felt that if they found a cause they could find a cure and we could have our baby. They did say they thought my left tube was blocked, but I had a working right tube, so my chances were only cut in half. I went on to become preg-



nant twice more and miscarried each time, so I had three miscarriages in a row. One at 5 weeks, one at 8 weeks and one at 11 weeks. In between my miscarriages there were years of trying.

Six years after we started trying to have another baby my husband and I decided this was it. Our oldest son was now 13 and our youngest 9. That last month of trying, I got a faint, very faint, but positive pregnancy test. I think I almost fainted. It was time to call the Dr and start worrying. I had a blood test and a progesterone test

which were in good range. But that was little comfort to me because with my previous pregnancies I had good HCG levels (doubling every 48 hours as they should) and decent progesterone levels and yet I miscarried anyway. I was not reassured, but I had faith. Two weeks later the ultrasound was scheduled. In the past I had several ultrasounds or scans as some call them. I was scared to death. I never, not once had ever seen a heartbeat on an ultrasound screen. When I was pregnant with my sons, they didn't do early scans, or at least I never had one. With my 3 previous miscarriages, there was never a heartbeat. So understandably, I was terrified of another bad ultrasound. My doctor was not in that day so a nurse performed my scan. Her findings were a very early pregnancy dating the correct date 6 weeks 3 days but no heartbeat. I was to return in three days for another. Three days later the same nurse performed another ultrasound and again there was no heartbeat, but growth was noted. As you can imagine I was on total edge and filled w/ worry.....I had experienced this before, why keep me waiting to tell me the bad news?? I had never seen a heartbeat and I just knew I wasn't going to see it now, this was all so unfair! The following week it was the same nurse and the same news, growth but no heartbeat. All the while my HCG levels were being tested every other day. I looked like a junkie. My arms were so bruised from the blood draws. My levels confirmed their fears or so they thought. My levels were rising but they were slow to rise which signified that this was another miscarriage. At 7 weeks 5 days the nurse took me in her office and scheduled a D&C. She said I was having a "missed abortion" and that my body didn't recognize that this was not a viable pregnancy and I would need a D&C" Although this was what I expected, I asked to speak with my doctor. She said she would have him

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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

Preemie Play groups

Family Outings

Preemie 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

Premature infants have many special needs that make their care different from that of full-term infants, which is why they often begin their lives after delivery in a neonatal intensive care unit (NICU). The NICU is designed to meet the basic healthcare needs of the infant to ensure proper growth and development, while limiting complications. In order to prevent life threatening complications, infants are often connected to multiple machines which require the infant to be in certain positions for extended periods of time and limit certain other movements. After leaving the NICU, premature infants sometimes require further care to address development of the nervous system, achievement of motor skills, hearing, vision, speech, behavior and other residual deficits.

One distinct clinical diagnosis that is often overlooked in the midst of addressing so many other important concerns is Torticollis. Muscular Torticollis is commonly seen in newborns, infants and children. It is especially prevalent in premature infants due to the difficulty balancing proper positioning with the necessity of life sustaining equipment. Torticollis in this form refers to a neck posture in which the infant's head is asymmetrically side bent (ear to shoulder) in relationship to the trunk. This side bending occurs in conjunction with varying degrees of head rotation. As a result, the chin points to one side and up when the infant's head would normally be in neutral, straight ahead. This can

occur with or without a contracture of the neck muscles, primarily the sternocleidomastoid (SCM) muscle, on the opposite side. Early detection and treatment is essential to resolution when Torticollis posture is observed. Conservative treatment such as physical therapy is effective in greater than 80% of the cases if it is initiated in children less than one year of age. Rarely Torticollis may present with other underlying disorders such as, tumors, reflux, vision problems, asymmetrical vertebrae, one sided absence of a neck muscle, hiatal hernia, herniated cervical discs, cervical vertebral fracture or syndromes such as Klippel-Feil syndrome. Torticollis is commonly accompanied by a flat head, facial asymmetry, scoliosis, and shortening of other muscles.

Observing your infant's postural patterns is helpful when assessing for Torticollis. Even if your child was not diagnosed with Torticollis as an infant, it would be good to observe your child to ensure the diagnosis did not go undetected. Tightening, of the right SCM appears to be more

common than the left. In this case, the child will prefer to face left with the top of the head tilting down to the right. The left SCM is elongated and weak. The opposite pattern is observed for a left Torticollis. An increase in thickness of the muscles on one side of the neck versus the other (either near the collar bone or at the base of the skull) can be an indicator of Torticollis. The child's ability to perform neck rotation and side bending (ear to shoulder) will be asymmetrical. Secondly, with Torticollis the trunk muscles may be misaligned, or scoliosed, due to the neck imbalance. More specifically, you may notice an elevated shoulder on the side with Torticollis, shifting of the head toward that side, weak trunk muscles (e.g., slumping to one side in sitting or in the car seat) and/or curves in the neck or back to one side. Studies have shown that decreased range of motion and asymmetry of the neck can lead to other asymmetrical motor developments in children. Therefore, if you notice any asymmetries, consult with your pediatrician, pediatric orthopedist, physical therapist, or occupational therapist for early detection and treatment which are paramount to complete resolution of Torticollis and alleviation of other associated problems.



Kyra demonstrates the typical Torticollis posture

While Torticollis has been accurately diagnosed for decades treatment among healthcare practitioners continues to be controversial depending on the underlying cause. However, if the underlying problem is purely muscular, treatment will usually include stretching of the tight muscle, strengthening of the weak muscle, proper positioning, proper handling, and proper posturing. The most successful treatment typically includes daily home exercise by parents in addition to periodic clinical reassessment and treatment. Consult with your child's physical therapist before performing any home treatment to ensure individualized and proper treatment régime and technique. Stretching usually includes rotation and side bending. Strengthening can be performed during play in a variety of positions. During treatment for Torticollis, as with many things in children, it is important to recognize the potential for regression of Torticollis posture during a growth spurt, illness, teething, or acquisition of new milestones.

This month's contributor is Secili DeStefano PT, DPT, OCS. She is a practicing physical therapist in Northern Virginia and mom to full term, Kyra.

MARCH OF DIMES WALK AMERICA 2007

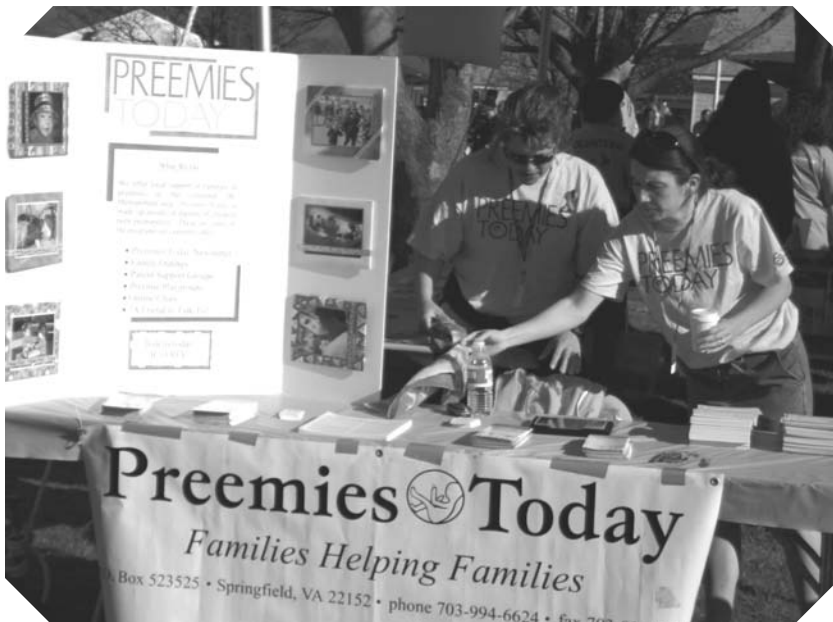


Carol Evans and Stephanie Miller, grandmother and mom to a 34 weeker, get ready to walk.

Walk America, the March of Dimes biggest fundraiser, has been taking place in different locations in the DC Metro area over the past several weeks. The proceeds from Walk America go to fund research, community awareness, and educational programs to help fight prematurity and lower the infant mortality rate in our country. In Fairfax County, Walk America took place on April 22, 2007 at Lake Fairfax Park in Reston, VA. Over 1100 walkers came out to show their support for such an important cause. In addition to walking either the 3 mile or 6 mile course walkers enjoyed food, music, and a variety of entertainment for their children. One of the highlights of the event was a "Thank you for Walking" celebration/memorial parade. It included families that had been affected by prematurity as well as families whose babies are with us in memory. Here are some picture from the walk.



Madison and Lexi Hazelgrove show off their face painting.

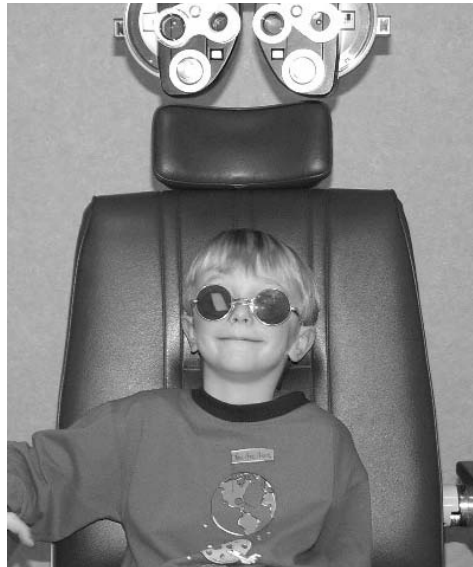


Stephanie Miller and Mary Beth Hazelgrove man the Premies Today table

Preemie of the Month Update: Jack Gillespie is Six Years Old!

"I really, really love you mommy." Tears sting the back of my eyes even though Jack says this spontaneously at least once a day. "I love you, too, buddy." Grandmothers in grocery stores smile approvingly and other moms look wistfully at their cranky kids. "How lucky you are to have such a sweet child", they say.

Lucky, indeed! This kid is a miracle – a micro preemie born at 24 weeks weighing just 1 lb 13 oz. His eyes were fused shut, his skin was transparent and he could fit in the palm of my hand if I had been able to hold him. He spent almost four months in the NICU fighting to survive. I can't dwell on that anymore because he just celebrated a beautiful milestone. Jack Gillespie turned six years old this month!



Captain Jack Gillespie, Pilot of the Galaxy,
powers his way through an eye exam!

I can still see the tiny pinprick scars on the backs of his hands and feet from daily blood drawings, and his NEC surgery scar spans his belly from side to side where doctors removed half his colon and part of his small intestine to save his life and allow him to finally eat. But the most damaging affect of his prematurity was his stage 4 ROP (Retinopathy of Prematurity), which required surgery in both eyes to reattach his damaged retinas. Jack has extremely limited sight in one eye and very poor vision in the other. He wore glasses by 9 months and struggles to see things even a couple of inches away.

We learned to be advocates for Jack's survival in the NICU, and now we're learning a whole new vocabulary – special education lingo. Because of Jack's early birth, he had always qualified marginally for special ed through Fairfax County and had received wonderful services like OT, PT, and nutrition counseling. He had shown just enough of a frustrating delay in several areas to require services but nothing that the therapists could point to and say, "We can fix this." But now, as he is finishing Kindergarten, he has been diagnosed with a non-verbal learning disorder. The therapists suspect the vision problems are driving this and resulting in his slight social delay. Children learn social skills by picking up nuances and visual cues from other faces – things that Jack can't see. He can't run fast and watch the ground at the same time so he falls often, which pretty much rules out most team sports. He can't see the teacher very well so he tries to mimic what the kids next to him are doing, which always puts him a step behind. But, he relies on his excellent aural skills to make up for this deficiency.

However, I know he's going to be fine. Jack is sweet and funny and adored by everyone, especially the girls in his class who cuddle him when he falls. He doesn't seem to notice any problems so we won't let on that we're still watching closely for signs of other emerging delays. It will be a constant vigil on my part, one that I suspect will last way beyond his college years. But, wow, Jack graduating from college in only 15 years....what a milestone to plan for!

Kelley Gillespie is mom to Jack and Finn. She is also a conference planner and member of the board of the March of Dimes, National Capital Chapter.

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 assis-

tance or would like to volunteer to help others, please contact Susan at 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

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.

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 Mother's Day

Preemies Today members will be manning tables at local NICUs Mother's Day morning. We will have coffee and other treats to honor moms celebrating with their NICU babies. Dads are welcome to partake in the goodies as well! For more information, or to volunteer to help out please email us at info@premiestoday.org

Fourth Annual Celebration and Silent Auction

The Preemies Today Annual Celebration will take place on June 9, at the Physicians Conference Center at Inova Fairfax Hospital. We will have a wonderful silent auction with plenty of items for the kids. There will also be children's activities and we will present our Health Professional of the Year award. Please join us to celebrate 4 great years of Preemies Today. For more information email us at info@premiestoday.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

continued from cover, Bailey's Story

call me . He called me the following day to tell me they had set up a D&C for later that week and that he was very sorry, then he asked me to hold on a minute. He came back on the line and asked if I would come in the following day for another ultra sound, this one performed by him. He told me that the sac was only measuring 9 mm and he didn't expect to even see a heart beat until it was 12 mm. He was saying a lot of mumbo jumbo as far as I was concerned and was just trying to give me a smidgen of faith. I was way beyond that until my husband took me out into his garage and pulled out a 9 mm socket. He said "look at this, look how small this is, give it a chance." But, I was so sick of the merry go round of emotions.

The next morning as the doctor started to perform the scan he said "I have your D&C scheduled for Friday morning, nothing to eat or drink after midnight Thursday night" I turned away from the screen. All of the sudden the doctor said "LORI, LOOK AT THE SCREEN----- LOOK AT THE SCREEN, there is your baby and that is it's beating HEART" I swear I thought I had died and gone to heaven! No words could have been sweeter to me! He started pointing and showing me things "this is this and this is that and I will print you pictures" I started shaking and crying (happy tears of course) the nurse brought me in juice and made me lay down again until I could pull myself together. The doctor said "you have a titled uterus which might have made it very hard to see the heartbeat". The baby was measuring 8 weeks and 1 day and his heart beat was 175 beats per minute!

I then started what I thought would be an uneventful pregnancy. All my appointments and ultrasounds throughout the pregnancy were always perfect. They always said "you have a nice size baby in there." Both of my boys were full term and weighed just 6 pounds, so no one was expecting a large baby. On Jan 4th, 2005 I started having contractions. Every 15 minutes for about a half

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

Deadline Extended!

Health Professional of the Year: Call for Nominations

Preemies Today is currently accepting nominations for our annual Health Professional of the Year Award. This is a great way to thank someone who went above and beyond for you and your preemie. Please submit an essay of no more than 500 words about your nominee. The nominee can be a nurse, doctor, therapist, or any other health professional that cared for your child in the NICU or after discharge. Just let us know why they are special and how they help preemies and preemie families. All submissions must be received by May 15, 2007 to be considered. Please submit your entry to DeborahLeaf@premiestoday.org.

an hour progressing quickly to every 5 minutes. They were INTENSE contractions. It was unreal, I could not be in labor. I had a scheduled c-section set for 38 weeks and I was just 34 weeks.

I began bleeding and leaking fluid and my water broke on the way to the hospital. In Labor and Delivery they gave me shots to stop the contractions so they could set up for the c-section. At 11 pm Bailey Mason Hooper was born. He weighed 6 pounds 3 oz and was 19 inches. He was absolutely beautiful! When they announced his weight I thought wow, at 34 weeks he weighed as much as both of my sons did full term. Amazing! Although he was breathing on his own and his apgar scores were good, he was whisked off to the NICU. He was having some breathing issues but didn't need oxygen. I didn't get to see him or hold him until 3 am.

Bailey stayed in the NICU at Fair Oaks Hospital for five days. Although he was the biggest baby in the NICU, he had trouble eating. He couldn't remember to suck, swallow and breathe all at the same time. He was fed by IV for two days. He also had jaundice and spent a day under the lights. Five days later he was well enough to come home. I had been released from the hospital days earlier so bringing him home was such a wonderful moment. Bailey did well over all. He had colic and reflux and at his 6 week check up they noticed his heart rate was too fast. He was sent to see a cardiologist and was hospitalized few weeks later to check his heart. The doctors found that it was pain related. He had such severe reflux that the pain caused his heart rate to speed up. Once he was on medication for the reflux three times a day his heart rate returned to normal. Today Bailey is a happy and healthy 2 year old. A typical busy toddler, keeping us all on our toes! Bailey really is a miracle and well worth the wait!

Helpful Resources:

National Resources

Social Security Administration:

1-800-772-1213

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

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

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

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**

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@preemiestoday.org or you may go to our website at www.PremiesToday.org and click on "Join us."

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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**