

# PREEMIES TODAY

## *Families Helping Families*

### PREEMIE OF THE MONTH:

*August's Premie of the Month is Nate Scott, a micropreemie with the heart of a lion. Here is his story as told by mom, Jennifer.*

Our son, Wesley Nathaniel Scott, a.k.a. "Nate the Great", was born on April 8, 2005 at 25 weeks 6 days gestation weighing only 1 lb. 13 oz. He was delivered by c-section after 5 weeks bedrest. Very early in the pregnancy I had bleeding and was told it was due to ruptured blood vessels on the outside of the placenta and I had a couple of battles with preterm labor that up until this point had been controlled by medication, Procardia. I had low amniotic fluid starting at about week 20, which is why I was put on bedrest. The decision to deliver Nate was made in the hospital when my contractions broke through and it was determined that there was very little amniotic fluid surrounding Nate. None of my doctors are exactly sure what caused these problems. My husband, Adam, and I were at peace with the decision once it was made. We told our family and we all prayed because we knew Nate's life was in God's hands now.

We were warned about the long road we would face and were told very clearly how small a chance Nate had to survive and all the problems he might have. Nate entered the world with a small cry and beautiful dark hair. Although we were warned we really had no idea what we were going to face over the next three months.

Nate was ushered immediately to the Shady Grove NICU where he spent his first three weeks of life on low amounts of oxygen through simply a nasal cannula. I thought at the time how much the betamethasone shots must have helped. He reached full feeds and was gaining weight. Adam and I were able to hold him every other day and were very active in his care. I think we both believed Nate would be different. He wasn't going to have all of these preemie problems. It was just going to take a little while for him to

grow and he'd be okay. After the peaceful three weeks the "roller coaster" that we had been warned about kicked in and Nate stopped breathing on his own. We were called in and this was our first experience really worrying that we might lose him. He was intubated and our crash course on ventilators began. Nate was on jet vents, oscillating vents, and regular vents; sometimes needing almost 100% oxygen to help his little



lungs. This terrifying process went on for another three weeks. We watched him grow and get a little chunky for the first time while he had this awful tube down his throat. It was hard to watch him everyday but we did praying his lungs would heal and he'd breathe on his own. He extubated himself once and made it for a few days before being back on the vent for another five days. Finally he was weaned off of the vent down to CPAP and eventually back to the nasal cannula.

On our anniversary, June 15, 2005, Nate gave us the present of coming out of his isolette and into an open air crib. This was such a

wonderful surprise. He was eating and growing. We could hold him when we want, bathe him, I could nurse him. We could start to imagine bringing him home. The primary problem was his lungs because he still needed oxygen. We began to prepare for him coming home on oxygen though we were still hopeful. We took our CPR and other classes and information so we could bring him home. On July 18, 2005 only 2 days after Nate's original due date he came home on oxygen and a monitor weighing just over 5 pounds. He was on sodium, iron, and an aldactazide.

Nate's biggest problem has always been his lungs. His ROPE eventually resolved itself and his bilateral hernias would need repair. We know we are blessed because Nate could have had so many other issues. We were scared and excited bringing him home and I am thankful for the wonderful family support that we have. We survived false alarms in the middle of the night when Nate decided he'd had enough of the electrodes attached to him and low heart rate alarms when he thought eating was more important than breathing. We survived the Synagis shots and the fights with insurance to get them to cover the shots. We made it through our first respiratory infections and several ear infections. The pulse ox machine was our best friend at times. Our family was excited to make it through our first winter with no hospitalizations for Nate.

On January 24th, 2006 Nate finally grew strong enough to leave the oxygen behind. This was huge! We kept all of our equipment for a month and then let it go. Another fear, I no longer had the pulse ox to check his breathing but we made it. On March 28th we braved a return to the hospital so that Nate could have his hernias repaired and were terrified he'd have trouble coming out of anesthesia and be back on a vent. Everything went fine and we came home as scheduled the same day. On April 8 we celebrated his 1st birthday with lots of family and friends.

The decision to get pregnant after having an infant born prematurely is a difficult one. For many couples the fear of having another preemie is enough to deter them from having more children, but there are also those that still want to grow their families. With the right medical care many women go on to have full term babies after having a preemie. Here are some commonly asked questions about getting pregnant again after having a preemie.

### **1. I want to get pregnant again after giving birth prematurely, what steps can I take to prevent another premature birth?**

The first step is to go to a perinatologist for preconception counseling. A perinatologist is a doctor that specializes in high risk pregnancy. It is important to bring all medical records from your previous pregnancies to the appointment. This will give the doctor an opportunity to review your medical information and determine if further testing is needed to find out the cause of your previous preterm delivery. Based on all the medical information, the perinatologist may be able to give you recommendations on how to manage your next pregnancy to decrease the risk of having another infant born prematurely.

### **2. What if the doctors are not able to determine why I gave birth prematurely, will I be able to prevent it from happening again?**

In many cases the doctors can not determine the exact cause of preterm birth. However, an experienced doctor can give an educated guess based on the circumstances surrounding the birth. This is why seeing a perinatologist is so important for many women looking to get pregnant again after giving birth prematurely. It is important to remember that even if there is clear cause for preterm delivery no doctor can guarantee it will not happen again.

### **3. Will I have to go on bedrest?**

That depends entirely on the cause of your previous preterm delivery, but if you were on bedrest with previous pregnancies there is a good chance that you will be on bedrest again.

### **4. How do I find a perinatologist?**

The ideal way is to ask your current OB for recommendations and also talk to other mothers who have had high-risk pregnancies. Of course, what health insurance you have can restrict what doctor you can see. It is often helpful to first get a list of perinatologists that work with your insurance and then ask around about those doctors. If you are unable to find a perinatologist who works with your health insurance, contact a case manager at your insurance company. They should be able to help you get an out of network authorization to see a perinatologist.

### **5. If I have given birth prematurely before can I still have my OB deliver my next baby?**

While many OBs are willing to take on high-risk pregnancies, it is important to discuss your plans with your OB before you get pregnant. Many OBs will co-manage high-risk patients with a perinatologist. If your OB has experience with high-risk pregnancies and is comfortable handling your case, you may want to stay with them.

Below is a list of resources for women considering getting pregnant after having a premature infant.

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

The March of Dimes has a wealth of information about premature birth, including causes of and risk factors for preterm delivery and signs of preterm labor.

Sidelines National Support Network- [www.sidelines.org](http://www.sidelines.org)

Sidelines is a support group from woman experiencing high-risk pregnancy with a particular emphasis on bed rest. Sidelines provides direct support over the phone or by emails through their volunteer network.

Post Preemie Pregnancy Yahoo Group

<http://health.groups.yahoo.com/group/pppg/>

This is an online support group for women currently pregnant or thinking about getting pregnant after having a preemie. It is a great place to get information and advice from other women who have experienced premature birth.

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*continued from cover, Nate*

We wanted to show off the miracle child that we had hidden all winter for fear of viruses and most of all RSV. It was wonderful to see Nate play and interact with other children his age and to see him put his hands in his first birthday cake. On July 28th we faced another small hurdle when Nate had tubes put in his ears. He's had persistent ear infections and constant fluid in his ears. A hearing test showed that he's not hearing as well as he should so the decision was made for tubes.

This wasn't so scary after all we'd faced. There was no IV needed or breathing machines and by that same afternoon Nate was cruising around like nothing happened. Nate is now 16 months; 13 months corrected age and is a thriving child. At his 15-month appointment he weighed 22 lbs. 10 oz and was 31 3/8 inches long. He has six beautiful teeth and a contagious laugh. He's not walking yet but he pulls up and "cruises" around everything and can climb the stairs if you turn

your head for a second. He's not a picky eater but some of his favorites are yogurt and French fries, actually anything potato. He loves his grandparents, aunts, and uncles. He also loves to play in the pool. It's been an amazing year with lots of ups and downs but when I look at him it all fades. I am so thankful to all of the doctors and nurses that helped Nate survive and loved on him when we couldn't be there as well as the amazing support of all of our family and friends.

## Local News:

### Announcements:

#### August Outing: Annual Members Meeting

Please join us for our Annual Meeting of Members to vote in the new Board of Directors of Preemies Today. This year we will have the meeting at the home of Elaine Noto, but it won't be all business! We will vote while relaxing poolside in Elaine's backyard. There will be a swim instructor organizing pool games for the kids and giving tips to parents about pool safety. And, of course the grill will be going.

#### Party Details

**Place:** Home of Elaine Noto  
10901 Henderson Road  
Fairfax Station, VA 22039

**Date and Time:** 8/20/06 at 4pm

**RSVP:** Elaine at [ejcbrit@aol.com](mailto:ejcbrit@aol.com)

\*\*please indicate if you will be able to bring a side dish and what that dish will be.

*Please be aware that there will not be a life-guard on duty and that parents are responsible for staying with their children in and around the pool at all times.*

#### Join the Preemies Today Board

Do you want to help other families affected by prematurity? Do you want to help shape the direction of Preemies Today? Do you just need an excuse to get out of the house one night a month? Then run for a position on the Preemies Today Board of Directors. It is a great opportunity to get involved with other families and help the preemie community in the Metro DC region. If you are interested in running for a board position, please contact Deborah at [deborah\\_leaf@yahoo.com](mailto:deborah_leaf@yahoo.com)

#### Help Educate the Next Generation of Doctors.

Parents of premature infants are invited to speak at an Ethics course for medical students about the NICU and preemie experience. If you are interested, please RSVP as indicated below.

WHEN: August 22 2006, 11:30 am - 4:00 pm

WHERE: USUHS Campus

4301 Jones Bridge Rd.

Bethesda, MD 20814-4799

RSVP: Kathy Vestermark, Patient & Family Coordinator / USUHS, [vestermarkx8@cox.net](mailto:vestermarkx8@cox.net) or 703-264-067.

#### 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

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.

#### 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](mailto: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](mailto: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:

### Prince William County Social Services:

[www.co.prince-william.va.us/csb/programsandservices/](http://www.co.prince-william.va.us/csb/programsandservices/)

### Fairfax County Department of Family Services:

(703) 324-7500

[www.co.fairfax.va.us/services/dfs/](http://www.co.fairfax.va.us/services/dfs/)

### Social Security Administration:

1-800-772-1213

[www.ssa.org](http://www.ssa.org)

### SIDS Mid-Atlantic

(703) 933-9100

[www.sidsma.org](http://www.sidsma.org)

### March of Dimes

1-800-326-BABY

(703) 425-BABY (Metro DC)

[www.marchofdimes.com](http://www.marchofdimes.com)

### Sidelines National Support

1-888-447-4754

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

### Early Intervention/ Infant Toddler Connection

Fairfax County- (703) 246-7121

Alexandria- (703) 838-5060

Prince William- (703) 792-7879

Arlington County- (703) 228-1630

Loudoun County- (703)-777-0561

Washington DC- (202)727-8300

Montgomery County- (240) 777-3997

Prince George's County-(301) 265-8415

### 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.PreemiesToday.com](http://www.PreemiesToday.com)**

## 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.*

**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 the newsletter please email us at [premienewsletter@yahoo.com](mailto:premienewsletter@yahoo.com). If you would like to become a member of Premies Today please email us at [premiemembership@yahoo.com](mailto:premiemembership@yahoo.com). Our website is **[www.PremiesToday.com](http://www.PremiesToday.com)**

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Premies 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**