

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

This month we are featuring the “Premie for a Day” program sponsored by the March of Dimes and the INOVA Health System. The program’s purpose was to give NICU nurses and staff a glimpse into how the NICU is experienced by premature infants and their families. Premies Today was represented at the event by Mary Beth Hazelgrove, and this is her “story.”

I was born too many weeks too early and I weighed less than either of my parents had ever expected. My mother likes to tell the story of one of her visits with her OB when the doctor thought she would have a baby that would weigh between 7 and 10 pounds. Boy was he wrong!

I remember the day that I was born clearly. I wasn’t feeling quite right but I was tucked in a nice warm place where I could hear the soft tone of my mother’s voice. Suddenly, my sense of security was quickly taken away. My immature organs were forced to function. Stress! I remember lots of bright lights, noise, and bitter coldness.

My nurses and doctors tried to comfort me by shielding my eyes. See, my eyes lids were thin and could not adequately block the overhead lights. They warmed their hands and the instruments before they touched my body. As soon as they could my nurses placed me in a side-lying position with my hands near my face. This gave me a feeling of security like when I was in my mother’s tummy. It was important to tuck my legs, and keep my hips, shoulders, neck, head, and ankles flexed. These positions were comfortable for me and made it easier for my muscles and body when I started crawling and walking. My nurses would also try to keep my head in midline and support the back of my head with a gel-pillow to help with my development and the shape of my head. I was also placed in a snuggly with bumpers around me to help me feel more contained. Whenever my little foot popped out from my blankets my nurses repositioned it back in the snuggly and placed a blanket over top. I liked pushing my foot on something because it helped remind me of what it was like inside my mother.

My NICU nurses and doctors cared for me with such compassion. They let me rest when they knew that I needed it. They draped a blanket over my isolette so that I would not be disturbed by too much light. They spoke to my parents with ease and away from my bedside. They repeated important information not just once or twice but sometimes up to seven times because they knew how overwhelming the NICU could be for

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FOCUS OF THE MONTH:

The March of Dimes, Prematurity Awareness Day was held on Wednesday, November 16, 2006. The purpose of Prematurity Awareness Day is to raise awareness in the community about the growing problem of premature birth. This year the March of Dimes also cosponsored the “Premie for a Day” program for health professionals with INOVA program helps NICU staff to experience the NICU from the perspective of the infant.

The “Premie for a Day” program was held at INOVA Fair Oaks hospital and attended by NICU nurses and staff. The main topics focused on were admission to the NICU, positioning and handling, feeding the preterm infant, and family involvement and communication.

Participants became “preemies” and experienced both typical NICU care and developmentally supportive and family centered care. The goal was to teach staff ways to improve care and discuss how change can be made in the NICU.

The main event for Prematurity Awareness Day was held at INOVA Fairfax hospital in the Physicians Conference Center. It was attended by many preemie families as well as nurses and doctors from the NICU. The entertainment started with a performance from a local dance studio and there was a magic show for the kids.

In keeping with March of Dimes tradition of lighting a building pink and blue, pink and blue luminaries lined the outside walkways of INOVA Fairfax. There were also lighting ceremonies at INOVA Fair Oaks Hospital and other sites in the Metropolitan area.

The highlight of the event at INOVA Fairfax was the “Parade of Stars”. Families decorated wagons, strollers, and even a scooter, as “preemie floats.” The floats were highlighted with glow in the dark pink and blue stars and the lights were dimmed. Parents paraded their preemies around the room to soft music. An isolette was also in the parade to represent the all preemies that could only be there in spirit. In the background, a slide show of preemie pictures played. Parents and family members stopped at the podium to tell the group about their preemie experience and a milestone that their preemie achieved. It was a very moving ceremony and wonderful tribute to our miraculous children.

Preemies Today Celebrates Prematurity Awareness Day



An isolette leads the way in the Premie Parade representing all the preemies who could not be there.



Kaitlyn Hall helps her float along in the Premie Parade

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them. They also encourage my parents to help get involved with my care beginning with diaper changes and temperature checks. My special nurses comforted me by giving me a pacifier to suck on. They also monitored the noise in the room and talked in low voices to help protect my ears.

One of my favorite memories of the NICU was of my swaddle bath. My nurse showed my mom how to do this and she soon started giving me one too. During my bath a blanket would be placed around me in a loose swaddle. I would be gently lowered into the warm water that was held by a tub just my size. The water would then be almost at my neck level. It felt so nice. One side was gently exposed to the water and washed nice and clean and then recovered. The next side would then be uncovered, washed, and recovered. My body would stay nice and warm and then I would be transferred to nice warm blankets and I never felt the cool air. I couldn't wait to take a little from my bottle before I would begin a restful sleep.



A NICU nurse experiences what infants go through when they are born prematurely

Eating, though, was always challenging. But my nurses took great care to make sure my parents were involved whenever they came to visit me. I would give everyone cues to let them know that I was hungry. Sometimes I would be drowsy, alert, or start rooting and have my hands to my mouth to show I was ready to eat. It took a long time for me to take all my food by bottle. For many weeks I had a tube that went down my nose and into my stomach. My nurses adapted my feeding routine to fit my needs. I started eating and gaining more and more weight. They always put me in a secure position and gave me facial support whenever I needed it. They taught both my parents these techniques as well so they were always involved in my care. I was able to go home soon after I was able to take all my feeding by mouth.

Before I transitioned home the nurses went over so many instructions with both of my parents. There was so much to learn. Being at home is very different than being in the hospital. They taught my parents that I was to sleep only on my back and I needed plenty of time on my tummy when I was awake. This is an important position to help me develop my muscles. I was also not allowed to have anything in my new bed at home. My parents soon learned that blankets, toys, and positioning aids could put me at risk for Sudden

Local News:

Announcements:

Holiday Party: Yoga Tales

The Preemies Today's Holiday party will take place at Yoga Tales studio in Bethesda, Maryland. Yoga Tales teaches yoga poses to children using props and a unique storytelling approach. Yoga is wonderful for children of all abilities but can be particularly helpful to children with low muscle tone and attention issues. Following the class, we will serve food and refreshments and have a visit from Santa Claus. Please bring an \$10 gift, wrapped for Santa to give your child(ren). Children of all ages are invited. Cost is free.

Date: Saturday, December 16, 2006

Time: 11:30am-1pm

Location: 8020 Norfolk Avenue, Bethesda, Maryland 20814

RSVP to marybethhazelgrove@yahoo.com

Preemies Today Cookie Exchange

The Preemies Today Cookie Exchange has become an annual tradition where we not only get to sample great cookies, but pass the holiday cheer along to the local NICUs. Please bring 6 dozen cookies to share and package for NICU families and staff.

Date: Sunday, December 17, 2006

Time: 2 pm

Location: 1593 Inlet Court, Reston, VA 20190

RSVP to Deborah at deborah_leaf@yahoo.com or (703)481-5862

Preemies Today Survey

Preemies Today needs your input! We are looking for families to participate in our online sur-

vey. 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.

Take a Break

Preemies Today offers meal preparation assistance and additional support for preemie families in crisis. If you are in need of assistance or would like to volunteer to help others, please contact Susan at susan.boucher@starpower.net.

Local Support Groups

Local support groups are going strong! On every 2nd Wednesday at 7:30 pm we hold our local support group meetings at the Barnes and Noble, Fair Lakes. 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/>

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Infant Death Syndrome (SIDS). Preemies have an increased risk for SIDS and parents have to be aware of the dangers of having these items in the bed. So, I was not even allowed to have a blanket with me any more when I transitioned to my home. It was different but I didn't mind. I was too busy enjoying the peacefulness of what I now knew as home. As for the blankets I did not miss them. I soon was introduced to a sleep sack which I love even more!

My parents will be forever grateful for the level of care that I received while I was in the NICU. My mom says that the nurses and the doctors are all heroes. They did not only save my life but they showed me compassion. They also cared for me in a way that gave me the best chance of reaching all my developmental milestones! Thank you to the entire NICU staff and to the hospitals that continually train and educate their healthcare professionals.

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.gov

SIDS Mid-Atlantic

(703) 933-9100

www.sidsma.org

March of Dimes

1-800-326-BABY

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.org

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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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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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**