

# PREEMIES TODAY

*National Premie Family Support Network*

## A Premie Boy Continues to Show His Tough Fighting Spirit

by Kelly Smith

I was 34 and my husband Mike was 31 when we learned we were expecting a baby. I experienced light spotting from the get go, but my mother assured me that this wasn't something to get too concerned about. She had spotting with both of her pregnancies, yet carried the babies to term. The first sign of real trouble in my pregnancy was when I failed the glucose tolerance test. I had gestational diabetes that was controlled through a strict diet. Early on I also started having contractions which my doctor assumed were Braxton-Hicks.

At 27 weeks, after a weekend in bed with severe back pain, I was seen by a nurse mid-wife at my HMO. She said the baby had dropped and she could feel the baby's head. She told me to go on total bed-rest. In hindsight if I had it to do all over again, I would have called an ambulance right then.

Within a few hours of returning home, my water broke. My HMO insisted I go to Fair Oaks Hospital. Later that evening, in rush hour traffic, I was transported by ambulance to Fairfax Hospital. My contractions were two minutes apart by the time we arrived due to a problem with my IV. Once inside the hospital, I was given magnesium sulfate to delay labor, terbutaline to stop the contractions, betamethasone to aid in the baby's lung development, and morphine for pain.

My doctor was convinced that my labor was under control and I would remain at Fairfax for two weeks or more before giving birth. That evening I developed an infection as well as a fever. Very quickly and unexpectedly our son was born weighing only 2 lbs., 10 ounces. We named him Jackson. He was immediately given oxygen and rushed to the NICU.

At first it appeared that Jackson was only experiencing typical premie complications. His prognosis was very good. However, when he was four days old he developed a pulmonary hemorrhage. With tears in her eyes, the neonatologist told us Jackson was not expected to live through the

night. We were taken in to the bereavement room and told to notify our family.



If I was going to lose my only child I had two requests. The first was that I be allowed to hold him before death. The second was that I needed a picture to remember him by. A nurse took the photo. I have never been able to bring myself to look at it.

Dr Galioto, a pediatric cardiologist, came to assess what could be done for Jackson. Although ice gavage, dripping freezing water into the baby's lungs, was not a proven remedy, he was willing to try anything to save our son's life. Jackson held on through the weekend. His nurses suctioned the blood out of his chest tube around the clock while in the ICU.

The team of neonatologists decided that if Jackson became strong enough they would perform a PDA ligation. He would need a blood transfusion. Mike do-

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# PREEMIES TODAY

**Preemies Today**  
P.O. Box 523525  
Springfield, VA 22152

**Founded:**  
March 2003

**web:**  
[www.preemiestoday.org](http://www.preemiestoday.org)

**e-mail:**  
[info@preemiestoday.org](mailto:info@preemiestoday.org)

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

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## Calendar of Events

### June

June 7, 4:00 p.m. - 6:00 p.m.  
Meet and Greet from  
Pat Troy's Restaurant & Pub  
111 N. Pitt St. Alexandria, VA 22314  
RSVP to [events@preemiestoday.org](mailto:events@preemiestoday.org)

June 8, 2:00 p.m. - 4:30 p.m.  
Patricia Lemer, M.Ed, NCC  
How do we prioritize and put it all together?  
Inova Fair Oaks Hospital  
3700 Joseph Siewick Dr.  
Fairfax, VA 22033  
RSVP to [events@preemiestoday.org](mailto:events@preemiestoday.org)

June 11, 7:30 p.m.  
Parent Support Meeting  
Barnes and Noble, Fair Lakes, VA  
RSVP to [events@preemiestoday.org](mailto:events@preemiestoday.org)

June 18, 10:00 a.m.  
VA Weekday Playgroup  
Fairfax, VA  
RSVP to Kim at [krwa@verizon.net](mailto:krwa@verizon.net)

June 22, 2:00 p.m. - 4:30 p.m.  
Fairfax Neonatal Associates  
What are current statistics on outcomes for premature infants?  
Inova Fair Oaks Physician Conference Center  
3700 Joseph Siewick Dr.  
Fairfax, VA 2203  
RSVP to [events@preemiestoday.org](mailto:events@preemiestoday.org)

June 28, 9:30 a.m.,  
VA Playgroup  
Frying Pan Farm Park, 2709 West Ox Road, Herndon, VA  
<http://www.fairfaxcounty.gov/parks/fpp/>  
Meet at the picnic tables overlooking the play tractors and barns.  
RSVP to [Margaret\\_Behrns@cox.net](mailto:Margaret_Behrns@cox.net)

### July

July 9, 7:30 p.m.  
Parent Support Meeting  
Barnes and Noble, Fair Lakes  
RSVP to [events@preemiestoday.org](mailto:events@preemiestoday.org)

### Mailbox :

Please send us your feedback, suggestions, or contributions for future articles by the 15th of each month to:

[info@preemiestoday.org](mailto:info@preemiestoday.org)

Preemies Today  
PO Box 523525  
Springfield, VA 22152

### Preemies Today Parent-to-Parent Telephone Line

Would you like to speak to a **veteran** preemie parent that has a similar experience?

Call:  
1-888-712-3208



# A Premie Boy Continues to Show His Tough Fighting Spirit

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nated blood but carried the cytomegalovirus so Jackson received blood from a donor. Three days later the surgery was successful and he remained in the critical care section of the NICU. Additionally, Jackson had several infections, broncho pulmonary dysplasia, apnea, bradycardia, jaundice, and reflux.

After three months, much of it spent in the more acute care section of the NICU, Jackson came home. He required oxygen during his feedings and had an apnea monitor constantly. Being Fairfax County residents, we were able to enroll Jackson in the apnea clinic. Jackson saw a pulmonologist, too. He was enrolled in the Early Intervention Program and received occupational therapy. He did not walk until he was 19 months old.

Around age 3, Jackson was enrolled in the Child Find Program where he received speech therapy as well as occupational therapy. Jackson will enter third grade this fall. Although he does not require services at this point, he will continue to be monitored by resource teachers with Fairfax County Public Schools.

*Jackson tries hard at everything he does, like a true survivor.*

Recently we had Jackson tested. He suffers from ADHD but has no learning disabilities. Jackson requires help with his work from Mike and I, but his grades are excellent. Luckily, Jackson has no known health problems as a result of his prematurity. He loves all sports. He plays football, baseball, and basketball. Jackson tries hard at everything he does, like a true survivor.

After Jackson's premature birth doctors discovered that I had an incompetent cervix. With the help of a perinatologist, we were able to give birth to two daughters. Both

were also high risk and were born at 36 weeks.

Jackson's 9th birthday is this July. It will certainly be a day of festivities for our family. However, we celebrate Jackson everyday because we know just how fortunate we are to have him in our lives.

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## Preemie Pictures & Milestones Look at me now!



Jason Miller, a 34 weeker and now 2 years old, is getting messy!

Mackenzie Hammert, a 27 weeker and now 17 months old.



Here she is for the first time walking with her push toy. She is so proud of herself!

# Program Updates

## ***Thank you to all our volunteers!***

- A special thank you to all of the volunteers who made bracelets, cards, and helped with the deliveries to local hospitals over Mother's Day weekend.
- Thank you to Heather Hall for her dedication to the newsletter.
- Thank you also to Meg Nelson for assisting with the Preemie Parent Lecture Series.

If you'd like to volunteer to participate in our Preemies Today Mentor Program, distribute NICU Care Kits, or assist with special events, please e-mail [info@premiestoday.org](mailto:info@premiestoday.org)

## ***Thank you to our recent donors:***

- United Way Campaign donors
- Exxon Mobil Employee's Favorite Charities Campaign
- FDA's farewell gift honoring coworker Malou Gemeniano
- Thank you to Kathleen Molloy and her family for sponsoring a Preemies Today Meet and Greet from 4 p.m. - 6 p.m. on June 7th at their family's restaurant: Pat Troy's Restaurant & Pub 111 N. Pitt St. Alexandria, VA 22314



**Elaine Noto delivering NICU Care Packages to Lisa Klein at Inova Fair Oaks Hospital**



*Picture taken from an evening event at the Chicago VONN Conference. Pictured are Mary Zapalo, RT; Mary Beth Hazelgrove; Marti Howar, RN; MaryAnn Zeqeer, RN; Alex Kline, MD; Becky Beck, and Jim Beck*

## **Message from Our President:**

I had the wonderful opportunity to attend the Vermont Oxford Conference, a national evidence-based quality improvement collaborative, in Chicago, IL this past April. Inova Fairfax Hospital in Falls Church, VA asked me to join their team of health care professionals as their parent representative. I was honored and found this conference to be a wonderful learning experience. I was also able to meet parents representing other hospitals from around the country.

One of the topics discussed at this conference was Family-Centered Care. There currently is a strong emphasis placed on this developmental approach in NICUs across the United States. Family-Centered Care is a very broad term making families an integral part of their child's health care team and providing better avenues to support parents while their children are in NICUs. I would encourage all NICU families to discuss Family-Centered Care with your child's doctors and nurses. Ask how you can become more involved in your child's care. Learn about the importance of Kangaroo Care and call our phone line to speak to a parent mentor. Parents who have been there can add much needed support during difficult times. Call 1-888-712-3208 to be matched with a veteran preemie parent from Preemies Today.

Mary Beth Hazelgrove

# Resources for Children Who are Blind or Visually Impaired

By Kim Avila, M.A., COMS

If you suspect your child may have a visual impairment or is blind, he or she is entitled to services from a teacher of the visually impaired (TVI) and Orientation & Mobility Specialist. Services for the blind and visually impaired are an important part of your child's early intervention and education. Instruction in compensatory techniques, travel skills, literacy development, independent living skills, adaptive play and leisure activities, support for family and caregivers, and overall developmental and educational support require specific instruction from a qualified TVI.

Contact your local early intervention agency or school to request services from a TVI. You will need a letter from your child's ophthalmologist documenting the presence of a visual impairment. Keep in mind, many children who are visually impaired may not "look" or "act" blind. They may have usable vision, but the impairment may affect their ability to read and see a chalkboard, even with glasses. A TVI will perform a Functional Vision Assessment to determine the amount of usable vision present. Adaptive aids and accommodations may be prescribed to assist your child in accessing the environment equally with his or her peers. Your child's early intervention case manager or your school's special education teacher should also refer you to your local branch of the Virginia Department for the Blind and Vision Impaired. Contact information for this agency is listed below.

## Contacts:

*Virginia Department for the Blind and Vision Impaired (VDBVI)*  
<http://www.vdbvi.org/>



Bristol Regional Office (276) 642-7300	Fairfax Regional Office (703) 359-1100
Headquarters Office (804) 371-3140	Norfolk Regional Office (757) 858-6724
Richmond Regional Office (804) 371-3353	Roanoke Regional Office (540) 857-7122
Staunton Regional Office (540) 332-7729	

## Support Organizations:

National Association for Parents of Children with Visual Impairments  
<http://www.spedex.com/napvi/>

The National Organization of Parents of Blind Children  
[http://www.nfb.org/nfb/Parents\\_and\\_Teachers.asp](http://www.nfb.org/nfb/Parents_and_Teachers.asp)

***Ms. Avila has worked in the public schools as a vision specialist and is a mother of a child born prematurely.***

# Preemie Update: Dylan Tucker

by Aimee Tucker

Dylan and Jack Tucker were born on March 27, 2003. The boys were born 16 weeks prematurely due to an undiagnosed incompetent cervix. Each weighed 1 lb., 9 ounces. Dylan followed his twin brother Jack by one minute exactly. The doctors assured us that their birth weights were pretty good for twins born at 24 weeks of gestation.



Dylan and Jack were put on oscillating ventilators at the INOVA Fairfax NICU. One day later they both went into surgery to close the holes in their hearts. They both survived their surgeries. The boys were doing well, all things considered, for the next few days. However on the 8th day, the NICU told us that Jack had taken a turn for the worse. By the time we made it into the NICU, he had passed away due to respiratory failure.

Since that time Dylan has amazed and surprised us at every turn. The smiling, laughing, rolling, and walking developmental milestones occurred on time for his “adjusted” age. He had a way of making you laugh even when he was still in the crib. After he finally got his walking shoes, he could not be stopped. Now, Dylan takes great pride in surprising us with his stunts on the living room furniture.

Like most micro-preemie parents, we

to see an educator to help facilitate some fine motor and gross motor progress. When he turned two, he was admitted to the Early Childhood Special Education Program for preschoolers. Dylan made tremendous progress his first two years in the program. As we finish his final year in preschool, we will forever be grateful to his teachers and therapists for their unwavering commitment to Dylan’s success. He continues to receive speech, occupational, and physical therapy while at school. These therapy sessions address lingering gross and fine motor delays, as well as articulation issues. Nonetheless, everyone agrees Dylan should be ready for kindergarten right on time.

Dylan is like most 5-year-old boys. He loves cars, trains, playing on the computer, and making his friends laugh. When his full-term brother Shane was born two years ago, Dylan relished the idea of becoming a big brother. He is

*“Like most micro-preemies we monitored Dylan’s progress closely. Despite regular pediatric visits and several evaluations, Dylan never qualified for Early Intervention Services.”*

Dylan persevered and experienced the entire laundry list of complications during his NICU stay. His complications included Stage 3+ ROP, PDA, and BPD. He also had a blocked bile duct resulting from the long amount of time he was on TPN. This was resolved during a cholangiogram which flushed out the blockage. He was released after 118 days in the NICU.

monitored Dylan’s progress extremely closely. Despite regular pediatric visits and several evaluations, Dylan never qualified for Early Intervention Services. We continued to be diligent about follow-up appointments and making sure we were seen at close intervals for re-evaluation. Dylan finally qualified for services through Loudoun County’s Early Intervention Program at around 1 ½ years of age. He started

doing an outstanding job of showing his younger brother everything he knows. Despite everything we’ve had to go through, there isn’t a day that goes by that we don’t count our blessings. Dylan is a constant source of joy in our lives. His brother Jack was only here for a short time, but remains in our hearts forever.

## Are You Considering a Post-Preemie Pregnancy?

1. Make a **pre-conception** appointment with a perinatologist or maternal fetal medicine doctor to discuss your case history and determine a plan of action for future pregnancies.
2. Continue to take your folic acid. Folic acid has been proven to help prevent birth defects and may even help prevent premature birth.
3. Visit the March of Dimes website to learn more about high-risk pregnancies at [www.marchofdimes.com](http://www.marchofdimes.com).

## **March of Dimes**.....[www.marchofdimes.com](http://www.marchofdimes.com)

The March of Dimes offers a wealth of information about preterm labor and premature birth.

## **Social Security**

### **Administration**.....[www.ssa.gov](http://www.ssa.gov)

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](http://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](http://www.sidelines.org)

Sidelines provides support for pregnant women on bedrest and those dealing with the after effects of bedrest.

## **Child Find**

Preschool Child Find serves as a resource for preschool children and their families by providing therapy or educational services in the home or in various local elementary schools for children that qualify starting at age 2 through age 5. This program is provided at no cost. If you suspect your child has a developmental delay, call now. It may take up to four months or longer to begin services.

## **Virginia**

Alexandria (703) 824-6708

Arlington (703) 228-6042

Fairfax County

(703) 876-5244 Devonshire office,

(703) 446-2100 Lorton office

Falls Church City (703) 248-5655

Prince William County (703) 791-8857

## **Maryland**

Montgomery County (301) 929-2222

Prince Georges County (301) 808-2719

## **Washington DC**

(202) 727-8300

## **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

## **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. Waiting lists may exist. Call as soon as possible.

### **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

## **Membership/Subscription Information:**

We offer the Preemies Today newsletter, family outings, parent support groups, preemie play-groups, and a Parent-to-Parent telephone 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 e-mail us at [info@preemiestoday.org](mailto:info@preemiestoday.org) or you may go to our website at [www.PreemiesToday.org](http://www.PreemiesToday.org) and click on "Join Us".

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## **Don't Miss These Events!**

### **Parent Support Meeting**

June 11th/July 9th, 7:30 pm, Barnes and Noble  
Fairfax, VA

### **Preemie Parent Lecture Series**

Inova Fair Oaks Hospital  
June 8th, Patricia Lemer  
June 22nd, Fairfax Neonatal Associates  
Be sure to register today!

***Please RSVP to [events@preemiestoday.org](mailto:events@preemiestoday.org)***

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