

PREEMIES TODAY

Families Helping Families

Preemie of the Month: Maison Ramsy

Overcoming the Odds!

by his mother, Chrissy Ettehadieh

Yes, we were having another baby! It took two years to conceive my first born son, Kameron, and at 34 years old I wanted another baby. It happened much sooner than I thought all together. Kameron was only 8 months old when Maison was delivered by emergency c-section at 25 weeks and weighed 1 lb., 12 ounces. To top it all off, my husband and I both left our jobs to pursue our dreams of opening our own business. Our family's financial future was riding on our restaurant, Cheezy's Pizza--which opened 11 days after Maison was born.

I was induced after my due date with Kameron. I had a healthy first pregnancy and took very good care of myself. I even forced down prenatal vitamins that made me sick. I dared not ingest even an aspirin because I wanted a healthy baby. The plan worked like a charm with my first pregnancy. It was the same story with my second pregnancy until, at 23 weeks, I had some light discharge. I called my doctor, and spoke to a partner who told me to come in the next week and not to worry. Upon the doctor's advice, I relaxed.



this same test done. I was completely in denial of the whole situation and even stopped for Starbucks. This enabled me to remain calm as I was wheeled into the hospital.

The fetal fibronectin test was done just as my mother had predicted and I was in labor. I was 4 cm dilated and the contractions were two minutes apart. I was shocked! Where were my antibiotics so I could go home? I still had vacuuming to do, an 8 month old at home, and a restaurant opening in a few weeks! When my husband went to move our car, my contractions started coming harder and faster. I was terrified when I realized the baby was really coming. I thought he would die. I laid there wondering about what I could have done to cause preterm labor. I was then rushed up to the high-risk pregnancy unit in the trendelenburg position----completely immobile and being pumped full of huge doses of antibiotics, steroids, and magnesium sulfate.

I soon was leaking small amounts of urine throughout the day whenever I moved just a little. Suddenly I felt something ballooning out of me! My husband took a peak and almost fainted while he noticed a foot inside of the amniotic sac. Things still weren't adding up for me. I told my husband and my sister who were staying with me that night, "Sshh, don't tell the nurse because I don't want to have the baby this early. I want to wait." The doctors rushed into the room, gave me another ultrasound, and a physical exam.

The director of neonatology and another neonatologist lined up firmly against the wall to tell us the harsh reality for a 24 or 25 weeker. We were told our son would be very ill and would have a high risk for disabilities----not a very bright future for our little bundle of hopes and dreams. I was numb and terrified. I had chosen a Catholic hospital and found myself surrounded by pictures of Mother Mary and Holy Scriptures. I found comfort in these surroundings and decided to let God's will be done. I said, "If my son will not have any

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Two nights later I had a few of what we thought were Braxton Hicks contractions. The next morning I noticed a miniscule amount of blood. Then I phoned my mom and oddly enough she had read a magazine article the same day about a fetal fibronectin test done on a woman to detect early labor. It was ironic that soon afterwards I was on my way to the emergency room to have

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

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Calendar of Events

October

Parent Meet and Greet
October 13, 5-7 pm
Chevys Restaurant, Falls Church, VA
Appetizers, Door Prizes, Meet our Families

The Bus Starts Here
October 18, 10-1 pm
Share your story on video on the Prematurity Awareness Bus at
INOVA Fairfax Hospital
<http://www.marchofdimes.com/everybaby/>

Halloween Spooktacular Event
October 27, 1:30 pm
Train and Carousel Shelter
Burke Lake Park, Burke, VA

November

Prematurity Awareness Day
November 13
Display your March of Dimes Lawn Sign. Prematurity is a growing epidemic. One out of 8 babies are born prematurely! **You may purchase signs starting Oct. 25.** Contact Dona Dei at ddei@marchofdimes.com to purchase one for your family. A donation of \$5 is appreciated if possible.

Mailbox

Please send us any feedback, suggestions, comments, or contributions including poems, high calorie recipes, or articles for the next issue to:

info@preemiestoday.org

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Program Updates

Introducing our new board members:

Lauren Greenberg, Bethesda Maryland

Lauren is the mother of a 34-weeker who spent his first 28 days in the NICUs at Sibley and Georgetown. She knows firsthand how the birth of a preemie can be a life-altering experience. She hopes she will help make the journey just a little bit easier on other moms, dads, and babies by serving on the Board of Premies Today. Lauren is also a former elementary school teacher and an experienced organizer of child-friendly events. She is looking forward to working with other preemie parents.

Lisa Hollaender, Gaithersburg, Maryland

Lisa has spent four years caring for her son, Christian who continues to feel the effects of his prematurity. She has worked to bring premature birth awareness in her Montgomery County, Maryland neighborhood through writing articles that have featured neighborhood preemies. She has also urged her neighbors to participate in the March of Dimes annual walk.

Malou Gemeniano, Bethesda, MD

Two years ago, Malou's son, Matthew was born 2 1/2 months early and stayed in the NICU for two months. She has drawn tremendous strength and resources from the stories and families of older preemies, and she hopes to give back support to families in the preemie community. She also understands the feelings of isolation that accompany the newborn preemie journey. She feels the Premies Today families from Virginia have extended their arms in support to the families in Maryland. As a resident of Maryland, she would very much like to continue this spirit and outreach to other families in Maryland and strengthen Premies Today's Maryland base.

Danette Cruthirds, Sterling, VA

Danette looks forward to the opportunity to serve on the Premies Today Board of Directors. As a medical professional she is involved in research and is a mother of two preemies. Danette can offer us a unique perspective to our wonderful support group. She also knows what it is like to feel overwhelmed about the whole NICU process.

Play Groups--Interested in Joining?

Please contact Julie Kipers at juliekipers@premiestoday.org

SALE! SALE! SALE!

White House Ornaments!

-Don't Miss Out - \$20

All Proceeds to Benefit the Holidays in the NICU Project

Contact: **Elaine Noto** at elainenoto@premiestoday.org

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.

Programs:

Monthly Newsletter
Parent Support Meetings
NICU Preemie Care Packages
Telephone Hotline
Play Groups
Family Outings
Parent Education
Resources Brochures
Yahoo Group
Online Chat

Join Our Yahoogroup!

Subscribe:

<http://groups.yahoo.com/group/PreemiesToday/>

Meet wonderful parents from the DC metropolitan area as well as elsewhere in the United States.

Volunteer

Email us at info@premiestoday.org for more information.

News flash:

September 9, 2007

Premies Today was featured in the **Austin-American Statesman** as one of the premiere preemie parent support organizations in the United States!

Ten Ways to Keep Your Preemie Healthy This Winter

By Deborah Leaf RN MSN FNP and mom to Jake a 27 weeker now age 4

The onset of cold and flu season can be a difficult time for the parents of premature infants. We all want to keep our preemies healthy and avoid a possible hospital admission due to infection. While there are no guarantees, by following some simple tips we can keep our preemies healthy throughout the winter months.

1) Hand washing, Hand washing, Hand washing!

Hand washing cannot be emphasized enough. It is the single best way to avoid the spread of disease. Every single person who touches a preemie, or any baby, should first wash their hands. This includes friends, family, siblings, health care workers, and even parents. **The CDC recommends the following technique for hand washing:**

- ◆ First wet your hands and apply liquid or clean bar soap. Place the bar soap on a rack and allow it to drain.
- ◆ Next rub your hands vigorously together and scrub all surfaces.
- ◆ Continue for 10 - 15 seconds or about the length of a little tune. It is the soap combined with the scrubbing action that helps dislodge and remove germs.
- ◆ Rinse well and dry your hands.

2) Stay away from sick people

This may seem obvious, but do not let sick people visit and do not visit them with your preemie.

3) Avoid crowds

The grocery store and malls are full of people and germs this time of year. Even churches and synagogues can be a hazard, especially because everyone will want to admire your preemie up close. If you have to go out with your preemie pick a time of day when there will be minimal exposure to crowds and do not be afraid to ask people to step back.

4) Hand Sanitizer

Recent studies have shown that the proper use of hand sanitizer can decrease the transmission of disease in the home. It comes in large containers for home use and travel size bottles that fit right into the diaper bag. It is a great option when there is no sink available or when you have the baby on the changing table.

5) Smart scheduling

When making doctors appointments ask for the first appointment of the day or the first appointment after lunch. This decreases the risk of exposure to other children in the office. Most offices will be happy to accommodate preemies any way they can and will put preemies into an exam room right away instead of leaving them in waiting rooms, if the parents ask.

6) RSV and Flu Preventatives

RSV is a virus that presents itself as nothing more than a common cold in most children, but it can be very serious and potentially deadly for many preemies. Ninety percent of the population is exposed to RSV before they reach two years old, which means it is very likely that your preemie will be exposed to RSV at some point. The drug Synagis is given as a monthly injection to protect against RSV. Synagis decreases the severity of RSV, but it does not totally prevent children from contracting RSV.

The flu is also a very serious illness in young children. The flu vaccine should be given to all children ages 6 months chronologically until their 5th birthday. Older children with chronic illnesses may also need a flu vaccine. Check with your pediatrician to see if your child qualifies for Synagis and/or the flu vaccine.

7) Be the Gatekeeper for Your Child

One of the most important responsibilities any parent has is to be the gatekeeper for their child. This is especially true for preemies. Do not feel bad telling well meaning strangers that they cannot touch your child. Let family and friends know that they cannot come into your home with so much as a sniffle. These strict guidelines can be hard for some people to accept, so just remember to blame the doctors and nurses. Stating, "The doctor told me I can't do X with the baby," to friends and relatives can take the pressure off you as the parent. Your child's healthcare providers are happy to take the blame in order to keep your child healthy.

8) No smoking

Smoking has been shown to increase the risk of RSV and other respiratory illness in preemies. Your preemie's health is another good reason to quit smoking and to ban it from your home.

9) Limit Exposure from older siblings

If there are older siblings in school it is important to teach them how to prevent the spread of infection. Some parents may choose to keep preschoolers home from school during the winter months, but this is not necessary in every case. Emphasizing hand washing and limiting close contact as much as possible, especially if the sibling is sick, are the best ways to keep older siblings from spreading illness to your preemie.

10) Stay Healthy

As a primary caregiver you need to stay healthy for yourself and your preemie. Aside from frequent hand washing you also should avoid touching your eyes, nose and face.

For more information about preventing infection check out the CDC website at www.cdc.gov and for more about RSV check out www.rsvprevention.com.

Get Up and Go Cookies

This is a recipe that I found from an old SUNA (Society of Urological Nurses and Associates) conference I attended once during a lecture on **preventing constipation and urinary retention problems in children** that I thought some of you might be interested in having. These are quite yummy, extremely healthy and our whole family has enjoyed them. They are fun to make with kids and freeze well, too.

1/2 cup margarine or butter *
1 cup brown sugar
1/2 cup prune puree **
1 egg
1 cup sugar applesauce - any flavor (we use sugar free)
2 cups all bran cereal
1 1/2 cups flour
1/2 teaspoon baking soda
1 tsp cinnamon or nutmeg if you'd like

Optional : 1/2 -1 cup raisons, chocolate chips, sunflower seeds, oatmeal, nuts or whatever you want to add for a different flavor anytime

Directions:

In a large bowl, cream margarine with sugar. Add egg, then prune puree, then applesauce and mix well. Add dry ingredients. Mix well. Drop by spoonfuls onto 3 cookie sheets (12 cookies per sheet

Bake in 350 degree oven for about 15 minutes. cool on pans for a few minutes and then remove. Freeze cookies and start with eating 2 cookies a day.

* We use only 1/4 cup of butter and increase to 1 1/4 cups applesauce instead

**To make prune puree, you can mash prunes from a can/jar with juice or use baby food prune puree

Enjoy!

submitted by: Daisy Opstal, RN

1997 Continnence Program, St. Joseph's Community Health Centre, Hamilton, Ontario PD 3432

Maison Ramsy continued from page 1...

quality of life please do not resuscitate!" If he wasn't going to have a good quality of life, I wanted my angel in heaven looking down on us. I was not going to selfishly keep him here to suffer just for me. Without a minutes hesitation, my family nodded their heads in agreement in total loving support of my decision.

Soon I was looking at a bundled baby boy delivered via emergency c-section who looked small but healthy—I was way off. After my high fever disappeared, I saw Maison. He looked like a baby bird that had fallen from its nest. His eyes were fused shut and he was covered in medical tubing. His skin was paper thin, too. I almost collapsed! I was repeatedly told this would be an emotional roller coaster ride. I cannot believe the ride lasted six months and toured four different hospitals!

One morning, I received a phone call from Maison's neonatologist who told us to get to the hospital immediately. Maison was septic, because he had E.coli and NEC. He then told us that they were flying him to Children's National Medical Center in Washington, D.C.----it was an hour from us!

Maison had every premie issue possible including Stage 3 brain bleeds, numerous blood transfusions, four months on a ventilator, then to CPAP, then back on a ventilator, inguinal hernia repair two times, six months on a feeding tube, multiple infections including E.coli, severe reflux, chronic lung disease, oral motor dysfunction, Stage 4 ROP, laser surgery

Everyone says he is the happiest baby they have ever seen!

two times and sclera buckles, a false positive for biliary atresia, hyperbilirunemia, apnea monitor, large amounts medications, breathing treatments, feeding issues, weeks booked for appointments, rehospitalized twice with pneumonia and RSV. Believe it or not I am sure there are other things that I am forgetting!

Maison had a rough start and remarkably has very few problems as a result of his premature birth. Everyone says he is the happiest baby they have ever seen! He is in Maryland's Infant and Toddler Program and receives monthly physical therapy, occupational therapy, nursing, and school of the blind services. He is also being followed by a neurologist and pediatric ophthalmologist who have greatly assisted with his development. Maison is extremely nearsighted with possible blindness in the eye with sclera buckle. He is still using patching therapy, but he is on no medications and has outgrown his lung disease and GERD. He is now crawling at 11 months adjusted age and weighs 20 lbs! He is talking nonstop and even beating up his two-year old brother on occasion! We never could have imagined this amazing progress. Whenever we feel sorry for ourselves and think about the challenges our son may face, we remember his rough start and think look at him now!

By the way, Cheezy's Pizza is a success! If you find yourself in Towson, Maryland, please stop by and say you read Maison's story for a discount!

Preemie Update: Aidan Miller

An Athlete in the Making

Aidan Gehrig Miller was born on August 2nd, 2002---he is a surviving twin. Aidan was born at 25 weeks weighing 1 lb., 15 ounces and measuring 13 inches long.

Aidan was born unresponsive and not breathing. Doctor Vera at Alexandria Hospital spent fifteen minutes reviving him. Thankfully, Aidan came to life. However, as a result of oxygen deprivation at birth, the doctors had no idea if he would ever walk, talk, or function as a typical child.

Aidan spent his first 93 days in the NICU at Alexandria Hospital. Although he had no major setbacks during that time, we never knew what to expect of him. This past August we celebrated his 5th birthday with joy and amazement.

Aidan is our professional athlete in training. If there is a sport that involves a ball of any type, he plays it. If you want to keep Aidan occupied for a while, throw him any round object. Aidan's two favorite sports are golf and basketball; he dabbles in soccer, baseball, bowling, ping pong, football and hockey. As a word of caution when in this sports enthusiast's presence, be aware that he will throw any of these balls or round objects of the moment at your head when you least expect it. Our Aidan will keep you on your toes.

On our weekly golf outings to the driving range it's inevitable that he draws comments from the other golfers, especially when he hits the ball about 70 yards off of the tee. Not bad for 30 lb., 39 inch five year old. Nonetheless, Aidan's favorite part of golf is driving the golf cart.

Ever since being diagnosed with reflux in the NICU, Aidan has had feeding issues. Sitting down to eat is not one of his favorite things to do. As a result, his growth has suffered. He

has developed into a great outside jumper in basketball due to his small stature. With two non-athletic parents, it's hard to believe this is our child.



In September, he'll see an endocrinologist to see whether his slow growth is a preemie related issue, a genetic issue, or if it's just normal for him.

We've decided to hold Aidan back from starting kindergarten this year. He will continue going to the Montessori school he started last year and will begin kindergarten next fall.

Even with Aidan's traumatic start, he's only suffered minor delays and has hit his developmental milestones almost on target.

He crawled at 10 months, walked at 18 months, and began speaking by about 2 years old. Since birth, Aidan has received some sort of early intervention service through our city. He started off with some physical therapy to keep him on track and had speech therapy to help his feeding issues. During the school year he spends one hour a week with a special education teacher at the local elementary school. His social skills and fine motor skills are the focus of his IEP—only minor delays have been noted.

When Aidan was about 2 ½ years old, his sister Avery was born. She was the result of a full-term and uneventful pregnancy. Aidan finally has a live-in playmate to compete with. They enjoy playing with each other and she has taught him that there are other things to play besides sports.

Written by Aidan's dad, Sean Miller, a fundraiser for the National Republican Senatorial Committee. Aidan Miller was first featured in the September 2004 issue of the Premies Today Newsletter.



Local News...



October 28

Preemies Today Halloween Spooktacular

Burke Lake Park, 1:30-2:30 pm



We will meet at the shelter by the train and carousel. If you'd like have the kids wear their costumes and bring a Halloween-themed dish to share. We will be riding the "ghost train."

RSVP at events@premiestoday.org

Clipart from www.teachersguide.com

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.org
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.

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

**For more resources
go to www.preemiestoday.org**

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.

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

Women Infants & Children (WIC)

The WIC program provides food vouchers and nutrition counseling services to low-income women and children.

Virginia

Arlington- (703) 228-1260
Alexandria- (703) 838-4879
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

Membership/Subscription Information:

We offer the Preemies Today newsletter, family outings, parent support groups, preemie play-groups, 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 Preemies Today please email us at info@preemiestoday.org or you may go to our website at **www.PreemiesToday.org** and click on "Join us."

This newsletter was funded by a Community Grant from the March of Dimes. 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 the March of Dimes.

Don't Miss These Events!

Parent Meet and Greet

October 13, 5-7pm, Chevys restaurant
Falls Church, VA

Halloween Spooktacular

October 27, 1:30-3:30 pm, Burke Lake Park

Please RSVP to events@preemiestoday.org

**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
or
703-552-0163