

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

We have a double preemie story this month, Aidan and Padraig Hall. After Aidan was born prematurely, the Halls decided to try a "post-preemie" pregnancy and were blessed with Padraig. Here is their story as told by mom, Heather.

My husband and I met in college and dated several years before finally tying the knot in 1999. We settled in Burke, Virginia and decided to have some fun as newly weds before starting a family. We saw lots of concerts and traveled to places that we had dreamed of seeing together.

One evening, my husband began to talk seriously to me about the idea of having children. Our friends were starting to have kids and it seemed that his biological clock was not just ticking, but screaming. I was in the process of leaving a job that wasn't "family friendly" and within two weeks of leaving my job, I had a positive pregnancy test. I took a second test just to be sure and got the same result. Both my husband and I were overjoyed that we had gotten pregnant so quickly. My doctor advised us to keep the pregnancy to ourselves for the first three months, so we only told my mother and stepfather.

I decided not to return to work and enjoyed sleeping in, attending low impact Jazzercise classes, and spending time at my parents' vacation homes. My last routine examination was the week before the fourth of July in 2002. My blood pressure was fine and there were absolutely no signs that I was going to deliver early. I decided to make one more trip with my mother before the baby arrived to see my relatives in Pennsylvania and stay at her lake house. My feet swelled at the lake house and I was beginning to feel uncomfortably pregnant in the heat. I had a healthy pregnancy, with the exception of a case of sinusitis, and felt good until this point.

Once back in Virginia, I fell back into my old routine. On July 10th, I went to my

Jazzercise class in the morning, came home for a little bite to eat, and headed to Target to shop for the baby. I was at 32 weeks and had begun nesting. On the drive home from Target my water broke in the car. I was shocked; What could this be? Certainly it wasn't time. Once home I ran inside and phoned my husband, the doctor, and my parents. My husband left work and headed home to take me to Potomac Hospital. Ironically my doctor was having foot surgery, so I received a call back from the on call doctor who I had never met before. He instructed me to get to the hospital as soon as possible.



Luckily I had attended my first breast feeding seminar at Potomac Hospital the night before and had pre-registered at the hospital. I was put in a room immediately upon arrival. My husband and I were worried about the baby's health and I was terrified of the birthing process itself since I had not taken Lamaze yet. I was having lots of discomfort from the contractions and kindly asked a nurse to help teach me how to count and breathe through the mountains of pain.

After shots of betamethasone, hours of wondering if our baby was going to be all right, some pitosin, and a bit of hard labor Aidan Patrick was born at Potomac Hospital on Thursday, July 11th, 2002 at 3:13 am, approximately 10 hours after my membranes rup-

tured. Just prior to delivery a team from the NICU entered the room and the doctor said, "It's a boy." The doctor passed the baby to the team quickly. I just remember thinking that there must be some mistake about me delivering two months early as the baby felt so large during the birthing process. Aidan weighed 4 lbs, 5.8 oz and was 18 inches long. I kept asking, "Why isn't he crying?" No one answered me. I was told shortly after Aidan was whisked away that they were working on him and would allow us to see him once he was in stable condition.

We finally got to see our son four hours later. As we stared at our baby close up for the first time in his isolette, I remember saying, "He's beautiful, he's just perfect," turning towards my husband and seeing a tear roll down his cheek. Aidan was in respiratory distress at birth and required intubation. He received a dose of surfactant and was extubated to nasal canula at 9 hours of life and was off of nasal canula the next day. He had periodic apnea and received caffeine treatment. He spent a good deal of time in the isolette under lights for jaundice. He was also treated with Reglan for reflux. He had trouble at feedings and as a result he was breast fed, bottle fed, and gavage fed.

Aidan was discharged on August 8th, 2002 after a 29 day stay in the NICU. He came home with a prescription for epogen to be given by a home health nurse for his first two weeks home. The sun was shining on the Occoquan River and as we crossed the bridge leaving Prince William County into Fairfax County and all seemed right with the world. Little did we know that our preemie journey was not over.

We took great precautions to keep Aidan away from large groups during cold and flu season and he received Synagis shots during his first RSV season. We were militant about hand washing and banned anyone with a sniff-

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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

**Do you want to volunteer or become
more involved with Preemies Today?**

Preemies Today invites you to learn more about us at our next
Board Meeting.

Join us at the home of Elaine Noto
Sunday, July 29
2pm.

Please email elainenoto@preemiestoday.org for more details.

continued from cover, Adian and Padrig's Story

fle from our home. Aidan was a pleasant baby, but it was clear that he was developmentally delayed at two years of age. We were concerned because he didn't call us anything and didn't hug us or wave bye like other kids his age. Our doctor had us wait until he was 27 months before she would refer us and finally gave us the number for The United Way in Richmond, VA. They, in turn referred us to the Infant and Toddler Connection (ITC) of Fairfax-FallsChurch. It took about six weeks to have Aidan evaluated by the ITC. He had delays both expressive and receptive language skills and had both fine and gross motor delays as well. He also had feeding issues. Also, as a result of his language delays he had terrible temper tantrums. We worked with both speech and occupational therapists, but found that the tantruming was best helped by a Childhood Development Specialist.

After six months with the Infant and Toddler Connection, we transitioned to the Child Find Preschool Program. Aidan has just completed his second year with Child Find and has made tremendous progress. We are filled with pride every time with think of just how far Aidan has come. We often tell him, "You've come a long way baby!"

Aidan continues to improve in all areas. On the advice of our developmental pediatrician, we have decided send Aidan to a private mainstream preschool this fall to give him an extra year before kindergarten. We were concerned about Aidan going from a classroom of 8 to a classroom of 25 children. This fall he will be in a class of 12 and it is where we had enrolled Aidan before he was placed in Child Find. We are pleased to have him attend the school we chose for him.

My husband and I began talking about the possibility of a second child when Aidan was two. We both wanted another child and the only thing holding us back was the frightening memory of Aidan's birth. We finally decided to go for it, though we knew there where no guarantees. After Aidan's birth, I realized that we had placed too much faith in what our doctors were telling us. No doctor's sonogram is a crystal ball that can determine the fate of both mother and child.

In December, 2004 I learned I was pregnant for a second time. I decided at that moment that I would not only rely on the doctors to get

me through this pregnancy. Instead, I would listen to my body very closely. Regardless of how well things appeared to be going, I would listen to my inner voice. But, my label of "High Risk" was not going to stop me from being happy that our family was growing.

We phoned our doctor and he referred us to a high risk team at Fairfax Hospital. Upon our initial consultation with Perinatal Associates, we were told I would be monitored very closely to be certain that my cervix was not dilated. Aidan was born prematurely due to PROM, but the doctors didn't know if my cervix was to blame. Throughout the pregnancy I had several examinations that included both internal and external sonograms. My cervix remained intact and all was going well. However, I began to have anxiety and lose sleep just before I was at 32 weeks. I was told by one of the nurses during a sonogram that the post-traumatic stress I was experiencing was very common. It made me feel better to know that I was not alone in my fear that I might have another preemie.

I awoke on Friday, August 19th and noticed that my right foot was swollen. During my first pregnancy my right foot was swollen more than my left. It was going to be another hot day summer day and a friend asked if Aidan could come over for a play date. I told her that we'd come, but that I would have to sit in the air-conditioning with my feet elevated. I phoned my mother and told her that the time was coming and not to be surprised if we phoned to tell her that I was delivering.

Later that day I had some spotting and was admitted to the hospital at 9 pm. I was taken to triage and told that the contractions were five minutes apart. The baby was breach and the nurse informed me that unless the contractions stopped, I would need a c-section. The shock of learning that I might go under the knife coupled with the side effects of terbutaline made me weep. I was also given shots of betamethazone to help the baby's lungs. I was eventually moved to labor and delivery spent the first night there. The third shot of terbutaline managed to stop the contractions. I was moved to the high risk unit, put on bed rest, and given oral terbutaline.

It appeared that I had a slow leak of amniotic fluid, but the tests kept coming back negative because the fluid was masked by mucus

in the culture. The doctors assured me that a slow leak had subsided and that the amniotic sac could reseal itself. I was discharged on Tuesday, August 23rd at 3 pm. When the doctor came into the room to tell me I was being discharged, my mother told him I would be back in the hospital delivering well before two weeks was up. I was sent home to be on bed rest for two weeks with a prescription for oral terbutaline.

That night I had a hard time falling to sleep after taking the terbutaline. At 3am I got up to use the bathroom and my water broke. I immediately phoned my doctor to alert him. When I arrived at the hospital my cervix was at 7cm. I waited 45 minutes for the epidural and my doctor arrived 15 minutes later. Padraig Ryan was delivered on August 24th, 2005 at 6:43 am, via c-section because he was breech. He weighed 6lbs, 9oz and was 19 inches long. Though I could not see him being pulled out, I heard the doctor say, "It's a boy and he's huge". Next, I heard our son's sweet cry. No one arrived from the NICU and we felt a great sense of relief. After the newborn examination, the nurse brought Padraig over to meet me. As my husband held the baby near my face, I was in disbelief that this child was mine, his head was perfectly shaped unlike Aidan's that was dented from vaginal birth. It was as if a stork had delivered him from the sky. Padraig was then whisked away to get something to eat while I got sutured. He was apparently made very hungry by the ordeal. Padraig and I were then reunited and taken to our room. As we were wheeled to the room, I felt like I was dreaming. We were discharged on the 28th and it was truly a thrill to have our baby boy come home with us this time around.

Looking back on the second pregnancy, we have no regrets about deciding to have a second child despite the high risk label. The second pregnancy was an emotional roller coaster for us, but it was well worth the gamble. Padraig is a healthy boy and was tested by the ITC at 18 months and appears to be on track. Having a younger brother has forced Aidan to be more assertive. As the boys approach their birthdays, Aidan will be 5 in July and Padraig will be 2 in August, they are really enjoying each others company. They play so well together. We are very lucky to have such happy boys and despite our personal struggle to get to this point, all is right with the world.

Preemies Today Celebrates Four Years: Annual Celebration and Silent Auction

On June 9, 2007, Preemies Today celebrated its Fourth Anniversary with delicious food sponsored by Outback Steakhouse, fun children's activities sponsored by Sensibilities for Kids, and a fantastic silent auction at the INOVA Fairfax Hospital Physician's Conference Center in Falls Church, Virginia. In attendance were our preemies, their parents, siblings, grandparents, friends, therapists, and nurses.

In the Children's Area, Sensibilities for Kids of Leesburg, VA provided a fantastic array of sensory activities to engage the children's attention as well as their senses. Separate stations were set up such as the Shake, Rattle, and Roll ball pit; the Peace and Quiet tents with glow-in-the-dark toys; the Super Sensory station with special 'blubber' and cookie cutters for the kids to explore; and an Art station.

While the kids were busy in the Children's area the parents had an opportunity to bid on auction items ranging from Disney Hopper passes, Air Duct Cleanings for your home, and a beautiful McLaren Techno XLR stroller. One of the grand highlighted items which was raffled off in a live auction was a hand-painted flower pot signed by Governor Tim Kaine.

We were also much honored to present our Health Professional of the Year Award to Deb Smith of INOVA Fair Oaks Hospital. Deb Smith was nominated by member Dagny Sheils for Deb Smith's wonderful care of her son as well as how she orchestrated a special first meeting between Dagny's three-year-old daughter and her new brother. Deb Smith is a 20-year veteran of the INOVA Health System and working in the Fair Oaks Hospital

NICU she continues to share her experience and care with families every day.

A wonderful slide show depicting the history of Preemies Today which was put together by Susan Boucher was also shown during the awards ceremony. The entertainment continued with performances from two of our special volunteers Miss Teen Annapolis and Miss Susquehanna. The performances did not end there. The children were entertained for a final time by Miss Roberta from Music Together as the auction winners were checking out their items.

The night's silent auction was a huge success and raised over \$5000! This will help fund our support hotline, support groups, Take a Break program, and NICU support programs. Not only was this night's event a celebration of our organization but the silent auction shows our support from community businesses, premie related businesses, as well as businesses around the United States. We also thank all our generous bidders for their contributions to Preemies Today.

And of course a big thank you for all the volunteers that came out to assist with festivities. A special thank you to those that made the night possible: Elaine Noto and Heather Ablondi Event Chairs; Stephanie Miller; Melissa Macri; Susan Salguero; Tom Noto; Caitlyn Noto; Susan Boucher; Ashley Hall; Deborah Leaf; Julie Kipers; Mary Beth Hazelgrove; Kathy Mingledorff; Heather Molnar, Miss Annapolis; Hannah Mollerick, Miss Maryland's Outstanding Teen; Cheryl Gill, Miss Susquehanna; Caroline Pledger, Miss Annapolis' Outstanding Teen; Jolene Mollerick; Courtney Palmer; and Erin McCoy. Thanks again to everyone who helped put together such a fantastic event, and we are looking forward to another incredible year as an organization.



The bidding heats up for Caitlyn Noto



Zander Macri explores the "Peace and Quiet" tent



Rebecca Noto and Emily Miller hang out in the ball pit (above).



Miss Roberta entertains the crowd (right).

THANK YOU TO OUR SPONSORS

Event Sponsors

Outback Steakhouse, Fairfax, VA
 Sensibilities for Kids, Leesburg, VA, www.sa4kids.com
 Kent Ealey of Agent “E” and Associates, Century 21
 Matt Chae of Keller Williams Realty
 Jennifer Noto Fund

Silent Auction Sponsors

Walt Disney Word
 Maclaren Stroller
 March of Dimes, National Capital Area
 Duct Cleaning Pros, LLP
 Friends of the National Zoo
 Ingelside Winery, Oak Grove, VA
 Jetset Baby by Nina Yim
 Moe’s Southwest Grill, Centreville, VA
 Top Golf USA
 Cindy Belsky, Southern Living at Home
 Dinner is Served- Chef Cal Craft
 Omni Hotels—Charlotte, NC
 Whiteail Mountain Resort, Mercersburg PA
 Miss Roberta Music Together
 Portrait Innovations
 Arena Stage
 George Mason Center for the Arts

Feld Entertainment
 Big Apple Circus
 Fairfax County Park Authority
 University Mall Theatre
 NOW This! DC Children’s Improv
 Leaf Family
 Hazelgrove Family
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 Ashburn Ice house
 Petite Ballet, Bethesda, MD
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 Melissa Macri-Moon Bounce Rental
 Red Robin
 Dinner Done
 Kokoon Clothes
 Mary Kay—Tina Dempsey
 The Ritz Carlton—Tysons Corner
 Gold’s Gym
 Arthur Murray Dance Studio, Tysons Corner, VA
 Mommy Bracelets
 Bark Vineyards
 Radiance Medspa
 Ronnie Elias Salon
 Jus Massage
 Handwriting Detective Club
 Silverbrook Nursery
 Cartoon Cuts
 Tiny Fingers, Alexandria, VA—Sign Language classes

Simply Create Photography
 Main Event Caterers
 Moving Comfort
 Pat-a-Cake prints
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 Bonefish Grill
 Melissa Macri—Tupperware
 Chipotle
 Healthy Little Ones—Diaper Bag Signs
 Tiny Steps—NICU Journal
 Therapy Shoppe
 Stitches So Sweet
 Gabrielle Vorst
 Potomac Nationals
 Debra Southall
 Kay Greene, www.MyPreciousKids.com
 7-11
 Silver Dinner

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Preemie of the Month Update: Nathaniel Kipers

Nathaniel is a 24-week preemie that was born on St. Patrick's Day in 2000. He should have been born on the 4th of July so he is truly a holiday baby! Now that he's seven, people sometimes ask why I say he "is" a preemie versus he "was" a preemie. Although he's overcome many medical challenges and most people cannot tell he was premature, I feel that the preemie experience will always be a part of our family history. Nathaniel spent four months in the NICU and experienced several hernias that resulted in two surgeries, a staf infection, and lots of feeding and respiratory issues. We worked with physical therapists and occupational therapists beginning when he came home from the hospital. Around 2 _ we added speech therapy as he had very low muscle tone in his face and was only speaking three or four words. With the help of just five signs in sign language we were able to minimize frustration for both him and us. It took until age four for his language skills to improve, but he hasn't stopped talking since! The medical issues that have lingered the longest are reflux, low muscle tone, and sensory integration issues.

The Fairfax County preschool developmental program let us continue his therapy as he got older. As Nathaniel enters second grade next year in public school we continue to work with his teachers through the



Individual Education Plan (IEP) process. Handwriting has been the most noticeable issue, as Nathaniel is still developing his fine motor skills. For gross motor skills, Nathaniel goes to swimming classes and Tae Kwon Do classes. He is so proud every time he earns a new belt or stripe at Tae Kwon Do. It's great to see!

Nathaniel loves to collect things and is a Star Wars fanatic. He is almost always in a good mood and believes that all doctors are there to help him. Instead of being anxious about going to doctors or therapists, he loves all the one-on-one attention he gets! I am happy to say that the doctor's visits are not every week or every month anymore. Now we follow up with specialists as needed, usually once or twice a year.

I don't think we'll ever know what educational issues may be due to prematurity versus being related to family traits. I do believe the preemie experience has given us a special way of looking at his development and helped us advocate for him no matter the reason for any issues. Even small milestones mean so much. His latest accomplishments: hitting 50% on the weight chart for the first time, climbing all the equipment on the playground without help, and being able to say his lines in the school play.

Julie Kipers is mom to Nathaniel and works in government consulting for LMI.

Local News:

Preemies Today Board Meeting

Are you interested in learning more about Preemies Today or becoming a volunteer to assist with one of our programs? Preemies Today invites all interested parties to the home of Elaine Noto on Sunday, July 29 at 2pm. Please email elainenoto@preemiestoday.org for more details.

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 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

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 assistance 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.

Yahogroup!

Come and join our yahogroup and meet some of our wonderful parents where you can exchange information on preemie parenting. You can subscribe at <http://groups.yahoo.com/group/PreemiesToday/>

Helpful Resources:

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@premiesto-day.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**