

NIDCAP Federation International (NFI)

Founded in 2001, the NFI is an international, non-profit membership organization. The NFI encourages the implementation of developmental care and assures the quality of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) approach in all intensive, special care and newborn nurseries around the world. The NFI serves as the authoritative leader for research, development, and dissemination of NIDCAP, and for the certification of trainers, health care professionals, and nurseries in the NIDCAP approach.

“It is not the strongest of the species that survive, nor the most intelligent, but the one most responsive to change.”

CHARLES DARWIN 1809-1882

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Voice of the Newborn: A Premature Infant's Pride and Destiny

Holly Hearn, RN

In November 2012 I had the privilege of facilitating a session on “A Bird’s Eye View: What Parents Experience in the NICU” as part of the 28th Annual Developmental Interventions of the Newborn conference in Orlando, Florida. At the end of that session a petite young woman came up to talk with me about some of the long term emotional aspects of prematurity. No sooner had Holly Hearn shared her personal story of prematurity with me than I immediately asked her if she would be willing to share her story in our NFI Newsletter. As you read Holly’s story, you too will be touched by her unique insight and compassion as a neonatal nurse. —gretchen Lawhon



Holly in her early days as a premature infant born at 26 weeks.

Some things in life happen by chance. Other things in life occur due to choices made after deep thought, or some quickly in time of emergency. It was 28 years ago when the doctor told my parents, “We have to deliver her now. We can’t wait any longer.” Soon after, a baby girl who weighed as much as a box of cornflakes at 1 pound, 2 ounces, entered the world at 26 weeks gestation. She was born three months too soon. Intubated in the delivery room, my first photo is one with all my extremities flailed out to the sides, before being whisked to the NICU down the hallway. There I began what would be a five and a half month journey, an emotional roller coaster for all of those involved.

My parents were allowed to visit for only a short time each day. It was much different than the family-centered care that is practiced now in most newborn intensive care units (NICU). They came every day, and each day they received a photo that was taken of me. From my parents’ perspective, photos not medical information, are what document my journey in the NICU.

I began in an open bed with an overhead warmer, with many tubes inserted, and monitor lines attached to my body. There I lay for the world to see, no snugglies or frogs around my tiny body to support my self-regulatory attempts. There was not even a diaper that was an appropriate size. After surviving the first few weeks, I was moved



Holly caring for premature infants as a neonatal nurse.

into an isolette where the bright lights and loud noises from the lifesaving machines were somewhat decreased by a plastic covering. This is where the most photos were taken of me as I progressed day by day. One day, several months into my stay, I decided I had grown too big for my breathing tube and pulled it out myself. All the staff ran to my bed as the alarms sounded. Now, as a NICU nurse myself, I know of the urgency that ensued in the next few moments. My doctor was in the unit when this occurred and he decided not to reintubate me. Instead, I was placed under an oxyhood. The doctor warned my parents that there was a great possibility I would need to be reintubated again to support my breathing efforts. However, I progressed on to receiving oxygen from nasal cannula and then finally, I could breathe room air. Other challenges such as eating and maintaining my temperature, were also chronicled in photos.

Although there are photos of my mother giving me my first tub bath as well as bottle feeding me, many of the photos are only of me. My nurses seemed to provide most of the hands on care such as diaper changes, even as discharge approached, due to the visitation rules. After a night of rooming in with my parents, it was finally time to go home. On Sept. 15, 1984, I was finally

discharged home with a breathing monitor to check my respirations, and two very nervous parents. There was a party for me that many of my nurses attended, even on their day off from work. Although I have the best parents, I feel that these ladies were my first “hospital mothers” caring for me when my mother could not. I still keep in contact with one nurse in particular after her son and I were in the same class in school. She beams with pride every time I see her. It is only now that I know that her love comes from a special place as she saw me struggle in my darkest and most critical days of my young life. She has seen me blossom into a young woman filled with life, just as I was during my first few moments of life.

I have always known that it is a miracle that I am alive with no major long term problems, resulting from my NICU stay. It wasn't until several years into my nursing career, that I understood fully the challenges and problems a premature infant faces every day. This had somehow eluded me. There were no intestinal perforations, no brain hemorrhages, PDA ligations or chronic lung disease. I was relatively healthy in my childhood and flourished in the classroom. Although I was always small for my age, it was never a hindrance and developmental milestones were met. Speech therapy was involved, but it was successful because those close to me know I love to talk! I know that the best care that was possible during that time period was provided to me. I am extremely grateful that my doctor, a well-known pediatric cardiologist in his field, had opened the NICU only a few years before my birth in Monroe, Louisiana. I know the care was the most up to date of that time and it saved my life.

I knew that I wanted to work in a NICU since early childhood. My beginning journey in pre-med led me into the nursing field. I was very fortunate to have received a job offer in a Level IV NICU at Cook Children's Medical Center right out of nursing school. Attending Texas Christian University in Fort Worth, I had spent an observation day in the NICU during my pediatric clinical experience. I knew I wanted to be a part of this organization after nursing school. On my observation day, I watched for several hours straight as a team of doctors, nurses and respiratory therapists worked to save the life of a micro-premie, like myself. I knew then that I definitely wanted to join this team of extraordinary people in the NICU.

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Developmental Observer

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Marla Wood, RN, MEd and Bonni Moyer, MS, PT

St. Joseph's Hospital in Phoenix Arizona



Marla Wood, RN, MEd and Bonni Moyer, MS, PT.

Arizona has a rich NIDCAP history, so the opening of the 20th NIDCAP Training Center in the world at St. Joseph's Hospital in Phoenix was greatly anticipated. Under the leadership of Dr. Elsa Sell, NIDCAP blazed a trail into the deserts of the Southwestern United States in 1987, with the opening of the Saguaro Training Center at the University of Arizona in Tucson. After attending a NIDCAP lecture presented by Dr. Sell, a program manager at the Arizona Department of Health Services (ADHS) was moved into action. By 1988, ADHS provided financial and administrative support for developmental care projects in the ten Nursery ICUs (NICU) that existed in the state at the time. Each NICU identified a developmental coordinator who would embark on a journey toward NIDCAP reliability. NIDCAP Trainers from around the U.S. flocked to the state to provide this massive training initiative. The coordinators, once reliability was achieved, performed behavioral assessments on the highest risk infants in their units, while providing training for staff and offering support to families. In 1991, The Developmental Care Council of Arizona was created by the coordinators of the hospital programs as a way of networking, reflecting, and providing support for each other. Meetings of this group occurred every three months and continue today. In 1993, the expansion of NIDCAP programs into Level 2 NICUs, that care for premature newborns born 28 weeks and older, was initiated. Coordinators in these step-down NICUs were hired and they began their journey toward NIDCAP Certification.

During this time, ADHS also created a developmental care consultant position to provide support and guidance to the developmental coordinators in the state. The council created Developmental Care Guidelines in 1998 and recently revised

them in 2012. Some key principles in the guidelines emphasize that: 1) developmentally supportive care is mandatory; 2) parents are the most important resource in a child's life and should be active participants in their care; and 3) all children have intrinsic value and the right to maximize their potential.

The NIDCAP Training Center in Tucson closed in 1997 and soon after, St. Joseph's Hospital, Phoenix, Arizona began to make plans to create the next Arizona Training Center. On March 13, 2012, that goal was realized when St. Joseph's NIDCAP Training Center opened with two newly certified trainers, Bonni Moyer, MS, PT and Marla Wood, RN, MEd

Over eight years ago, Sharon Glanville, executive director of Women's and Children's Services began her commitment in the development of the St. Joseph's NIDCAP Training Center. "We realized how important this aspect of care was, and that there were no NIDCAP Training Centers nearby, which made it a long and costly process to get the staff certified. With the full support of our executive leadership team, we committed to this journey. We couldn't be more proud of our Nursery ICU team and the outstanding care that they provide every day."

In 2005, Marla Wood was hired to begin the training process to become the first NIDCAP Trainer for Arizona's next NIDCAP Training Center. Soon after, Bonni Moyer who at that time was working in the Physical/Occupational Therapy Department, began her own journey as a NIDCAP Trainer. Throughout the years of their NIDCAP Training, Bonni and Marla continued their work with the Developmental Care Council, meeting quarterly and identifying the needs of individual hospitals as well as ongoing and new programs developed throughout the state.

St. Joseph's Hospital is a Level III Nursery with a variety of subspecialty staff, including neonatologists, respiratory therapists, occupational therapists (OT), physical therapists (PT), and speech language (SLP) therapists who are integrated into the idea of developmentally supportive and family centered care. The Developmental team has expanded and strengthened throughout the years. Now meeting once a month, the committee consists of nursing staff, a March of Dimes representative, families, OTs, PTs, SLPs, dietician, social workers, nurse management, neonatologists, grief counselors and a chaplain, as well as the team of developmental specialists and NIDCAP Trainers. This committee has continually accomplished goals to improve the awareness of behavioral cues of the infant and increase family involvement. The therapy team receives orders on almost all the infants, allowing them to assist with fourhanded care during care giving interaction. The input from the family liaison is invaluable, as it allows the team to identify needs from the family perspective and shift things to meet their needs.

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Marcel Panas

Supporting Parents of Multiples in the NICU:

Words of Wisdom from a Father's Perspective

The news of a multiple birth can come as a surprise and is a life-altering event. When confronted with the preterm delivery of twins, the special circumstances associated with their arrival, becomes increasingly complex. Marcel Panas provides a vivid illustration of the unique challenges that parents of multiples face, while also sharing the insight he gained through his experience in the newborn intensive care nursery, and the lessons he learned from his twins.—Debra Paul, OTR

“Above all ... don't lose hope” — JANN MARTEL, LIFE OF PI

I am at the final night of prenatal classes being held in the basement of the hospital. I've been the only “single dad” there for the past five weeks. My wife, Laurina, has been lying practically motionless in a lonely bed a few floors above since week 19 when “Baby A” tried to get through a shortened cervix. A voice that I have learned to listen to during the past few weeks of the class, had me leave tonight's session early. I found a fearful Laurina attached to a series of monitors. It's time.

Shortly before midnight on November 29, 2006, at 24 weeks and 3 days, Alex and Andrew Panas make their long awaited, yet all too early entrance into this world. I'm introduced to my son, Andrew, when he grasps my finger. The doctor asks me to “cut the cord”. Having grieved the loss of a “normal” pregnancy, I overwhelmingly welcome a moment to feel like any other new



Alex is cuddled by his father's hands. “When he couldn't be held, we made sure he felt our touch as much as possible.”

dad should. I push Andrew up to the NICU while his team squeezes air into his little lungs. The last vision I have of Laurina is seeing her lying in the operating room as the medical team tries desperately to start Alex's tiny heart.

Organized chaos welcomes Andrew and me as we enter the NICU. Minutes later, Alex is placed in the bed next to Andrew. Alex's heart stops again and more compressions start. I'm shocked. Frightened. Helpless. Someone brings me a chair and a glass of water. Alex's heart starts again. After spending a couple minutes with my new family, I take two Polaroid pictures of our boys and then take the photos to their mom who is just waking up in the recovery room. Through emotions I cannot describe, I can only say “They're alive. You're a mom!” It would be days before Laurina was well enough to meet the children she had given life to and brought into the world.

I wheel Laurina so she can see Andrew. She reaches through the tiny porthole and takes his hand in hers for the first time. His nurse asks Laurina “Do you want to hold him?” Is this even possible? Minutes later, he is placed on her chest. Never sure we'd ever get this moment, tears of fear and joy slide down her face as she feels the subtle movements of Andrew wriggling on her chest.

Things go fairly well the first week or so. Laurina is still quite ill, so I spend the nights sleeping on the floor next to her hospital bed. In between brief periods of rest, I wash breast pump equipment and deliver milk to the NICU. On day eight we face one of our most serious setbacks.

“There has been a change with Alex” says his neonatologist. We sit devastated in a dark, grey conference room with his medical team, social workers and spiritual care. Alex's lungs are sick and he is on high frequency ventilation at 100% oxygen. He is paralyzed from the medications. “There is little else we can do medically. We recommend that care be withdrawn.” This



On the day he was “supposed to die,” Alex chooses life in the arms of his mother.

can't be. He's alive! We don't understand! We sob. I hold Laurina tight. Withdrawing care is something we just can't be at peace with. "Can we let Alex decide?" we ask. Another physician shares a different, yet equally dire opinion. He asks "Has he ever been held?" He hasn't. He's been too sick. "You should hold him" the doctor says compassionately. Alex's aunts and grandparents say their good-byes. Laurina sits in a chair. As a team of four lift Alex from his bed, his breathing quickens and his heart races. They rush to place him on Laurina's chest. I take a quick picture of the three of us ...even as painful as this moment is, I tell Laurina to smile. This is all we had ever wanted...to be parents and hold our children. Within seconds of his mom's skin next to his, Alex's vitals begin to stabilize. His oxygen requirements steadily decline until they settle at 35%. We hold Alex for eight straight hours. We hold him all weekend until we can no longer bear to see the letters "DNR" on his chart. Alex HAD decided. His journey would continue.

It was early in our journey when we were introduced to NIDCAP. I was initially surprised that there was an official acronym for this. Shouldn't responding to their needs and cues just be a natural way of caring for children? I soon learned to appreciate what NIDCAP meant to the people who practice it and the children and families who benefit from it. Holding our boys in kangaroo care was the most special time we spent as a family. When they couldn't be held, we made sure Alex and Andrew felt our touch as often as possible ...especially during tests and procedures, which we never missed. Andrew's first breaths were taken in the arms of his mother when he was extubated. Alex chose life the moment he felt his mother's embrace.

Being thrust into the NICU experience is very overwhelming. It's especially challenging for us dads. We want to fix what's broken and feel helpless when we can't. We do want to be part of the day to day care of our children...we're just terrified. We are the guys talking about the hockey game to another dad ...while washing our wife's breast pump supplies. We are the guys falling asleep on the floor of a hospital room wondering if we'll make our mortgage payments ... but we just cannot leave our family. We feel we are expected to hold ourselves and our families together while the world around us crumbles apart. We appear strong but are the ones crying in a hospital stairwell when no one else is looking.

As Alex's health continues to improve, Andrew takes a turn for the worse. As we watch the clock ring in a new year above Andrew's bed, his medical team tries to stabilize him. We don't even leave that floor of the hospital for the next 10 days until he is stable enough to be transferred to another hospital for surgery. We spend countless hours at Andrew's bedside, or waiting outside of the operating room for the results of yet another surgery, test or procedure.

After six weeks of our family being separated by the river that splits our city, and our hearts, Andrew is reunited with his brother. Although 3 ½ months old, we celebrate their "0" birthday party on their due date. This would be the happiest day the four of us would ever spend together. For the first time we allow ourselves the belief and hope that our entire family will all come home one day soon.

Two weeks later I am awake two seconds before the phone rings. The compassionate voice on the other end says "There's been a change with Andrew, you need to come in." Within minutes we are in the unit looking at our sick little boy. How could this be? He was doing so well yesterday! The doctors can't explain it. They suggest we transfer Andrew back to the other hospital for surgery to see what is happening. Without any hesitation I say "We have to stop!" Everyone, including Laurina, is taken aback by my response. I picture Andrew dying all alone in the ambulance on the way to the other hospital. "If he is to die, he should do it here. With his brother. With us. With his family." Seconds later, a nurse walks into the conference room and says "you need to come now".

"Give me my boy!" exclaims Laurina as we both rush into Andrew's pod. He's quickly placed in her arms. His medical team keeps him breathing long enough for us to say all we need to say. We tell Andrew we love him. We're proud of him...and he's our special little boy. Yet there never is enough time. You're always left with words you should have said. I nod to the respiratory therapist to stop squeezing the bag. She steps back with tears streaming down her own face. I take comfort in this. The monitors are turned off. As the leads and tubes are removed, one by one, Andrew turns into our perfect little boy. Within minutes his breathing fades and his heart stops. He falls asleep forever in his mother's arms. I'm seated next to them with Alex in my own arms. We are surrounded by the rest of his family (of which include not only his aunts and grandparents, but the staff who cared for Andrew in the only home he's ever known).

Today, Alex is an active, happy and healthy six year old who's left his medical challenges long behind him. He loves to travel the world with his mom and dad. He is curious and adventurous and never short on questions of the world around him ...and his brother, Andrew. All queries we are only too eager to answer. Yet, it is my boys who continue to teach me. They've shown me a world of unconditional love, determination and compassion. They showed me how to look for what is possible rather than what cannot be. And above all ...they showed me how to never lose hope.



Laurina, Marcel and Alex today. Embarking on another adventure!

Soon after Alex was discharged from the NICU, Marcel Panas became the Co-Chair of the Stollery Children's Hospital Family Centered Care Council and a founding member of the NICU Family Advisory Care Team. Marcel now currently holds the position of Coordinator of Family Centered Care at the Stollery Children's Hospital in Edmonton, Alberta, Canada.



Anna Hall Quarles

“Anna Hall Quarles has a master’s degree in social work and public health, and was working as a therapist with preschool children and their families before her twins were born at 25 weeks. She and her husband have shared their experiences in a blog that included such thoughtful reflections that Melissa Johnson asked her to share her thoughts with the readers of the Developmental Observer. Anna’s thoughts about the role of memories and the mix of joyful and painful emotions she experienced after her children went home are particularly relevant to those who work with premature infants and their families both within the NICU and at home.” –Melissa Johnson, PhD

After an enjoyable pregnancy, I unexpectedly had to go to the emergency room in the middle of the night. I knew before I got there, that I was most likely not coming home; so I was not surprised when admitted to the hospital that I was immediately placed on bed rest in a room adjacent to the labor and delivery room. I was 24 weeks and 1 day pregnant. Almost a week later at exactly 25 weeks I delivered a baby boy and baby girl. Jamison weighed 1 pound 11.5 ounces and Emma weighed 1 pound 7.5 ounces. Jamison and Emma’s 105 and 136 days in the hospital are forever a part of who I am. From that point forward our lives have permanently been changed. Thus far, our lives have three phases: before the NICU, during the NICU and after the NICU. It is hard to describe how our feelings have evolved since we’ve left the hospital. It’s almost as if each day I am carrying both a special gift and also a deep wound. I feel so much gratitude and happiness to see their smiling faces each morning, yet they can also take me back to the months that I woke up when they were no longer in my belly, but were also not in our home. Our life now and then is connected in my head and heart, and is all part of our story as a family.

Many of us have those moments when we are doing something and then unexpectedly, we are reflecting back onto another memory. For most of my life those intangible connections have been good, however that is no longer the case, since experiencing Emma and Jamison’s unexpected early births. Although time dragged on, or even stood still, while they were in the NICU it was also a very busy time, which did not leave room or energy to process what was going on around me. Instead, those feelings were pushed back to make room for others. Yet they did not disappear. They are still within me. Now that the strain of those



Jeb and Anna holding their twins, Jamison and Emma.

early months has passed, those feelings have been pushing their way back to the surface.

There are lovely and dreadful examples of how these subconscious connections of the children’s stay in the hospital, come back to me now that we’re all home together. The main culprit of the troublesome thoughts that creep back into my days is breathing. I love to hear, see, feel and yes smell their breaths. But if the rhythm of their breathing shifts even the slightest I cannot help but place my hand on their back and look to see if the color around their eyes has become...now I cannot remember the “term” for the bluish unnatural look that I was told to watch out for during feeding...a sign they are inhaling milk or basically choking. This fear was certainly more powerful when they first came home. Many mothers have a worry that their baby may stop breathing, but fortunately only a few have the memory of it actual happening, and what it looks like. The sound of the monitors going off, as the nurse quickly yet calmly scoops your baby out of your arms, firmly rubbing their back as they put them back into their crib to place the “blow by” over their face with extra oxygen. We few carry this as a litmus test for every future breath. With each breath that goes in and out we can exhale, but we can never forget.

To say Emma and Jamison's hospitalization was hard doesn't even begin to describe it. So it came to me unexpectedly that even amidst such terrifying and unpredictable days and nights, I also have memories that are powerfully beautiful. Shortly after they were born, I resigned from my job aching to do two things and only two things – hold them and pump. Delivering at 25 weeks denied me the chance to hold my newborn babies after they were born. It wasn't until weeks later that I first got that opportunity with my son, and I do not need to look back at the photograph to recall the swirling mix of fear and relief that came with it. I held my daughter two weeks after she was born, for a brief minute as they switched out her ventilator and bed. I am forever thankful for the respiratory therapist who urged and supported me to hold her since he would be doing it otherwise. These were not what I expected my first times holding my babies to be like, but they are memories that I will hold close to my heart forever. During their time in the hospital my new job was to “kangaroo” my babies and I did this for five to ten hours a day. This became one of the few gifts that I could give them and that no one else at the hospital could. It also gave me time to be fully present and take each of them in. Emma, even at two pounds, would move her arms and place them just under her chin as she slept on my chest. Jamison would wake up, and somehow had the strength to lift his head and look up to me, before collapsing back into sleep. These memories come back almost nightly as they drift into sleep in my arms before bed. Jamison's big body now requires that I lay my cheek on



Happy Jamison and surprised Emma sitting for a photo.

About four months after they came home neither would settle without being held. I managed to scoop them both up and propped pillows around me. As I sat there, holding them, and they both fell asleep in my arms, I began to cry. Within that moment of calm joy, the weight of 30 pounds of babies brought me back to the first time they both were placed on my chest. At that time their physical weight was just less than three pounds combined, yet the weight I was under was almost too much.

A handful of our close friends and family still cannot comprehend it all and will supportively say “well thank goodness that's behind you.” I am glad they have not had this experience to fully understand where we've been and where we are now. However for myself or any other parent of a premie I feel the need to speak up. I explain that being the parent to a premie does not mean there is a finish line we cross when they survive or when we get to bring them home. These certainly are two of the biggest achievements, but there is much more ahead, once an infant has been discharged home (for all parents of premies). Currently, we are in the throes of more frequent doctors' appointments (neonatology, nephrology, cardiology, urology, and pediatric surgery), regular ultrasounds, physical therapy evaluations, and RSV shots. We have hardly crossed a finish line, and I never have expected to. Even if the tangible aspects of their premature birth pass I know that the emotional memory will remain. And I am starting to be okay with that. I am fortunate that, although a typical day often holds a stomach sinking shadow, there is also a shimmering sparkly milestone. This is hard since the shadows lurk, where you least expect them, but in letting myself cry and reflect on those moments I have found that only brings more light to our successes and blessings. For me being a parent to two preemies has not been a fairy tale, but ours is absolutely a happy story.



Jamison held against his mother's chest for resting and relaxation.

his head while his legs fold up to fit in my lap, and Emma's head perfectly nestles in the space where her entire body once lay. These bedtime moments take me back to the hours of kangaroo care and how far they have come. They also are slowly filling the void of the months and months that I could not put them to bed. These moments are exquisite yet complicated.

A French Experience

Hélène Gheysens

For any parent, the birth of a child is a life-defining moment.

Our son was born 6 years ago at 28 weeks and 4 days. His birth was magical but also brutal and unexpected. However, we have been able to see the magic no matter how stressful the situation was in reality and that is thanks to the teams we met at the Port Royal hospital in Paris.

They demonstrated an incredibly high degree of professionalism and dedication. Before the birth, they took the time to explain to us what was going on...one day at a time; that was exactly what we needed. After his birth, Alex and his mother and father were well cared for. As parents, we have been quickly but efficiently trained by the medical team about the processes, the gestures, the schedules...everything to help us play our role as parents with this fragile but strong and courageous baby. It is never easy to become parents and each person has to develop their own style. Being supported through this experience by this highly competent team of medical and nursing professionals was tremendously helpful.

The medical team was very positive about our baby, very attentive as well. They always knew how he was doing, and were able to explain to us the different steps of medical and nursing interventions that were needed by Alex on a daily basis, and week after week. This team of professionals were also available to listen to and empathize with our emotional responses, as we faced new challenges, while Alex was living in the newborn intensive care nursery. For example, bed space was limited at Port Royal and with Alex recovering fast, they had to transfer him to another unit. They told us about this plan and this made us really uncomfortable. We were just starting to adjust to Alex's unexpected birth and they wanted to change everything. The team agreed to delay the transfer and we were quite relieved. One week later we were ready to face this transfer. We actually understood that we were lucky to have this team and that other babies should be able to benefit from this as well.

We have been so grateful to the whole team for how much they have done for our baby. We will definitely never forget them. It felt natural to look for ways to show them our appreciation. Coming from an international background, we were familiar with how fundraising was a good way to support and communicate about a cause. So my husband decided to realize one of his lifelong challenges (he never did it before

and never did it after), run a marathon. He chose the New York marathon. We decided to match any financial contribution that our friends would make to Port Royal on that occasion.

In 2007, this was quite new in France, especially as there was no foundation like PremUp then, so no tax credit was given, which is a big encouragement for giving in France today. In the end we received large support from our foreign friends and local friends as well. We managed to raise €20,000, not enough to purchase an incubator, but enough to still make a difference.

It is in this context that my husband met with Professor Jarreau, head of neonatology at Port Royal. Having a career in Finance, my husband was very keen to understand the financial issues of such a great organization. This is when he heard about NIDCAP. The amount we were able to raise was enough to train new people in NIDCAP and improve the care that infants receive from the team. Knowing that this money could help other infants have a better experience and help parents to feel more empowered in that situation made us very happy. Since then, we have been willing to do more.

In the following years, we had two other infants, born at 37 weeks (with cervical stitching managed in Port Royal). While I was going to my regular check-ups I heard about Prem'up, a foundation that raised money for research in neonatology at Port Royal and other institutions. My husband and I were enthusiastic about this initiative. We met with the teams and thought that it would be great to be able to participate in their effort, at our level. We decided to give another €30,000 from our savings. Considering that what made the difference for us was not only the medical follow-up, but also the attention and behavioral coaching. We were happy that those additional funds were used to finance the development of NIDCAP trainings within Port Royal.

Our son is now six years old. He is a fantastic human being, a loving child, a great older brother and a brilliant student. We are grateful everyday to the professionals who helped him get where he is now. We feel responsible to do our best to continue this great work and help other children to benefit from the support we and our children were so lucky to receive.

Developmental Care in the Moment



A tender moment.

Photograph by Melissa Barnes



NFI Mission Statement

The NIDCAP Federation International (NFI) promotes the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). NIDCAP is the most comprehensive, evidence-based model of developmentally supportive care and assessment for preterm and full-term newborns and their families in the hospital, and the transition home.

The NFI aspires for all newborns and families to receive hospital care and assessment in the relationship based, family integrated NIDCAP model.

The NFI assures the quality of NIDCAP education, training and certification for professionals and hospital systems, and advances the philosophy and science of such care.

Adopted by the NFI Board, April 27, 2013



Parents reading to their Infants in the NICU: Does it make a Difference?

Background

Enhancing and supporting parents and their interactions with their child is an essential aspect of providing family-centered developmentally supportive care.¹ Yet, finding creative ways to enhance this developing relationship in the chaotic environment of the newborn intensive care unit (NICU) is often challenging. Although the environment of the NICU is evolving into a quieter and calmer place, there are still times when the chaos increases the anxiety of the most experienced health professional, let alone the frightened new parent. Adding auditory interventions to this environment may not be something to consider for the vulnerable high risk infant, yet should we be overlooking interactive opportunities that would enhance the developing parent-child relationship while at the same time promoting the child's long term cognitive development? Research on the use of the mother's voice as an intervention has been explored for some time with mostly promising outcomes,² however, finding ways for the mother to feel more comfortable talking to her child in the NICU with everyone "watching on," can sometimes make supporting this positive intervention stressful for everyone involved.

Objective

I am sure that we would all agree that supporting parents and the developing relationship with their child during the crisis of neonatal intensive care is, without doubt, of critical importance. How can we foster this developing relationship without adding stress for the vulnerable infant given the intensity of the environment? It is my premise that parents want to interact with their child but often feel uncomfortable doing so. Parents report feeling very out of place in the NICU, and that the environment is not conducive to "normal parenting".¹ Routine parent reading to full-term infants has been found to foster the parent-child relationship in early infancy with long lasting cognitive effects for the child.³⁻⁵ The question that is the basis for this review is: "What is the potential for use of this intervention with parents and infants in the NICU?"

Methods

A search of the recent literature in PubMed and CINAHL for studies particularly related to parents reading to infants in the NICU was used to support the recommendations for practice from this review. This review is not considered to be comprehensive and represents the findings of only a few recent studies. The framework for this review rests on the foundation provided to us by Dr. Als.⁶ Early experiences are the experiences for which all later experiences are based upon. Early experiences change how the brain develops and provide the foundation and structure for later cognitive development.

Summary of evidence

The findings of two studies are highlighted in this review. Both are studies about parent reading in the NICU. Jones and Englestad (2004) developed a creative program for providing reading materials for parents.⁷ After carefully considering the needs of high risk infants and their parents, high school students were enlisted to write poems and stories to be formatted as reading materials for use by parents. The collection of over 250 children's stories with illustrations entitled, "*Cuddle Time Tales*," was formatted into a single volume and provided to all parents with an infant in the NICU once they had settled into the environment. Parents were at first guided in their reading with some information provided about outcomes of parents reading to infants while in utero and to full term infants. They learned that the rhythmicity of their voice could be soothing to their infant and that they needed to recognize their infant's behavioral cues before and during the reading so they could adjust the intensity of the interaction based on their infant's reactions. A parent handout was also created to provide education about the benefits of reading to young infants. Although the results of this program are not stated in measurable terms, the authors provided many anecdotal examples of the success of the implementation of the program.

Lariviere and Rennick (2011) examined the effects of parent book reading in the NICU on parent-child interaction and on whether parents were continuing to read to the child post-discharge. In a retrospective control trial; 59 infants who received the reading intervention were compared to 57 infants who were in the NICU just prior to the institution of the reading program in the NICU. At three months post-discharge, both groups of parents received questionnaires in the mail and were interviewed over the phone about their NICU experiences and their activities with their child since being home. Groups were compared

on parenting activities and in particular on whether parents were reading to their infants in the home. Findings indicated that parents who were reading to their infants were more likely to report that the time spent reading made them feel closer to their infant (69%) and found book reading to be an enjoyable interaction with their infant (86%). In addition, parents from the NICU parent reading group (intervention) were also twice as likely to be reading to their infant at least three times a week after discharge; reinforcing the idea that implementation of parent reading in the NICU would also enhance parent-child interactions after discharge. Although there is no long term follow-up within this study to continue to examine effects on cognitive development, the positive effects on the parent-infant interactions seem enough to consider this intervention for further study in the NICU.

Recommendations for Practice

Neither of the studies provides much information about the environments of the NICUs where the studies took place; although it seems safe to say that most of the participants were convalescent infants past the crisis of intensive care. That being said, the sound and activity in the environment cannot be ignored if a reading intervention is to be effective and not increasingly stressful for both the infant and the parent. Effective routine implementation of this intervention requires that parents have a good understanding of their infant's behaviors and can distinguish between infant behaviors that signal disorganization and infant behaviors that represent organization and comfort. Parents must be supported in reading the behaviors of their infant before such an intervention can be put in place. In addition, the ability

to adjust the environment, such as decreasing noise and activity around the bedside, must also be considered.

Conclusions

Finding creative ways to foster the parent-child relationship in the NICU needs further exploration. The numbers of studies in this area are limited. More research is needed to better understand how to best support parents who would like to read to their child in the NICU environment. Reading to their child may put parents more at ease and may add to a sense of "normalcy" for families during a time when everything about their relationship with their child can seem abnormal in the environment of the NICU. Health professionals need to find creative ways to support the parenting role and this includes incorporating routine parenting activities such as reading to their infant.

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Elected Officers of the NIDCAP Federation International 2012–2013

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Inga Warren, DIP COT, MSc



Joke Wielenga, RN, PhD

Publications

Abraham M, Moretz J. Implementing Patient- and Family-Centered Care: Part I - Understanding the Challenges. *Pediatric Nursing* 2012; 38 (1): 44-7.

Alberts, JR, Pickler RL. Evolution and development of dual ingestive systems in mammals: Notes on a new thesis and its clinical implications. *International Journal of Pediatrics*. 2012;2012:730673. doi: 10.1155/2012/730673. Epub 2012, September 18.

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Conferences

The 8th International Neonatal Nursing Conference (COINN 2013) in Belfast Northern Ireland, 5-8 September, 2013. <http://coinn2013.com/>

Websites and Downloads

<http://www.bliss.org.uk/improving-care/family-centred-care/developmental-care-sig/nidcap/>

<http://ebookbrowse.com/2012-01-nidcap-gm-pdf-d278373888>

<http://ebookbrowse.com/nidcap-chu-mpl-parents-pdf-d96184392>

<http://ebookbrowse.com/newborn-individualized-developmental-care-assessment-program-nidcap-200603-pdf-d2870752>

Video and movie (fragments) in English

How do Neonatal Therapists help with Developmental Care in NICU?
<http://www.youtube.com/watch?v=4wZBWx1N13Q>

We invite you to send in information that you may encounter, such as upcoming conferences, websites, books, journals, articles, videos, etc., that may be shared with our readers. Please send items for inclusion in the Developmental Observer to Joke Wielenga, RN, PhD at: developmentalobserver@nidcap.org.

NIDCAPnurse

<http://www.youtube.com/watch?v=9VKX2KUntLA>

Ten videos on newborn care best practices from Global Health Media Project
<http://globalhealthmedia.org/>

Assessment of Preterm Infants' Behavior (APIB)

The Assessment of Preterm Infants' Behavior (APIB) is a comprehensive and systematic neurobehavioral assessment of preterm and fullterm newborns developed by Heidelise Als, PhD and her colleagues (published in 1982, see www.nidcap.org for details). The APIB requires in-depth training and provides a highly valuable resource in support of developmental care provision by professionals and families.

Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), originated in 1984 by Heidelise Als, PhD, is a developmental, family centered, and evidence-based care approach. NIDCAP focuses on adapting the newborn intensive care nursery, including all care and treatment and the physical environment, to the unique neurodevelopmental strengths and goals of each high risk newborn and his or her family, the infant's most important nurturers and supporters. For a complete description of training centers and the training process please visit our website: www.nidcap.org.

NIDCAP Nursery Certification Program (NNCP)

The NIDCAP Nursery Certification Program (NNCP) under the auspices of the NIDCAP Federation International (NFI) recognizes the excellence of a hospital nursery's commitment to and integration of the principles of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) for infants and their families. NIDCAP Nursery Certification is both a goal and a process. Nurseries that apply for this certification will, by the process of the application and by their self evaluation, define the areas of their current strengths and areas for future growth. Successful NIDCAP Nursery Certification represents distinction in the provision of a consistently high level of NIDCAP care for infants and their families, as well as for the staff, and as such is to be commended and celebrated as an inspiration for all. For information on eligibility requirements and the certification process please see: www.nidcap.org; and/or contact Rodd Hedlund, MEd, NNCP Director at: nncpdirector@nidcap.org or 785-841-5440.

NIDCAP as a Process of Creating and Sustaining Transformations—an example from the Faro Neonatal and Pediatric Intensive care Nursery, Portugal

Elsa Silva, RN, NIDCAP Professional



Twins resting comfortably with one another.

Developmental Care has come a long way in the Faro Neonatal Unit. From simple routine measures that adapted the environment, with attempts to reduce noxious sensorial stimuli, to the implementation of individualized developmental care, it has been a five to six year journey. Today, with the desire to achieve better medical and nursing care we also incorporate practices that reflect individualized developmental and family centered care in our daily practice and in our organizational polices and recommendations.

We began NIDCAP training in 2009 with a nurse and a pediatrician who reached NIDCAP reliability in January, 2011. Many changes have been accomplished since then; doctors and nurses have worked together to improve neonatal care for the infant and family.

The Team: After NIDCAP training, special attention was given to team training. Workshops, training and mentoring raised staff awareness of the vulnerability of infants born preterm or ill, and their families. Now the doctors and nurses coordinate to improve opportunities for rest and sleep, and for family activities in the unit. In 2011, the NIDCAP Professional nurse introduced a more personal approach to training to give every member of staff the opportunity to learn to observe baby behavior and to implement more individualized nursing care.

In 2012, we formed the NIDCAP Coordination Group that consisted of the Nursery Coordinator, Nurse Manager, Nurse Supervisor (a link to the hospital administration), NIDCAP Professionals (a pediatrician and a nurse), psychologist, social worker and a parent representative. This was a very important step in the implementation of the NIDCAP program. This group meets monthly. Since its formation, many changes have taken place, including: structural changes that were made to the unit; newly drafted standards and protocols; and practices that were less suitable to the individualized and family centered approach to care were changed.

Families: Many changes have been made to facilitate family involvement in the care of their infant and to support the evolving parent-infant relationship. Nursing and physician's rounds are now made outside the care area. This allows parents to be with their infants without the interruption of clinicians at the bedside. A room for families was built to promote breastfeeding and the developing infant-family relationship; siblings can come to be with their sister or brother anytime. Family involvement in the care of their infant has increased. Parents are supported to offer skin-to-skin contact with their infant as soon as possible; and breastfeeding or breastmilk feeding is supported by the many breastfeeding consultants and promoters that we have in the unit. Meetings are arranged with every family in the first week of the baby's admission. Parents can talk about the baby's situation with the baby's nurse and doctor. This also provides an opportunity to improve communication and relationships between staff and parents, and to better integrate parents into the unit's routines. Additionally there is a monthly meeting—*Momentos de partilha* (sharing moments)—where any parent can come and talk about anything they want



Caregiver support for organizing an infant's alertness.

with our psychologist, the nursery coordinator and/or the nursing manager.

Unit Structural Changes: We still have an open plan unit but it is now divided into three sections. The intensive care unit has twelve incubators. There are five incubators for intensive care, four incubators for special care and there are three for intermediate level care. In addition there are three designated isolation rooms that are utilized to protect very tiny and ill babies in their first days of life, from fluctuating sound and activity levels. The workstation has been moved from the center of the care area to protect infants and their families from the sounds of staff conversations, telephones and printers. Another enormous and positive change!

Environment Changes: The sound levels in the nursery are monitored and as a result the environment is calmer and more quiet. Lighting in the nursery consists of natural light at day time, and indirect soft lighting when needed. At night time (at about 9:00 or 10:00 PM) the lights are turned off and individualized lights are used to perform care giving as needed. Incubators are covered according to our environmental light protocol (Incubators are partially covered up to 34 weeks gestational age. When the



Nursery staff supporting a family to be together.

infant is able to reach and maintain a quiet alert state, the covers are removed as needed). Positioning and comfort devices are used and individualized according to the baby's clinical, developmental and comfort needs.

These changes have been very demanding for all, especially supporting the parents to be with their infant, and with the team. Reflection has become common practice in the team—*Momentos de reflexão* (Time for Reflection, a quarterly staff meeting where a specific agenda is discussed related to NIDCAP). We congratulate ourselves on having a very united team where doctors and nurses speak the same language and have the same goals of promoting individualized developmental and family friendly care (better than centered care).

Many other subtle changes have been accomplished. Despite all this effort, we know that more can be done to improve and maintain optimal care for infants and their families. For example, family sharing opportunities need improvement; breastfeeding rates could be higher among infants born premature; and parents could be more involved in clinical decision making. The infants' need for their mother's voice, body and milk are at the center of our action plans (while still supporting the fathers' desire to be with their infant during both caregiving and quiet times).

It is with joy that we have embraced the NIDCAP philosophy in our unit and we hope with this we can share that joy, and the sense of doing something for the well being of infants and families in Portugal. We have recognized that these babies and their families are at the center of our unit and care, and that everything and everyone matters in the attempt to improve the future for them.

I want to share our gratitude to Inga Warren for her support and friendship during our NIDCAP journey, and to the Faro Neonatal Intensive Care Unit staff for their openness, joy and efforts to accomplish our achievements so far.



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NFI Membership Meeting

September 29, 2012

As Vice President, I have taken the liberty to usurp a few moments of our meeting for a short yet hopefully powerful testament to our Founder and President Heidelise Als. It has been my honor to bear witness to the evolution of an exacting scientific inquiry into the comprehensive approach to care that is developmentally supportive and individualized to the infant's goals and level of stability that has become NIDCAP.

From the earliest research to a former nurse administrator colleague Rita Gibes, now Grossman, who asked a simple but unforgettable question, "Heidi, can't you teach other people how to do this observation and recommendations?" For thirty years Heidi has been our Sacajawea in guiding, leading, mentoring and facilitating the transformation of each of us as NIDCAP Professionals.

At this time Heidi is graciously responding to the wishes of the NFI



Smaller version of the award made from the design of the NNCP Nursery Certification Award.

membership in creating opportunities for new leadership perspectives through a term limit of a maximum of two consecutive years as President.

It is imperative that we pause and acknowledge with heartfelt gratitude the thirty years of formal NIDCAP guidance and education from the 1982 establishment of the first NIDCAP Center; her 23 years leadership for our annual NIDCAP Trainers meetings and now eleven years as Founder and President of the NIDCAP Federation International.

Her unfailing vision, passion and endurance will continue in her ongoing role as a member of our Board of Directors and Chair of the Quality Assurance Committee. On behalf of all of us Heidi, please accept this small token of our appreciation.

—gretchen Lawhon, PhD, RN, CBC, FAAN

The 24th Annual NIDCAP Trainers Meeting

Hosted by the Carolina NIDCAP Training Center

The Graylyn International Conference Center

Winston-Salem, North Carolina USA

Saturday, October 5—Tuesday Morning, October 8, 2013

(By Invitation Only)



More information will be available in the Summer, 2013.

I have progressed in my career from a shy new graduate, into an experienced nurse. It is not only my own NICU experience, but the NICU experiences of all the infants and their families, that have molded the care that I provide as a NICU nurse. I don't tell my story to all I meet, but to those whom I do tell, I make sure that they understand my story is the exception. Many challenges face an infant that enters the world too soon. The journey can be like riding a rollercoaster. One mother of a micro-preemie told me that my story gave her hope in her son's first few critical days of life. Several months later, I had the privilege of being the nurse for this family the night of their rooming in. The mother had remembered me and my story, during her infant's stay in the NICU and she was so excited she could finally take her baby home. In this case, I understood the feelings that my own nurses had felt about my discharge, all those years before.

When caring for my patients, sometimes it is the little things that help the family and the infant feel the most comfortable. The linen is clean and smooth. The patient's arms and legs are tucked in to midline and the infant is securely positioned in his snuggly or Z-Flow mattress for a good night's rest. Supporting parents as they care for their infant at bedside is so important to the infant as well as the parents. Taking a temperature or changing a diaper lets the parents feel like "real parents" in the high technological world of the NICU, often dominated by tubes, lines and drips, that are keeping their tiny infant alive.

I try to keep the infant's stress level in mind by keeping the lights low and silencing alarms as soon as possible. Even the slightest movement can cause stress to an infant's neurophysiological system that is not ready for this high-tech world. As technology has improved, so many changes have occurred in the NICU. We are able to take care of the tiniest and most critical infants. They now have an increased chance at life instead of automatically saying to a parent "I'm sorry, there is nothing that can be done to save your child's life." All the tiniest infant needs is just a chance, a chance to fight for a life that began too soon.

Although I am quiet by nature, I have a strong resolve to give my patients the best care possible. It is personal because I once was in one of those incubators fighting for every breath. I will be forever grateful for those doctors and nurses that never gave up believing in me almost 30 years ago. I love my job and truly look forward to coming to work every day. Some nights are extremely difficult, but it is that "chance for life" that I support each infant to strive for, that makes me proud to be here at Cook Children's. I often wonder how I was able to leave the NICU with no major problems, after the circumstances of my birth, and the time of the mid 1980s. I feel it is because I was born to be a NICU nurse and share my story, if not in words, then by the care I give to infants and their families. One truly never knows the future of the tiny infants for whom we are caring for, for they may grow up to be someone special.

NIDCAP TRAINING CENTERS FROM AROUND THE WORLD Continued from page 3

The St. Joseph's Training Center focuses on several different aspects of the infant's care. These include:

- 1) The overall environment. Many changes have recently been made to decrease the overall stimulation that the infant is receiving. These include private and semi-private rooms, decreased lighting, decreased noise, primary nursing and fourhanded care giving;
- 2) Family-centered care. We recognize the family as a key element in the infant's care and provide support and encouragement to allow the families to feel confident in their infant's care. St. Joseph's has recently embarked on a campaign to increase skin-to-skin care. As seen in various research studies, skin-to-skin has been shown to improve the infant's overall medical status as well as emotional state and bond with their family;
- 3) Interactions with the infant during care. The nursing staff is educated on a consistent basis regarding the behavioral cues that are expressed by the infant as a way of communicating the infant's needs for co-regulatory support, or desire to be held within the warm comfort of his mother's arms while being fed. There are lectures and continuous support to assist the nursing staff to read these signs, as well as proper positioning and handling to provide the infant with support when needed and sensitive reflective caregiving; and

- 4) Collaboration with staff. The staff at St. Joseph's Hospital is extremely committed and loyal to the families and the infants. The developmental committee provides support in times of stress for the staff and recognizes the demands of caring for medically fragile infants and their families.

St. Joseph's Hospital is proud to claim to be the only site for a March of Dimes representative in the state of Arizona. Jill Burch, a mother of a premature infant and an employee of March of Dimes, provides an amazing resource for our families. Due to her own experience, Jill presents a support system that is invaluable to many of the families. March of Dimes also provides therapeutic activities, such as scrapbooking, educational classes and sibling activities, allowing an outlet for families to talk and support each other. St. Joseph's is committed to growing this program and allowing this continuous support to develop.

Overall, St. Joseph's Hospital and the entire state of Arizona has been committed to the NIDCAP program and developmentally supportive care. With a Training Center in the state now open, we can only hope that this support strengthens and proves to be a positive outcome for all of the NICU's throughout the state. We look forward to working closely with the state of Arizona, the NFI and NIDCAP Trainers from around the world.

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Federation International

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NIDCAP TRAINING CENTERS

by order of establishment

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Sooner NIDCAP Training Center

University of Oklahoma Health Sciences Center
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West Coast NIDCAP and APiB Training Center

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Carolina NIDCAP Training Center

WakeMed, Division of Neonatology
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Colorado NIDCAP Center

University of Colorado Denver
School of Medicine and The Children's Hospital
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St. Luke's NIDCAP Training Center

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Mid-Atlantic NIDCAP Center

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Karolinska NIDCAP Training Center

Astrid Lindgren Children's Hospital at Karolinska University Hospital
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Connecticut Children's NIDCAP Training Center

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French NIDCAP Center

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Sophia NIDCAP Training Center

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Centro Latinoamericano NIDCAP & APiB

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Children's Hospital of University of Illinois (CHUI) NIDCAP Training Center

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NIDCAP Training and Research Center at Cincinnati Children's

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The Brussels NIDCAP Training Center

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