

Preemies Today



Families Helping Families

PREEMIE OF THE MONTH:

June's Preemie of the Month is Norah-Mai Nguyen. Although Norah still faces obstacles related to her prematurity, she is a sweet and happy little girl. Here is her story as told by her mother, Lan.

Shortly after making the decision to start a family, I became pregnant. With the exception of a few nauseous days, my pregnancy went smoothly. Around the seventh month, my legs and feet started to swell and my belly was still relatively small. However, my doctor wasn't worried since all medical signs indicated that everything was going well. As weeks went by, the swelling became more pronounced and I felt more and more tired. Through it all, I thought being tired and swollen was simply part of a normal pregnancy.

Thirty two weeks into my pregnancy, just a few days before was Norah born, I wasn't feeling well. I felt exhausted and was bed ridden. I didn't feel particularly worried since it was only a few more days until my next scheduled doctor's appointment. Perhaps some extra rest was all I needed to get better. Well, I never made it to that appointment. On April 13, 2004, I woke up feeling horrible. My husband was in a rush and had to leave early for work. All alone at home, it was difficult for me to get out of bed. I quickly became disoriented and confused. In a matter of minutes, I lost my vision and I was retching. Gripped with fear, I frantically attempted to crawl my way to the phone. Blind and confused, I tried calling 911 and was only able to get through after several clumsy attempts.

I was rushed to the INOVA Alexandria hospital where the last thing I heard was

"We gotta get this baby out NOW!" before waking up in the ICU. I was diagnosed with preeclampsia, HELLP syndrome, and a blood clotting disorder. Norah was born via emergency c-section weighing 2 lbs 13 oz and 15 inches in length at the beginning of my 33rd week



of pregnancy. Norah had an Apgar score of 1, 6, and 7. She had respiratory distress and needed oxygen but was quickly breathing on her own. For the first few weeks of her life, her Dad looked after her while I struggled to recover my health and vision. Too weak to get out of bed, the nurse brought Norah down to me on the fourth day. I could barely open my eyes for than a few seconds but I saw my tiny skinny little Norah for the first time. I didn't know how to react. I was in a state of total shock and confusion about what was going on around me. It took a month for my blood pressure, vision, and strength to return to normal. The whole NICU experience is a blur to me still.

Norah did wonderfully in the NICU with no issues except for jaundice. We were so thankful that things were turning out so well for her. She had been in the NICU for five weeks when we brought her home weighing 4 lbs 6 oz.

We thought the trauma had passed since she did so well in the NICU. Unfortunately, it was just the beginning of many stressful months ahead. After a couple of weeks at home, Norah started vomiting and that's when our reflux hell started. With all the vomiting, Norah wasn't drinking much so gaining weight was always a challenge. By her fifth month, I could only feed her while she was sleeping. By the sixth month, she refused to eat anymore even during sleep. She would scream and cry at the sight of a bottle even though she was starving. She would go 16 hours without anything and would finally drink perhaps 2 oz. We didn't have any choice except to put a nasogastric (NG) tube via her nose to her tummy for hydration and nutrition. We desperately hoped it was a temporary solution until she would want to eat again. Sadly, Norah never regained her desire to suck the bottle and the NG tube added to her food aversion. Even to this day, she still refuses the bottle. After 2.5 months with the NG tube, she got her G tube placed in January, 2005. She will continue to have the G tube until she can eat enough on her own to gain weight.

We have tried so many different things to control the reflux but nothing has worked. So far we have tried changing formula (Breast milk, Milk based, Soy, Alimentum, Nutrimagen, Neocate, Nutren Jr, and Peptamen Jr), motility

Focus of the Month:

A Day in the Life of a Preschool Special Education Class

If your child has been receiving early intervention services, your child may qualify for a preschool special education class. At a quick glance, the preschool special education classroom may not look any different from a typical preschool or daycare. However, you'll notice that the student to teacher ratio is very small and the lesson plans are tailored to meet specific objectives on your child's individualized plan which is developed with your input. Also, if you ask the teacher to explain everything around the room, you'd quickly learn that every toy, picture, furniture, and all materials were purchased and placed for a specific reason, in a specific way to maximize student learning. To help others better understand what I did in my class, I thought I'd choose just 3 activities I had everyday and give a brief explanation of the purpose for those activities. Our days were jam packed with lots of learning.

Circle Time – This was a great time to help build receptive and expressive language skills and incorporate other educational objectives. I started off with a greeting which required the child to express themselves to others and learn basic social skills. Sometimes the greeting was a handshake, song, or chant. Then we sang a familiar group song together. These songs were always paired with sign language to help the students build their expressive language skills. By incorporating the simple signs, it gave students with language delays another mode of communication and the signs also helped their fine motor skills. Then we did a group activity. These activities varied from day to day and sometimes followed a month long theme. One example of an activity was a mini obstacle course. The students had to go “in”, “out” and “over”, “under” and “around” different objects. Not only did this help develop gross motor skills, but it tested their receptive language.

Centers – These times were less structured but not just “free play”. There were specific materials laid out in each area for students to play with and explore and manipulate. These materials also followed the month long theme. (Themes helped the students build their vocabulary and helped them make connections from one activity to another) While the students went from center to center, I had a clip board with students' names so I could write down any anecdotal observations. This was also the best time for me to work with students one-on-one on certain objectives as needed.

Snack/Lunch – This was the best time to help any students with self-help skills and oral motor skills. I always showed pictures of food choices and each student had

their own board. They got to choose a snack by pointing to a picture and moving it to their snack board or verbally telling us their choice. For lunch, I always told the students what was on the menu with pictures and signs and pointed to each food item. Then depending on their level of self-feeding skills, we assisted with special spoons or forks. Students learned how to let us know they were finished and they had to “clean up” their area.

The best thing about being in a preschool special education classroom was the in-class therapist support. The speech therapist, occupational therapist and physical therapist came in during specific times and worked directly with the students or with a group. We often collaborated and planned our weeks and themes together so they would use the same language and signs with the students. They also gave me suggestions for activities when they were not there. As a preschool special education teacher, I felt like I was able to incorporate and implement every type of therapy a child needed. Also home visits were an integral part of the child's education so the parents were actively involved in the goal setting process. I really enjoyed my years as a preschool special education teacher and found it to be a very enriching experience.

You may be wondering if your child is right for a preschool program. Some things to look out for is whether or not your child is emotionally ready to be apart from you and would benefit from social interactions with other peers and adults and whether or not your child can receive the same level of services at home as she can at school. Also talk with other parents who had their child in preschool programs and parents who opted not to send their child. Now that I'm a parent of a preemie, I can see why it would be a difficult decision. I strongly feel that it is your own decision, so don't let anyone pressure you one way or the other. Remember, you know your child best.

This month's contributor is Sara Chae, parent of Zachary (25 weeker). Sara is also a former Preschool Special Education Teacher for Arlington County and currently a 1st grade teacher for Fairfax County. For any questions about this article please contact her at sara@teamchae.com

Local News:

Susan Torres Fund—please join Premies Today on Wednesday, June 29th at Chevy's restaurant in Falls Church, Virginia. Chevy's will donate 20% of your food and beverage check to help support the Torres family. Be sure to indicate that you are with Premies Today. Susan Torres is a 26 year old woman from Alexandria, Virginia who collapsed of a brain hemorrhage. She was rushed to the Virginia Hospital Center in Arlington, where she has been diagnosed with stage four melanoma and is brain dead with no hope of recovery. Doctors are fighting to keep her alive through artificial respiration and other means until at least July 11 to give her baby a fighting chance at life. The baby will be approximately 25 weeks gestation at birth. It is costing the family around \$1500 a day to keep her alive after insurance. So please come by Chevy's for this worthy cause. You can find out more about her story by going to her website: <http://www.susantorresfund.org>

June Family Outing—please join us at 4:00 p.m. on Saturday, June 25 at Fairfax Corner. It is located near the Fairfax Government Center. There is built in water fountain where the children can splash around and cool off. There is also a Ben and Jerry's where you can enjoy an ice cream treat on a hot summer afternoon. RSVP to Mary Beth at marybethhazelgrove@yahoo.com.

continued from cover, Norah's story

meds (reglan, erythromycin, and bethanecol), reflux meds (Zantac and prevacid), thickened formula with rice cereal or oatmeal, and slow feeds via a feeding pump.

Currently, we are still riding the reflux roller coaster. For now, we plan to let her outgrow her reflux instead of pursuing drastic surgery. Thankfully she does not have any pulmonary issues, ear infections, or inflamed esophagus as a result of her reflux. It's been a traumatic year for us with all the stress over adequate nutrition, food aversion, and hospitalizations.

Throughout this whole ordeal, Norah's spirit continues to inspire us every day. Norah has grown up to be a cute, easy going, and happy baby weighing 17.5 lbs at 13 months. We have never smiled or laughed so much as we have with Norah in our life.

Support Resources:

"A Friend to Talk to"

Please call us on our "Friend to Talk to" support line and one of our premie parent volunteers can offer you some much needed support. The support line telephone number is 703-994-6624.

NICU Support Group

INOVA Healthsource offers 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. 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

Premies Today Playgroups

Premies Today continues to offer monthly playgroups. Monthly playgroups offer our children a stress-free environment to play. Playgroups typically meet in a member's home or in a location of the group's choice. For more information contact Deborah at Deborah_Leaf@yahoo.com

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/program-sandservices/

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

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

Misson of Premies Today:

The birth of a premature infant is an extremely frightening and life altering time. Premies Today strives to form a network of families to offer help, comfort, and understanding to one another through their knowl - edge and personal experience.

Membership/Subscription

Information:

We offer the Premies Today newsletter, family outings, parent support groups, preemie play-groups, and “A Friend to Talk To”, our call-in line for parents and families of preemies.

To subscribe to the newsletter please contact us at (703) 944-6624. If you would like to become a member of Premies Today please contact Mary at mlundregan@strategicm.com or call (703) 535-1421. Our website is **www.PremiesToday.com**

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Susan Torres Fund**

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