

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

This month's preemie is Cate Mitchell. Whether on the coast or high in the Rockies, Cate proves that great things come in small packages. Here is her story as told by mom, Courtney.

In February 2001, my husband, Will, and I moved to Virginia from Colorado. This was an exciting time because we were pregnant with our first child, and moving to Virginia was a move closer to both our families. Just before we left Colorado, I had an ultrasound and all looked good with our baby although she measured in the 38th percentile. This, the radiologist assured me, was not unusual as many Colorado babies are slightly smaller than average due to the high altitude.

After we arrived in Virginia, I commenced standard prenatal visits with an OB/GYN. On my second visit with her at 25 weeks, the doctor was concerned about my blood pressure and tested my urine for protein. The results concerned her enough to get another ultrasound. The ultrasound showed that the placenta was almost completely void of amniotic fluid. I was admitted to Reston Hospital immediately, and remained there for two days until a bed was available for me in the perinatal unit at INOVAFairfax.

The doctors on the perinatal unit monitored Cate's movement in utero every day with an ultrasound, explaining that they'd keep her inside until that was no longer the safest place for her to be. My blood pressure was lower and Cate felt active, so I settled in to hospital life for the long haul. Unfortunately, Cate had other ideas. On April 24th, at 28 weeks gestation, the doctors decided it was time for Cate to be born after our daily ultrasound. I was rushed to the operating room for a C-section, as she was far too small to be born vaginally. Cate was born at 3:09 pm, weighing 1 lb 7 oz with APGAR's of 5 and 8. When the doctor lifted Cate out, Cate cried and sucked the doctor's finger! Incredible for a 28 weeker! My husband counted nine NICU repre-

sentatives present in the delivery room, waiting to help Cate and soon as she was ready.

As a result of the placenta pulling away from my uterus, Cate was IUGR so she was very long and skinny with a big head. Our wedding rings hung on Cate's arms like bangle bracelets! Diapers the size of a deck of playing cards looked enormous on her. Our roller



coaster ride in the NICU had begun. Cate remained on the respirator for only three days after her birth, and was then transitioned directly on to a nasal canula because her nose was too small to accommodate a CPAP. High alk phos levels and digestive issues developed quickly and remained the entire length of Cate's stay in the NICU. Cate's stomach was extremely distended for weeks, but her doctors worked successfully to avoid surgery. Cate was unable to process formula or even breast milk and her weight gain was stunted as a result. Once Cate's digestive issues began to resolve themselves, another issue presented itself. Cate's blood sugar levels were very high so she got special "high octane" 26 calorie formula, and heel pricks

for blood sugar level checks every four hours.

Two weeks before Cate came home, she was transferred to Fair Oaks Hospital for observation of her blood sugar levels. Her oxygen levels and body temperature had stabilized by this point, so she came off the canula at this point and was in an open crib as well.

Cate came home on July 13, 2001, one day before her original due date! Cate was on a cardiac monitor for three weeks after she came home from the hospital, and needed Reglan for reflux. Cate had been diagnosed with Stage II ROP, but within a few months of coming home that diagnosis had resolved itself. Fairfax County provided physical therapy and developmental evaluation in our home each month until she was 11 months old, at which point we were on our own! Our biggest challenge in Cate's first year was eating. Weeks, and sometimes months, would go by where we couldn't understand how she lived on the meager amount of food she ate. It would take an hour and a half to feed her three ounces of formula! We also kept her away from crowds and enforced a hand-washing policy for visitors that sometimes was not too well received, but helped Cate to avoid RSV and other bronchial issues during her first year at home.

Today, Cate has achieved her developmental milestones right on time and is preparing for kindergarten in the fall. Her doctor told us that school age would be the next checkpoint for developmental delays, and she is still on track! Even her eating has developed in to three full meals and snacks most days. Last year, at her 4th year well-check, Cate hit the growth chart for weight for the first time – in the 3rd percentile!

Almost two years after Cate was born, we moved back to Colorado and Cate now enjoys skiing, dirt biking, soccer, ice skating, and hiking – taking full advantage of all that Colorado has to offer.

Focus of the Month: Preemies Today Health Professionals of the Year, 2006

This year Preemies Today is introducing a new tradition at our Annual Celebration. We will be honoring two outstanding health professionals who have made a difference in the lives of many of our Preemies Today families. Our inaugural honorees are Lynn Kuba, RN and Donna Reed, RN.

In order to get to know our honorees better Preemies Today asked them about their background and NICU experiences:

PT: What is your educational and professional background?

Lynn Kuba (LK): I graduated from Catholic University of America in 1978 with a BSN in Nursing. I worked at Children's Hospital in DC for 1 year then moved to Los Angeles and worked as a NICU primary nurse and transport nurse at Children's Hospital of Los Angeles for 5 years. We moved back to the DC area in 1984 and I worked in Georgetown's NICU briefly and did home care for preemies. I worked part time in Columbia Hospital for Women's NICU from 1984-1990. I've been employed by Inova since 1987 in various perinatal nursing education roles.

Donna Reed (DR): I graduated from Washington Hospital School of Nursing in 1967 and worked as a staff nurse on the pediatric unit at Fairfax Hospital for four years. I was then the Head Nurse of the Children's unit at Fairfax until 1986 when I decided to work as a nurse recruiter at Fairfax Hospital for two years. I started as a staff nurse in the Neonatal Intermediate Care Unit and Neonatal Intensive Care Unit at Fairfax Hospital in 1988.

What is your current role in working with preemies and their families?

LK: Through Inova HealthSource, I facilitate the Inova Fairfax Hospital NICU parent support group and I am a perinatal nurse educator and consultant for the AOL Wellbaby Program. I am a member of Operation Premie and on the Board of SIDS of the Mid-Atlantic. I am also on the Fetal Infant Mortality Review Committee and do home visits for families who have lost babies from 20 wks gestation through the first year of life. In FIMR we review cases to help us prevent

and educate about recurrent prematurity.

DR: As a staff nurse in the NICU, and working in the intermediate area I see my major roles as care giver/ educator . . . facilitating their preparation for discharge.

How long have you worked with preemies?

LK: During college in 1977-78, I worked as a nurse's aide in Holy Cross Hospital's newborn nursery. They had a small NICU then and a NICU nurse introduced me to the preemies. I started working as a new grad at CNMC in DC in June, 1978 in the NICU.

DR: From 1988 until the present.

Why did you choose to work with preemies and their families?

LK: Actually, I wanted to start at Children's in Toddler Medicine. When they saw that I had newborn experience they placed me in the NICU. I fell in love with the babies and families and never switched!

DR: Fairfax was establishing an intermediate care unit due to increasing census in their NICU. . . . Since most of my career experience was in Maternal-Child Health I decided it was a fantastic opportunity to be at the planning stage of a new unit . . . The collaborative practice model of working closely with neonatologists, neonatal nurse practitioners and coworkers was a definite draw . . . In addition, ongoing research and participation in said research certainly contributed to positive outcomes. This gave me a chance to educate families, allay fears, and perhaps prevent or decrease the number of readmissions. This work with families has been phenomenal. I have met many who were exceptional and gained so much respect for them. There is no question this was the right decision.

Can you describe one of your most rewarding experiences?

LK: I think every family I've ever worked with has taught me something, which brings an abundance of rewards. I have many favorite families and babies. Of course, the babies who continue to improve and do well are very rewarding.

Some of my favorite families are families who have lost babies and have been brave enough to be parents again.

One of my favorite babies, was a mildly premature Vietnamese, girl named Fren who was born in 1981 in Los Angeles. Her parents were boat immigrants after the Vietnamese war and spoke no English. Fren was born with ectopia cordis (heart outside her chest), partial rib cage, cleft lip and palate and other cardiac and GI abnormalities probable as a result of her mother's exposure to Agent Orange. She was not expected to live more than a few days, but she survived for 9 months. Despite all the discomfort and multiple procedures she endured, her eyes sparkled and she was the sweetest baby I've ever cared for. She and her family brought many challenges to the NICU and taught me to be a staunch advocate for babies and families.

DR: I can't choose one single experience, but I will say I get the best reward is from the gratification of helping preemie parents prepare to take their babies home. The happiness the families show is wonderful. The day they have looked forward to for so long is finally here. Knowing I helped transition families to this level gives me personal satisfaction. There is no question there is some apprehension, but with the proper preparation, we know they can do it.

What do you think NICU families should know?

LK: That the staff wants to support them as parents and involve them as much as possible. It's very hard especially at first when parents are in shock and overwhelmed. Hopefully, the parents start to know their baby best of all and become the baby's best advocate. If parents aren't feeling supported or involved they need to speak up. Also, parents need to take care of themselves and to accept any or all offers of help from friends, family etc. Having a baby in NICU is a crisis and parents can't get enough TLC and support. The better the parents are taken care of, the better they will be able to take care of their baby.

DR: It won't be easy at first to take a premature infant home. The confidence that you are hoping for prior to discharge will not come

Local News:

Announcements:

Preemies Today Annual Celebration and Silent Auction

This year's celebration will take place on May 21, 2006* at the Sully Government Center in Chantilly, VA. Come and enjoy our VIP area (for the Very Important Preemies), great food, and make your bid on some exciting auction items. This year we have airline tickets, Disney Hopper passes, a private tour of the National Zoo, Warner Theater tickets, childrens items and much more. The Great Zucchini will be coming out to entertain the kids with his special brand of magic. We will be honoring our Health Professionals of the Year, Lynn Kuba and Donna Reed for all they do for families and premature infants. Proceeds from the Silent auction will help support our programs such as our NICU Welcome Home bags. We will also be donating 20% of the proceeds to a NICU in New Orleans affected by Hurricane Katrina. If you would like to help volunteer at the event or if you have an auction item you would like to donate please contact Deborah Leaf at deborah_leaf@yahoo.com.

*Please note that we have moved our Annual Celebration from March to May due to RSV season.

March of Dimes, Walk America

The totals are in and the Preemies Today Walk America Team has brought in a grand total of \$33,000. A big thank you goes to the Hall Family who raised \$23,000. Way to go! Thanks to everyone who walked this year on the Preemies Today team and to all our sponsors.

Support Groups:

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until you have done it yourself There is a time of adjustment both for the baby and the parent, but the babies will grow and thrive in a loving environment.

What is the biggest change that you have seen in the NICU and how has it affected care?

LK: Respiratory support: betamethasone, surfactant, improved ventilation support. More babies survive and have less chronic lung disease. Also, a better understanding of preemie development. In the early 1980's it was still thought that preemies and newborns didn't feel pain! We used to take babies up to the OR for even open chest surgery without using any pain meds or anesthesia. It was thought that the side

Take a Break

Preemies Today offers meal preparation assistance, babysitting, and other additional support options for preemie families in crisis. If you are in need of assistance or would like to volunteer to help others, please contact Sara at sara@teamchae.com.

"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.

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 email preemiestoday@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/>

effects of those meds were too dangerous! Many babies died of stress related complications.

DR: Our preemies are going home so much sooner. When I started in the NICU they stayed until they were eating 2 ounces every four hours and about 5 pounds. Now we do send some home less than 4 pounds. The parents are presented with much smaller and sicker babies then they had been before. Many go home with feeding tubes, respiratory support, apnea monitors and often numerous medications turning a home into a mini hospital room. With the follow-up home care provided to parents, they are able to meet this challenge.

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

Arlington County- (703) 228-1630

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**

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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Mission of Premies Today:

Premies 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.

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**