

Preemies Today

Families Helping Families

PREEMIE OF THE MONTH:

This month's preemie is Alexa Trainer. Alexa may have started off tiny but has the heart of a lion. Her story is told by her mom, Natalie.

I always wanted children but was on a drug called lithium carbonate, a category "C" drug for pregnancy, and was advised against it. I decided to try anyway and had two miscarriages six years apart and neither had anything to do with lithium.

I did conceive in 2001 and my son Joshua was born at almost 38 weeks. However, I did have bad contractions at 31 weeks and was put on terbutaline and bed rest for the remainder of the pregnancy. I was diagnosed with an irritable uterus.

We decided we wanted Josh to have a sibling and to our shock I conceived twins in 2003. The CVS came out clean and we were more afraid of having two babies at once than anything like premature birth.

Unfortunately I had a severe case of bronchitis at 12 weeks and lost 8 lbs. Then at 17 weeks I began having contractions. I told the doctor at my prenatal visit and he said "It's too early." I did not challenge his answer. Somehow I held out until 23 weeks when once again at another prenatal visit I told a different doctor that my right side hurt and it felt like my episiotomy was hanging out. To make a long story short he sent me home with an order form for a uterus bra.

Four days later I drove myself to the hospital because I had passed a clot that morning, and had a bad contraction a few days earlier. It was Sunday night. The doctor at the hospital checked the babies on the monitor and everything sounded good. She was about to send me home, but wanted to check my cervix. I remember just causally talking with her, and then... silence. She then told me I was dilat-

ed 2 to 3 centimeter and an appendage was hanging out of my cervix. She announced "You are in premature labor."

She immediately hung me literally upside down and administered magnesium sulfate. An ambulance drove me to Fairfax INOVA. I was 23 weeks 5 days. Once at Fairfax I continued to dilate, remained awake and chewed ice since I was not allowed to eat or drink



before surgery.

I had two shots in the rump 12 hours apart of betamethesone, a steroid to help the babies' lung grow and I contracted even more as they were given. By Monday night I was completely dilated, and an emergency C-section was performed. I was 23 weeks 6 days. I remember them asking if I wanted to try to save the babies. I said yes.

Both the babies cried when they entered the world, but they were weak cries. Baby "A" was 525 grams and Baby "B" was 528 grams. Baby "B", named Helen, passed away in the

NICU after 17 days from a distended right lung. The last couple of days she was alive she blew up like a balloon, and I didn't want to see her suffer any more. The doctor agreed that they had "maxed out" on the drugs they were giving, and her gases, blood pressure and oxygen saturation continued to plunge. I wondered to myself if I should have let my babies go naturally. I did hold her as she passed and that was probably the most healing thing I could have done for myself, and maybe for Helen too. My minister came and baptized her while she was still living, and my family joined me once she had passed.

Alexa on the other hand had a rough time from birth with a tight nuchal chord and a very low apgar score. The crisis continued, but she kept fighting though. She had to have PDA surgery, blood clots developed from the umbilical line, and she had ongoing lung issues. The first 8 weeks were touch and go.

After 114 days in the NICU Alexa came home at 5 lbs. 3 ounces with an apnea monitor and oxygen for feeds. We fed her every 3 hours around the clock for a month and held her upright after each feed for 20 to 30 minutes to avoid reflux. ANICU doctor told us it took about 20 minutes for the food to empty into the small intestine. She was also on zantac. We also propped her NICU car seat upright and she slept that way for 4 or 5 months. She graduated from the pulmonologist and apnea monitor 3 months after being home.

Alexa began Physical Therapy at 3 months corrected and we began deep massage, hand and feet slaps and joint compressions. She sat then crawled and now walks. It was amazing to see. Speech Therapy came second because her tone in and around her mouth was so weak. The ventilator and C-PAP kept her alive, but all her muscles atrophied since she

New parents desire and need to bond with their child and form attachments. If your baby was premature (a “preemie”) or experienced complications resulting in NICU care, it may have been difficult to bond naturally through cuddling, breast feeding, or sharing a family bad. A baby’s experience in the NICU can be very schedule oriented, requiring certain feeding times, medicine and treatment times, and monitoring of equipment. In addition, your birth experience may involve personal recovery which may hinder you from visiting your new baby. However, as you stabilize, it may become possible to visit your baby. The nurses in the NICU will be able to advise and instruct you as to how to interact with your baby under the current conditions, but the nursing staff’s key focus is stabilizing your baby and taking care of his/her critical needs.

One aspect of bonding and forming attachments in the beginning stage of life is through positive touch, skin stimulation. Often a preemie’s condition in the NICU can appear intimidating due to various monitors, IVs and incubators. If you inquire about the best way to hold or touch your baby, NICU nurses will most likely have knowledge of infant massage or touching techniques and will be able to assist you with these techniques. Positive touch in the form of a “touch hold” or “resting hands” is a good way for your baby to feel your presence and feel comforted. A touch hold involves taking your hands and holding or encompassing a specific part of the baby’s body, such as the leg. Your own relaxation is essential. As you relax your hands and talk softly to your baby, your relaxation along with the warmth of your hands will assist your baby in relaxing his leg or specific body part. Another approach, called resting hands, is performed by lightly resting your hands on your baby’s chest, back or head. Focus your thoughts on your baby or even quietly talk to him/her. Your skin to skin contact will assist your baby in relaxing and getting to know your touch, voice and smell. Your touch and contact with your child can offer him/her a feeling of security and love.

Massage has many proven benefits for preemies when applied consistently, including greater weight gain, increased activity and alertness, and shortened hospital stays (Fields, 1986). If your baby is presently in the NICU, talk to the nurses and your baby’s doctors about using some type of massage or touch holds under their supervision. However, keep in mind that the baby’s medical conditions and current medicines need to be considered. In addition, babies communicate signs of stress or over-stimulation through behavior cues. NICU nurses may be able to help you identify these stress cues resulting from over-stimulation through holding or touching your baby. Therefore, there may be occasions when the NICU nurse recommends stopping the touch stimulation or making other adjustments to the manner in which you are touching your baby.

After your baby has stabilized and is ready to come home you may want to consider taking an infant massage class after settling into your home routines. Infant massage provides many benefits to you and your baby, including: promoting parent /child bonding; facilitating relaxation and a deeper sleep; stimulating growth; learning stress cues; and learning techniques to alleviate gas/colic and constipation. Benefits to preemies include the above, as well as, the following: helping to stimulate muscle tone; relaxing tight muscles; assisting in toler-

ating positive touch; and stimulating the circulatory and gastrointestinal systems. Being a parent of a preemie in the NICU may have delayed your personal interaction with your baby. Through massage you learn to purposefully comfort and soothe your baby, as well as, reinforce your parenting skills. A baby in the NICU may develop sensitive areas due to having IVs or monitors attached to its body and experiencing numerous needle pricks. Massage can assist your baby in decreasing the sensitivity of these areas and alleviating any discomforts.

Infant massage classes are taught by a Certified Infant Massage Instructor (CIMI), who has been certified through the International Association of Infant Massage (IAIM). The massage strokes, as well as, the certification program were developed by Vimala McClure in 1978 and include such techniques as Swedish massage, Indian massage and reflexology. Some instructors may have additional training in working with infants with special needs. A basic massage class would involve 3 or 4 sessions in which a full body massage is taught, along with techniques to alleviate discomforts, such as gas, colic and constipation. The instructor demonstrates strokes on a doll, which parents practice with their babies. The class atmosphere is relaxed, allowing parents to take care of the baby’s needs throughout the duration of class. The class instructor usually includes the following information: massage strokes; benefits; information on behavior states and stress cues; hand-outs; and other various resources. An additional benefit of attending an infant massage class is meeting other parents in an atmosphere where conversation on baby topics or concerns can be discussed openly.

If you are interested in learning to massage your baby, consult with your baby’s doctor to ensure that your baby’s past complications and present medical condition are compatible with massage. Massage techniques can be adapted and precautions taken to address particular circumstances, such as reflux, feeding tubes, edema, hydrocephalus, and shunts. The present condition of your baby, as well as past history, should be shared with the CIMI so that any necessary adjustments to massage techniques can be made. To locate a certified instructor, check with local hospitals which often offer infant massage classes. In addition, the International Association of Infant Massage website offers instructor listings, <http://iaim.homestead.com> or <http://iaim-us.com>. The local chapter, IAIM East, lists instructors offering classes within the Maryland, Virginia and Washington D. C. area, <http://iaim-east.com>.

References/Resources:

Field, T., Schanberg, S., Scafidi, F., Bauer, C., Vaga-Lahr, N., Garcia, R., Nystrom, J., Kuhn, C. (1986, May). Tactile/kinesthetic stimulation effects on preterm neonates. *Pediatrics*. Vol. 77(5), 654-658.

McClure, V. (2000). *Infant Massage: A Handbook For Loving Parents*. New York: Bantam Books.

This month’s contributor is Gina Schmid, MA, CIMI. Gina teaches infant massage at the Maternity Center in Bethesda, MD. If you are interested in classes contact her at lovinghands99@cox.net.

Local News:

Preemies Today Elections

The results are in and the second Board of Directors for Preemies Today has been elected. This year's Board Members are Kathy Paz, Deborah Leaf, Elaine Noto, Christine Miller, Jenna Kassis, and Mary Beth Hazelgrove. Thank you for dedicating your time and making a difference in the preemie community.

September Outing

Our September family outing will take place at the Hidden Pond Nature Center. It is located at 8511 Greeley Boulevard in Springfield, VA. Hidden pond has indoor exhibits, a nature trail, a pond, tot lot, and picnic shelter. We will be meeting at the picnic shelter at 10:30 a.m. on Saturday, September 17. You can check out their website for more information: www.hiddenpond.org. Please bring a dish to share and RSVP to Mary Beth at marybethhazelgrove@yahoo.com. Following lunch we will tour the indoor exhibit.

Pentagon City Fundraiser

Preemies Today will be participating in the Simon Youth Foundation "Day of Giving" fundraiser at Pentagon City Mall on Sunday, November 20th. You can beat the rush and get a jump on your holiday shopping. This year's event will take place during normal mall hours! Last year over 30 charities participated in this event. There will be exclusive sales, a fashion show, celebrities, makeovers, food, and Santa Claus. Tickets are on sale for \$10. Three dollars of every ticket will go to the Simon Youth Foundation to help at-risk youths, and seven dollars of every ticket will go to Preemies Today to help fund our programs. To find out more information, or to buy tickets, please contact Elaine Noto at ejcbrit@aol.com.

Walk America

Walk America is the March of Dimes biggest fundraiser. Preemies Today was awarded a plaque of recognition this past August for raising over \$7000. Congratulations Preemies Today families. Especially big congratulations for the Hall family for raising \$4000. March of Dimes continues to fund research and educational projects that help fight prematurity. To learn more, check out their website at www.marchofdimes.org.

Support Resources:

"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 **703-994-6624**.

NICU Support Group

INOVA Healthsource is continuing to offer 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 and is a great opportunity to talk about your experience in the NICU. For more information contact INOVAHealthsource at 703-204-3366.

Preemies 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 preemiestoday@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/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

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.PreemiesToday.com

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was immobilized. We began mouth exercises, but she still would only take about an ounce each time she drank. Eating solids was another challenge. I spoon fed her a caloric protein mixture until she refused me at 21 months. It took about 3 hours a day. I listened to lots of music and danced around to try to stay sane and entertained her anyway I could. An Occupational Therapist works with her now covering all three specialties. We also work with a Behaviorist and Pediatric Nutritionist all through Early Intervention. Lastly, we have worked with one Pediatrician throughout her growth.

Alexa has suffered from RSV twice and a couple of gastrointestinal viruses, but in June she got a cold and it stayed upper respiratory. We jumped for joy. She now is 22 months and almost 21 lbs. Her favorite activities include drawing on the porch with sidewalk chalk, splashing in the pool and jumping fully clothed into the bath to join her brother. She has about 15 words in her vocabulary, the most common is..."no". All in all we are grateful for her spirit and energy.

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.

To subscribe to the newsletter or to become a member of Premies Today please contact us at (703) 944-6624 or email us at premiestoday@yahoo.com. For more information about our organization please see our website at, www.PremiesToday.com

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Mission 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 knowledge and personal experience.

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.

Premies Today
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