

# Developmental Observer

The Official Newsletter of the NIDCAP® Federation International

## 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.

*“Patience and perseverance have a magical effect before which difficulties disappear and obstacles vanish.”*

JOHN QUINCY ADAMS QUOTES  
(6TH US PRESIDENT [1825-29],  
ELDEST SON OF JOHN ADAMS,  
2ND US PRESIDENT [1767-1848]).

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## Making Progress Over the Last 20 Years

The NICU at Elliot Hospital, Manchester, New Hampshire

*As in all large projects, our NIDCAP certification started with an impassioned person who was exposed to a new idea, who then shared that idea with someone who cultivated a vision. That vision, having gone through the fires of reformation brought on by changing staff, financial highs and lows, and what we call “life,” persisted due to the desires that were born in our unit about six years ago.*

*Herein lies the beginning and middle of our NIDCAP story, but of course the ending will never be written—it will be lived out daily with our families.*



Front row left to right: Shari DeYoung, PT, BS; Terri Jones, RN; Kristy Hanson, RN, Back row left to right: Pamela Bedford, RNC, BSN; Elaine Pino RN, BA; Maureen Lemay, RN, BSN

As is common with many Newborn Intensive Care Units, or so it seems, ours has evolved from meager beginnings. The NICU started in a small basement space housing six incubators and three cribs, a few nurses and one very passionate neonatologist. Developmental care was seen by our nurses as primarily a physical therapy initiative back then. By the middle of 1993, we were delighted to have moved upstairs into a single large room with a capacity for 17 beds and two critical bed spaces tucked into its framework. Our nurses started to become more aware and intrigued with developmental care interventions through continuing education opportunities, promoted by our physical therapist and an inspiring newly hired nurse who had recently come from a hospital where developmental care was part of the routine patient care. By March of 2005, we had moved into our current unit, complete with 14 private and semi-private rooms and a capacity for 23 patients; its design was based on the 2002 Newborn ICU Design Standards from the Fifth Consensus Conference. The NICU is now staffed with 40 nurses and five neonatologists. The planning and development of our new “state of the art” structure was due to the forward thinking of several key directors, staff members and parents who had an innate appreciation for the emerging practice of developmental care for the newborn. Our unit’s Nursing Director, seeing this new unit she had spearheaded, rightfully realized that this specialized environment was just the beginning of a much greater project to bring an educated practice of developmental care to our NICU. What has followed was the further support found

in the actions taken by our Developmental Care Committee in the form of staff education, the integration of a Developmental Care Specialist position and finally, our NIDCAP certification program which was formulated in conjunction with our Developmental Care Specialist and NICU Leadership. The six of us that are working towards our NIDCAP certification represent the most recent steps towards the goals that were set into action years ago--even before five out of the six of us began working at Elliot Hospital.

## How NIDCAP Training Began

Moving to this newly designed unit was truly inspirational. Family-centered, developmentally supportive care seemed to flourish overnight, regardless of any human intervention. The nursing director overseeing our beautiful "state of the art" NICU repeatedly encouraged us all to "Shoot for the stars!" This was the inspiration needed and the time was right. Over the next six month period, the new Developmental Care Specialist constructed a comprehensive NIDCAP training proposal. She presented it to the nursing director, hospital administrators, the hospital Board of Directors and the Mary & John Elliot Charitable Foundation, a non-profit, charitable organization created to provide financial support to the various needs of the Elliot Health System. The proposal was accepted and the funds were allocated for the training of six NICU staff. In preparation for the training, Master Trainer gretchen Lawhon, RN, PhD was contacted and planning continued with the Developmental Care Specialist and NICU leaders. A large multidisciplinary group including two former NICU parents was formed and was referred to as the NIDCAP Leadership Committee. This committee was charged with filling out the NICU Site Assessment and was later transformed into a powerful steering committee that focused on family centered care and the implementation of the NIDCAP process. Simultaneously, a selection committee was designated to define and carry out the trainee selection process. Five NICU nurses and one physical therapist were selected for training which began on January 25, 2010.

## Meet the Trainees

The NICU's Developmental Care Specialist, *Pamela Bedford, RNC, BSN* provides the leadership for the NIDCAP Trainees while simultaneously going through the training herself. This

model of embedded leadership allows for both collaboration and role modeling as the training progresses. Pam is dedicated to the challenge of practice and culture change in the NICU and hopes to further this through the implementation of NIDCAP Training. She is proud to say that the entire NICU team recognizes an elevated standard of care as family-centered developmentally supportive care that has become ingrained into their patient care delivery in our NICU.

*Kristy Hanson, RN, ADN* a Clinical Leader on the night shift, is in an excellent position to spread her NIDCAP knowledge to our colleagues and her dedication to this training provides an important level of credibility for the staff. Kristy has been actively committed to the implementation of the developmental care program since the first developmental care committee formed. She has been instrumental in supporting the program and NIDCAP Training from a management perspective. Kristy chose to be NIDCAP certified to enhance her knowledge and better support the NICU staff with individualized, family-centered, developmental care planning.

*Elaine Pino RN, BA* brings twelve years of neonatal nursing to the NIDCAP work and demonstrates an especially strong attitude toward the multidisciplinary approach to care in the unit. She would like to be NIDCAP certified because she believes that improving her observational skills will allow for a more consistent and sensitive approach to caregiving. Elaine also recognizes the need for all newborn caregivers to gain a higher level of understanding for developmentally supportive care.

*Maureen Lemay, RN, BSN* was a newly graduated nurse when she started working in the NICU eight years ago. She has been an active member of the NICU Developmental Care Committee and is the NICU's resource nurse for breastfeeding and bottle feeding practices. Maureen strives to make a greater impact on care delivery through supporting the sensitive attunement of care providers and parents to the infants' neurobehavioral organization. She came to NIDCAP Training with the expectation that it would facilitate more family-centered individualized care plans and improve the overall quality of care.

*Shari DeYoung, PT, BS* has 18 years of newborn experience along with her genuine enthusiasm for the NIDCAP work. Shari's perspective as a physical therapist trained in the Neonatal Oral Motor Assessment Scale (NOMAS®),<sup>1</sup> adds to the group's

## Developmental Observer

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### Contributions

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overall level of expertise. She has facilitated a number of developmental care initiatives in the NICU over the years. Shari joined NIDCAP Training with the objective of expanding her knowledge base and improving her observational skills in order to enhance developmental care practices and parent education. She anticipates that the process will help to integrate a team approach to infant care.

*Terri Jones, RN* brings a wealth of experience from a variety of different settings including Oakland Children's which was in the forefront of individualized developmentally supportive care since the mid-eighties. Terri's nearly twenty years of neonatal nursing experience makes her an ideal trainee as well as an excellent role model. Through NIDCAP Training, Terri expects to be able to apply her new skills and knowledge within her own practice; to be an effective resource for all disciplines; and to make improvements to the care practices in the NICU. She feels that NIDCAP is a perfect fit for her because its concepts are aligned with her professional values and motivation for promoting the family unit.

As time has evolved, a larger percentage of our families are staying at the bedside and thus have a direct impact on their baby's care. It is an evolution that has been born out of a more sincere, honest commitment from our nurses and other care providers to invite them to stay. This progression has been guided by the Leadership Committee who defined and acknowledged a commitment to include parents in rounds and to hold ourselves responsible for opening up communication between parents and

staff. It was NIDCAP that gave our vision a name and a face for all of our staff.

### The End Result

The family has taken a principal role in nurturing and caring for their infant and our unit has changed for the better! Our parents have a visible place here - on their terms, not just on ours. Of course, we now have a new set of challenges but we will continue to shoot for the stars!

After 19 months of NIDCAP training, we are so pleased and excited for the NIDCAP Reliability Day scheduled for September 12th of this year!

### NIDCAP Training Update

Congratulations are offered to each one of these outstanding women of "The Elliot Six" who have now successfully transformed themselves from NIDCAP Trainees to NIDCAP Professionals as well as to their supportive staff and administration of the Elliot Hospital Newborn Intensive Care Unit. This NICU has been "forever changed" by the growth and development highlighted in the six remarkable Advanced Practicum experiences of six infants and their families which became a multidisciplinary unit-wide implementation of NIDCAP.

#### References

1. Palmer M. Neonatal oral motor assessment scale (NOMAS®). 1983

## The Brest NICU Achieves NFI NIDCAP Nursery Certification in 2011

Jacques Sizun, MD

*The Brest NICU Team is very happy to have achieved the NFI NIDCAP Nursery Certification.*

The NIDCAP Nursery Certification Program (NNCP) was seen as an institutional quality improvement process and an opportunity to share the philosophy of NIDCAP in a whole Mother and Child Department (Brest University Hospital).

The process started in early 2010 with the translation of the NNCP Criterion Scales Manual<sup>1</sup> supported by the Brittany Regional Hospital Agency. Then four groups of professionals worked hard to perform the self-evaluation suggesting 10 points of improvement. The Department Board selected five actions in October 2010 for immediate changes.

The NNCP Site Review visit took place in December, despite a snowstorm at the Paris Airport! Parents, staff and directors were very excited by these three days of interviews, document analysis and observations.

Next steps: To pursue the quality improvement process toward a more individualized family-centered approach to care; to present this NNCP experience to our National Certification visitors from the Haute Autorité de Santé in September 2011; and to share this experience with European NICUs.

#### Reference:

1. Smith K, Buehler D, & Als H. *NIDCAP Nursery Certification Criterion Scales*. 2008. Boston, Mass: NIDCAP Federation International, Inc.



*The Brest NIDCAP Team holding the NNCP Award. Pictured from left to right: Sylvie Minguy RN, Isabelle Olivard RN, Cathy Boucher RN, Jacques Sizun MD, Maryvonne Quéneá RN, Nathalie Ratynski MD, Béatrice Kerleroux RN.*



*NIDCAP Nursery Certification was celebrated during the first French-speaking annual NIDCAP meeting in Brest, May 26-27, 2011.*



# Transitions within the NFI Board of Directors

gretchen Lawhon, RN, PhD and Deborah Buehler, PhD

*Following the recent election at the NFI Membership meeting in September there has been a change within the NFI Board of Directors and we would like to express our appreciation to two departing Board Members of long standing as we welcome two new Board Members. The NIDCAP Federation International would like to acknowledge the many contributions of two Board Members, Karen M. Smith, RNC, MEd and Roger Sheldon, MD, MPH, who have completed their terms.*



**Karen Smith, RNC, MEd** is the Clinical Developmental Specialist and Developmental Care Educator with the Newborn Intensive Care Unit and NICU Follow Up Clinic at St. Luke's Regional Medical Center in Boise, Idaho. She has over twenty-eight years of neonatal nursing experience and has been involved with NIDCAP since 1989, when she became a NIDCAP Trainee through the Uni-

versity of Washington Infant Transition Project. While Ms. Smith was working on her basic NIDCAP training, she made a decision and firm commitment to become a NIDCAP Trainer. Much to her credit as well as dedication and perseverance, Ms. Smith realized her goal of becoming a NIDCAP Trainer in record time. In 1995, Ms. Smith created the St. Luke's NIDCAP Center in Boise, Idaho. She has been attending our annual NIDCAP Trainers Meetings since 1992 and hosted two of them in the breathtaking Idaho surroundings of McCall in 1997 and Sun Valley in 2006.

Prior to becoming a member of the NFI Board of Directors, Ms. Smith was and remains a highly valued and active NFI member who has been the Co-Chair of the Committee on NIDCAP Nursery Acknowledgment. As a Board Member, in 2004 Karen agreed to chair that committee and renamed it the Nursery Recognition Committee. Re-elected in 2005 and again in 2008, Ms. Smith continues to provide enormous energy and exemplary leadership in growing the NFI NIDCAP Nursery Certification Program (NNCP). Further, Ms. Smith and her colleagues created an exemplary NFI-certified NIDCAP Nursery in their own hospital. From being the first in the pilot phase for the NNCP, Karen experienced and continues to help to refine the process for her own and other units. The Newborn Intensive Care Unit at St. Luke's Medical Center is an ideal flagship for the NNCP and provides both the nurturing environment for infants, families and staff combined with the most respectful attitude and care that is the NIDCAP model.

Ms. Smith is a Master NIDCAP Trainer and is nearing completion of her APIB Trainer training. She teaches NIDCAP on a global basis including units in the United States, Norway, Italy and Taiwan. With great appreciation for her direction, leadership and dedication, we thank Ms. Smith for her past seven years of amazing productivity as a member of the NFI Board of Directors. And we are grateful that she has agreed to continue her invaluable contributions with the NFI and the NNCP in her role as Co-Chair of the NNCP Committee.



**Roger Sheldon, MD, MPH** has also completed seven years of service as a member of the NFI Board of Directors. Dr. Sheldon was one of the very first neonatologists to participate in NIDCAP training both from an administrative and individual professional perspective in the early eighties. He provided the medical leadership and support for the first NIDCAP Training Center outside

of Boston with the creation of the Sooner NIDCAP Training Center at Oklahoma Children's Hospital in Oklahoma in 1986. Dr. Sheldon and his colleagues in Oklahoma hosted two of our annual NIDCAP Trainers Meetings, one on Monkey Island in 1994 and the other in Oklahoma City in 2004. Both of these meetings provided NIDCAP professionals with unique Mid-western cultural experiences and a special perspective on Native Americans.

Dr. Sheldon was first elected to the NFI Board of Directors in 2004 and was re-elected twice in 2005 and 2008. He joined the Nursery Recognition Committee in 2005 and has served on the NNCP Committee as Chair of the Application Subcommittee, from 2006 to 2008. He has been actively involved as a physician site reviewer, offering his invaluable perspective to the pilot process and now the actual program. In 2005, Dr. Sheldon joined the newly established NFI Membership Committee and provides much appreciated contributions to that committee. Further, he serves with leadership and diligence on the Nominations, Appointments and Elections Committee since 2006 and was the Chair of the Outreach Committee since 2009.

Recently, Dr. Sheldon has retired from his long standing position as Professor of Pediatrics with the University of Oklahoma and Medical Director of the Oklahoma Infant Transition Program and Sooner NIDCAP Training Center and moved to Minnesota. Although Dr. Sheldon has completed his tenure on the NFI Board, he graciously will continue to be an active NFI member, NNCP Site Reviewer, and has committed to continue the work he began on publishing an evidence review article on NIDCAP within the context of the American Academy of Pediatrics.

With deep appreciation for their countless and ongoing contributions, we stand to honor Karen Smith, RNC, MEd and Roger Sheldon, MD, MPH. for their seminal work with the NIDCAP Federation International.

*The NFI Board of Directors would like to welcome our two newly elected members, Jeffrey Alberts, PhD and Inga Warren, Dip COT, MSc.*



**Dr. Alberts** is a Professor of Psychological and Brain Sciences at Indiana University, Bloomington. He has devoted much of his career to studying behavioral, sensory, and physiological aspects of development – in fetal, newborn, and infant rodents (i.e. rats and mice). He has received research support and recognition from the National Institutes of Health (NIMH and

NICHHD), the National Science Foundation, and NASA, including a Research Scientist Development Award and a MERIT award from the NIH. While maintaining his lab and teaching, he served for 12 years in administration at Indiana University as Associate Vice President for Research. Since 2010, Dr. Alberts has been a NIDCAP Trainee at Cincinnati Children's Hospital.



**Inga Warren, DipCOT, MSc** is the Director and Lead Trainer for the UK's NIDCAP Centre, based at St. Mary's Hospital, linked to Imperial College and a network of neonatal units in Northwest London. As an occupational therapist, she has worked in neonatal care since 1990 with children and families from a wide variety of healthcare settings, Ms. Warren's main area of interest

currently is education and finding innovative and effective ways to make the NIDCAP philosophy and principles more widely known and understood and the training more accessible. In recent years, her work has taken her to fourteen countries, and she is interested in how NIDCAP can be adapted to meet the different challenges that each country, and indeed each unit, faces and how to set them on the path to NIDCAP.

### **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](http://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](http://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](http://www.nidcap.org); and/or contact the NNCP Director at: [nncpdirector@nidcap.org](mailto:nncpdirector@nidcap.org) or 785-841-5440.

# Martha Hayden Kendal Holmes, BFA, MSW

August 5, 1945 – June 27, 2011

*Martha Hayden Kendall Holmes, BFA, MSW was born August 5, 1945 in Sayre, Oklahoma, to Marie Hayden and James Melton Kendall. She grew up in Sayre and graduated from Sayre High School in 1963. Martha received a Bachelor of Music, 1970, University of Oklahoma and a Master's Degree in Social Work, 1976, University of Oklahoma (OU). During the 1970s, Martha was one of the original people to organize the Oklahoma City Parents Assistance Center. She was a Clinical Assistant Professor of Pediatrics at the University of Oklahoma Health Sciences Center. In 2009 Martha, and her life companion Tedd Fulp, were presented with the Phil Wahl Abolitionists of the Year Award, from The Oklahoma Commission to Abolish the Death Penalty. Martha was preceded in death by her parents, Marie and James; her sister, Norma Jane; and her husband, Fred. She is survived by her life-partner, Tedd Fulp; her niece, Marquita Lopez, and her husband, Tony; several cousins; numerous long-term friends; and her beloved and faithful dogs, Buddy and Gypsy. Martha was blessed with the ability to develop and maintain friendships and was known as an advocate for children and families who went the extra mile to achieve positive results. She will be dearly missed by those who knew and loved her (excerpted from "The Oklahoman" July 10, 2011).*



*The reflections of Martha below celebrate her life, work and the dynamic and innovative person that she was. For those of you who had the opportunity to know Martha, she was a rare gift indeed... "What a gift! What a life! What a gal!" (from The Oklahoma Commission to Abolish the Death Penalty, In Memory & Gratitude for Martha Kendall Holmes, June 27, 2011).*

## A Remembrance

The NFI and the NIDCAP world suffered an enormous loss on June 27 when Martha Kendall Holmes died unexpectedly at her home in Oklahoma City of an apparent heart attack. The Sooner Training Center and the Neonatal Section at the University of Oklahoma as well as colleagues from other parts of her life mourned her passing at a memorial service held on July 12. I shared some of my thoughts, but I also learned about my friend and colleague of 31 years. We heard about her dedication to the NICU infants and their families, about her musical talents, her devotion to social work, and her many service contributions to causes like the Coalition to Abolish the Death Penalty, ZONTA International (a global organization working to advance the status of women worldwide through service and advocacy), and the Democratic Party. And we heard about her beloved dogs.

Martha was born in western Oklahoma where, her childhood friends recalled, she distinguished herself as a good friend and excellent musician even in grade school—every performance of soloist or choir in Sayre, Oklahoma in the late '50's seemed to

be accompanied by Martha Kendall. These talents earned her a place in the piano program at the OU Music School starting in 1959. One of her soloists from that time sang at the memorial service and remembered her friend and accompanist as a stand-out musician and loyal friend. How many people do you know who can play any song in any key—just by hearing the melody? And she could dress it up with rhythms, arpeggios and glissandos you wouldn't believe. Martha had a musician's heart and soul. My most moving musical memory of Martha came when she improvised accompaniment for another close friend, an operatic and professional soprano, to sing and play "Sweet Little Jesus Boy" off the cuff at a Christmas gathering in my home. I still tear up remembering the soft and sweet music they made.

However, she also had a heart and soul for the children and the disadvantaged. She earned her Masters' in Social Work from OU and began working in child welfare for the State Department of Institutions, Social and Rehabilitative Services (now called the Department of Human Services). She moved to the Children's Hospital as the only social worker in our 35-bed NICU. It was there I met her in 1979 and quickly came to respect the huge difference she could make in the experience (and



the lives) of the NICU parents, and thus their babies. When a grant became available to start the Oklahoma Infant Transition Program (OITP), Martha was the obvious choice to lead this team of social workers and family advocates in enhancing our services to families.

It was in this post in the early 80's that Martha noted, and quickly understood the importance of Wheelock College's Project Welcome and the NIDCAP revolution underway at Boston Children's. She visited both and came home with the idea for extending NIDCAP to Oklahoma. I was uncertain about this, but she convinced me (I can be slow sometimes) that it was the right way to build families and better babies, and that we should look into it. Therefore, she convinced Heidi Als, PhD and gretchen Lawhon, RN, PhD to visit Oklahoma City and show us how it was done. Heidi recalls being impressed that we had numerous doctors in the audience right from the start—Martha made that happen.

We also learned that it could take longer than one visit to establish a training center, but Martha would not be deterred, and we were able to start the first NIDCAP Training Center outside Boston. She took the Training Center into her OITP program and secured state and federal funding, selling it as an expanded transition service for building families and improving outcomes. It continues there, more than 20 years later.

Looking back, I am amazed at the prescience and perception that allowed her to see this opportunity and bring it to pass. She truly understood the implications of NIDCAP and developmental care before anyone else outside Boston. What a change she made in our care of babies and families!

Martha was also central in the founding of the National Association of Perinatal Social Workers, and very active in the National Association of Social Workers, which honored her as National Social Worker of the Year in 1999. Our trip to Washington for the presentation was a wonderful experience; the award was well-deserved. Martha also served the NASW again as Executive Director of the Oklahoma Chapter during the last few years of her working career.

Martha didn't have an easy life—an unassuming small town start, the loss of her husband of two years in an auto accident, a long and hard career in high-pressure environments—but you never heard her complain or bemoan her lot. She prevailed and made enormous contributions to the wellbeing of our patients and families in Oklahoma, and by extension all over the nation. The babies and families don't know it yet, but they too will miss Martha Holmes, almost as much as I do.

Roger Sheldon, MD, MPH  
*Emeritus Professor of Pediatrics (Neonatology)*  
*University of Oklahoma*

### **“A Mover and a Shaker”**

Martha was a mover and a shaker, although my memories of her were of her sitting at a desk in the Oklahoma Infant Transition Program calmly directing the activities and being there for anyone who needed someone to listen and to care.

Martha was also formidable. When she was not happy with a decision or an activity, she would say “Well, we'll just see about that.” The next thing I knew, the issue had been addressed and the people involved were pleased with the outcome. When she wanted something done, it was always “Well, that just needs to happen and we will make it happen.” And it did.

My first encounter with Martha was when I moved from New Mexico, a newly trained and reliable APIB administrator, to Oklahoma. I received a call from a friendly sounding woman who said “You need to come and work with us.” No, “Hello, welcome to Oklahoma!” No, “What education and experience do you have?” No, “Would you like to work with us?” It was another example of “whatever Martha wants, Martha gets.” Her positive attitude and “can do” approach is why she was such a wonder back then and what her legacy represents.

Martha loved classical piano music, but she really loved her dogs. She enjoyed knowing that her oldest dog was named “Duffy,” a familiar name in the NIDCAP world. Martha adopted and had three feisty dogs at a time. She proudly displayed their portraits on her desk. She also loved going to the most recent movie releases. She spent much of Thanksgiving and Christmas day in the theater and entertained us with her evaluations of the screen play and the acting, not to mention the music score.

Martha's spirit lives on in the people who learned that her enthusiasm, perseverance and being certain with what you believe in are keys to moving our work forward. I will miss her grace, her poise and her always open ear both to the music of the piano and the tempo of the people she worked with.

Joy V. Browne, PhD, PCNS-BC, IMH (IV) Mentor  
*Professor, Departments of Pediatrics and Psychiatry, UC SOM*  
*Director, Center for Family and Infant Interaction*

### **“A Broad Thinker and Innovative Visionary”**

Martha passed away unexpectedly on June 27, 2011. She and I had a telephone call scheduled upon my return from international NIDCAP Training travel that took me to Shanghai, China. Needless to say, Roger Sheldon's email informing us that Martha had passed away came as a great shock.

I heard of Martha first in 1982; gretchen Lawhon RN, PhD with whom I worked at the Brigham and Women's Hospital (BWH) at the time in developing a teaching and training framework for our NIDCAP research, told me that a social worker from Oklahoma had come to visit her and Alexandra Melzar, our first in-house “NIDCAP Trainer.” Martha had heard that the BWH NICU does things differently from other NICUs and she had decided to come and see for herself. As she told me later, “The NICU was dark and quiet and the nurses were very quiet, there were parents everywhere, the incubators had covers draped over them; babies on warming tables slept under sun umbrellas or behind blankets hung tent-like from the radiant warmers above them shielding them, from their surroundings. She saw a mother breast feeding her baby sitting in a padded chair next to the baby's incubator.” She was determined to make this happen also in Oklahoma at the University Hospital's NICU.

She convinced Roger Sheldon, MD the medical director of their NICU, to invite gretchen and me to come to Oklahoma City and teach the neonatologist and nurses about this work and how to see and read the baby. This is how NIDCAP training at other sites began. I am convinced that gretchen and I learned more during our visits to Oklahoma than “our students” would have imagined. Eager students go a long way to create passable teachers. The motivation and determination of the group and the insight and leadership that Martha and Roger brought to the process was assuring and validating. The “Oklahoma group” did their assigned homework and they wanted us to come back! Soon they decided that they wanted to establish a Training Center of their own so that they could train more of their staff and those at neighboring NICUs and in the State. The rest is NIDCAP history. And thus NIDCAP Trainer Training and Center development was born. Martha was invested in improving the State’s infant health and development situation and support parents of high risk infants from the very beginning. Under her leadership the Oklahoma Infant Transition Program, funded by the State of Oklahoma, worked with families in the NICU and upon discharge into the community. NIDCAP would fill in the piece from NICU admission forward.

Martha was a broad thinker and innovative visionary and determined to improve the lives of all infants and families and most of all of those who were in greatest need of support. She was an avant garde social revolutionary, and was so in one of the most conservative states in the US. And Martha was the only social worker the formal NIDCAP family has ever had as member or as Center Director, which in itself speaks for her uniqueness.

Martha and I became good friends. I learned about her earlier life before Social Work, her training as classical concert pianist, her love for music, all music and particularly classical music, Chopin, Mozart and many others. There was always a record, or later a CD, playing at her home. And she introduced me also to the music of country singer Reba McEntire (whom everyone knew it seemed except I); she taught me about American Indian culture, Red Earth, and the Trail of Tears (she sent me a book to read to inform myself) and she took me to the American Indian Museum to enrich my understanding. Martha shared with me the tragic story of her very brief and cruelly curtailed marriage, when her new groom was killed on the spot in a terrible car accident on his way to meet her at a restaurant where she waited for him for a meal together as newlyweds.

I learned that Martha not only cared for babies, their families, other professionals and for people in general, but she also cared for dogs. And she always had at least one or two dogs, they always had tragic pasts and/or were otherwise “in-need-of being-cared-for.” One little very sweet dog I met had been so abused that she had become blind. Martha gave her a loving home; one was named Duffy (my husband’s last name) whom she had adopted when the family who owned him no longer was in a position to care for him. Martha promptly sent me a photo of her own Duffy and a children’s book, “Duffy on the Farm,”<sup>1</sup> explaining that she hoped that Frank would understand

the choice of name. We still have the book and Frank and the children loved it.

Martha was a pioneering multi-culturist; many of you will remember fondly the NIDCAP Trainers Meeting exercise *BaFa’ BaFa’* that Martha led in order to help us all become culturally more sensitive. We learned a great deal about ourselves and one another, regardless of which population group we belonged to and what ‘language’ (words were not allowed for communication among these preverbal groups, only gestures, as two very different population groups encountered one another and were confronted with sharing sparse resources). No doubt there are some priceless photos in the NIDCAP archives of the NIDCAP group’s *BaFa’ BaFa’* experience.

Martha and Tedd Fulp, her life’s partner of many years, were very gracious hosts at home and wherever we met. She was always stylish, a smartly dressed professional, no matter what the Oklahoma heat at the time; she wore heels always, and never had a hair out of place. She made me often feel like sprucing up my appearance a bit. Martha was a most generous person, always fully present for her company, and she always took action to help others in a thousand small ways and in very big ways. She helped a young pregnant Oklahoma woman who attempted to take her life by shooting herself just outside of a Mall, and ended up in the ICU with brain damage. Martha found her and her husband the multidisciplinary services required to heal, recover and carry the baby to term, a big nearly 10 pound baby boy, and an ultimately thriving young family after such a terrific multifaceted life’s interlude. The experience led Martha to work on pre-partum depression, a very new topic at the time. Martha “gave her all” for days and weeks on end in the wake of the cruel Oklahoma Bombing; she served in the ER and she counseled and supported numerous families and children. She supported the Memorial Museum and planted a seedling in her garden of the one surviving tree at the bombsite. She took me there and shared again the perspective of caring and deep responsibility for one another and she led a big effort to abolish the death penalty in Oklahoma, even for Timothy McVeigh, the Oklahoma bomber, in her mind foremost a person and in need of redemption and rehabilitation. I admired Martha, her principles and steadfast convictions, her ethics and integrity. I miss Martha. Her memory will carry and guide us who knew her, for many years to come. She has made the world a better place for all of us by who she was and what she stood for.

In sadness, and grateful to have known Martha for many years.

Heidelise Als, PhD

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## Our Journey to Breastfeeding



*Nitzan Paster Benor was born at the NICU at Meir Medical Center, Kfar Saba, Israel on February 22, 2011. At the time of her birth, she was 25 weeks gestational age and weighed 700 grams. Pictured are Nitzan and her mother Shirly.*

My name is Shirly. I gave birth to my daughter Nitzan in the 25<sup>th</sup> week of pregnancy because of severe hypertension (pre-eclampsia). As a mother of my older child, Gefen, now two years old, it was clear to me that I'd like to breastfeed Nitzan and enjoy the great connection it creates between us, as well as the nutritional and immunological advantages. When I first came to the NICU, the doctor explained to me that human milk was proven to minimize inflammation of the bowel wall (Necrotizing enterocolitis; NEC) and also has a positive impact on infant outcome. During the first few days the nurses gently supported me to start pumping breastmilk so my body would start the production of milk. But then, I discovered it is not an easy mission. It turned out that a lot of mothers of very young premature babies (24-27 weeks after conception) experience difficulty after a few weeks of pumping, as it is very demanding, both physically and mentally. I was very motivated to make this work.

Nitzan is now three months old, in her 39<sup>th</sup> week, and has started to drink from bottles and breastfeed, some weeks ago. Throughout this period, my own milk nurtured her, and this was a great thing for me. As I succeeded in this mission (for now...), I'd like to share some tips and ideas which might help other mothers in their journey:

- **Stay motivated:** I kept thinking that this is the best thing I can do for Nitzan. For me, it is part of giving life to her. The pumping task became part of my routine and I kept regular pumping times. My previous breastfeeding experiences helped me get through some difficult times.

- **Enjoy skin-to-skin holding:** I tried to provide Nitzan with skin-to-skin holding two times a day. I placed a comfortable arm-chair next to her incubator, so that Nitzan and I would enjoy it as much as we could. I feel skin-to-skin holding served an important role in creating a close connection between me and Nitzan. It also had a great impact on my breastmilk production. In my first pumping, after starting skin-to-skin holding, I doubled the amount of milk produced!
- **Pump from both breasts at the same time:** This saved me a lot of time and increased my milk production rate.
- **Solicit support and motivation from your partner:** I recommend that other mothers support their partners to be part of the mission; support them to be aware and involved in the process and challenges.
- **Solicit support from the nursery staff:** Information, facilities (pumping room, deep freeze, etc.) and emotional support helped me along the way.
- **Review "case studies":** I had several talks with other mothers of older children, in order to better understand the reasons for breastfeeding success and, at times, its challenges.
- **Keep a written record:** I kept a record of my pumping amounts so I could control the total amount of milk production and have a baseline per pumping to compare it to.
- **Take care of yourself:** Drink a lot of water, eat balanced nutritional meals, and get a good night's sleep (although this is not easy...).

Nitzan and I are still learning, and have a way to go with breastfeeding. I am encouraged by what we have done so far, and hope we can make it eventually to complete breastfeeding.

### Developmental Care in the Moment

*Being together with nurturance and nutrition*



Photograph by Elsa Silva



Sarah Cluff



*"In April of 2011, I was sitting in a Newborn Intensive Care Unit (NICU) watching my nearly adult child, Jenna, hold her little brother, only three days old. In a flash of nostalgia, I found myself completely overcome with emotion."*

Our journey into the world of the NICU began 18 years ago as we welcomed our first child into our family. From that eventful day in February of 1993 until present, we have been a part of ten different NICU facilities, welcoming into our family seven daughters and one delightful little boy.

Jenna was born on February 8, 1993 at 28 weeks, after weeks of unexplained preterm labor. She weighed three pounds, five ounces, and to me, she was the most beautiful sight I had ever the privilege to gaze upon. My first glimpse was fleeting as half a dozen medical personnel rushed her past me into the adjoining room, promptly hooking her up to hundreds of pounds of machinery. It took me nearly an hour to gather the courage to disregard the nursing staff that had been trying to prevent me from entering the NICU, afraid, I suppose, that I would not be able to mentally handle the sight that I was about to walk in upon.

There she was, our tiny miracle, hardly visible for all the equipment needed to keep her alive. We stood in the corner of the NICU for close to 20 minutes before anyone noticed "baby Cluff's parents" had entered. I stood there, feeling the unbearable ache and longing to reach out and comfort this beautiful little creature that had been wrenched away from me far too soon. I was scared and emotional, and I felt lonely and alone in such a sterile, medical environment.

I was surprised at how seldom I would see other parents at their baby's bedside, but as the days passed I began to understand why. I was made to feel superfluous and uninvited. I consistently felt like an obstacle in the way of the nurses. Often I would be

told that there was nothing I could do for my baby and I should get some rest. Well-meaning people would even suggest that I "take advantage" of the situation and go back to work while I had the best babysitters in the world caring for my infant. It seemed that at every moment, there were "professionals" trying to convince me that I was not needed yet, and should return in a few weeks when I was. Decisions were routinely made without regard to my opinion, or even the slightest explanation about why different procedures were being carried out. Asking questions would inevitably bring about patronizing answers, hastily and loftily given. The more unwelcome I began to feel, the more determined I was to spend every possible moment at our daughter's bedside, commonly staying 16 to 18 hours a day.

Two days into our journey, one nurse finally asked me what we had decided to name our daughter. At that moment, I was consumed with intense incredulity. How could anyone look upon these beautiful miracles and not think of them as babies with names and families? It was a harsh concept to grasp that, to the majority of the NICU staff, our Jenna would be only "baby Cluff - girl," just one of the nondescript infants passing through the nursery. By the end of the third day, I had been allowed to hold my daughter only one time, for a total of 15 minutes; her daddy, James, had not yet enjoyed this privilege at all. Needing to feel actively engaged, I would place my hand in the hole on the side of the incubator as often as possible, and without fail, be reprimanded by a nurse for doing so.

Every moment that followed for the next five weeks was a journey of indescribable pain, joy, love, heartache, frustration, and ultimately, confidence. Confidence because of one extraordinary nurse who gave us the priceless gift of education. She took us on a journey from young newlyweds to parents.

On the fourth day of Jenna's NICU stay, we met gretchen Lawhon, a nurse working on her research to earn her PhD. gretchen quietly watched us for a few minutes as we began our daily routine of scrubbing, gowning, and sitting beside our daughter. I will never forget the first thing gretchen ever said to us. She said, "Jenna is beautiful. Will you tell me about your daughter?" That was the first moment I felt like a mother. gretchen had not only spoken of our daughter by name, but had actually ASKED me about her! Over the ensuing weeks, gretchen taught us how to understand our baby, how to read the subtle signs that Jenna was giving us so we could better communicate with her and meet her needs. We were encouraged to watch our baby, not the monitors. We began to be more assertive with the hospital staff, persistent about receiving explanations and in-depth answers to all our many questions. We began to have the confidence to demand that we be included in the primary care of our daughter. gretchen taught us how to properly care for our new little daughter, and this support has continued to bless our lives with every addition to our family.

Our third baby daughter Abigail, born at 35 weeks was a very healthy seven pounds, three ounces but presented us with an entirely different set of circumstances. For reasons unknown, she was crashing fast. Again we were shuttled up to the major hospital over two hours away where her needs could be cared for. In the 18 months since we had seen it, the unit had been completely overhauled and remodeled. It was an entirely different NICU from the one we previously endured. Upon arrival, we were met by a team of care providers whose specific intent was to educate us about the NICU. We were offered an empty patient room just down the hall and told it would be at our disposal as long as the hospital didn't need the bed for a patient. Arrangements were again made to care for our daughters at home, and again, the familiar routine of caring for an infant with special needs began.

At such a healthy size and relative healthy gestation, the cause of the crisis was not premature lungs, or inability to maintain body heat. There was no concern for typical preterm presentation of apnea or bradycardia. We faced a reality that no specialist or professional of any kind was able to discover the cause of her rapid decline. She suffered a cardio respiratory arrest and was intubated. As the hours passed, seizures became commonplace and each would leave physical indents in her muscles with the slightest touch. She had no reflexes and the results of an EEG showed no activity. We were invited into a quiet room where we were confronted with the cold sober faces of half a dozen medical professionals prepared to methodically explain that our daughter was going to die. This snapshot is seared forever into memory, never to fade. The excruciating decision was made that life support would need to be terminated.

We left that room dazed and in shock, but not numb. Anything but numb. Ironically, it was at this moment I absorbed some of the many changes that had occurred in the NICU. Several parents were sitting bedside to their tiny infants. One mother was looking at a chart, another talking to a doctor. There were three fathers in the room that day, two of them seemingly there to give the mothers a much needed moment to rest, shower



*From left, Jenna Cluff two years old, Abigail Cluff at 12 days old...seven days before hospital discharge, and Mckinlei Cluff at 18 months.*

or eat. In every direction, people were holding, cuddling, feeding, or otherwise attending to miraculous life in the form of miracle babies. One family was completing the necessary tests and paperwork to discharge their son. The boy's mother briefly looked in my eyes before turning away,



*The Cluff Family*

unable to face the pain emanating from my very soul. I found myself hungry to sit by my daughter's bedside, eager to again be the obstruction in the NICU interfering with conventional routine. Did I really, just hours ago, anticipate with horror the weeks I might have spent here? We insisted on an exception to the "no children allowed" so we could bring Jenna and Mckinlei to the bedside of their sister the next morning and for one brief moment, allow our family to be together and whole.

That night, amidst bouts of tears and unsuccessful attempts at sleep, we received a phone call that would change the path we were about to walk. It was about 2:30 in the morning and on the other end of the phone was an unfamiliar voice. My first excruciating thought was that it was too late, that our daughter had already passed away. Unexpectedly, I was greeted by the wonderful British accent belonging to a doctor by the name of Niel R. Buist announcing the possibility that the source of Abby's overwhelming sepsis may have been discovered and was possibly treatable. He asked our permission to begin treatment. We were told that there was great probability that Abby's brain was merely paralyzed due to a toxic amount of ammonia in her blood. We rushed to the hospital with our children where we were educated about the extremely rare diagnostic possibility of THAN - transient hyperammonemia of the newborn. We were informed that the ammonia level in our seven pound daughter's body was well over 1000. We learned that when an adult has a level of around 60, coma is likely. Dr. Buist theorized that if we could wash the blood of ammonia through dialysis, perhaps her brain would be able to wake up. This course of treatment was started immediately.

This phenomenal man, instructed the nurses to allow our children to see their baby sister and make arrangements for us to have a room at the nearby Ronald McDonald House. For the next 16 days, I rarely left Abby's bedside. Never once did someone reprimand me for touching her too much. I was encouraged to ask questions and told that if there was anything I did not understand they would answer, find the answer or arrange to have the doctor come and answer any question I had. We were even encouraged to be available when the doctors met each morning to discuss care and treatment during "rounds". Never once was I made to feel like an obstruction, but rather, a vital member of the team whose entire purpose was to heal a devastating illness and allow our daughter to come home.

I was never denied audience with Dr. Buist and had the opportunity to discuss with him the different NICU experiences

*Continued on page 18*





Dorothy Vittner, RN, MSN

### Connecticut Children's NIDCAP Training Center



*Seated: Tracy Brundage, MOT, OTR/L, Marla Booker, RN, BSN, Standing Caryn Bradley, PT MMSc, Dorothy Vittner, RN, MSN, Marilyn Sanders, MD, Ann Milanese, MD*

Connecticut Children's is an academic medical center with a broad spectrum of over 150 sub-specialty services dedicated to the care of children and their families, located in the heart of the city of Hartford, Connecticut. Connecticut Children's is a young organization established in 1996 as a collaborative effort between Newington Children's Hospital, Hartford Hospital and the University of Connecticut Health Center. Although it is a relatively small hospital with 147 beds; the intensive care nursery is a tertiary referral center for over nineteen hospitals throughout the state and provides complex medical and surgical services to critically ill and premature infants.

The NIDCAP Training Center at Connecticut Children's first opened at the University of Connecticut Health Center in 2002 through a collaborative multidisciplinary effort between rehabilitative services, medical and nursing support and facilitated via the leadership of Cathy Daguio, OTR/L, MPH, MEd†, Marilyn Sanders, MD and Dorothy Vittner, RN, MSN. The Training Center transitioned to Connecticut Children's in 2007. The NIDCAP program was integrated into the Neonatology Program which was designated as the hospital's inaugural Premier Program in the fall of 2008. The intensive care nursery embarked on a systems change initiative to support individualized developmentally supportive care practices within the nursery and began formal developmental training in September 2009.

The Connecticut Children's NIDCAP Training Center provides educational opportunities on a variety of topics for

professional staff within the hospital as well as the larger community. It is home to the University of Connecticut's Department of Pediatrics and division of Pediatric Surgery pursuing innovative clinical research and providing pediatric training to over 500 physicians and allied health professionals annually. Connecticut Children's partners with many colleges and universities to train health professionals from a variety of disciplines including: nursing; mid-level practitioners; respiratory therapy; occupational and physical; speech therapy; audiology; clinical nutrition; pharmacy; child life; social work; and radiology to learn about pediatrics. NIDCAP concepts have been integrated into mentoring and shadowing experiences within the nursery and are provided to foster a comprehensive understanding of infant development as well as support professional learning and growth. The developmental team is used as a resource to share their unique knowledge with professionals who seek to better understand infant behavior and development.

The Connecticut Children's NIDCAP Training Center has focused on four key elements of individualized developmentally supportive care: interactions with infants as care is provided; family-centered care principles; the sensory environment including the physical as well as the emotional atmosphere; and mutually supportive relationships among the care team.

The intensive care nursery has strengthened and expanded developmental services to create a cohesive multidisciplinary developmental team from physical therapy, occupational therapy and nursing. This team has redefined service criteria, assessment strategies, documentation and integration into the health team incorporating therapeutic principles within the NIDCAP framework. Historically a nurse developmentalist provided assessments and input to the health team which utilized therapeutic consultations for specific complex medical diagnosis. The rehabilitation department has embraced NIDCAP principles and has encouraged their staff to participate in multiple educational opportunities. Resources from speech therapy and craniofacial services are also utilized as needed to support the infant's developmental needs. The developmental team continues to create strong foundations for infant interactions and experiences collaborating with the health care team.

The nursery leadership at Connecticut Children's takes pride in supporting an environment of innovation, creating a culture of continued growth and learning, exploring new ideas and creating dynamic teams embedded in strong family centered care principles partnering with families. The intensive care nursery uses a collaborative approach with resources from families, nutrition, social work, lactation consultants, developmental specialist,

nursing, case managers, advanced practice and medicine to create individualized plans of care to support each infant in the nursery. In addition to medical rounds the multidisciplinary care team meets on a regular basis with families to define and update the infant's plan of care. A nursing discharge coordinator facilitates transitional plans of care with each family having input from each discipline as the infant is discharged from the nursery to ease the transition for the infant and family.

Connecticut Children's nursery is nationally recognized as a center for excellence for low infection rates, high ratings in family and patient satisfaction and has been a pioneer in supporting a mother's desire to breastfeed their premature and/or critically ill infant. Three board certified Lactation Consultants and 23 Certified Lactation Counselors from various disciplines within the hospital provide extensive lactation services with a multitude of clinical lactation services to support the use of breast milk in the intensive care nursery and hospital setting. The Lactation Consultants provide support to lactating mothers throughout the hospital including the emergency department and feeding team clinics with one on one consultation services and integration into the health care team. All families who receive inpatient or outpatient lactation services receive follow up phone calls for at least four weeks after discharge. The intensive care nursery has established human donor milk as the standard of care for all very low birth weight infants if their mother is not able to provide milk of her own. A variety of annual educational opportunities are provided to all hospital staff to enhance their knowledge and competence to support breast milk fed infants. The staff is also encouraged and supported to provide breast milk to their own children with free in-home lactation services, comfortable private rooms to express their milk while they are at work and reduced fees to rent electric breast pumps.

The hospital is committed to partnering with families to provide exceptional care to children and has collaborated with the Institute of Family-Centered Care to strengthen family-centered care practices throughout the hospital. Many family-centered care strategies have been implemented with changes in the physical environment, training to hospital staff, and the creation of a resource library for families. The family resource library is available 24 hours a day. It is located in a private room with comfortable overstuffed leather sofa and chairs, a separate desk area with a computer which has internet services, a large bookshelf lined with books, videos and CDs as well as a television are available for families to use in this room. A nursery education committee maintains the library and assures the resources provided are current and comprehensive. A few years back, a hospital-wide Family Advisory Board was created with a nursery based Family Advisory Board following to provide input into the nursery's many aspects of decision making. Families are integrated into daily medical rounds which increases partnerships and communication regarding individualized plans of care. Privacy is sustained by speaking with soft voices during rounds



at each bedside. Occasionally, rounds or a formal interdisciplinary discussion of the infant's plan of care will take place in a separate private room close to the nursery if the conversation is anticipated to be difficult or disruptive to the nursery. When this happens the care team often will consult with the family on their preference for where they would like to have the conversation. The family is encouraged to participate and bring forth their priorities during rounds. Although the nursery staff was initially apprehensive and concerned with privacy and impacts on sounds levels in the nursery, the transition to include all families was eased as the physician group and nursery leadership modeled successful implementation.

Connecticut Children's is a growing dynamic organization committed to improving the lives of children and their families.

### From the Editors

We invite you to write us with your comments regarding the content of any of the columns presented in this newsletter.

We are also interested in any suggestions that you have with regard to future topics that you would like to see addressed in the Developmental Observer. Please contact us at: [developmentalobserver@nidcap.org](mailto:developmentalobserver@nidcap.org).

### Developmentally yours,

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## An International Scientific Symposium on Very Early Interventions for Infants Born Too Early

Stockholm, Sweden, 2010

In November, 2010 the Karolinska Institute, Stockholm, Sweden hosted a second international scientific meeting on “Ultra Early Intervention,” allowing the Danderyd, Sweden site to proudly share their transformation to a Couplet Care Unit. Hugo Lagercrantz, MD, PhD opened the day with a discussion of fetal and preterm consciousness,<sup>1</sup> citing recent work on Resting State Networks (RSN) and cortical responses to pain as examples of a growing body of neuro-evidence for preterm consciousness. It appears that the perspectives of neuroscientists and behavioral observers are converging, adding weight to the six presentations that followed, each of which included behavioral observation as part of family centered care.

Zack Boukydis, PhD, University of Turku, Finland described a project that trains NICU staff to join parents in observing and interpreting the meaning of infant behavior, which he hypothesizes leads to improved care for the infant. Training begins with a week of lectures and demonstrations, followed by a month of paired practice with a mentor and supervision groups. Observations are made utilizing the NICU Network Neurobehavioral Scale.<sup>2,3,4</sup> At the time of this presentation, 50% of the staff on the NICU had been trained and it was anticipated that mentors would lead the rest of the staff through the program in the third year. During 2011, a pre- and post-cohort comparison will be made using measures that evaluate the effect on staff and parents as well as infant development.

Margot Forcada Guex, PhD, Department of Pediatrics, University Hospital at Lausanne, Switzerland gave an update on the maternal stress study<sup>5</sup> looking at the effect of an intervention program on prematurely born children's endocrine responses to separation. The infants were randomized to an intervention that included joint observations with parents at 33 weeks, followed by the administration of the Neonatal Behavioral Assessment Scale<sup>6</sup> and a clinical interview at term, plus sessions of interactive guidance with parents including video recordings. Salivary cortisol measures were compared with mothers who reported symptoms of post-traumatic stress at 12 months corrected age. The hypothesis was that the intervention would counteract the tendency for maternal stress to affect children's stress reactivity. There was a trend in this direction that was not significant; possible reasons were discussed.

The Infant Behavioral Assessment and Intervention Program (IBAIP)<sup>7</sup> conceived and developed by Rodd Hedlund, MEd applies the conceptual framework of the Synactive Model<sup>8</sup> and the NIDCAP<sup>9</sup> approach to care to a neurobehavioral developmental support program for high risk infants recently discharged from the hospital NICU/SCN. Infants and their families begin receiving IBAIP intervention when the infant is one month old (corrected age). A team of researchers, Karen Koldweijn, PhD and Marie-Jeanne Wolf, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands have been the first in Europe to test this intervention approach. In two earlier pilot studies investigating the IBAIP, Koldweijn and Wolf<sup>10-11</sup> found that the Infant Behavioral Assessment (IBA)<sup>12</sup> was a valuable instrument in discriminating differences in self-regulation, and that the IBAIP improved scores on the Bayley Scales of Infant Development (BSID-II)<sup>13</sup>

Karen Koldweijn, PhD presented the most recent results of two IBAIP randomized controlled trials. In the first study, infants in the experimental group (n=86) received one hospital visit shortly before discharge from the hospital, and six to eight intervention visits at home, until they reached six months corrected age.<sup>14</sup> Parents were guided by an IBAIP trained pediatric physical therapist to observe their infant's self-regulatory competence and the child's attempts to process and explore information during a social or caregiving interaction. Parents were also encouraged to offer their infant co-regulatory support and/or modify the environment based upon the infant's behavioural communication. Infants in the control group (n=90) received regular care. Developmental and behavioral outcomes were evaluated at six months corrected age with the Bayley Scales of Infant Development-II (BSID-II). Neurobehavioral functioning was evaluated with the Infant Behavioral Assessment (IBA) at baseline and at six months corrected age. Despite randomization, some differences in neonatal characteristics were found between the intervention and control infants. After adjustment, intervention effects of 7.2 points ( $\pm$  standard error 3.1) on the Mental Developmental Index (MDI) and  $6.4 \pm 2.4$  points on the Psychomotor Developmental Index (PDI) of the BSID-II favored the intervention infants. The Behavioral Rating Scale of the BSID-II ( $P \pm .000$ ) and the IBA (more approach [ $P \pm .003$ ] and less stress [ $P \pm .001$ ] over time) also favored the intervention infants.

The second study presented by Koldweijn consisted of follow-up evaluations of both the experimental and control groups, cited above, at 24 months of age.<sup>15</sup> Development and behavior were evaluated with the BSID-II and the Child Behavior Checklist (CBCL).<sup>16</sup> Eighty-three intervention and 78 control infants were available for follow-up. After adjustment for differences in perinatal characteristics, an intervention effect of 6.4 points



( $\pm$  standard error, 2.4) on the PDI of the BSID-II favored the intervention infants. Groups did not differ on the MDI or the Behavioral Rating Scale of the BSID-II, or on the CBCL. However, in post hoc analyses, the investigators found improved motor as well as improved mental development after IBAIP intervention in subgroups of children with BPD and children with multiple risks. In addition, significantly fewer intervention infants received paramedical services after 6 months, and they were more compliant with follow-up, which underlines the positive effects of the intervention. Further studies are warranted to explore these promising effects of the IBAIP in high-risk infants.<sup>29</sup>

The Dutch government is currently supporting the adoption of the IBAIP as a standard of care for all high risk preterm infants, with ongoing nationwide IBAIP Training for all pediatric physical therapists. All studies relating to IBAIP as well as those cited above, may be found at: [www.ibaip.org](http://www.ibaip.org); click on "Evidence Based Research: IBAIP."

In the 1980s a study in Vermont trialled the Mother Infant Transaction Programme (MITP)<sup>17,18</sup> which introduced parents to infant behavioral communication through a series of teaching sessions during and just after their stay on the neonatal unit. This small study was intriguing because the developmental benefits seemed to increase as the children grew up. Marianne Norrhov, MD presented the results of a randomised trial using a modified version of the MITP conducted by a team of researchers at the Department of Pediatrics, University of North Norway and the University of Tromsø, Norway (146 preterm infants and 57 non-randomized term controls). The intervention consisted of seven in-hospital intervention sessions and four home interventions sessions (at 3, 14, 30, and 90 days after discharge). This study found no significant developmental benefit at two years of age<sup>19</sup> but by five years of age the intervention babies had significantly higher IQ scores.<sup>20</sup> In addition, parenting stress scores showed that both mothers and fathers in the experimental group had much lower stress level than those of preterm controls, and were similar to term controls over the five year period. Child rearing attitudes<sup>21</sup> were also more positive and parents reported fewer behavioural problems, particularly with attention. The intervention was introduced towards the end of the hospital stay and it was speculated that parents may have been most receptive at this stage when their infant had become more medically stabilized and had developed a more trusting relationship with the nurses.

Annica Ötenstrand, PhD, Karolinska Institute, Stockholm, Sweden presented the results of a study entitled the Stockholm Neonatal Family Centered Care Study.<sup>22</sup> The aim of this study was to increase family participation in the care of their infant. Families were randomly assigned to a Family Centered Care group (experimental) or Standard Care group (control) on admission of the infant (n=386 families and their infants; 186 per group). Parents in the experimental group were provided the use

of a private room 24 hours a day, from the first day of their infant's admission to discharge (the room was located on the nursery ward). The infant would then join the family in this room as soon as the infant was medically stable. Those parents assigned to the control group received standard care. The primary outcome was the effect on the infant's length of stay which was reduced by 5.3 days (p 0.05) for the experimental group, most of which was accounted for by time spent in intensive care. This study suggests: 1) that parents who spend most of their time with their newborn may have a greater opportunity to interpret and act on signs of distress and other needs of the infant compared with what is possible for the nursery staff, who have more than one infant to care for; and 2) parental presence may also contribute to better sleep organization which may promote improved brain maturation. In addition, mothers in the experimental group, reported less mental distress at discharge and again at the infant's three months corrected age after discharge.

These presentations were part of a day full of interest and excellent networking opportunities. All the presentations, and also those from the 2009 symposium, are available on the internet: [http://web22.abiliteam.com/ability/show/khchcp/ab-bott\\_20101118/speed.asp](http://web22.abiliteam.com/ability/show/khchcp/ab-bott_20101118/speed.asp). This will take you to the conference home page; sign in and then click on: "VISA." A second Conference on Ultra Early Intervention is scheduled for March 15, 2012.

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## Single–Room NICU Care: What does it mean for developmental care?

In the past several decades, there has been a slow but accelerating trend in Newborn Intensive Care Unit (NICU) design toward increasing privacy for infants and families.<sup>1-3</sup> For many involved in developmentally supportive, family-focused care, it has always been a mystery why fragile infants and their families seem to represent the last population to be cared for in a manner honoring their individuality and humanity equal to that of any other patient. Gradually, however, this picture is changing. As designs have progressed from the antiquated “baby barns” where individualizing the environment was almost impossible, to individual rooms allowing families to be nurtured and to nurture their infant together, many important issues need to be considered by those who provide developmental leadership in the NICU.

Julie Swanson,<sup>4</sup> RN, BSN, a developmental educator at St. Luke’s Regional Medical Center in Boise, Idaho, was asked to reflect on the journey in her unit toward more private and peaceful environments. Her thoughts are shared below; some of the issues she raises will then be discussed.

*Several years ago our NICU was remodeled and we transformed our unit. We went from a unit of three large rooms with numerous infants in one room to a unit of multiple rooms with a maximum of three infants in one room. We added three rooming-in rooms where parents can stay overnight with their infant while their child is monitored and staff is available for any medical needs the infant might have. The new layout has come with challenges and many benefits for both the staff and the families under our care.*

*The most significant change I have seen is the decrease in sound and activity levels within the nursery. One of the first things people say when they come into our nursery is “It is so quiet here.” This is due to the addition of carpeting, ceiling tiles and interior walls, as well as the ability to close doors. With only a few patients in one room, the infants have limited exposure to fluctuating activity and sound levels. We now may place an infant in a private room for protection from stimulation or to provide privacy for the family.*

*The ability to offer family privacy is of great benefit to the infant and family alike. In our old unit, we had limited ability to change the environment for the infant and family. We could only place one upright chair next to the bed; had only a drawn*

*curtain to offer privacy; and had limited control over the light, sound and activity level within the nursery. Now, an infant may experience skin-to-skin holding with both parents seated in large reclining chairs at the bedside, with the lights turned off, the curtain drawn, and the door closed. The family can rest together and they stay for longer periods of time.*

*Families are encouraged to decorate the room as if it were their infant’s private nursery room. There are shelves for the placement of stuffed toys, “knick knacks” and books; dressers for family and infant personal items; a choice in seating; wall space to hang pictures, and windows to look out of. If there are twins or other multiples, they are all placed in the same room, or adjoining rooms if necessary, so that parents can be with all of their children at one time. In this way the family is available to the infant at all times.*

*It used to be that when an infant was admitted, every staff person, infant and parent experienced this admission. Now, this scenario has been alleviated with the remodeling of our nursery. This is wonderful for the infant and family. The creation of our new nursery has, however, been quite an adjustment, and difficult for some of our staff. Prior to the nursery remodel, most of the staff could easily observe what was taking place in the nursery and offer assistance when needed. Now, the staff must physically take the time to ask for help.*

*One of the biggest concerns for the nursery is staffing. It often takes more staff to care for the number of infants due to the location of each of the infant’s bedside. We try to avoid moving infants from one room to another to help with staffing. However, this frequently occurs due to the availability of staff and their skill level. In addition, the coordination of staff breaks is more difficult because we have a standard that a staff person must be immediately present to respond to the infants’ and families’ needs.*

Each paragraph in Ms. Swanson’s reflections contains both valuable wisdom and springboards for discussion. To begin with a few key issues, she describes one model on the continuum. In addition to the model of multiple smaller “semiprivate” rooms with several rooms accommodating families with their babies, some units incorporate a limited number of single rooms along with several larger open bay rooms, while still others have accomplished a transition to completely private rooms for all babies and families. The most advanced level of care, to be the topic of a later article, may be the concept of “couplet care” and skin-to-skin holding, allowing simultaneous care of mother and premature baby. The small amount of literature that is emerging on the various models points to advantages and challenges with each model. For example, Greer<sup>5</sup> notes the possibility that in

“mixed” models, stresses may emerge as families note that not all infants have access to the same level of privacy and space.

As early observational research begins to emerge, however, the advantages of single-room care reflected in Ms. Swanson’s lived experience are being supported. Ambient sound, lighting, and even air quality have been found to show significant advantages in individual rooms.<sup>6</sup> The vastly improved privacy provided by single rooms appear to be facilitating increased participation in skin-to-skin holding, as well as improvements in breastfeeding success rates, both of which may be expected to have significant positive effects on developmental outcomes and family functioning.<sup>6,7</sup>

Concerns that have been raised, including those noted by Ms. Swanson, include staffing and their associated cost issues; questions of staff and/or parent isolation; as well as safety issues raised by those who are accustomed to having direct visual observation of infants most of the time. Interestingly, early-published observations appear to be indicating that these issues either do not present the problems that were anticipated, or are prevented with good planning. In fact, Domanico<sup>6</sup> noted several safety and infection control dimensions that favored the infants in single-room care.

It will be very interesting to observe the progress of this model of care and the results for infants and families. Perhaps of greatest interest is the thought that the evolution of NICU care

will progress toward models that have been suggested by pioneers in Sweden,<sup>8</sup> Argentina,<sup>9</sup> and South Africa,<sup>10</sup> where the unit of care is the mother-baby pair, as intended by human evolution and neurobiology.

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## Developmental Care in the Moment

*Intimacy and room for all*



Photograph by Inga Warren, Dip COT, MSc



we had survived. He said he was familiar with the NIDCAP approach. He cited statistics about Kangaroo care, parental involvement, and shortened hospital stays as well as decreased re-admittance rates. He shared with me one of the most profound statements that I continue to remind myself to this day, and which would become particularly useful in years to come as we welcomed more children into this world. He said, "The practice of medicine is just that, it is PRACTICE, and it is ultimately your decision to allow medical professionals to practice on your child."

Abby was discharged after 16 days of intensive care and an additional day in the special care nursery where I was encouraged to room in with and completely care for my bundle of joy. James and I administered all the necessary procedures and medications that would be needed at home. We felt triumphant and confident caring for our baby; quite in contrast to prior experiences, where the predominant feeling of elation at discharge was matched by insecurity about our abilities. Oftentimes, making appropriate care decisions; interpreting preterm infant behavior; and attempting to understand the best way to protect and encourage bonding, development and support felt ambiguous at best. Today, Abigail is a healthy 15 year old who excels in school.

The NIDCAP approach to care has provided parents the priceless gift of confidence and determination, supporting them in their appropriate role as parents despite the daunting circumstances that may lie ahead of them. NIDCAP certified professionals and nurseries have gradually helped to change hospital nurseries around the world. Health care professionals and

medical facilities have steadily come to a more complete understanding of the undeniable positive outcomes of individualized, developmental, relationship-based care...a portal to infant health.

Over the years as our family has continued to grow, we have experienced the NICU with the birth of each of our other six children. Each birth has presented its own special challenges, but we also became aware of the gradual changes in the nursery, and the care provided, that has taken place over the course of the last 18 years. The NICU can be a place that annihilates parents causing indefinable harm to families. With every subsequent NICU we have been a part of over the last 18 years, changes are evident regarding preterm behavioral understanding and support for both the families and the babies.

It has been almost a year now since I had the awe inspiring experience of seeing my darling Jenna cradle her tiny baby brother in her gentle arms as we sat in the NICU in April. Tears fell unrestrained as I was overcome with the realization that my beautiful daughter possessed all the confidence that had been initially ripped from me in those first few days after her birth. It will be a miraculous day when the norm is supporting parents and giving them the gift of confidence to care for these precious miracles born too early. I am of the opinion that the NIDCAP philosophy of caregiving quite possibly could prevent scenarios of child abuse, failure to bond, failure to thrive, and other such catastrophic events that have an irreversible negative impact on families. I am indescribably grateful for the blessing that NIDCAP has bestowed upon nearly two generations of our family.

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