

## A Silver Lining...

As my 25<sup>th</sup> anniversary approaches, I feel privileged to be in such a special subspecialty. After graduation, I had decided to go into pediatrics and was told to take a position in the NICU as there were currently no openings, and could transfer when one opened up. I took a job sight unseen!!!

I compare my career to a cross-stitching project...many stitches and knots later, a finished picture. My decision not to transfer came five years later. As I walked into the unit one morning, a nursing student met me. We walked up to my infant's bedside and as I peered behind the screens, I was stunned and felt a whole array of emotions ranging from shock, crying, fainting and throwing up to name a few. There before me lay a set of conjoined twins! The student was excited and eager. I on the other hand wasn't sure what I was going to do and could feel my heart sinking into my stomach. The next shift was learning how to take care of these two little boys. No textbooks, or my colleagues could have taught me how to care for them. Simple care-giving tasks became a challenge. The boys shared one body and were only separated by the two arms in the middle of which were fused up to the elbows.

The day before the hospital was to release information to the media confirming their births, they passed away. That morning they were both fussier than usual and I could not console them after feeds and sedation had already been administered. The boy on the left was having trouble breathing with the fussiness. A challenge was finding positions of comfort for them due to the anatomical configuration of their arms. The infant on the left kept waking his brother whenever he moved his arm. I remember crying while gently stroking their torso and whispering telling them "there is nothing more humanly possible that we could offer the both of you and if you feel you must go, it'll be okay". A short time later, my nursing instinct told me that now was the time to hold them and asked my charge nurse to help me. She looked at me with astonishment and asked me if I was sure I wanted to do this? I nodded yes and told her that I felt it was time and their deaths were "imminent". We swaddled them and as I sat down in the rocker, the left little boy's HR dipped into the 60s and then he died. The right little boy was initially pink, then turned dusky and over the next 20 minutes or so drifted as peacefully into asystole. This once in a lifetime experience has kept me at the bedside all these years. The greatest gifts for your patients are your physical assessment skills and intuitive eye that comes with clinical experience.

Our roles as nurses are pivotal and provide many opportunities for us to witness strengths and weaknesses of the human spirits in these little people and their families. We are the advocates, gatekeepers, nurturers, mentors, and caregivers with a heart. I feel that I've come a long way from being that rose bud that was dropped off many years ago and grew into a clinician as each petal began to open into a fully opened flower. I've had the honor of being a part of many families and privileged to have shared their "moments". Some moments last a lifetime and to be able to witness parents pack a lifetime of love into a few minutes and hours reminds us of the utter fragility of life for each and every one of us.

A concept to remember is that anyone can learn the tasks of being an NICU nurse, but it takes compassion to be able to make a difference in the lives of your patients, families, and peers. Whether interacting with a colleague, family, or infant...a heart that shows love makes all the difference. I would like to acknowledge all the patients, families and colleagues who have allowed me to be a part of their lives. As I drive to work today, and as I have over the last 25 years, I pray that I can make a difference in the lives that I will touch ---whether a heart to show love, being a listening ear, offering words of reassurance to a colleague, supporting a family, or holding the hand of an infant...the silver lining!!!

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Some things happen in the most unexpected ways, don't they? Here I am, pumping my own gasoline at a local station, and holding back tears. These things can happen. I'll explain.

We all know that the levels of personal satisfaction experienced in the helping professions go almost without saying. Yet, sometimes in the course of a life's work, the extraordinary can happen; things that leave a mark so meaningful, a feeling so unforgettable, it renews one's faith in life's most hopeful possibilities, as if heaven itself has graced you with eternity in a moment. It is a fulfillment beyond happiness and you are never quite the same.

And so it was on that late afternoon of an otherwise unremarkable weekend day in 1996 when I was approached by name at the service station by the friendly face of a man I couldn't place at the moment. "Isn't your name Milagros?" How did he know me? Did I know him? Naturally I was apprehensive, offering only a weak "yes" in reply. His expression became soft. "I'll never forget you. The Neonatal Intensive Care Unit at L.A. County Hospital, thirteen-years ago. You took care of my little girl, you were her nurse then." My heart leaped but too soon with joy—his moistened eyes said it all, his baby, an innocent born too fragile, too sick to be saved, was taken on the wings of angels. So terribly soon. This is the heart-breaking reality of the NICU. The mightiest technology cannot overcome all of nature's plans. "We know she died in peace. My wife and I saw how tenderly you cared for our daughter. You did everything you could. You did it with such love." The instinctive consolation I began to interject, to perhaps once again attempt to give explanation to the unexplainable, was not needed. He indeed understood. . . "We saw. You were the best thing that happened to us during that difficult time. You'll always be a part of our family." It was a beautiful and touching moment, beyond words, and one of profound humility for me in response to the depth of gratitude expressed. I too am grateful, for such fulfillment enabled by a nursing profession in which the fundamental spirit is one of sincere compassion.

Before we parted, the man proudly showed me pictures of his other children. It was obvious that this little family knows much love. He then hugged me and said, "thank you so much. I'm glad to know you're still taking care of the babies." His face was peaceful. As we went our own ways, emotions almost overwhelming me, I realized. . . "my cup runneth over," indeed.

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I remember the first time I met Fletcher's Family. I was helping the nurse in the room next door with little Fletcher's care. We called his parents to his bedside because we were not certain he would make it through the night, but little Fletcher did indeed make it through the night. This little baby changed me not only as a nurse, but also as a person.

The night after I first met the family, Fletcher was my patient. His Mom Erin shared with me that night what a miracle Fletcher already had been. He was born at 25 weeks and 3 days. Weighing in at 1lb 9 ounces, his mother delivered him early due to her developing HELLP syndrome. Fletcher had already been around a while before this; he had been a frozen embryo for months before being implanted. The story of his conception is amazing in itself. As a new nurse, I was

amazed at what this family had gone through just to be a family of three. I was so impressed with Erin and Trevor during Fletcher's stay with us in the NICU; they are amazing people. As Fletcher stabilized and started to grow, I had more of an opportunity to bond with them. Erin learned everything she could about premature babies and Trevor always had a smile for everyone. His wife's description of him as a goofball fits him perfectly. I mean that in the best way!

Fletcher had a rough start, but eventually stabilized. His head ultrasounds remained normal and I became encouraged by that. One night when I came into work Erin was by the doorway crying, Fletcher's MRI had come back very badly. His MRI showed changes in his brain, and it was not good. I hugged her and cried as she shared her news. I question if crying was the professional thing to do, but I had no choice. I was so sad for their family. In the days following the MRI I worried about them. When we talked about it, Erin told me she had prayed and prayed for a miracle and maybe she had already received it. The devotion and love Erin and Trevor have shown their baby, other NICU parents, and the NICU staff inspires me to learn as much as I can to care for these little miracles. When I first started nursing school, I thought I wanted to work in the NICU, but I also considered labor and delivery. Now after being in the NICU for almost a year and seeing little 25 weekers grow and go home, I know it is where I belong. I love being able to see the progress these little miracles make. I love watching their parents learn to care for them and cherishing the progress they make. I am truly blessed to be a NICU nurse and thankful that I got to meet Fletcher, Erin and Trevor.

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## A Broken Heart

When you first become pregnant, people ask you if you want a boy or a girl. You always answer "I don't care as long as it's healthy", but you don't really think that your baby won't be healthy. You figure as long as you do what the doctors tell you and eat right you'll have a strong, healthy baby. At least, that's what I thought.

I went for all my routine checkups with my obstetrician. He was always cheerful and said "things are right on course" or "no problems". I would hear on TV about birth defects and feel a little apprehensive, but then I would feel my baby kick and my fears would go away.

The labor pains began to fade when I heard that first tiny wail. When the nurse placed our baby in my arms the memory of any discomfort disappeared. She was perfect with all her fingers and toes and her blue eyes stared at us with such intensity that we couldn't believe she wasn't really seeing us. Our feelings were of immense pride in this being we made and complete exhaustion now that the long nine months were over. After our baby was taken to the nursery to be checked, we just relaxed and daydreamed about first steps and first words, of ball games and dance recitals. My husband and I never knew we could be so happy.

Then the Pediatrician came in. He seemed solemn and I sensed that something was wrong. Very carefully he told us that our baby girl was born with a broken heart. He called it Hypoplastic Left Heart Syndrome. He told us that a very important part of her heart never developed and to keep her alive she would have to be transferred to the Neonatal Intensive Care Unit. There she would receive a special medicine that would allow her heart to function normally for the time being. He reassured me that there was nothing I could have done differently during my pregnancy to prevent this from happening. During the conversation he asked frequently if we understood. We nodded yes, but we really didn't. How could anything be wrong? We just held her and she was

perfect. The doctors kept us posted on her condition and we were allowed to visit her in the ICU Nursery, but were no longer able to hold her. She was connected to an endless number of tubes and wires.

The nurse explained everything to us, everything except why this had to happen to our little girl. She had a tube in her mouth that helped with her breathing and IV fluids that gave her the nutrients that I longed to provide for her. The nurse also pointed out the tube that held her special medicine. We stared in disbelief. Why was this happening? Just hours ago we held her in our arms, happy and content. Now she only seemed to be suffering as she fought against the breathing machine and gasped for air as they suctioned her periodically. It always took a while to get her to relax after her numerous tests and procedures.

Things were a blur and happening fast, but really too slow because we longed to be told exactly what was going to happen and what the end result would be. Then the doctors came by our baby's bed to talk to us. They gave us three choices. The first choice they gave us involved putting our baby through at least three surgeries over the next several years. The idea of surgery on such a small baby was unimaginable to us. We felt confident that the doctors would do the best they could, but we were concerned about the pain our daughter would have to endure. We were also told the odds for success were poor. So we decided not to sentence her to a life of pain and suffering.

The second choice they gave us was a heart transplant. The doctors felt this was a little more successful, but we would have to leave her in the hospital until a heart was found and this could take months. There was also a chance that our baby would die before a heart was found. In the end we decided we couldn't hope for the death of another child for the chance of saving ours.

The third option was to take our baby home and watch her die. The doctors and nurses would teach us how to take care of her and assured us she wouldn't suffer. It finally sunk in. My husband and I were responsible for making a decision that would determine this tiny human being's life. The two of us made her together, and now it was up to us to decide what kind of life she would have.

The idea that we had to make this type of decision was devastating. We had only thought of deciding what school she would go to and when to take the training wheels off her bike. We felt very young and not wise enough to make such a decision. We desperately wanted the doctors to tell us what to do. My husband and I have a deep faith in God. We believe that He has a reason for everything even though we aren't always allowed to see it right away. We prayed together that we would make the right decision for the little girl the Lord had entrusted us with.

So, with God's help, we took our baby home. We decided that for the time she had left we would not watch her die, but instead, watch her live. For three months she slept in the nursery we had made for her. I dressed her in the clothes bought for her, and friends and family came to call and offer words of love and hope. Most of all we held her close. We talked to her and sang her songs in the privacy of our own home. We expressed personal thoughts to our baby that would have felt uncomfortable to say in the presence of the nurses and doctors.

I saw recognition in her eyes and have no doubt that she knows that she was loved. We were only able to share in her life for three short months, but this time is forever in our hearts. She is a real and lasting part of our family.

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## Diego's story

Diego is the first child of an 18 year old married Hispanic woman, born at 36 weeks gestation. Gastroschisis was diagnosed on routine prenatal ultrasound; reduced in the delivery room, and closed one week later. At one month, ileal atresia was surgically resected along with fifty percent of necrotic small bowel and colon, and the ileo-cecal valve. At 4 months of age, after repeated feeding failures, adhesions were surgically released and a gastrostomy tube was placed. He was first successfully fed at 4½ months of age, an elemental formula by continual drip, 0.5 cc/hr.

At 5 months of age, Diego's developmental milestones were normal and his parents were very involved with his care. His short gut would require very slow transition from parenteral to enteral nutrition, necessitating long-term hospitalization, sub-optimal for his development. The multidisciplinary team agreed that discharge on IV fluids and continual feedings would be best for Diego. The parents were ecstatic at this possibility.

A 3 Fr PICC was placed for home infusion, allowing for saline-lock and blood sampling. An experienced Spanish speaking NICU home care nurse facilitated discharge by teaching the parents all aspects of Diego's care. The nurse was impressed with the parent's eagerness, intelligence, and commitment to their son. Diego was discharged at 5 months of age on g-tube feedings at 5cc/hour, and TPN 16 hours daily.

The home care nurse visited daily initially, then 3 times a week. She draws blood samples weekly and transports blood to the hospital lab. The nutrition/GI team orders IV fluids for the following week, adjusting to complement his enteral feedings which are increasing slowly, as tolerated. The parents rapidly became independent with Diego's care. Diego's mother guides his care, as she knows when the feedings can be advanced, and when he is not doing well.

Diego has been readmitted to the hospital occasionally, once with fever and cough, twice with vomiting and once with bloody stools. He continues to have an intermittent partial bowel obstruction, and may require another surgery for adhesion release. He continues to have loose stools, as expected due to his short gut. His feedings have been increased slowly and he is tolerating about 2/3 enteral nutrition.

Developmentally, at 10 months old, Diego is normal except for mild gross motor delay. He loves to be read to, blows kisses, and plays peek-a-boo. He is a happy, thriving infant. He drinks small amounts of Pedialyte from the bottle, and takes some infant cereal and rice water by spoon. He receives physical, occupational, and speech therapies weekly in his home. His parents have been very happy caring for their son at home. Diego has thrived, and has had no bloodstream infections since NICU discharge.

Diego's story shows that, clearly, HOME IS BEST. His parents have provided an excellent home for Diego, despite being young, non-affluent, and non-English speaking. Diego's success at home is also due to his excellent home nurse, working with a committed team, dedicated to Diego and his family.

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## Brighter Tomorrows

As a high school English teacher, the last thing from my mind was a sick or premature infant. As a matter of fact, the only time I thought of the NICU was when I met my sister for lunch where she worked in the NICU as an RN. I remember thinking, "How sad. How can you deal with sick and dying babies every day?" Her reply was that there simply was nothing else she'd rather do.

I always admired her for caring for those that couldn't care for themselves. What a calling! What a gift! I thought I had chosen my career and would be a teacher forever. I loved connecting with students and teaching them things they could use in their future, but the more I learned about what my sister was doing in the lives of those she touched, I was truly amazed.

As it often happens in life, my plans were not the same as the Lord's plans for me. As circumstances fell like rain around me, I found myself in need of finding a new job. I was devastated that I had "failed" as a teacher. I had no idea what I would do because I had never failed at anything. I was sinking.

I hadn't considered going back to school before I had lost my teaching job. This was my life preserver. I knew this would change MY life. I could hardly predict how much I would be affecting the lives of my patients and their families.

I decided to go back to school for nursing. I didn't know where the winds of change would carry me, but I followed in my sister's footsteps. I let go of my fears, and I let God be the captain of my vessel. In 2004, I graduated with my degree in nursing not even thinking about what I would do if I couldn't work in the NICU. Luckily, I was blessed with a job in the same NICU as my sister. She continues to be a mentor for me. As I continue to grow in my profession, I love my job more each day. I can't imagine doing anything else! As I have watched my sister continue to grow in her career from RN to NNP, I have been spurred on to continue to grow professionally. I am now in the process of getting my certification and applying to graduate school for NNP.

I think I am the luckiest person in the world. I have learned at an early age that life is full of ebbs and tides. It is up to each of us to decide whether or we will sink or swim. Becoming and RN in the NICU has definitely been a journey that I am glad I was able to take. I look forward to every day that I get to come to work. The NICU has changed my life.

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The infants receiving my nursing care have seen brighter tomorrows because of the mentoring I have received as a newborn intensive care nurse.

Having been a pediatric nurse/supervisor since the late 1970's, a position opened in the NICU at Children's Hospital in Omaha for a nurse to provide care to intermediate status infants. Bea Coleman, a Licensed Practical Nurse (LPN) under my supervision on the Children's Medical Surgical unit had asked me to move to the NICU back in 1995. We were responsible for the 8 babies in the "Little NICU". Pam Carlson, the Director of Inpatient Nursing hired me and encouraged me during this change. Every day until Bea's retirement about 5 years later, we worked eight hour days side by side. I would listen as Bea would tell stories to first-time parents to help them feel more comfortable and confident. I would learn how to properly feed and bundle premature infants as well as become more confident in my family education. I will always remember the day Bea pulled me aside to inform me that a mother had been crying in the hallway. She had asked me if her infant would have to go home on oxygen. I told her in no

uncertain terms, yes. Bea reminded me that when speaking with families, it is important to be truthful but to always allow them to remain hopeful.

Over the next six years I became involved on our unit action councils as well as the professional practice council. I learned about neonatal standards of care and how our unit policies and practices affected an infant's development. With the guidance of Martha Evans, we were able to have an article on PICC lines published in "Neonatal Network".

In 2000 Linda Stawniak had completed her education from an LPN to an RN. In her orientation she was learning things such as drawing from an arterial line that I had never done. Also we were completing the renovation of our NICU. Along with the physical change of the unit, Pam Carlson envisioned a philosophical change in which all nurses would be trained in the care of intensive status as well as intermediate status so that infants would no longer need to be moved to a different bedside when extubated. Although I would be grandfathered, her inspirational message as well as the hard work and example of my friend Linda inspired me to complete intensive status nursing education.

After developing my skills in both intermediate and intensive status nursing over the years, I applied for a supervisor position in the NICU. Again I felt the support and encouragement of Pam Carlson as well as from Barb Petersen, my manager and Kelly Noren, my mentor supervisor. Within the past year I became certified as a neonatal intensive care nurse. Each day as an NICU supervisor, I face new challenges while interacting with families, physicians, staff, and management. But I know because of the caring, support, and encouragement from all my mentors, I will be able to provide brighter tomorrows for the infants of the Children's Hospital NICU for many years.

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Neonatal Nursing is exploring a new frontier with the beginning of delivering and resuscitations of 22 to 23 weeks. Our NICU has just recently implemented this change of practice. We had our first 22 6/7 week infant this past December who lived for one month. In March of 2007 triplets were born. There was a set of Di-Di twins and a singleton. One of the twins weighed 421 grams. She experienced a twin/twin transfusion and gave up much of her blood volume. The medical and nursing staff had never taken care of such a small preemie.

We all had to work as an interdisciplinary team to help solve her medical issues. For example she had an umbilical artery line place with a 2.5 cm. We had no policy to support this small of a line. At one week we had to change the artery line due to clotting off. Now that was a challenge-finding the artery after removing the line. At that point the infant was down to 384 grams! The infant started on insulin within 12 hours of life. The glucoses were labile. The dosing of the insulin required ongoing intense consultation of the pharmacist, neonatologist, and nursing to stabilize. Giving blood was just another problem we all discussed. We were unable to find a vein large enough to start a peripheral IV. The infant had dopamine and insulin going through the umbilical vein. We ended up pushing it through the 3.5 cm umbilical vein line intermittently. This is was outside of unit standard for giving blood.

This infant is now a month old. This experience of taking care of an ultra micro-preemie has made the entire interdisciplinary team feel a sense of accomplishment. We are all learning to deal with the special needs of these infants. The novice to the clinical expert on the unit has come together. This has been a multiple generational learning experience, which has truly been rewarding for the medical staff. I have been a neonatal nurse for twenty-one years. I never

thought that we would be able to help keep this infant alive. I tell the new NICU nurses that the next frontier in neonatology is just starting to shine on these babies. We all look forward to their brighter tomorrows.

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I had been a NICU nurse for just over five years when the unexpected happened to me, I became the mommy to a 27 week baby boy named Noah. The experience greatly changed the way I practice nursing today and I would like to share our story. I was having a great pregnancy, until my water broke. I was admitted to the hospital, placed on bed rest and received two doses of steroids for the baby's lungs. Three days later on August 16, 2006, the baby went into fetal distress and we had an emergency Cesarean section. The first trip into the unit to see my baby, I saw the unit through a parent's eyes. A NICU unit can be a very scary place, lots of high tech equipment, unfamiliar faces, and doctors explaining the condition of your new baby, who is so incredibly tiny under everything in place just to help him live.

I now understand what it is like to be a parent in the NICU. Even as a nurse, I had problems understanding what the doctors were telling me. My mind was so full of questions and concern I couldn't seem to absorb what they were telling me. I know how hard it is to leave a baby and go home, especially the day I was discharged and had to walk into the house for the first time without my baby. I know what it is like to lose my third trimester and have to pump breast milk instead of breastfeed my baby. I know the extreme emotions felt with a baby in the NICU: guilt, sadness, envy, anger, and even happiness. I know how difficult it is to have my baby doing so well one minute and then be so sick the next. I also know the extreme joy the day I got to take my baby home, and how surprised I was that the premie issues didn't stop when we left the hospital.

Whether one day or many months, a stay in the NICU leaves an impression on a parent for the rest of his or her life. I had Noah eight months ago, took him home five months ago and went back to work three months ago. Everyday it feels like it just happened yesterday. When I walk into the unit to go to work, I remember what it was like to walk into the unit as a parent for the first time and for the one hundredth time. I treat my parents with the same respect I wanted. I take the time they need from me even if it does put me behind schedule. I learned that being a nurse in the NICU doesn't mean that I only take care of the babies I am assigned, I also take care of the parents and sometimes the parents actually need more care than the baby! I treat every baby the way I would want Noah to be treated and I have learned that one person can make a difference, especially to the family in the NICU.

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### The Beautiful Patina of Experience

*Patina: the appearance of something grown beautiful, especially with age or use.*

I was talking with one of our experienced nurses who had just gone through a hard death with one of the babies. "I'm getting too old for this," she said. While I certainly could empathize with her feelings, I immediately knew that it was her age and experience that allowed her to do such a good job with that family. This is not to say that younger nurses

don't do a good job, but there are some things that only come with having been through things a lot of different times in a lot of different circumstances.

I am a fan of the Antiques Roadshow on PBS. If you've watched it, you know how excited the appraisers get when someone brings in a piece that is old and never been refinished. The wood or metal has a depth and glow that happens over time and it makes or breaks the value of the piece. I remember one lady who brought in a telephone table that she picked up at a garage sale and had been sitting in her hallway for over thirty years. She had only done light dusting and polishing through the years. The table turned out to be over 200 years old and worth a fortune! Much of the value was in the amazing patina of the wood.

So what does a beautiful patina look like in an NICU nurse? It is usually so subtle that you might not even notice it. It knows when to put a quiet hand on a shoulder to bring comfort and when it is time to leave a family alone. It knows when to talk and when to listen. It knows a baby is getting sick before anything changes. It anticipates needs before anyone has time to voice them. I remember a day when a baby started to brady and desat. There were three or four experienced nurses in the area. It was quickly clear that action was needed. One went to get the Respiratory Therapist, one went to get the doc, and one went for the intubation equipment. No one really said much, and once the necessary help was gathered the nurses just faded away back to their own babies. The whole thing took less than two minutes. It was the beautiful patina of experience glowing.

Those of us who have been around for a while may think of ourselves as "old nurses." We feel a little worn, have some scratches and maybe some parts need restoration. But under the dust and the surface dirt, there is something beautiful that only comes from our age and experience.

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