

PREEMIES TODAY

Families Helping Families

PREEMIES OF THE MONTH:

This month we are featuring twins, John and Eleanor Boucher-Ferry. These active toddlers are proof positive that the whole is greater than the sum of its parts! Here is their story as told by mom, Susan.

I thought that the hard part of having children for me was over once I finally got pregnant. I thought for sure that the rest would work itself out and my twins would be born near term and healthy.

At about 20 weeks into my pregnancy I had one slightly high blood pressure reading at an OB appointment. I thought very little of it and continued to enjoy my pregnancy. My husband and I were on top of the world. We were having a boy and a girl; life seemed perfect.

At 24 weeks, my blood pressure was high again. This time, it was much higher and the doctor was very concerned. I was put on bed rest and thought that I would spend the next few months on the couch reading and purchasing items for our nursery online. I was still sure that my doctors were just being extra cautious; I certainly didn't feel like something bad was happening to my body or my babies.

One night, when I was barely 25 weeks pregnant, things changed. I felt as though blood was rushing to my head. There was an intense squeezing sensation in my head and neck. I knew that something wasn't right. When we arrived at the hospital, my blood pressure was higher than ever and Baby A, our daughter, hadn't grown in two weeks.

Tests were ordered, I was given steroids to help the babies' lungs, and we were told that I was not leaving the hospital until I had given birth, which might happen very soon. I was diagnosed with preeclampsia. My body was

essentially rejecting my placenta and starving my babies.

I had biophysical profiles done several times a week and blood work done several times a day. We were taken on a tour of the NICU at Georgetown, and while my husband was relieved to see such small babies alive, it didn't comfort me.



My husband and I settled into a routine in the hospital. Rather than trying to get to 36 weeks, our goals changed. Twenty-eight weeks was now our goal. If we could make it to 28 weeks, our babies had a better chance. At exactly 28 weeks, my platelets started to drop and my liver functions were failing. A resident with whom I had spent much time talking to, came back with the lab report and gave me the news. He had an apologetic look on his face when he told me that we'd held off the inevitable for as long as possible; I would have a C-section that day.

My husband and I are still amazed when we think about how well the doctors and nurses handled our delivery and the aftermath. Everyone was upbeat and happy. The OB I

had come to love and trust stayed late to perform my surgery. We will be forever grateful for the care we received. Everyone congratulated us, and as our children were born and whisked away without so much as a whimper, we felt happy.

We were surprised at their birth weights. The numerous ultrasounds indicated that the babies would be much larger than they actually were. John weighed two pounds at birth and Eleanor weighed one pound 7 ounces. Our first neonatologists asked if we were sure about our dates. John and Eleanor acted more like 25 or 26 weekers than the 28 weekers we, and our fertility specialist, knew they were.

During our NICU stay we met many wonderful doctors and nurses. We were terrified at what might happen. I spent the first two months of John and Eleanor's lives worrying that they might not live. Then one day, about a week from their discharge, I panicked about what their lives may be like. I worried that the lasting effects of their prematurity would prevent them from living normal, happy lives.

John and Eleanor endured five weeks on the ventilator, sepsis, spinal taps, countless x-rays, blood tests, blood transfusions, and ultrasounds. John spent three days at Children's National Medical Center for a PDA ligation. We told our families not to visit for fear of infection and lived in fear of a phone call from the NICU.

At times we had the sickest babies in the NICU. At other times we felt guilty because our children were doing well while other babies clung to life. We had many days when our babies weren't stable enough for us to hold them, and we sat by their incubators trying to be as close to them as we could. I spent most of the day with them, just hoping that

Focus of the Month:

Top Ten Ways to Keep Your Premie Healthy this Winter

The onset of cold and flu season can be a difficult time for the parents of premature infants. We all want to keep our preemies healthy and avoid a possible hospital admission due to infection. While there are no guarantees, by following some simple tips we can keep our preemies healthy throughout the winter months.

1) Hand washing, Hand washing, Hand washing!

Hand washing cannot be emphasized enough. It is the single best way to avoid the spread of disease. Every single person who touches a preemie (or any baby) should first wash their hands. This includes friends, family, siblings, health care workers, and even parents. The CDC recommends the following technique for hand washing:

- First wet your hands and apply liquid or clean bar soap. Place the bar soap on a rack and allow it to drain.
- Next rub your hands vigorously together and scrub all surfaces.
- Continue for 10 - 15 seconds or about the length of a little tune. It is the soap combined with the scrubbing action that helps dislodge and remove germs.
- Rinse well and dry your hands.

2) Stay away from sick people

This may seem obvious, but do not let sick people visit and do not visit them with your preemie.

3) Avoid crowds

The grocery store and malls are full of people and germs this time of year. Even churches and synagogues can be a hazard, especially because everyone will want to admire your preemie up close. If you have to go out with your preemie pick a time of day when there will be minimal exposure to crowds and do not be afraid to ask people to step back.

4) Hand Sanitizer

Recent studies have shown that the proper

use of hand sanitizer can decrease the transmission of disease in the home. It comes in large containers for home use and travel size bottles that fit right into the diaper bag. It is a great option when there is no sink available or when you have the baby on the changing table.

5) Smart scheduling

When making doctors appointments ask for the first appointment of the day or the first appointment after lunch. This decreases the risk of exposure to other children in the office. Most offices will be happy to accommodate preemies any way they can and will put preemies into an exam room right away instead of leaving them in waiting rooms, if the parents ask.

6) RSV and Flu Preventatives

RSV is a virus that presents as nothing more than a cold in most children, but it can be very serious for children at risk including many preemies. Ninety percent of the population is exposed to RSV before they reach two years old, which means it is very likely that your preemie will be exposed to RSV at some point. The drug Synagis is given as a monthly injection to protect against RSV. Synagis decreases the severity of RSV but it does not totally prevent children from contracting RSV.

The flu is also a very serious illness in young children. The flu vaccine should be given to all children under the age of two but older children with chronic health issues may also qualify. Check with your pediatrician to see if your child qualifies for Synagis and/or the flu vaccine.

7) Be the Gatekeeper for Your Child

One of the most important responsibilities any parent has is to be the gatekeeper for their child. This is especially true for preemies. Do not feel bad telling well meaning strangers that they cannot touch your child. Let family and friends know that they cannot come into your home with so much as a sniffle and do not feel guilty about not visiting an elderly relative in a nursing home with your preemie. These strict guidelines can be hard for some people to accept, so just remember to blame

the doctors and nurses. Stating, "The doctor told me I can't do X with the baby," to friends and relatives can take the pressure off you as the parent. Your child's health-care providers are happy to take the blame in order to keep your child healthy.

8) No smoking

Smoking has been shown to increase the risk of RSV and other respiratory illness in preemies. Yet another good reason to quit and to ban smoking in your home.

9) Limit Exposure from older siblings

If there are older siblings in school it is important to teach them how to prevent the spread of infection. Some parents may choose to keep preschoolers home from school during the winter months, but this is not necessary in every case. Emphasizing hand washing and limiting close contact as much as possible, especially if the sibling is sick, are the best ways to keep older siblings from spreading illness to your preemie.

10) Stay Healthy

As a primary caregiver you need to stay healthy for yourself and your preemie. Aside from frequent hand washing you also should avoid touching your eyes, nose and face. Illness can also be avoided by practicing good health habits such as getting enough rest, eating nutritious foods and staying physically active. Although this may be difficult for anyone with children, it is important to try to do these things. Lastly, if you do happen to get sick try to stay away from your preemie and let another caregiver take over until you are no longer contagious.

For more information about preventing infection check out the CDC website at www.cdc.gov and for more about RSV check out www.rsvprevention.com.

This month's contributor is Deborah K Leaf, RN MSN FNP. Deborah is a member of the Premies Today board and the mom to former 27 weeker, Jake, and full termer, Sarah.

Local News:

Announcements:

Celebration of Remembrance

The annual SIDS Mid-Atlantic and MIS Celebration of Remembrance will be held Saturday, November 18 from 6 to 9 P.M. Family and friends of babies who have died from any cause are welcome to attend, and there will be baby sitting available. It will be held at:

The Unitarian Universalist Church of Arlington
4444 Arlington Boulevard
Arlington, Virginia

Please contact Betty Connal at 703-933-9100 or bconnal@aol.com for more information.

Preemies Today Yard Sale

The Preemies Today Yard Sale was held on September 30 and the home of Stephanie Miller. Despite the rain, it was a resounding success and we raised \$600. Thanks to Stephanie for providing the venue, those who donated items, and to all the volunteers who helped out.

Preemies Today Survey

Preemies Today needs your input! We are looking for families to participate in our online survey. All responses are anonymous. This survey

will let us know how well our programs are reaching families and what we can do better. Please log onto www.advancedsurvey.com and type in survey number 43558 in the "Take a Survey" box.

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.

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/>

continued from cover, John and Eleanor

they could feel how much we loved them.

John and Eleanor came home one day after their due date. They were on monitors and numerous medications. We had to feed them every three hours and I continued to pump breast milk to mix with formula for them. After three months at home they were able to successfully breast feed. It took a lot of patience, but was worth it to not have to prepare bottles in the middle of the night!

We still deal with the effects of prematurity. Both John and Eleanor have chronic lung dis-

ease. John has had numerous ER visits and one frightening PICU stay for asthma and Eleanor has had pneumonia three times. John and Eleanor receive occupational therapy and physical therapy to help with their developmental milestones, which aren't very far off target. John and Eleanor have reflux, and John has a weak, raspy voice caused by scar tissue as a result of his intubation.

All of these things are minor compared to what we could have faced. I still need to remind myself of that sometimes, when we can't take

music classes in the winter because of RSV and when our plans suddenly change because someone is sick. John and Eleanor now walk, talk, climb, laugh and dance. They are small but feisty and truly success stories.

Their neonatologists call them "good outcomes." After we put them to bed at night, my husband and I don't talk about the strain that their prematurity has put on our finances, careers, and general sense of calm. Instead, we marvel at how amazing it is with them each day.

Helpful Resources:

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

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

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. 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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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**