



## COFFEE BREAKS

Please join us for coffee, juice and cookies at our weekly coffee breaks on the unit. We also host last Thursday of the month "Pizza Nights" and also monthly Saturday scrap booking classes. The breaks are hosted by a Parent Connection Volunteer who has experienced the hospitalization of a newborn.

**THURSDAY  
6:30-8PM**

**SATURDAY  
10:30am-12:00pm  
Neonatal**

**Waiting Room.**  
Scrapbooking and Beading are on the 3rd Thursday of every month at 2:00pm in the NICU Conference Room.

## Connecting Lines



You may now view Connecting Lines on the Parent Connection website at <http://www.huntingtonhospital.com/main/parentconnection.aspx>. Should you wish to receive your newsletter electronically please contact us. A publication for families of critically ill newborns and neonatal graduates.

## Join Us On Facebook



Parent Connection is now on Facebook and we would like you to join. This is a closed group where you can share your story, talk to other NICU graduate parents, and find out what's new in the premie world. To join go to <http://www.facebook.com/groups/NICUparentConnection/> click on Ask to Join Group button.

### In each issue of Connecting Lines we feature one family's story... Eve's Life

In the intensive care unit, a priest stood over my daughter's bassinet just two weeks after she was born, making the sign of the cross, giving her last rites. I saw my beautiful baby laying on her back, barely recognizable. Her body was swollen and covered in pink spider veins. Her kidneys had failed. The doctors couldn't say why.

Eve had been born about two weeks earlier, on Dec. 21, 1998, at St. Tammany Parish Hospital in Covington, La. Her big brother had picked her name just hours before she was born. She looked as healthy as any baby girl when she arrived -- 9 lbs., 21 inches long. But soon the doctors told me she couldn't breathe on her own. She had persistent pulmonary hypertension. Before a baby is born she receives oxygen through her mother's umbilical cord. Once birth occurs, the lungs take in oxygen from their own blood. But in Eve's condition, the oxygenated blood bypassed her lungs, making it difficult to breathe. My heart ached when I heard this. But somehow, I felt a sense of strength. She would get through this, I told myself. **Continued on Page 3**



**SAVE THE DATE**  
**Huntington Hospital's Neonatal  
Intensive Care Reunion**  
**May 16, 2015**

**WE ARE LISTENING!**  
If you receive a customer satisfaction survey, please fill it out and send it back. You make a difference.

Parent Connection is a group of volunteer parents who have personally experienced the hospitalization of a newborn. We offer support and resources to families of NICU parents. If you would like more information, please call (626)397-8509, [mary.holzer@huntingtonhospital.com](mailto:mary.holzer@huntingtonhospital.com), Huntington Hospital Parent Connection Facebook or our web page <http://www.huntingtonhospital.com/Main/ParentConnection.aspx>



**HELP SUPPORT  
PARENT  
CONNECTION:  
BUY A T-SHIRT**

Be a “Proud Parent of an HMH Neonatal Graduate” or show your baby off with “I graduated, HMH Neonatal Unit” T-shirt. Adult and children through infant sizes available for \$10. All proceeds from T-shirt Sales benefit the Parent Connection, CPR Classes. Call Mary Holzer at (626)397-8509 or e-mail [mary.holzer@huntingtonhospital.com](mailto:mary.holzer@huntingtonhospital.com)

**GIVE THE  
ULTIMATE GIFT  
OF LIFE, GIVE  
BLOOD**

Donate blood today and give someone the opportunity to celebrate. Call the Blood Donor Center at (626)397-5422 to schedule your appointment or walk-in to the center located on the ground floor of the Wingate Building at Huntington Hospital.

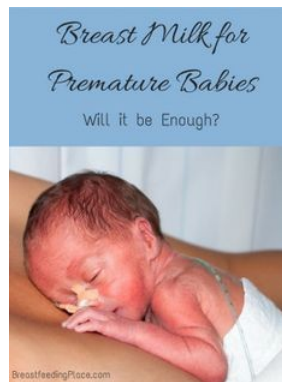


**BREASTFEEDING NEWS  
LAURA BARADA, RN**

**Check this out on Pinterest**

**NICU Breastfeeding Support  
(Group 4, Spring 2014)**

- Our goal is to provide resources for NICU mothers to continue breastfeeding and overcome various challenges as their babies are discharged.



**HUNTINGTON HOSPITAL'S BREASTFEEDING  
SUPPORT GROUP**

The Breastfeeding Center hosts an ongoing support group for breastfeeding mothers and their infants. Here, under the supervision of a lactation specialist, mothers meet to share encouragement and support for their decision to breastfeed. Any breastfeeding mother and her infant may attend these no-cost meetings, provided both are free of communicable illnesses (i.e. cold, flu, cough, etc.). Due to safety considerations, infants are permitted to attend only until they are able to crawl. The group meets every Thursday morning from 10:00 a.m. to 11:30 a.m., except for holidays. For more information on meetings and room locations, please contact the Breastfeeding Center at (626) 397-3172, or the hospital's Perinatal Health Education Department at (626)397-8768.

## Our Family Story ..... Eve's Life

Soon we had to make the agonizing decision to put her in a helicopter to Ochsner Medical Foundation, in New Orleans, a larger hospital, across Lake Ponchartrain. They could take care of her better there, but she might die along the way. A medic would have to pump air into her lungs manually during the flight.

Eve arrived in the Ochsner NICU before we did. The neonatologists there were using an experimental gas to treat infants with this condition. Some of the babies in the unit with Eve weighed just a pound, but she was just as sick. It would take a few days to tell if the gas worked, but it was already calming her. The next two weeks were up and down. Eve was given medications that paralyzed her, and then morphine for pain. She was fighting to breathe and cry. I ached to feel her in my arms, but couldn't. All I could do was pray. I felt like I was living in a bubble. I often turned away family and friends that came to visit; we asked them to go home and pray.

One night I was able to go home with my son, then eight years old. We got a phone call early in the morning from the NICU telling us to come as soon as we could. Eve had taken a turn for the worse and they didn't think she would make it through the day. They asked if we wanted a priest.

An ultrasound located a clot that had formed in Eve's left renal artery. She was given many medications to rule out infection, to dissolve the clot and to decrease the swelling. Hours later, she improved. Days later, it became clear, finally, that she would live. Her kidneys were working. The hypertension had subsided. She was slowly weaned off of the morphine and the paralyzing medication. I hoped she would be home soon.

On January 7, 1999, I was finally able to hold her. The nurse took her feeding tube out and I nursed her for the first time. When Eve was discharged, the doctors told us that she wouldn't have any longstanding problems from her life-threatening ordeal.

We wouldn't find out until much later that the same medications that saved her life had also taken her hearing. At 18 months, she was diagnosed with a profound bilateral hearing loss. The news was difficult, but nothing so frightening as the prospect of losing my daughter. The caring, compassionate doctors and nurses at Ochsner Medical Foundation had gone to great lengths to save her and care for her. I will be forever grateful.

Eve is now 15 years old and a freshman at Burbank High School. She wears bilateral cochlear implants that allow her to hear. She uses American Sign Language and she also speaks beautifully. She makes good grades, swims and plays soccer on her high school teams, and has recently taken up riding horses. We can't imagine life without her.



## ONE-ON-ONE SUPPORT

If you would like to talk to someone who has had a baby in the NICU and understands your unique needs, a Parent Connection support parent would be happy to call you. One-on-One support is available prenatal through post-discharge. Please call Mary Holzer at (626)397-8509.



## PARENT CONNECTION NEEDS VOLUNTEER PARENTS!

Parent Connection is a support group of parents who have had a baby in the NICU. Our group is made up of mothers and fathers of extremely premature, late-preterm, full-term infants with varying conditions, and multiples.

Our parents provide support to families who have experienced the hospitalization of a newborn by hosting twice weekly “Coffee Breaks”, “Pizza Nights”, and “Baby Showers”. A parent that has experienced a



similar situation can also contact you by phone or internet and let you know how they dealt with the trials of having an NICU baby. Parents also help plan our reunion and other activities.

There is no minimum time commitment, we know that you are busy parents with small children and most of you are working, so even an hour a month can help another parent.

Please contact Mary Holzer at (626)397-8509 or email at [mary.holzer@huntingtonhospital.com](mailto:mary.holzer@huntingtonhospital.com).

## CAR SEAT SAFETY

The most precious cargo you will ever carry is your baby. Did you know that 90% of people using car seats are doing so incorrectly? Make sure your car seat is properly installed by making an appointment with your nearest California Highway Patrol for a “Safety Seat Checkup” or contacting SafetyBelt Safe, U.S.A. at (310)222-6860 (English) or (310)222-6862 (Spanish). You may also research car seat information and recalls at [www.carseat.org](http://www.carseat.org).



## LEARN INFANT CPR

Parent Connection offers free, weekly infant CPR classes for current and recently discharged NICU families. The classes are taught by a certified instructor on Tuesdays, 4:00-5:00pm, in the NICU Conference room. To attend, please call to make a reservation, (626)397-8509.







I attended the Preemie Parent Alliance conference September 11 to the 13<sup>th</sup> in Phoenix they are a relatively new group consisting of parent support coordinators from all over the country. Luckily I didn't need to worry about changes in weather or temperature since both LA and Phoenix were 105 degrees.

The conference provided informative speakers such as Dr. Alan Spitzer, Senior Vice President and Director of the Center for Research, Education and Quality with Pediatrix who spoke on how parents can be influential in the NICU. A Resolve through Sharing educator spoke on the different types of grief of parents. "Feeding Difficulties in Premies" was extremely interesting and I suggest checking out their website at <https://www.feedingmatters.org/>. It gives great insight into what happens to some infants discharged from the NICU. "Navigating the Education System" provided information on how to obtain educational services for premies. Nick Hall was our last presenter, he is the founder and president of Graham's Foundation. Their foundation sends parents of preemie's care packages at no charge.

I also participated in networking exercises with other participants, attended lunch time topic discussions of social media, and communications in the NICU. I am excited to post some new ideas I got from these discussions on our Facebook page, Huntington Hospital Parent Connection.

In checking out the sponsor and member exhibits I found an organization called "Angel Gowns". They make burial gowns for miscarriages, stillborns and NICU losses from donated wedding dresses and send them free of charge to hospitals. I have put in an order for our NICU and Labor and Delivery to receive these beautiful gowns. All in all it was a good conference providing me with some new resources and ideas on how to support families.



## DON'T KNOW WHAT TO DO WITH THAT OLD WEDDING DRESS?

Donate your wedding gown to NICU Helping Hands' Angel Gown Program. The program began in 2013 because we recognized the overwhelming need to support families who lost a baby while in the hospital. Our Angel Gown Program provides comfort for families by providing a beautiful gown for final photos and for burial services. There is no greater gift that can be given to a grieving family than affirming the importance of the life of their child by offering this simple gift. Go to <http://www.nicuhelpinghands.org/lend-a-helping-hand/angel-gowns/> to find out more information on donating your wedding gown.



## PREMATURE BABY DISCUSSION GROUPS ON THE WEB

### **Preemie Guide:**

preemies.guide@about.com

Features articles about infants in the NICU and after discharge

### **Team Inspire:**

subscriptions@inspire.com

Preemie support community

discussion group

### **Preemie World:**

<http://www.linkedin.com/groups?homeNewMember=&gid=2142351&trk=&ut=0itaE-T0JF>

Discussion group with educational articles

**Feeding Matters:** Parent Support and information on infant and children's pediatric feeding struggles

**The views expressed in the above mentioned websites do not necessarily reflect the views of Huntington Hospital or Parent Connection .**

## NOMINATE A NURSE FOR THE DAISY AWARD



DAISY Award honorees personify the Huntington Hospital remarkable patient experience. These nurses consistently demonstrate excellence through their clinical expertise and extraordinary compassionate care, and they are recognized as outstanding role models in our nursing community.

### **How To Nominate An Extraordinary Nurse**

Patients, visitors, nurses, physicians, employees may nominate a deserving nurse by filling out a form and submitting it to a member of the nursing staff or by mail. An electronic version will soon be available on the Huntington hospital public website.

### **About The Daisy Foundation**

The DAISY Foundation was established in 1999 by the family of J. Patrick Barnes who died of complications of the autoimmune disease Idiopathic Thrombocytopenia Purpura (ITP) at the age of 33. (DAISY is an acronym for diseases attacking the immune system.) During Pat's eight week hospitalization, his family was awestruck by the care and compassion his nurses provided not only Pat but to everyone in his family. So one of the goals they set in creating a Foundation in Pat's memory was to recognize extraordinary nurses everywhere who make an enormous difference in the lives of so many people by the super-human work they do everyday. If you have any questions, please contact [sarah.summer@huntingtonhospital.com](mailto:sarah.summer@huntingtonhospital.com)

### **Terrific Twosome Mothers of Multiples**

P.O. Box 8304

La Crescenta, CA 91214-0304

For more information, please contact: [info@ttmom.org](mailto:info@ttmom.org)

