

Preemies Today

Families Helping Families

PREEMIES OF THE MONTH:

Although having preemie twins may be twice the worry, Alyssa and Andrew Franco also bring their parents twice the joy. Here is their story as told by mom, Audrie.

Swollen legs, aching ankles and knuckles, and wearing shoes 2 sizes larger than usual. Sound familiar? For some, it's a completely normal part of pregnancy. For others, like me, they are signs of a very scary ailment called pre-eclampsia. If it were only for those more visible symptoms, I never would have known I was headed toward pre-term delivery of my twins. I was unaware that I was spilling protein and that my platelets were dropping rapidly. My OB/GYN put me on bed rest after a routine visit, however, when I returned for monitoring 3 days later, I was told there was "No time to go home and pack, head straight to the hospital".

The nurses wrapped two fetal heart monitors around my belly and I was lucky to have held out long enough to receive four steroid doses. We didn't know what to expect. One of the NICU nurses was asked to talk with us and address any concerns we had, so my husband and I proceeded to make a list of about 20 specific questions to ask. Thankfully, she was so very patient and answered every last one. I was admitted on Friday and scheduled for an emergency C-section on Monday morning.

Alyssa and Andrew made their way into our hearts and lives at 30 weeks gestation- each weighing 2 pounds, 13 ounces and 15 to 15 1/2 inches long. They spent 5 weeks in the NICU and went through several apnea and bradycardia scares. Alyssa appeared to progress more rapidly as she was intubated for only three days, whereas

my son was intubated for a few days longer. They were both under bilirubin lights quite often with those funny little sunglasses, but we thought they were just the most precious gifts we'd ever been given. My husband and I were so grateful that they never needed surgery and progressed beautifully.

Andrew did have some issues with feeding though. At first I attributed it to having been gavage fed for so long, however, he turned blue during feedings on several



occasions and once home he would take more than an hour to swallow two ounces of breast milk. We had to tickle his tiny chin and constantly probe him during feedings because he would fall asleep, poor little guy. The feedings were just exhausting him. Both twins suffered from reflux as well and were prescribed Reglan and Zantac.

They had such a strong will to live and even then we could see personality traits shining through. The nurses nicknamed Alyssa "feisty" as she'd kick and flail her skinny little legs about as they'd change her diaper. And Andrew would put up quite a fuss when his cap would roll down over his eyes, he didn't want to miss all that was going on around him. They both fortunate-

ly passed hearing and sight tests with flying colors.

When the twins were 8 months old (6 months corrected) we sold our home in Florida and relocated to the D.C. area for my husband's job. Although it meant that I would not have any family support and that we had the added stress of finding a new home, I was thrilled that I would be staying home with them full-time. The paperwork that had been started with the Infant and Toddler Connection in Florida was transferred. Some time was lost in the transition, but soon enough Andrew and Alyssa were receiving physical therapy once a week. We moved again a few months after that and were glad to have learned that a team would be coming to our home to reevaluate them. This time they qualified for language development so an Infant Educator worked with them for a couple of months.

Soon after, they turned two and were eligible for services through the public school system's Child Find office in Fairfax County. Once again the twins were evaluated and were still delayed in language skills and fine motor development. A teacher was assigned and has been working with them for over a year. She comes to our home once a week and the kids just adore her! She has helped them progress tremendously and works so hard to make sure that they reach their predetermined goals.

As for Andrew's feeding problems- they continued until almost recently (and they turned 3 in June!) I was at a complete loss once he started to slip on the growth charts. I saw a nutritionist and took him to the pediatrician many times. I am forever

Focus of the Month:

Preemies Today Annual Report

The year 2005 was a great year of growth for Preemies Today. Our programs and publications this year have reached thousands of people in the Washington DC area and beyond. Our newsletter production has grown from 200 to 700 copies per month. We are excited to announce that this fall our Board of Directors voted to eliminate membership dues in order to help more families who have been affected by a preterm birth. Preemies Today continues to hold close to our mission to reach out and provide support to families of premature infants beginning at birth and throughout childhood.

We started this year by being awarded our first grant from the March of Dimes which supported our monthly newsletter and resource brochure. Our individual subscriber list includes over one hundred people from 20 different states. We have increased our distribution from four local hospitals to nine local hospitals, four health departments, several doctors' offices, and two therapy centers. We are also proud to announce that we began translating our newsletter into Spanish. Our Spanish newsletter is distributed to local area hospitals and health departments.

One of our biggest events of the year was our Second Annual Celebration which we celebrated on March 20th. We celebrated our second anniversary with musical entertainment, children's activities, and a wonderful silent auction that raised \$1,700 to help support our programs. This wonderful event was attended by our special guest star Alex Brown from the Signing Time video series to the delight of our children. We also had the wonderful musical entertainment from jazz vocalist and guitarist, Karen and Baxter. In attendance were preemie families, friends, grandparents, aunts, uncles, nurses, and therapists. It was a wonderful event that we will remember for a long time to come.

During the year 2005 our programs continued to develop and gain strength such as our monthly outings, biweekly support groups, and our yahoo group now consists of 79 members! This year we were also able to add our "Friend to Talk to" telephone-support line, our "Take a Break" program, and Welcome Home kits to our list of our new programs.

Our "Friend to Talk to" telephone-support line offers families the opportunity to speak with other parents who have shared similar experiences. Our support line has been coordinated by Sonia Mehta and her team of volunteers. Thanks to all those that took the time to talk to parents, and for Kelley and John Gillespie's donation of the telephone.

The "Take a Break" program is an opportunity for us to help families in need. We provide meal preparation, babysitting, and other additional support options for preemie families in crisis. Sara Chae leads the Take a Break program along with her team of volunteers.

Our Welcome Home Kits consist of resource brochures on the Fairfax County's Health Departments Infant Development Program, Early

Intervention, SIDS Back to Sleep Campaign Sleep Sack, and Preemies Today's Family Guide to Preemies Resources. Included also are some baby essentials and other educational materials for families leaving the NICU. We started this program at Reston Hospital and hope to expand to other area hospitals in 2006.

Preemies Today has also continued to support the March of Dimes in 2005. Our families are aware how the research and funding from the March of Dimes programs saves the lives of babies every day. Parents and children from our organization participated in Walk America 2005 which we raised \$7,000. Some of our members also participated in the Ride for Babies, Hurricane Relief projects, the March of Dimes Signature Chef's Auction, and National Prematurity Day.

We will be ending this year with our holiday programs at several local area hospitals. We will help distribute Toys for Tots for siblings of NICU patients, cookies baked by our volunteers for NICU families, and even a visit from Santa Claus at Fairfax Hospital NICU on Christmas Day.

We would like to take this opportunity to thank all the volunteers who have devoted their time to help families of children born prematurely--you are the strength of this organization. We would also like to thank all of those that have sponsored us this year. Thank you for believing in the idea that we can make a difference for the families in our community. Without your help and support none of our efforts would be possible.

Our Volunteers

2005-2006 Board of Directors

Mary Beth Hazelgrove, Chairman of the Board
Kathy Paz, President and Founder
Susan Salguero, Vice President
Deborah Leaf, Treasurer
Elaine Noto, Secretary
Christine Miller, Membership Chair
Jenna Kassis, Resource Brochure Editor

2004-2005 Board of Directors

Kathy Paz, President and Founder
Mary Beth Hazelgrove, Vice President
Kelley Gillespie, Treasurer
Sonia Mehta, Secretary
Susan Embry Busch
Deborah Discenza
Deborah Leaf
Mary Lundregan,

Publications

Newsletter— Deborah Leaf, editor
Spanish Newsletter— Kathy Paz, editor

Resource Brochure— Jenna Kassis

Website— Julie Kipers

Contributors of our monthly Focus Articles— Lorna Sher, OTR/L; Paula Gorman, Family Resource Coordinator, Infant Toddler Connection Fairfax-Falls Church; ; Rachel Coleman, SigningTime!; Sara Chae, Premie Mom and former Preschool Special Education teacher; Colleen Wood, MPT; Gina Schmidt MA, CIMI (Infant Instructor), Dori Fishbone, OTR.

Support Group Coordinators

Deborah Leaf and Susan Salguero

Friend to Talk to Line

Sonia Mehta, coordinator

Julie Kipers

Alicia Micheals

Deborah Discenza

Mary Lundregan

Erin Lee

Susan Embry-Busch

Take a Break

Sara Chae, coordinator

(along with many Premies Today families)

Fundraising

Annual Celebration Silent Auction Chair— Kelley Gillespie

Garage Sale— Kelley Gillespie

Simon Day— Elaine Noto

Welcome Home Kits

Christine Miller, coordinator

Holiday Program

Santa Claus— Al Leightley

Our 2005 Sponsors

Cooley Godward

Sherri Hughes

Signing Time!

Peter Gaylor

Simply Create Photography

Silverbrook Nursery

Ronnie Elias

MOMS Club Falls Church

Table to Table

Alexandre de Paris

DC United

Great American Restaurants

My Gym

Olive Garden, Tysons

Kennedy Center

Toys R Us, Fair Lakes

Keller William Reality

Cindy Belsky

My Gym, Burke

Buy, Buy, Baby

Outback Steakhouse

Wegmans, Fairfax

South Moon Under

Zaidee Coco

American Tap Room

Edibles Incredible

Main Event Caterers

March of Dimes

Caribou Coffee

Einstein Bagels

Giant Foods, Chantilly

Costco, Fairfax

Trader Joes, Springfield

Jeremy Burch

Elaine and Tom Noto

Helping Hands

Cheri Corrado

Falls Church Moms Club

Simone Beeman

Mulu Kumssa

Joseph Peaks

George Weedon

Terry Straley

Nancy Gorman

Sue Stormoen

Danis Duds

We hope that everyone has a safe and happy holiday season and we look forward to an exciting new year!

Kathy Paz, President and Founder, Premies Today

Mary Beth Hazelgrove, Chairman of the Board, Premies Today

Dear Premies Today Newsletter Recipient,

We are asking for your help as a part of a survey we are conducting regarding our newsletter. The questions found on our survey describe what we are studying and why. Your response to this survey is totally voluntary and anonymous, but it would be very helpful if you do respond.

You may respond to the survey by clicking the following URL: <http://www.AdvancedSurvey.com>. When you arrive at the Advanced Survey homepage, type in survey number 32535 in the "Take A Survey" box.

If you have any questions, please contact Mary Beth Hazelgrove at marybethhazelgrove@yahoo.com. Thank you very much. We look forward to hearing from you!

Sincerely,

The PremiesToday Board of Directors

Treasurer's Report for 2005

I am excited to report we will end our first fiscal year as a 501(c)(3) nonprofit corporation squarely in the the black. Thanks to all the support we have received from the March of Dimes and the community at large we will have approximately two thousand dollars in surplus at the end of December. We plan to place about seven hundred dollars into an interest bearing account to be held in reserves to hedge against fluctuations in grant money and contributions. The rest of our surplus will go to expanding our existing programs, such as the Welcome Home kits and Take a Break. We are also going to obtain a toll free number for our "Friend to Talk To" hotline so that families living outside the (703) area code do not have to pay to call us.

Thank you to everyone who has helped to make this such successful year for Premies Today

-Deborah Leaf, Treasurer

**Please note that the following reports January 1, 2005 through November 30, 2005.

Income

Annual Celebration Income	1,793.00
Donations	1,940.00
March of Dimes Grant	3,140.00
Member Dues	325.00
Simon Day of Giving	130.00
Yard Sale Income	559.65

Total Income	7,887.65

Expenses

Administrative costs	275.00
Annual Celebration	802.52
Bank Charges	93.00
Charitable contribution	670.00
Events	41.83
Membership Committee	9.42
Miscellaneous	222.30
MOD Grant expenses 2005	2,131.18
Open House	17.09
Take a Break	139.60
Yard Sale Expenses	118.39

Total Expenses	4,520.33

Total Income/Expenses 3,367.32 (as of 11/30/05)

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grateful to one of his pediatricians in particular. She had me chart his intake for two weeks- and looked it over carefully at a follow-up visit. Per her urging we had made arrangements to take him to the Feeding Clinic at Children's, but it never progressed to that point. She suggested that the biggest mistake I was making was giving him chocolate milk whenever he asked for it- not a good idea in his case. He was maintaining his blood sugar at an even level and it would never drop enough to make him hungry. In addition to changing that, he pretty much outgrew his aversion to meat. I don't know if it was the taste or the texture, but for the

longest time he wouldn't eat any meat (while his twin sister has always been quite the carnivore).

Alyssa and Andrew started preschool this fall and every day I am amazed at how much they have grown and how much they've learned. It was a troublesome beginning for them, but through the dedication of wonderful doctors, nurses, educators, and specialists- they will hopefully attain goals I once questioned possible. Neither my husband nor I could imagine our lives without our sweet, happy, high-energy bundles of joy!

Local News:

Announcements:

Mission Statement Revised!

The Premies Today Board of Directors has been working hard on revising our mission statement to better meet our organization's needs and vision. Recently, by unanimous vote, the board has approved the mission statement that you see in this issue. Cheers!

Logo Redone

The Board is also collaborating with the company Nola Flash on a redesign of our current logo and website. We will keep you updated when further information is available.

Cookie Exchange

We will be organizing a cookie exchange on December 11 at 7 pm at the home of Deborah Leaf. You are asked to bring 5 dozen cookies. One dozen will be for swapping and the rest will go to the designated family waiting areas at several local area NICUs. You may RSVP to Deborah Leaf at deborah_leaf@yahoo.com.

Holiday Party

Premies Today will be organizing the third annual holiday party. This year's party will take place on December 18th from 3:30-5:30 in the conference room at Centreville Regional Library. Please bring a side dish to share. Premies Today will provide a main dish and drinks. There will be music and a visit from Santa Claus! You can RSVP to Kathy Paz at p. Please be advised and follow the Premies Today Illness Guidelines when bringing your preemie (especially during cold and flu season.)

Support Groups:

Take a Break

Premies Today offers meal preparation assistance, babysitting, and other additional support options for preemie families in cri-

sis. If you are in need of assistance or would like to help other families, 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 703-994-6624.

NICU Support Group

INOVA Healthsource is continuing to offer a NICU Support group for current INOVA Fairfax NICU families. 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.

Premies 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 contact us at premiestoday@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 look to subscribe at <http://groups.yahoo.com/group/PremiesToday/>

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.PremiesToday.com

Mission of Premies Today:

Premies 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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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.

Premies Today
P.O. Box 523525
Springfield, VA 22152