

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

This month's preemie is Michael Farfan. Although he started out small, he is now an active toddler. He is now making up for all his parents sleepless nights while he was in the NICU by being a champion sleeper! Here is his story, as told by his mom, Karen.

My perfect pregnancy suddenly became not-so-perfect on November 17, 2004 when I was pregnant with my first child. That evening I experienced some mild cramping while I was out shopping for maternity clothes. I didn't think too much about it, but I did lie down on the couch when I returned home. The next morning I started getting ready for work while still feeling the cramps. I was hoping they would just go away and I debated whether or not to call out sick. I was teaching fourth grade at the time, and never called out sick. However I decided I'd better be safe than sorry, so I called out sick and scheduled an appointment at my doctor's office.

At the appointment I was told I likely had a bladder infection and was given a prescription. Relieved that it was nothing to worry about, I returned to work the next day. Other than the mild cramps, I felt fine. Yet early in the afternoon, while sitting at my desk, I felt water leaking. Never having had a bladder infection, I ran to the bathroom thinking my bladder was leaking! Not really knowing what was happening, I summoned help from another teacher and soon an ambulance was on its way.

I was taken to Fair Oaks Hospital. The whole way there I kept thinking it was just a bladder infection...how silly for me to be going to the hospital! Once there, I waited for one of my doctors to arrive and examine me. He told me I was having contractions and they were going to give me something

to stop them. He said I would probably be on bed rest for a while. Before anything else could happen, my placenta ruptured and I was told I needed an emergency C-section. Needless to say I was shocked, but there wasn't much time to think twice.

Michael James Farfan was born less than 30 minutes later weighing 2 pounds at 25 weeks. I got a brief glimpse of him before



he was whisked away. I was left for what seemed like hours in the recovery room with absolutely no idea of what the future held or what life would be like with a preemie. I didn't get to see Michael for another five or six hours, right before he was transferred over to the NICU at Fairfax Hospital.

I was transferred over to Fairfax Hospital

the following day and our three month NICU journey began. It was so painful to see our tiny little baby in the incubator with a feeding tube and on a ventilator with wires everywhere. Alarms were always going off...low heart rate, low oxygen, low blood pressure...we didn't understand why nurses and doctors didn't come running when the alarms sounded. It was a confusing and stressful transition into life at the NICU.

One of the first big issues we were confronted with was his PDA, an open flap in his heart. Luckily it closed on its own, with the help of some medicine, in a few days so we avoided surgery. Then within the first week Michael was diagnosed with a Grade 3 bleed on the right side of his brain. It was such devastating and scary news. We felt so helpless and so sad for our newborn son. He had brain scans once a week from then on. We just dreaded those days and prayed for a miracle that one day it would just be gone. I just couldn't bring myself to discuss the possibility that Michael may have cerebral palsy. I just learned to take things one day at a time and focus on positive outcomes.

Apnea spells were a daily occurrence and one of the reasons Michael spent a month on the ventilator. After a week on CPAP, he switched to just Vapotherm and we were able to hold him for the first time on Christmas Eve....the best present ever! Soon after that we were able to start kangaroo care.

Over the next month and a half Michael gained and lost weight. He started new medicines and stop other medicines. He worked with an occupational therapist and he started on Zantac for reflux. He was diagnosed with Stage 2 ROP. Back in November he was overdosed on an anti-

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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

Do you need

A FRIEND TO TALK TO?



If you are stressed or have questions only
another preemie parent can answer, call us at
1-888-712-3208

A Letter from the new Premies Today President and Chairman of the Board:

Dear Premies Today Members and Friends,

As the Chairman and President of Premies Today for 2006-2007, we would like to take this opportunity to thank the outgoing board and others who made Premies Today such a success over the past year.

First, we would like to recognize Sara Chae for her hard work coordinating the “Take a Break” program. She provided a service that eased the stress and lifted the spirits of many Premies Today families. On behalf of those families and the organization at large, we thank you, Sara.

Two of our outgoing board members were not able to serve again this year. Susan Salguero and Christine Miller both brought enthusiasm and great ideas to Premies Today. Without their help programs like the “Premie Care Packages” and the distribution of the newsletter would have been far more difficult. Thank you for all that you both contributed, we will miss working with you at the monthly board meetings.

Lastly, Kathy Mingledorff, the founder of Premies Today, will no longer serve as our president or on the board. Words can not express our gratitude for all that she has done for Premies Today. Without her this wonderful support organization would not exist. Kathy, we wish you all the best in your return to school, and although we know this is not goodbye, we will miss you.

This thank you is not meant as a goodbye to any of outgoing board. We expect to see everyone at events throughout the year and hope that we can draw on your expertise in a less formal way. Without such dedicated people, Premies Today would not be what it is today.

Thank you again.

Elaine Noto
Chairman of the Board

Mary Beth Hazelgrove
President

Preemies Today Board of Directors, 2006-2007

We are happy to introduce the new Board of Directors of Preemies Today.

Heather Ablondi

Heather Ablondi decided to join Preemies Today after the premature birth of her daughter, Abigail, at 28 weeks gestation. Heather has been actively involved in nonprofit work for the past 11 years, mainly working with Mother's Against Drunk Driving. Professionally, she has worked as a Prevention Specialist for the Baltimore County Bureau of Substance Abuse and as the Young Driver Program Coordinator for the Maryland Highway Safety Office. Heather has traveled the country speaking to nearly 100,000 young people about the dangers of substance abuse and drunk driving. She has experience in fundraising and grant work and hopes to be able to increase the revenue of Preemies Today so that the organization will be able to provide more services to preemie families. Currently, she resides in Potomac Falls, VA with her husband, Steven, daughter, Abigail (who is now thriving!) and yellow lab, Bailey.

Susan Boucher

Susan is the proud mother of twin toddlers born at 28 weeks gestation. She recently completed her MA in Special Education at the Catholic University of America and teaches part-time. Prior to the birth of her children she taught for four years, working mostly with at-risk youth. As a volunteer with the National Capital Chapter of the March of Dimes, Susan lobbied members of Congress for the passage of the PRE-EMIE Act. After the House unanimously passed the bill she spoke at a press conference with Senators Dodd (D-CN) and Alexander (R-TN). Susan and her family were honored to cut the starting ribbon at this year's WalkAmerica in DC.

Susan looks forward to working with Preemies Today to help support families with preemies in the NICU and beyond. She hopes to help others through the fear and anxiety that often accompanies the birth of a premature infant and the unexpected life changes that come with raising a preemie.

Ashley Hall

Ashley Hall is the owner of a small company that provides software and analytical support to the government, primarily in the area of signal processing and communications. Her preemie journey began when her daughter was delivered via emergency C-section at 25 weeks because Ashley had developed HELLP syndrome. Katelyn weighed 15.5 oz and was 11 inches long and endured a 159-day NICU stay.

Ashley learned of Preemies Today from the local chapter of the March of Dimes (MOD). It all started when a coworker placed a magazine add on her desk at work about the MOD

National Prematurity Awareness Day on November 16, 2004, Katelyn's 1 year birthday. She contacted MOD and told them her story. They immediately embraced Ashley's family and asked them to get involved with National Prematurity Awareness Day. On that day, Ashley met several members of Preemies Today and learned more about the organization. Soon after she joined Preemies Today, but due to Katelyn's health risks (RSV) that winter and the next the family had to hibernate and were not able to take part in any activities. Since Katelyn's health issues are no longer acute, they are looking forward to getting more involved and Ashley is proud to serve as a board member. Please visit Katelyn's website at www.katelynsjourney.com to learn more about her and follow her progress.

Mary Beth Hazelgrove, President

Mary Beth Hazelgrove was born and raised in the Washington DC metro area. She went to Mary Washington College in Fredericksburg, VA where she received a BA in History and a license to teach elementary education. Following college, Mary Beth entered the Peace Corps and served in Moldova, a former Soviet republic. There she taught English, started a girls' soccer team, and even played a few games on the Moldovan Women's National team. It was in the Peace Corps where she met her husband Doug who was a health education teacher. After returning to the U.S. she taught sixth grade in Fairfax County.

Mary Beth now stays home with her two daughters Madison age 4, born at 26 weeks, and Lexi age two, born full-term. This will be Mary Beth's third year on the Preemies Today board and first year serving as President. She is excited in her new role and hopes to be able to continue to provide resources for parents of preemies, network with other preemie groups around the country, and continue to speak about and promote Preemies Today in our community.

Julie Kipers, Secretary

Julie Kipers is the mother of a 24-week preemie, Nathaniel who was born in 2000. She began working with Preemies Today in 2002. She has moderated on-line chats, designed the original website for the group, and participated in a variety of support activities as a committee member. This is her first year on the board. Julie is interested in giving the perspective of a parent of an older preemie who has used in-home and school based early intervention and therapy. Julie and her husband Jeff are happy to say Nathaniel is a thriving 1st grader this year! The issues Nathaniel dealt with include reflux, ROP, delayed speech, and delayed motor skills.

Deborah Leaf, Treasurer

Deborah is originally from Philadelphia and has lived in Northern VA for five years. She attended the University of

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Pennsylvania where she received a BS in Nursing and a BA in Anthropology. She worked as a nurse in kidney and liver transplant for three years and then attended the University of California, San Francisco and received her Master's in Nursing as a Family Nurse Practitioner. She worked in women's health until the birth of her son, Jacob, a 27 weeker, now three years old. She has been married to her husband, Brian, for nine years and also has a one year old daughter, Sarah.

Stephanie Miller, Membership Chair

Stephanie Miller of Centreville, VA is a stay-at-home mom to preemie Jason (14 mos old now) and Emily (4 1/2 yrs. old). She's married to Al Miller, a contractor at General Dynamics. Stephanie has a BS from Florida State University ('90) and has 10+ years of professional experience. She has worked in the field of sports marketing, association management and IT recruiting. She currently is the Fundraising Chair for Centreville Preschool, a member of the FSU Alumni Association, and works part time for Prince William Co Schools and Road Race Management, Inc. Hobbies include reading, working out at the gym, and volunteering in the community.

Elaine Noto, Chairman of the Board

Elaine Noto relocated from the U.K. in 2000. She married Tom in September 2001 and has two grown stepchildren. In 1988 she started working for ExxonMobil in London and is currently working in its Fairfax HQ.

Elaine first discovered Preemies Today in 2004 when her daughter Rebecca was ending her 163 day "sojourn" in the Fairfax Inova NICU. Rebecca is a surviving twin; she and Jennifer were born at 26 weeks after complications from twin to twin transfusion. Rebecca experienced her more severe complications while in the NICU; she came home with oxygen, various monitors and a g-tube.

The family was thrilled to find such a supportive resource. Elaine quickly became involved in family activities. She has frequently relied on Preemies Today families as a source of information for health and developmental questions, particularly when Rebecca first came home and more recently when Rebecca had a hospital stay. The family will be looking to Preemies Today families for advice/support as Rebecca starts the next challenge - preschool!

Elaine joined the Board of Preemies Today in 2005 and was elected Board Secretary. She has helped organize family events, served as a member of the Silent Auction Committee. This year Elaine is delighted to again serve on the Preemies Today Board, and has accepted a new role as Chairman. She is very excited about the new program Preemies Today has initiated - Preemie Care Kits and is especially energized about expanding the programs that Preemies Today offers and reaching out to engage more families in its Mission.

continued from front, Micheal's story

otic, which could lead to hearing lose, so more hearing screenings became necessary. The transition from the feeding tube to the bottle was difficult and took numerous attempts. Michael had many, many apnea and Brady spells and was given caffeine to help them decrease.

Finally on February 11, 2005, Michael was able to come home with us. He weighed just over six pounds. He didn't need oxygen, but he did have the beloved apnea monitor for 2-3 months. He received his monthly synagis shots at home and made it through his first two winters without anything more than an occasional runny nose, thanks to lots of hand washing. He didn't qualify early on for the county's early intervention services, so we've been doing private physical therapy since he came home.

Michael took his first independent steps when he was 19 months old. He does wear orthotics for extra ankle support. While the ROP did resolve itself, he developed strabismus and has been wearing an eye patch for a few hours a day since last fall. He recently started wearing glasses, too. Despite all of the obstacles Michael has faced over the last 21 months, he is doing remarkably well. He is a happy little guy who loves music, Elmo, balloons, and sleeping 12-13 hours a night!

As it turns out, I did not have a bladder infection and the cause of Michael's premature birth is still unknown.

Join Preemies Today at
BURKE LAKE PARK for a
SCREAMING good time.

Sunday October, 29
11am-1pm

Meet at the covered picnic
tables by the train and
CAROUSEL

Local News:

Announcements:

Preemies Today Recognized by the March of Dimes

Preemies Today was recognized at the March of Dimes WalkAmerica ceremony as one of the top fund raising teams for Fairfax County, Virginia. Thanks to all who walked on the Preemies Today team as we joined the March of Dimes in its fight to end premature birth.

Preemies Today Yard Sale

Preemies Today is holding a yard sale on Sunday, September 30 beginning at 8am. It will be at the home of Stephanie Miller in Centreville. If you are interested in donating items or attending, contact Stephanie at laxtodca@hotmail.com

Parent to Parent Training- Help support other Families

Parent to Parent Training is on September 28th at the Fairfax Infant Toddler Connection from 7 -9pm. Childcare is available. Come and be a part of the a telephone-matching program to help support other parents. For more information contact Mary Beth Hazelgrove at marybethhazelgrove@verizon.net.

October Family Outing

We will be celebrating Halloween with an ice cream party at Burke Lake Park on Sunday October 29, from 11-1. Come dressed as your favorite ghost or goblin. We will meet at the covered picnic tables near the Halloween train and carousel. Please RSVP to Mary Beth Hazelgrove at marybethhazelgrove@verizon.net.

SIDS Walk

Join SIDS Mid-Atlantic in their Walk to fight SIDS, September 10

Locust Shade Park in Triangle VA 8:45am to Noon. Contact SIDS Mid-Atlantic at 703- 933-9100 for more information.

Support Groups:

"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

INOVAHealthsource is continuing to offer a NICU Support group for NICU families at INOVAFairfax. 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 INOVAHealthsource at 703-204-3366.

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/>

Recipe of the month: Corn Mush

Ingredients:

One 16 oz can cream corn

One 16 oz. can whole kernel corn, drained

1 egg

2 oz. whole milk

2 oz. heavy cream

1 stick butter

1 Tablespoon granulated sugar

1 box Jiffy Corn Muffin Mix

Directions:

Combine first 6 ingredients in a bowl. Pour into an ungreased 9x14 inch pan and spread evenly. Sprinkle muffin mix evenly over batter. With a fork, lightly fold muffin mix into batter. Do not over fold. Bake at 350 degrees for 30 minutes. Serve warm or cool. Makes ten half cup servings.

Nutrition information:

One half cup serving = 287 calories, 5 grams protein, 16 grams fat, 35 grams carbohydrate, 3 grams fiber

Recipe submitted by Mary Beth Hazelgrove, mom to 26 weeker, Madison.

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.

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.PreemiesToday.org

Membership/Subscription Information:

We offer the Premies 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 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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Premies Today
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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