

# 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, healthcare professionals, and nurseries in the NIDCAP approach.

*“The world is moved along, not only by the mighty shoves of its heroes, but also by the aggregate of the tiny pushes of each honest worker.”*

HELLEN KELLER, 1908

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## On Transformation and Shining

Dalia Silberstein, RN, PhD

**I**n July 2013, the NIDCAP Federation International (NFI) certified the newborn intensive care unit (NICU) at Meir Medical Center in Kfar Saba, Israel, the first of its kind in the entire Middle East. This recognition is certainly the culmination of a gradual process and a very special reward for our nursery’s never ending willingness to keep moving forward, by



*The NFI-NIDCAP Nursery Certification Award Ceremony with Shmuel Arnon, MD, Ita Litmanovitz, MD, Dalia Silberstein, PhD, Kholood Shabita, RN, Heidelise Als, PhD, Tzofia Bauer, MD, and Tzipora Dolfin, MD*

reviewing and evaluating our practice and caregiving, that will ultimately improve the care that we offer to infants and their families. The certification afforded the nursery, in turn, a renewed opportunity to envision and plan its next steps towards the promotion of a family-centered, individualized, developmental approach to preterm infant care.

The nursery’s NIDCAP Nursery Certification was celebrated by means of a national professional conference entitled “*Witnessing New Beginnings*,” held at the Meir Medical Center in December, 2013. Some 200 caregivers, representing a variety of professions across the country including nurses, neonatologists, therapists, psychologists and nutritionists, as well as families, participated in this event. Professor Heidelise Als, representing the NFI, honored the meeting with her presence and inspired the audience with her lecture about the crucial role of the family during the infant’s stay in the NICU. Professor Als sensitively and convincingly emphasized the uniqueness of the emerging parent-infant relationship as it unfolds in the complex environment of the NICU, and the influences this bond exerts – both in an overt and hidden fashion - on the parent, infant and staff.

In addition, the meaningful long-term effects of skin-to-skin care on children’s physiological organization, behavioral control, and the mother-infant relationship across the first 10 years of life, were fascinatingly presented by Professor Ruth Feldman from Bar Ilan University. Other topics that were addressed during this conference included: 1) Challenges and strengths for organizational change in a reality of restrictive staffing conditions; 2) Reflections and insights from a mother’s NICU diary; 3) Enhancement of collaboration with families by means of multidisciplinary rounds with parents; and 4) The vision and trajectory of Meir’s NICU in NIDCAP-based developmental care.

This day of celebration culminated with an award ceremony, during which Professor Heidelise Als depicted the joint efforts made by the NICU staff and the families over the years in a sustained trajectory towards an individualized, developmental model of care



The multidisciplinary NICU Team at Meir Medical Center, receiving the NFI-NIDCAP Nursery Certification Award from Heidelise Als, PhD

guided by NIDCAP. The NIDCAP Nursery Award was enthusiastically received by the happy and proud NIDCAP Nursery Certification Award staff.

Now, for a few moments, let us reflect beyond this special professional moment of achievement, recognition, and culmination for the whole NICU staff.

Let us ask ourselves: *What was our NICU actually celebrating that very special day?*

**We celebrated** the honesty and humility that allowed us to say to ourselves that what we do, and how we care - is still not good enough.

**We celebrated** our shift from an *all or none approach* ("It is just not possible for us to achieve such high standards; we shouldn't even gaze in that direction"), to a responsible, thoughtful, *as good as we can approach* ("we can still make many significant improvements in the way we deliver care for infants and families; we can certainly make a difference").

**We celebrated** the fact that it is possible to deliver sensitive, supportive, family-centered care, even if nursing staffing conditions are unacceptable by all current standards of care and are kept essentially unchanged over many years.

**We celebrated** the enhancement of interdisciplinary collaboration and the promotion of a more fluent dialogue among professionals involved in the care of infants and their families.

**We celebrated** being able to grasp the challenge of true collaborative work with parents, while expanding the scope of our joint projects.

**We celebrated** our wisdom to look at what others do, and to learn from and get inspired by the way others conceptualize and deliver care.

**We celebrated** the achievement of realistic organizational change in such a highly complex system as the NICU and the healthcare setting. Interesting dynamics and mutual influences, which we did not experience before as an organization, took place:

*"A process of change that seemed to start in a bottom-up fashion (from staff to management), shifted at some point to a top-down direction (from management to staff), only to perpetuate these new currents of mutual influence and to potentiate its effects."*

**We celebrated** as all infants do at the very beginning of life, *being looked at and cared for by someone who really does care for the best outcomes.* The Certification process afforded a unique and seldom experienced opportunity to share and discuss our work with experienced and sensitive interlocutors, who were knowledgeable of the many facets, challenges and subtleties of preterm infant care.

Finally, **we celebrated** *the freedom to dream, to have a vision, and to crystallize it in a plan.* To grasp a broad concept, and to

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## Developmental Observer

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**Senior Editor** Rodd Hedlund, MEd  
**Associate Editors** Deborah Buehler, PhD  
 Sandra Kosta, BA  
 gretchen Lawhon, PhD, RN, CBC, FAAN



### Contributions

We would like to thank all of our individual donors for their generous support of the NFI and its continuing work.

# A Foster Mother's Story: Caring for an Infant Exposed to Drugs and Alcohol during Pregnancy

Juzer Tyebkhan, MD, Neonatologist and NIDCAP Trainer-In-Training, Edmonton, Canada

*The following article was written by an experienced mother and Foster Mother who has looked after many infants that have been exposed to drugs and alcohol during pregnancy. She informed us soon after observing the NIDCAP Observation Day, and reading the resulting NIDCAP Observation and Care Plan, that this experience had transformed her approach to caring for these infants. This Foster Mother continues to be involved with NIDCAP and our hospital in Edmonton, as she presents her experience of caring for these infants at our hospital Staff Education Days. She is also working with relevant agencies to ensure that all infants who may need foster care receive behaviorally sensitive care, including the provision of a consistent, familiar foster parent as early as possible.*

I have served as a foster parent for thirty years. For reasons that will be evident, I am writing this article anonymously. If I were to spell my name it could be followed by the initials BAF, representing the experiences I count among the most significant of my lifetime: **B**iological, **A**doptive and **F**oster Mom. On-the-job training for this career commenced 30 years ago and still offers endless “continuing education” opportunities. For the past two years, I have taken a break from serving as a foster parent, but finally ready to resume, I was waiting for the phone to ring.

The main character in this story is “identity protected” so rather than use the name on her birth certificate, I will call her Molly. Molly is the second-born child of teen-aged parents entrenched in a high-risk lifestyle. She was a full-term infant but had a heart abnormality known as atrial septal defect (ASD) and was now living in a hospital newborn intensive care unit (NICU). When she was two days old I received a phone call. It was a social worker asking if Molly could be placed in our home upon discharge from the hospital, saying that it would likely be in a day or so. Upon my arrival at the NICU, a nurse reported that Molly had spent a long night of agonized screaming, along with other symptoms of drug withdrawal. She had been given morphine to help soothe her. She was lying quietly in her plexiglas bassinet. I will never forget how she looked. Her mouth opened in a silent scream, her eyes were filled with fear, and her hands were tightly fisted at the ends of her rigidly clenched arms. Somehow though, in that moment, my entire heart ended up firmly within her grasp.

The next two weeks passed quickly with me traveling to the

hospital each day and taking over Molly's care while I was there. Though Molly was not the first infant I had taken home from the NICU, she was the first one delegated to me more than 24 hours previous to discharge, so this was my lengthiest encounter with these impossibly tiny infants, complicated medical machinery and highly-specialized caregiver skills of the NICU world. Molly appeared to be the least medically-fragile infant there, so I had the luxury of not being involved with life and death issues, but my questions were often met with conflicting information. How quickly should she be weaned from morphine? Could she be discharged before that happened? If so, how would I finish the process?

During my time with Molly on the NICU, I really valued two nurses in the nursery, one who was the best at explaining things to me; and the other nurse who was the best at listening to me. The “listening nurse” was the one who strongly advocated for a discharge plan which addressed my concerns. Though I didn't by any means speak with everybody involved in Molly's care, I dealt with over a dozen nurses, four neonatologists, three pharmacists, two hospital social workers, a nurse practitioner and the NIDCAP team.

Molly's last week in the hospital was quite eventful, and included: an opportunity to be the focus of a NIDCAP Training session; more long screaming ordeals as her morphine was reduced; some additional medications; and for the last two days, she had me as her roommate in one of the family suites. Molly was able to become more settled with the support of one caregiver in a quiet, dimly-lit room.

Though Molly had stabilized nicely, the medical/nursing team decided not to reduce the morphine again until a week after she had transitioned home. I anticipated that venturing into the big world beyond the hospital would be difficult for Molly so the day we left I shielded her visually with a blanket, but couldn't prevent the bombardment of other first-time sensations (e.g., car seat restraints, movement of a stroller, elevator, the smell of the outdoors, being placed inside a vehicle, and the sound of traffic, etc.). About 20 minutes into our trip home, her behavior became chaotic and from then on her medication appeared to have little or no effect. The next two weeks were a very intense adjustment period. Though we have a quiet household, Molly became overwhelmed going from one room to another, and the smell of food cooking set off intense crying. Because her caregiver (me) and the amount of morphine had not changed, I knew her environment was the variable and I thought of ways it could be

adapted to help her achieve the goals written on her NIDCAP observation. Oddly, I remembered a friend once telling me they confined their traumatized pet cat to one room for the first few days after moving to a new home. I wondered if something like that would help Molly. So in one of our bedrooms, I created a consistent, low-stimulus environment with dim lighting, a fan providing continuous background sound and I brought the care to her (e.g., bathing, diaper changes, and feeding). Visits by the public health nurse and social workers all took place in her bedroom. Molly would go 17 hours per day without sleeping for more than 10-15 minute intervals. If I laid her down, she would awake and begin crying immediately. So for the next two weeks I “camped out” with her in that one room.

Thanks to my husband, I ate mostly “room-service” meals during that time. Fortunately every night Molly was able to stay asleep for two to three hour stretches in her crib, so I didn’t become totally sleep-deprived. However, during the stress of those first weeks home I admit, once or twice, I used a bit of that rare off-duty time to do some “inconsolable crying” of my own. Reading back over the charts that I made to record her medications, feeds, diaper changes, behaviors, and sleep states, I see a few notes on the side-- Day Five: “Had to lay her down in crib when she couldn’t stop screaming, walked away and took a break;” Day Six: “Trying to stay calm but feel very emotional and trapped. I know it is five more hours of this before I can go to bed tonight for three hours;” Day Ten: “11:48 pm: I feel very discouraged like this is never going to end.” Happily, the tone changed on Day Thirteen: “Had the best evening since coming home from the hospital.”

Interestingly, there was a direct correlation between my despairing side-notes and Molly’s trips to town. The most difficult days always followed an outing. After each trip to the doctor’s office, and as we returned home, Molly would regress. She would, however, regain her pre-excursion state more quickly if we spent the following day or so back in her room.

In an e-mail sent to Molly’s social worker on the twenty-fifth day after coming home I said:

*“She is sleeping through the night consistently now which is wonderful for her (and for me) as she is still not sleeping at all during the day unless I am holding her, and even then only for a few minutes at a time. Most days she is eating every two hours to make up for the feedings that she misses between eleven PM and six AM. Her pediatrician says because she is not sleeping as much as most babies her age, she is not gaining weight as quickly as normal, but her double chin is evidence that she is not wasting away.”*

The doctor had also noted, “Molly doesn’t have that ‘crazy’ look in her eyes anymore and neither do you, for that matter,” but I didn’t include that in my notes to the worker!

The NIDCAP caregiver’s observation sparked a different approach to some aspects of infant care than I had never previously thought of using. The NIDCAP recommendations in support of

Molly’s growth and development appeared to help Molly settle and let me know that NIDCAP was a valuable tool for parenting fragile/traumatized babies.

Wanting to express my thanks to Dr. Juzer Tyebkhan, his NIDCAP Team and their Trainer, Dr. Joy Browne, I sent a follow-up email several months later. It read, in part:

*“I don’t know how often you get updates about the post-hospital experience of NICU ‘graduates’ and their caregivers but I thought I would send some feedback letting you know what NIDCAP has meant for Molly, and for me. Also, it is productive for me to summarize what I have learned, as it is my goal to continue pursuing opportunities that will add to my knowledge and experience. As you mentioned, much of what NIDCAP is based on seems like common-sense, but the recommendations in the material you shared provided me with new awareness that made all the difference during those difficult first weeks at home with Molly. I learned that:*

- 1. Rather than attempting to become more skilled at calming her, my goal was to recognize and respond to her cues as she worked towards achieving better self-regulation. This enabled me to identify subtle indications that she was ‘not ready for activity.’ And coping with the not-so-subtle cues that she was in a ‘disorganized’ state...such as the periods of sleeplessness and inconsolable screaming, became less stressful for me once I stopped viewing it as my failure to calm her. The simple shift of redefining my role in ‘supporting her as she develops a skill’ made it so much easier to regulate my own emotions.*
- 2. When she kicked outwards with her feet, rather than trying to get more space, what she was trying to do was to search for a secure boundary to push against. She settled more easily if there was always something solid for her to rest her feet against. Also if I could gently guide her hands to her chest, clasping each other or my finger she would relax more readily.*
- 3. The whole process of digestion was hard, complex work for her and the fewer distractions she had immediately before, during, and after her feeding times, the better.*
- 4. In the initial adjustment period, after leaving the hospital, she would immediately react to over-stimulation. For example, during the hour-long drive from the hospital to our home I had to stop my car on the side of the road, take her out of the car seat and hold her until she could stop screaming. After a couple of weeks passed, she would exhibit less noticeable signs of distress at the time she was introduced to a new stimulus (such as extra visitors in the house) but the effects would manifest in a few hours or even the next day in the form of digestive upset (e.g., increased regurgitation, constipation or diarrhea and intestinal cramping), sometimes severe enough to again cause bouts of screaming and sleeplessness.*

*When you asked if I was willing to take part in the NIDCAP observation I recognized it could be a valuable learning*

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# WakeMed Nursery Receives NFI-NIDCAP Nursery Certification Award



Members of the newborn intensive care unit (NICU) and Neonatology teams with the NFI-NNC Award (left to right): Anthony Tackman, MD; Tara Bastek, MD, MPH; Melissa Johnson, PhD; Susan Gutierrez, BSN, RNC-NIC; Jim Helm, PhD; Stephen Parsons, MD, PhD; James Perciaccante, MD; Jodi DeJoseph, BSN, RNC-NIC; and Thomas Young, MD

WakeMed's Neonatal Intensive Care Unit (NICU) is officially a NIDCAP Certified Nursery. The NIDCAP Nursery Certification Program (NNCP), under the authority of the NIDCAP Federation International (NFI), recognizes the excellent level of individualized, developmentally supportive, family-centered care a nursery provides its infants and their families, as well as the exceptional level of care and support for nursery staff.

*"I am extremely proud of our NICU team for achieving this elite recognition and for the remarkable level of care our staff continues to provide to infants and families,"* commented Jim Helm, PhD, Director of WakeMed's Carolina NIDCAP Training Center. The NIDCAP approach to developmentally supportive and family-centered care has been shown to greatly benefit infants and their families living in the nursery, both during the hospital stay and beyond. For 25 years, the WakeMed NICU has been a national leader in this approach, being one of ten NIDCAP training centers in the country.

Over the last two years, the NICU implemented more than 12 initiatives to enhance this work including: a new emphasis on kangaroo care (parents holding babies skin-to-skin), cue-based feeding, four-handed care assist from volunteers, bedside developmental guidelines for families, swaddle baths, and more requests for families to be on unit committees. In late September, 2012, the WakeMed NICU was notified that it was officially the fourth hospital in the world to receive NIDCAP Nursery Certification. *"I congratulate the whole team on this impressive honor and especially thank all of the nursing staff who work hard to ensure*

*the highest level of care for our tiniest patients,"* added Cindy Boily, RN, senior vice president and chief nursing officer. *"We commend you for the invaluable work that you do."*

In June 2013, WakeMed sponsored a celebration featuring Heidelise Als, PhD who presented supporting research for the NIDCAP approach. She presented at Pediatric Grand Rounds; a WakeMed Families First event ("What Parents of Premature Babies Need to Know"); and a special seminar for NICU nurses ("The Nurse's Role in Supporting Early Brain Development in the NICU").

*This article was adapted from: WakeMed newsletter, "Microscope," News For Employees and Friends of WakeMed, November, 2012. Photos WakeMed Employees and Scarborough Photos.*



Jim Helm, PhD; Heidelise Als, PhD; Melissa Johnson, PhD; Marie Reilly, PT, PhD; Ann Marie Elmore, MS, PT

## WakeMed Adds Private Rooms for the Care of Premature Infants and Their Families

Twelve premature infants at WakeMed moved into their own private rooms as the hospital's renovated neonatal intensive care unit opened on February 20, 2014.

The new newborn intensive care unit (NICU) space adds 12,000 square feet and 12 beds, for a total of 21,000 square feet and 48 beds. Most notably, the eight million dollar project adds 27 private rooms, something almost unheard of in such a unit. These new rooms have a recliner, a sofa that extends for sleeping, a refrigerator for breast milk, and artwork on the walls.

Parents will have considerably more personal space to freely move about. They can close the door to their room to ensure privacy and quiet time with their infant as they cherish and nurture their baby along his/her developmental trajectory. In addition, parents are supported to spend the night in the remaining weeks of their stay, before their infant is strong enough to go home.

Jim Helm, PhD, Infant Developmental Specialist said that,

*"The hospital prides itself on individualized care for all patients, including preemies. Doctors watch each baby's reaction to stimuli and change care accordingly. If you're sensitive to those individual differences, you can be more supportive. We hope the new rooms add to our ability to enhance the experience of families and babies. More privacy, more individually controlled environments. It's all about the baby."*

Read more here: <http://www.newsobserver.com/2014/02/20/3640299/wakemed-new-area-for-premature.html#storylink=cpy>

*This section was adapted from Samantha Gilman's article entitled "WakeMed's new area for premature babies includes private rooms," in newsobserver.com, February 20, 2014.*

### NIDCAP Care in the Moment



*Learning to recognize the infant's voice and opportunities for support*



## Culturally Competent Care in the Newborn Intensive Care Unit: Supporting “Fragile Interactions”

*Lenora Hendson, MB BCh, MSc, FRCP(C) is a neonatologist and Associate Clinical Professor in the Department of Pediatrics at the University of Calgary in Alberta, Canada. She completed her neonatology fellowship in Edmonton, Alberta, where she was actively involved in the Edmonton NIDCAP study. In addition to her work on family support and cultural competence, she has published on the medical outcomes of infants enrolled in the Edmonton NIDCAP study.*

*Melissa Johnson, PhD*

The Newborn Intensive Care Unit (NICU) is unique in the varying levels of acuity, the circumstances surrounding birth, death, parent bonding, and often, the lengthy stay of an infant. Integrated within care delivery, the philosophy of family centered care specifically honors racial, ethnic, cultural and socio-economic diversity.

In the last several decades, there has been increased immigration worldwide. Immigration is a determinant of health potentially imposing detrimental effects on wellbeing. Ethnic minorities and immigrant communities may experience poorer health related to inequities in opportunity and resources, and barriers to access services in healthcare. Immigrant women are at higher risk of preterm birth and having infants of low birth weight. Children of immigrant mothers may have more challenges with development.<sup>1</sup>

### What is culture and culturally competent care?

Culture is defined as a set of values, beliefs, and norms that provide a sense of identity and guide the thinking and decision making of a group. Culture exists at the level of the individual as well as the organization and community. Culture is not simply defined by race, ethnicity, country of origin, or religion. Other characteristics such as age, gender, socioeconomic status, sexual orientation, life experience, acculturation, and assimilation, influence an individual's culture. As such, the culture of the family as well as that of the healthcare provider is important for health and healthcare delivery.

Cultural competence in healthcare tailors delivery to meet patients' social, cultural, and linguistic needs. Culturally com-



*Supporting culturally competent care in the NICU*

petent care considers how these factors may interact to compromise access to quality healthcare. Cultural competence is thus a requisite skill for all healthcare providers. This requires a commitment from individual healthcare providers and organizations to venture on a developmental process of becoming culturally competent that involves awareness and sensitivity, knowledge and skill, and desire and experience. Many of the strategies for family centered care are applicable when providing culturally competent care, however they may take on exaggerated importance when providing cross cultural care.

### Our experience in the NICU: What are healthcare providers' perspectives?

Dr. David Nicholas (PhD, SW, University of Calgary), Misty Reis (NP, Alberta Health Services) and I conducted a qualitative study using grounded theory methodology to explore the experiences of healthcare providers when providing care to recently immigrated families whose child was admitted to the NICU. We used interdisciplinary focus group interviews to collect data as the conversational depth during these interviews reflected the team-based approach in the NICU. Interviews were completed at two tertiary level NICUs in Edmonton, Alberta, Canada. There were 58 participants, 80% of whom were Canadian born, congruent with the current statistic of one in five Canadians being foreign born.

Our study elucidated the nature of “fragile interactions” experienced by healthcare providers when treating new immigrant families in the NICU. Our theme was highlighted by the following: “It (cross cultural issues) just happens to be one more piece or burden which makes a fragile interaction worse or even makes a normal interaction fragile.” We defined fragile interactions as

the reciprocal relationship between healthcare provider and the family that was influenced by multiple factors including the infant's medical status and the perceived importance of cultural or religious practices and philosophies for the family.

Healthcare providers described how the fragility of interactions was amplified particularly around the family's decision-making process, differing expectations for survival, language and communication. Healthcare providers identified their own challenges providing cross cultural care around unintentional stereotyping, time constraints to carry out intangible activities, and lack of intuitive perceptions of new immigrant families' needs.

### Challenges related to family factors

Healthcare providers described dissonance when caring for newly immigrated families around who should be making decisions and how decisions are made. The individualistic Western tradition expects parents to play an active role in decision making. Alternatively, when families rely on collectivistic beliefs or advisors to make decisions, healthcare providers described a sense of unease. This was exacerbated in situations where continued intensive care was thought to be futile for the infant as illustrated by the following example:

*"We have had a few families where we have almost felt like things were futile to carry on, but the community support said "No," that they [the family] had to carry on at all costs, and that made caring for this person quite difficult because you were doing something that you did not feel was right."*

Healthcare providers described the difficulties newly immigrated families appear to have with expectations for survival, especially for extremely premature infants. In these instances newly immigrated families expect to lose their infant, and have to readjust to not only the survival of their infant, but potentially long term complications for their child, illustrated by this quote:

*"I had one family who said, "You know, in our home, babies born before this gestation just die." She was terrified to even come up and see the baby because this baby was really not supposed to be alive. It took her weeks and weeks to really work through that."*

Participants emphasized the impact of language and communication as a barrier to care, negatively affecting the efficiency of decision-making and daily care. Even with the use of translators, interpreting the words and understanding the message in emotionally charged situations was often described as delicate and extremely poignant, exemplified by this quote:

*"The dad's English was very good, he taught at the university and the Neonatologist said 'his English is fantastic, he understood everything.' I think his first language was French. I was on call and that is when he asked me if the baby was dying, and it was not that he did not have the English words for it. It was that he just could not ask in English, he had to ask in French."*

### Challenges related to staff practices

Healthcare providers described an attitudinal shift amongst staff as 'stereotyping' and at times felt that they were 'writing off' a family, in that staff were no longer trying to understand the cultural or situational circumstances of the newly immigrated family. This was passed on from person to person, shift to shift as illustrated by this quote:

*"We don't see them as individuals anymore. We have already given them a certain way of behaving. If they did it a little bit, they are all the way there. If they did not come in once, then they never come in. We need to be careful about that and start treating the families as individuals."*

Healthcare providers conveyed feeling caught between the tasks required in a NICU versus taking the time to forge relationships and effectively work with families. Whether it is due to language barriers or cultural differences, the time required to work with newly immigrated families was reported to be longer to teach families about the care of their infant. Nurses most commonly expressed that their efforts were undervalued in NICU organizational structures, and yet crucial to the care provided:

*"You are doing intangibles, something that is not measurable. You are talking, you are reassuring, you are helping, you are supporting, but you are not doing (with emphasis) anything."*

The ability to be perceptive to diverse cultural norms such as modesty, privacy, eye contact, and touch was described as having a significant influence on the healthcare provider's ability to engage new immigrant families. Healthcare providers reported that these are important aspects to convey respect and dignity, illustrated by this quote:

*"Whether or not mom is comfortable being in the curtain pumping while people are coming and walking through and/or kangaroo caring with a bare chest and whether or not dad is comfortable with mom doing that. There are probably rules about that and so, if we do not know what they are, it is hard for us to be sensitive to them."*

### Supporting fragile interactions

Healthcare providers from our study identified mitigating factors supportive of cross cultural care including seeking to understand the new immigrant family's perspective, requesting additional education, and building collaborative relationships.

Healthcare providers described actively supporting the newborn and the new immigrant family in various ways including asking families what they required, educating parents, and seeking to exhibit a non-judgmental attitude. They described advocating for services within the community such as access to multicultural healthcare brokers, immigration issues, and funding. They described the importance of stepping back, being humble, and listening to families' perspectives. One healthcare provider gave the following advice:

*"Find out what is important for that family. Every family is*

*unique and every culture is unique and if we don't know, we need to ask the question: 'How do you need this to be for your family right now?'"*

Healthcare providers desired education about other cultures and religions as a starting point to care for newly immigrated families. Education could be in the form of orientation, in-services, a manual of cultures, discussion following encounters with families, or graduate families returning to the NICU to educate staff on their cultural needs. At the same time, healthcare providers realized that families are all unique and that people differ in their adherence to cultural norms, hence care needs to be *individualized*. Healthcare providers nonetheless described the

potential benefit of having a baseline knowledge that could be refined according to the individual and family. Overall, healthcare providers exemplified this balance as follows:

*"It's respect and empathy and the fact that you educate yourself about different cultures so that you can be culturally sensitive."*

Healthcare providers were reflective about the stress of the families in the NICU and the emotional roller coaster experienced by the families. Regardless of the cultural background of the families, healthcare providers described how important it was to form genuine relationships, to be respectful of all individuals, and to empower parents. One healthcare provider reflected:

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## NFI French Chapter

Jacques Sizun, MD

**Developmental Observer (DO):** *Why did you start the process of creating an NFI Chapter?*

**Jacques Sizun (SJ):** NIDCAP is now a worldwide program. The NFI plays an important role by: supporting NIDCAP implementation, assuring the quality of training and education, and disseminating research data. The NFI is an international organization with 19 NIDCAP Training Centers and 209 NFI Members representing 28 countries. The annual NIDCAP Trainers Meeting is a success and is held each year in either the USA or Europe. The 24<sup>th</sup> meeting was held in 2013 in Winston-Salem, North Carolina. This year it will be held in Segovia, Spain.

Unfortunately most French professionals and family members are not fluent in speaking and/or reading English. This limits access to high-quality updated information on NIDCAP such as: articles in the Developmental Observer, international and research articles in medical and nursing journals, and US conferences and meetings.

Moreover, fundraising activities are complex as each country has its own legal tax rules. Soliciting funds from the French government to support a US-based organization is not easy.

However, interest in NIDCAP is growing in Europe and specifically in France. Seventeen French hospitals, mainly university hospitals, have NIDCAP Certified Professionals and/or Trainees. In most of these hospitals, at least one neonatologist is NIDCAP certified or involved in NIDCAP Training.

Creating a French structure to coordinate all these activities, under the NFI umbrella, appeared to be a necessary step.

**DO:** *How is the French Chapter organized?*

**JS:** The French NFI Chapter is a non-profit association according to the French Law called "Loi 1901". The statutes

have been submitted to and validated by the Prefecture.

The Chapter Board has seven members: Jacques Sizun (MD), Nathalie Ratynski (MD, NIDCAP Trainer), Sylvie Minguy (RN, NIDCAP Trainer), Morgane Dubourg (MD), Jean-Dominique Giroux (MD), Pierre Kuhn (MD) from Strasbourg University Hospital, Véronique Pierrat (MD) from Lille University Hospital.

This temporary Board is in charge of creating the administrative structure and defining the main objectives of the Chapter. A new board will be elected within one year in order to integrate more non-physician members from different regions in France.

**DO:** *What are the objectives of the French Chapter?*

**JS:** The Chapter has three main objectives including: 1) The integration of new professional and family members; one hundred members within one or two years is the goal; 2) Offering high quality French-written information on NIDCAP, using social media and the Internet; and 3) To develop fundraising activities in order to support translation, scientific meetings, and training of future French-speaking NNCP Site Visitors.

**DO:** *What is the relationship between the NFI and the chapter?*

**JS:** The Chapter has its own administrative organization due to French law. All future Chapter Members will be invited to join the NFI. All "current" Chapter Board Members are NFI Members.

The Chapter will send a scientific and financial report to the NFI each year. A short presentation of current "chapter" activities will be conducted each year during the NIDCAP Trainers meeting.

Ensuring the quality of the NIDCAP Training and education is the exclusive role of the NFI.



Maria Maestro, MD

## Fátima Mandar, MD



Fátima Mandar is a NIDCAP Professional, APIB Professional and future NIDCAP Trainer of The Barcelona-Vall d'Hebron NIDCAP Training Center, with whom I have been fortunate to work and share experiences. I have also been able to enjoy her friendship.

Fátima was born at 5:00 AM on January 1,

1978 at the Coruña Maternity Hospital (an early riser from the outset). When she was a little girl, she suffered from a disease from which she recovered, thanks to the wise and correct care of a pediatrician that her family still admires, respects and continues to feel sincere gratitude for. Fátima's subsequent vocation for medicine was doubtlessly fuelled by this illness, in addition to her mother's example of care and commitment to others.

From a very small age, Fatima was very interested in sports, in particular swimming and football, which she still practices today by taking part in a women's amateur football team. Fátima is also passionate about reading and travelling.

At the end of her adolescence, Fátima had a difficult choice to make between her advanced studies in mathematics, physics and health sciences, to which she felt especially attracted.

Today, we are happy that she chose medicine, which she studied at the Faculty of Medicine of Santiago de Compostela University.

Once she finished her degree, she decided to pursue pediatrics. This decision was influenced by a gratifying experience of successfully treating a child, who required a doctor's care when she was travelling. Fátima decided to continue training professionally in pediatrics.

Fátima found her training in pediatrics and neonatology to be a most enriching experience. The practice of pediatrics and the practical way that Dr. Pep Perapoch led

the team in initiating developmentally focused care, altered her way of understanding how to care and treat children and their families. Fátima fully identified with these theoretical principles and their practical application.

In addition to her gratifying professional life, Fátima was fortunate enough to meet Antonio, her husband-to-be, on a Galician language course in the summer of 2000. In Antonio's own words, "*Fátima is a tireless, reliable, committed worker who always sees things positively. She is a very good person with a heart of gold.*"

Fátima's initial contact with the NIDCAP approach to care was through Graciela Basso, MD, her NIDCAP Trainer. Dr. Basso had come to Barcelona in 2005 to commence NIDCAP Training with Dr. Pep Perapoch and María José, a nurse from her team. During Dr. Basso's stay in the Val de Hebrón Hospital unit, Fátima was able to familiarize herself with the principles on which NIDCAP is based and her personal affinity with this method. Fátima wholeheartedly supported the NIDCAP work group in her hospital from the beginning and she began her own training the following year. She benefited from Dr. Basso's knowledge, recommendations and advice, which she used in her care of children and their families in the nursery.

Dr. Perapoch describes his relationship with Fátima as one based on mutual admiration and respect. "*In spite of her reserved nature and the generation gap, I feel that Fátima is a person you can trust wholeheartedly, with whom one can share (and improve) all kinds of initiatives as well as concerns. I feel that she is a person you can always rely on.*"



The Second Iberian Meeting celebrated in Barcelona, Spain in June 2013

Fátima is currently preparing to become a NIDCAP Trainer. She and her colleagues, Estrella and Juliana, have successfully passed the training in the Assessment of Preterm Infants' Behavior (APIB). Personally, it was a pleasure for me to share in the administration of the APIB examination of several infants with Fátima. I must particularly highlight the way in which Fátima interacted with the infants during the course of this assessment. She understands what an infant is trying to express via his/her behavioral language and how she can help the infant, through carefully graded co-regulation, give the best of him/herself.

In performing NIDCAP fieldwork in Spain the collaboration between the hospitals Val de Hebrón in Barcelona and the Doce de Octubre in Madrid is now a reality. A result of the collaboration between both of these Spanish NIDCAP Training Centers led to the creation of the Iberian work days that are aimed at Spanish-speaking NIDCAP Professionals. Fátima was, and is one of the most important architects of this kind of meeting, which is increasingly becoming more successful. The second edition of this meeting, which took place in June, 2013 in Barcelona, gathered together almost 50 people, and was attended by Dr. Graciela Basso. With her work, Fátima has managed to create an environment in which everyone feels welcome, achieving a climate of collaboration among those attending the work days,

and always striving to convey the importance of the NIDCAP approach to care. Her future challenge is continuing to uphold the same level of quality and ensuring that people who do not speak English have a place where they can reflect and grow. I can vouch for this myself because I am fortunate enough to work shoulder to shoulder with Fátima in creating these work days.

From this forum I would like to express my admiration for Fátima's human qualities and warmth, both as a neonatologist and as a NIDCAP Professional. I am sure her goal to become a NIDCAP Trainer will be realized in the near future. The children and their families are extremely lucky indeed to have Fátima on their care team.

#### **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 Rodd Hedlund, MEd, NNCP Director at: [nncpdirector@nidcap.org](mailto:nncpdirector@nidcap.org) or 785-841-5440.



Chris Linn

## One Family's Journey

*The newborn intensive care unit (NICU) can be an intimidating place. For a family that is beginning the long journey through a hospitalization at this level, it can be exhausting as well as emotionally draining. An infant born extremely premature has complex needs and can require multiple services that involve substantial coordination and may extend an infant's stay. Patience and strength are critical for a family to navigate this environment and the specialized services that are needed following an infant's discharge to home. In this powerful story, the Linn family shares their experience and how their journey ultimately brought their family closer together and turned Chris Linn into a resource and strong advocate for others to follow.* Debra Paul, OTR

I'll never forget March 15, 2003. It's the day our dreams were shattered. It's the day our lives changed forever. It's the day we brought our 25-week twins into this world and began our journey of feelings we never knew were possible.

**Friday, March 14, 2003:** We were elated! The doctor just gave us a perfect checkup and actually cleared me to continue working because things were going so well. The twins were thriving, I was strong, and things couldn't have been better. Of course I was reminded we were in a critical window when, if things were to go wrong, things usually did around this gestational period. I was going to beat the odds! I went back to work and gave everyone the update. They were so excited to see me and had planned a baby shower for me on Monday.

**Saturday, March 15, 2003:** I just finished shopping for my baby shower outfit. I was feeling an overwhelming sense of exhaustion. Thank goodness I could go home and sleep all afternoon. I felt like I could sleep for hours. I stopped to use the restroom in the mall and I was spotting...okay try not to panic...I knew spotting can happen during pregnancy. I rushed home and yelled for my husband. As I got out of the car, blood was everywhere. We rushed to the hospital and my doctor met us there. The wonderful triage nurse prayed with me. The doctor said, "I'm sorry we need to take the babies and I don't have time to air evac you to a facility equipped for acute care." What does that mean? I'm in a hospital! Will they have a chance? What is going on? I had a wonderful checkup...this can't be happening. My husband is being asked to scrub up and I'm being rushed to the operating room. I remember asking the doctor, "What is the earliest gestational age a baby can survive?" He hesitated



*Chris, Emilie and Mark's smiling family portrait, July 2004*

and then said, "Honestly, 24-weeks is the earliest we see babies surviving." I knew we had a chance because we were at 25-weeks and three days gestation. All of a sudden, I hear a small cry and they bring each baby to me for a quick kiss before they rush them to the NICU. We didn't hear the lullaby over the loud speaker that we know is usually played when a baby is born. Why aren't they playing the lullaby?

I feel empty...where are my babies? Hours before I could feel some movement. They were a part of me. Now my stomach is still and empty. I cannot stop crying. People are coming to see me and the phones are ringing. People don't know what to say...do they congratulate us or cry with us? This isn't the way it's meant to be.

I get to see my babies...Baby A and Baby B. Their names are Zachary and Emilie. They have tubes and wires coming out of them from everywhere. They don't even look like infants. How can this be possible? I feel tremendous guilt and start replaying my day...I shouldn't have picked up that comforter...I shouldn't have gone to the mall...I know if I would've just rested this wouldn't have happened...It's all my fault! The neonatologist tells me a placental abruption can happen in your sleep and there is nothing I could have done to cause this. What? A placental abruption? But I just had a perfect check up! I can see the pain in his eyes as he watches me suffering and beating myself up. Please don't let this be happening.

My husband Mark is in shock and so scared for both me and our babies. I drifted off while in triage and he thought I was dying. My poor husband. My mom is hurting for me, her son-in-law, and her brand new grandchildren. My poor mom. Mark's

parents are devastated from a distance. They begin making immediate plans to figure out how to come be with us. Everyone wants to stop by for a visit. I just can't take the visitors right now...I just want to cry and be alone.

It's time for the "talk." The neonatologist visits us in our room later that evening and begins telling us about statistics... this percentage and that percentage. Our babies are sick; they may have learning disabilities; they may have cerebral palsy; they may not survive; they may need to be moved to a more critical care nursery, etc., etc., etc. Please make it go away...I can't hear this!

I'm only allowed to stay three days in the hospital. The nice young man arrives at my room with the wheelchair to escort me out of the hospital and he wants to know where the baby is. I can't talk, someone has to tell him that my babies are not coming home with me. I stare out the window as we drive home. I'm in disbelief...why can't I stay with my babies? This wasn't what I dreamed about.

Emilie needs to have heart surgery at three weeks old, and she needs to be transported to another hospital. The fear sets in and we can't believe it. Why now? Why did we not know about this before? How can we split them up? Another "talk,"...the number one risk is death. Please don't say that...we can't take it. The day after the surgery, the neonatologist calls us because they need to talk to us about Zach. Zachary has Downs Syndrome. But at least he is going to live...we ask about all the things we hear about. Does he have any heart defects? We are assured he doesn't. We lay in bed the next day unable to function...how can this be happening?

We feed our babies for the first time through a syringe into a feeding tube. My job is to produce the liquid gold. It's the ONE thing I can do to contribute to their survival. I become obsessed with pumping and thank goodness I can be a part of their care. We begin Kangaroo Care (skin-to-skin-contact) but I'm so afraid to move them because of all the wires and tubes. Shouldn't we just let them rest? I'm assured it's the best thing for them, and Mark and I begin holding them all the time. Sometimes, we are told, that holding becomes too stressful for our babies and their alarms go off and they need to go back into their incubators. It's heartbreaking when we feel we can't comfort them.

We get the call in the night...Emilie is sick. We shouldn't be surprised when we arrive to learn that she had to go back into an incubator. Why is this happening? She was starting to do so well. Did we get her sick? We can't be the reason. But I wasn't feeling well the other day...I'm sure it's my fault. I cry the rest of the night.

We are getting closer to Emilie's discharge. We begin to feed her with a bottle. Her alarms are going off. The nurse tells me, "It's what preemies do; she's being a stinker today." I suppress my gut feelings because all I want to do is take my baby home.

Its discharge day and everyone is throwing a party for us. We're scared and nervous, but it must be okay because this celebration means we're out of the woods, right? As soon as we walk out and the doors close behind us, we're on our way to a "typical"

experience, right? Emilie is going home with oxygen and an apnea monitor. We're sure it won't be long until she doesn't need it.

Zachary isn't ready yet and needs to be transferred to a step down unit. How will we manage to care for Emilie and still make adequate time to be with Zach? Mark is still working. My mom is trying to be with me as much as possible but she's still working so it's difficult. Mark stops to see Zach every night on his way home. I try to get to the unit whenever I have coverage for Emilie. It is so hard and I'm so tired.

Emilie is struggling and her feedings are going terrible. She is arching, crying, batting at the bottle, her lips are turning slightly blue and she's vomiting. She is breathing so heavily and her apnea monitor alarm goes off every now and again. Her pediatrician tells me that she must have reflux and prescribes some medication. She says to me, "I know this is your first child and you are nervous, but she is doing fine and gaining weight." I must be overreacting, right? I'm sure as soon as I leave the pediatrician's office, the feeds will begin to get better. But they don't. A wonderful home health nurse tells me Emilie needs to see a pulmonologist. What is that and why? I'm desperate...I will listen to anything anybody tells me at this point. I'm starting to fall apart. I'm not sleeping. Mark and I are holding Emilie upright all night long so her reflux doesn't act up. We can't go on this way. I request a pulmonology appointment and our pediatrician's office tells us it will take three weeks to get her in. I say to them, "She won't live for three weeks." I sit in an emergency room and won't leave until someone grants us an appointment with a pulmonologist. They want to send me home. I politely tell them I'm not leaving until she can see a pulmonologist. I can see them on the phone with the pulmonologist. I sense they are thinking that I'm a "crazy" mom who is overreacting and refusing to leave. Pulmonology sees her the next day and immediately admits her. Her apnea monitor shows a dangerous heart rate decline every time she's being fed. After an extensive work up, we find out that Emilie is silently aspirating. She is on her way to aspiration pneumonia. The weight gain on the scale was false weight. It was fluid



*Emilie and Zach resting together shortly after their birth*

retention from the aspiration. Thank God I fought for her. What could have happened if we continued to drown her during feeds?

At this point, I have a complete breakdown. I'm not eating. I'm not sleeping and I'm throwing up often. Without a formal diagnosis, it's obvious I'm having a nervous breakdown. My mom makes an appointment for me to be seen. I'm completely glazed over and the doctor takes my mom aside and tells her I can't be left alone. Although I'm not having any suicidal thoughts or thoughts of hurting Emilie, I definitely have become detached from my daughter, and I'm operating in survival mode. Now looking back, I can't imagine how I could have been that way. My love for Emilie is something I can't even describe. I don't know what I would ever do without her and I tell her that quite often. She always smiles.

Following the study that showed Emilie was aspirating, a nasogastric (NG) tube is placed but it doesn't mean the nightmare is over. Emilie is constantly throwing up from the volume and I'm told I must get so much volume in her or her brain is at risk for not growing properly. How do I make up the calories every time she vomits? I become a human calculator and I try measuring what she vomits so I can be sure to get the amount back in. It's a daily nightmare and every morning I wake up with dread because I know our day is going to be another day of worry.

Zachary remains hospitalized and his oxygen needs are getting worse. When I ask about this, the doctor and nurses do not seem concerned at all. I also share with them that Emilie was silently aspirating and I'm concerned Zachary may be having the same problem. I request a swallow study and it's denied. They don't send babies from the step down unit for swallow studies. I feel completely dismissed, frustrated and deflated. The minute Zachary is released from the unit and transitioned home, I get our gastroenterologist/GI doctor to see Zachary and he orders a swallow study. It comes back positive...Zachary has been silently aspirating and is placed on NG tube feedings. Now I have two babies at home on feeding tubes, oxygen and apnea monitors. I feel so alone and scared. Mark is doing his best to help me, but he also needs to work. I've already had to stop working and the bills are piling up. Luckily we were able to get some support from our Arizona early intervention program and we're granted at home nursing help.

Zachary isn't doing well. We take him in for an endoscopy and we are met in the waiting room by a cardiac physician who says, "Mr. and Mrs. Linn, we need to move Zachary to the Cardiac ICU. We aren't sure what is happening yet, but Zachary wasn't able to sustain himself under anesthesia and we need to get him to the ICU immediately." What? We aren't prepared for this. Zachary spends the next six months in and out of the hospital until the doctors tell us he has a terminal heart defect that can't be repaired. We lose him at one year and three days old. We get to hold him and tell him how much we love him. The pain is unbearable. At this point, I am pregnant with Zachary's brother. I ask Zachary to promise me he'll give part of his soul to his

baby brother because Zachary has the sweetest, kindest soul. Our Zachary kept his promise.

Emilie's feeds continue to be a nightmare. At almost three years old, our gastroenterologist suggests it may be time for an intensive feeding program. We had no idea feeding programs like this existed. We struggle for five months with the insurance company to get this covered. It will be a \$40,000 program and there is no way we can take on that type of debt. Thank goodness the insurance comes through. There were no intensive feeding programs in Arizona at the time so we leave the state to attend a 10-week feeding program in Virginia. My family takes turns staying with us in our hotel because Mark needs to stay home and work, and we need help with our two-year old, while Emilie attends the program. Emilie and I are at the hospital six hours a day, five days a week for ten weeks. She does well and comes home only being fed 25% of her nutrition through her feeding tube. We continue to make progress on our own because nobody is trained in Arizona to help carry on the protocol.

During our journey to Virginia, I was introduced to another wonderful mom named Shannon Goldwater. We were introduced by our children's feeding therapist. As it turns out, Shannon had triplets that were all on feeding tubes and she had been the one to recommend the Virginia program based on her experience with her triplets. Shannon and I discovered we lived within nine miles of each other. We went to the same pediatrician's office, the same GI practice office, and the same feeding therapist. I remember Shannon saying to me, "We can't be the only parents going through this. We need to do something about this." Shannon and her husband, Bob, proceeded to start a non-profit to help other infants, children and their families with feeding issues. When I returned from Virginia, I volunteered my time to help move the organization forward. The organization was established in 2006, and now eight years later, 'Feeding Matters®' has a mission to bring pediatric feeding struggles to the forefront so infants and children are identified earlier, families' voices are heard, and medical professionals are equipped to deliver collaborative care.

Our journey continued and at almost six years old, Emilie's gastrostomy tube (G tube) was removed. Emilie went nine months without using her tube for any nutrition or hydration and learned to take all of her medications by mouth. We were thrilled, but our nightmare didn't stop there. Two months after the tube was removed, we needed to change one of Emilie's medications. It turns out the medication she had been on made her very hungry and we didn't know it. Once the medication was removed from her treatment protocol, her appetite slowly declined. She began to fall off of the growth chart again. The doctors didn't seem as concerned as we were, so we took her out of state once again for feeding therapy. At seven years old, we visited an interdisciplinary feeding team in Wisconsin and they were very worried. They told us Emilie was malnourished and they wanted to put the G-tube back in. They reviewed all of the



*Emilie today, shining at ten-and-a-half years of age!*

records from our Arizona physicians. Why didn't our Arizona physicians seem concerned? Nobody had taken the time to look at Emilie as a whole child. When the pieces were put together by the Wisconsin team, the nutrition concerns were obvious. They conducted another swallow study and we discovered Emilie had extremely large tonsils. We learned that Emilie had been taking smaller amounts of food because of her large tonsils. I told them that Emilie took "bird bites." It all made sense after they took the time to further assess her. Of course, if we all ate our meals in "bird bite" sizes, we would become full much more quickly and this is what happened to Emilie. She had a sense of being full without getting enough nutrition to sustain her growing body.

After having her tonsils removed, Emilie began to catch up with weight gain.

Now at almost eleven years of age, Emilie is a happy, healthy fourth grader who takes all of her nutrition orally. Although we still worry about her, we are starting to "let go" and let her be her own person. Genetically, both Mark and I were very skinny as children, and part of this is going to play out the same way for Emilie. She struggles a bit in school, but overall, she is bright and does well among her peers. She is a fashion queen and loves animals. Emilie hopes to be a vet or a fashion designer. We capitalize on her strengths and do our best to preserve her self-esteem. She will be the successful young woman we always dreamed about. Today Mark and I talk about how "lucky" we are. We would never have used that word on March 15, 2003. Our marriage remains stronger than ever and we are one of the "statistics" that made it. So many marriages are challenged when faced with trauma, especially as it relates to losing a child.

Today I am the Executive Director for Feeding Matters and I love what I do every single day. I get to help others who are going through this journey. Although we wish we could have changed it all for Emilie and taken away all of the pain she endured, she gave us a gift and we will forever be grateful to her for it. We have met the most amazing people along the way and our lives will forever be changed. To all of the other parents out there who have struggled, we admire your strength and please know you are not alone.

*Chris Linn is the Executive Director of "Feeding Matters" and lives in Scottsdale, Arizona with her husband Mark, Emilie, and her younger brother Connor. She can be contacted at [clinn@feedingmatters.org](mailto:clinn@feedingmatters.org).*

## 25<sup>th</sup> Annual NIDCAP Trainers Meeting

**October 25 – 28, 2014**

**Parador de Segovia  
Segovia, Spain**

*Co-hosted by the Hospital Universitario 12 de Octubre NIDCAP Training Center, Madrid and The Barcelona-Vall d'Hebron NIDCAP Training Center, Barcelona, Spain.*

*(By Invitation Only)*



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Joke Wielenga, RN, PhD

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## Books

Inga Warren & Cherry Bond **Caring for Your Baby in the Neonatal Unit: A Parents' Handbook.** <http://www.earlybabies.com/>

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## Conferences

### The Fourth Annual NOMAS International Symposium:

Location: San Francisco, USA

Date: October 10-12, 2014

"It's all about feeding"

[http://www.nomasinternational.org/symp\\_2014.php](http://www.nomasinternational.org/symp_2014.php)

### The 5th Congress of the European Academy of Paediatric Societies (EAPS):

Date: October 17-21, 2014

Location: Barcelona, Spain

<http://www.kenes.com/paediatrics>

### Miami Neonatology 2014:

Location: Fontainebleau Miami Beach, USA

Date: November 12-15, 2014

<http://pediatrics.med.miami.edu/neonatology/international-neonatal-conference>

### Hot Topics in Neonatology:

Location: Washington, USA

Date: December 7-10, 2014

<http://www.hottopics.org/>

### Brain Monitoring & Neuroprotection in the Newborn:

Location: Clearwater Beach, Florida, USA

Date: not yet known, 2015

[www.cme.hsc.usf.edu](http://www.cme.hsc.usf.edu)

### 28<sup>th</sup> Gravens Conference on the Physical and Developmental Environment of the High Risk Infant:

Location: Clearwater Beach, Florida, USA

Date: March 2015

[www.cme.hsc.usf.edu](http://www.cme.hsc.usf.edu)

## The 25th Annual NIDCAP Trainers Meeting

Location: Segovia, Spain

Date: October 25 – 28, 2014

[http://www.nidcap.org/training\\_meeting.aspx](http://www.nidcap.org/training_meeting.aspx)

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## Websites and Downloads

<http://www.socksforlife.org/>

<http://www.efcni.org/>

<http://www.babybloom.nl/>

<http://www.preemieworld.com/>

[www.babyfirst.com](http://www.babyfirst.com)

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## Video and Movie Segments in English

### Noise in the NICU

<http://www.youtube.com/watch?v=yjQ7xDfq8Ng>

**Neonatal doctors and nurses can exchange insight and experiences online - across a range of neonatal care specialties**

<http://www.youtube.com/user/BabyFirstChannel>

*BabyFirstChannel*

**Inga Warren, an internationally recognized NIDCAP Trainer talks about the Zaky and Kangaroo Zak**

<http://www.youtube.com/watch?v=jQjsN6N4Mdc>

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](mailto:developmentalobserver@nidcap.org).

# Reflections on “The Early Days”

M. Kathleen Philbin, RN, PhD

Somehow I am drawn back to the very early days of bringing infant development to newborn intensive care, about 1990 to about 1994. In 1990 I moved to a large city with 6 NICUs and a combined bed capacity of over 200 infants. Shortly after taking up my position as a nursing instructor, I began making appointments at these hospitals in hopes of an affiliation. No one had heard of hospital care to advance the development of preterm infants. Outpatient, yes, but not before discharge; and no one was interested in trying it out. Except...the Clinical Director of a large, university affiliated children's hospital. He granted me an appointment and sat stone-faced listening to my presentation. When I got to the findings of the 1986 Als' study he got up, went straight to a certain file cabinet, opened a drawer and pulled out the reprint in one deft move, and began grilling me, to see if I knew what I was talking about. He invited me to join rounds when he was on service, and to attend the Fellows' weekly review classes preparing for Board examinations. I don't know if he was ever convinced on the merits, but he opened the door for infant development and NIDCAP in that famous NICU and gave me a chance to learn the pathophysiology of prematurity and, with it, enough credibility to enter the realm.

About 9 months later, an adventurous (and competitive) former NICU nurse, Vice President of the rival university hospital, had heard that something interesting was happening over there and paid the nursing school half my salary to bring “it” to her hospital. She quickly understood what “it” was about. She and the two successive nurse managers were the crux of changing policy and practice. The efforts of many would have died on the vine without the courageous personal support and exercise of authority of these three nurse executives.

Fortunately for me, the neonatology group was without a Director, distracted with internal conflict, and not at all interested in nursing. This gave a small group of us free reign to experiment, with the manager's blessing. I started a journal club open to anyone and it was well attended. This caught the neonatologists' attention and they assigned one of their own to check up on it. During the second or third meeting, the designee became quietly and increasingly agitated and finally burst out, “If there was anything to this we would be doing it already!” He stomped out and no one took his place.

In 1990, physical and occupational therapists and child life clinicians were barred from the NICU. After chipping away, the Nurse Manager and I got them in the door and together we observed infants and made verbal recommendations, for small changes in infant care, to the nurses we thought would not complain later. “Infant development” products had not yet been invented. Our small group of nurses and therapists learned to bed infants beautifully with undershirts, diapers, smooth procedure pads... whatever we could think of to fit a baby's body. The nurse manager, whose name was Ivy, devised a way to

twirl a blanket around the baby's trunk, hips, and legs to make a flexible boundary thus allowing intentional movement. The baby could be picked up in the same blanket without the disturbance of wrapping/rewrapping. We called it the Ivy Wrap. (It was not a burrito wrap.) For very small babies, a well-placed cotton ball, with an open diaper laid beneath, became a fine substitute for diapers, permitting legs, hips, and back to move freely. Staff were amazed at the infants' flexion into a ball. This can't happen with a diaper. A respiratory therapist (the first converted by less need for respiratory support) made a bed out of the paper box that packaged gauze, decorated it to look like a race car, and padded the inside. It was perfect for tiny infants who were still, at that time, required to remain on their backs. Some nurses started persuading medical students, residents, and fellows to skip the automatic morning blood draws. This was not easy because that person would then have to defend the omission to his/her superiors.

We tried various ways of connecting infants and parents. I'm fairly certain, that we were the first to use skin-to-skin care in this very big state. Of course there were no proper recliners and parents regularly departed from our planned seating to make themselves comfortable. I have a photo of a mother, tilted way back in a rocking chair with her feet up on the incubator bumper, talking on the phone. She and “Little Will” were happy that way for hours. At some point, the Nurse Manager became upset about one of the fathers, a lovely man from Mexico who came to the NICU in his best clothes...Western boots, fancy white shirt, and white cowboy hat. Having learned how to understand his own daughter, he sometimes went to settle other babies who were crying or uncomfortable. “Kathleen. This parents-being-relaxed thing has gone too far.”

An influential nurse was assigned to help me write the script for a videotape about feeding. At our first meeting we sat side-by-side at the table in the staff lounge, while she silently took a long time to read my draft. Finally, she turned and looked me in the face with the glare of a mother managing an impossible child, and said, “You can have ‘communicate,’ and you can have ‘facilitate,’ but you can't have both in the same sentence. Just too much PhD.” Then she grinned, and I actually fell off the chair laughing. In a presentation at a regional NANN conference a long-time NICU nurse concluded her remarks by saying, “I used to think it was my bed, my baby, and my space. Now I know it's the baby's bed, the mother's baby, and our space.” If that seems obvious now, it was profound at the time, and writing this still brings me to tears.

Of course it was not all roses and super care. The neonatologists finally hired a Director, “The Man of Science,” who truly did not get it. On his first rounds as Attending Physician he saw the brand new skin-to-skin reclining chair. He then gave a long explanation to the crowd about the complex physiologic changes

in fat with cold exposure. He then announced that the recliner had to go, and that holding infants outside the incubator had to stop. After hours of meetings and negotiations, a major staff training effort, and three weeks of a complex protocol with data collection and graphs, his attention shifted, and baby-holding faded back to nursing judgment. A year or so later, he was the primary neonatologist of a very small baby, Gabriel, with at least three DNRs and very bad BPD. His mother spent hours and hours of daily skin-to-skin holding. The nurses moved her to the isolation room to conceal it. Gabriel was discharged as a darling boy with lungs that, yes, would be a problem, but he was feeding and growing and having none of the usual BPD behavior. One day The Man of Science, who had never been in my office, opened the door abruptly looking quite stern and sat in the metal chair by the door. I was scared. He said, "It's your program. There's no other explanation for Gabriel." Trying for upbeat, I said, "Well, he had a good doctor for three months and his mother..." "No! It was your program." There was a silence and he left. So... The Man of Science was touched by an intense personal experience...not data. After that he was one of our most effective allies.

Many nurses wanted nothing to do with me because I had been hired by the Vice President and, therefore, must be involved in an administration trap. Older nurses trained in Egypt and The Philippines distained non-protocol nursing. They flatly refused any change in their bottle-feeding. Years later, one of them took me aside and said with some affection, "You know, Kathleen, I wasn't going to do anything because you said it. I had to find out for myself." By small degrees, and not without a little conflict and compromise...a wonderful, very quiet, family-centered NICU was created.

Life ebbs and flows. Life ebbs and flows. Financial consultants determined that "re-engineering," based on data from adult units, would increase customer satisfaction and save money. Ironically, the new system was implemented first in the NICU because we were the best organized for patient care. Among many other things, "re-engineering" undid our hard-won consistency of nurse to infant/family assignments, one of the reasons for our head-of-the-line selection. Many nurses quit, the consequent staff shortage was so bad that other nurses quit, and eventually new ones were hired. The champion Medical Director changed positions and a new one was hired along with some well-known neonatal physician scientists who lived by the emerging bludgeon of randomized controlled trials. There were no large randomized controlled trials of infant development and, therefore, it was junk; the overhead lights blazed on again.

An economic slump caused the hospital to be sold to a rich suburban chain and our champion Vice President was replaced by a very young protégé of the new, from-the-suburbs Chief Executive Officer. This young man, four years out of business school, announced at one staff meeting, "We don't want to be on the cutting edge. We want to be on the bleeding edge. Why waste money finding out what doesn't work? Other places can take care of that." His imposed cost savings reduced nursing numbers to the point that appropriate one-to-one assignments became three-to-one. A fine NIDCAP nurse who quit rather than give bad care said, "If it doesn't have to go on paper, it doesn't happen."

These years later, I don't know how infant care is delivered at that hospital. But I do know, if it's not corny or sentimental to put it this way, that "for one, brief, shining moment" we made life better for many infants and parents and caregivers. That is enough.



## 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*

# Award Recipients & Achievements of NIDCAP Professionals

## Heidelise Als, PhD



Congratulations to our Founder, Past President and Chair of the NFI Program Committee Heidelise Als, PhD in being named the recipient of the Serge Lebovici Award of the **World Association of Infant Mental Health (WAIMH)** given in recognition of significant contributions to the international development of infant mental health through her work with newborns, especially the assessment and treatment of premature infants and their families. The organization writes:

*“As a result of your work, you have changed the care of premature infants to respect the preterm baby’s sensitivities and to humanize the physical environment of the NICU, and, at the same time, by supporting the emotional experiences of preterm parents.”*

Nominees typically are individuals who have been actively involved in collaborative efforts that have cross-national implications for infant mental health. Past recipients include Charles Zeanah and Daniel Stern.

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## Jim Helm, PhD



Congratulations to Jim Helm, PhD, Director of the Carolina NIDCAP Training Center, WakeMed Health and Hospitals and Vice President for Administration of the NIDCAP Federation International (NFI). Jim is the recipient of the Healthcare Hero Award in the Medical Professional category from Triangle Business Journal. As a developmental specialist and infant-family specialist, Jim helps to guide and support the intensive nursery in providing individualized, developmentally supportive, family-centered care. He works with medical staff, nurses, families, other hospital colleagues and community organizations to support babies and their families that

come through WakeMed’s newborn intensive care nursery (NICU).

Jim was instrumental in guiding and supporting WakeMed’s NICU to achieve NIDCAP Nursery Certification – the fourth nursery in the world to be recognized by the NFI as an exemplary nursery in providing developmentally supportive care at a very high level, that is integrated throughout the nursery experience, and is a part of WakeMed Health and Hospitals’ care philosophy and practice.

*As Jim said, “Each baby, each family has their own story, their own communication – it’s fascinating.”*

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## Debra Paul, OTR



Congratulations are offered to Debra Paul, Program Manager of the Occupational Therapy Department and NIDCAP Professional at Children’s Hospital Colorado. She was elected as Co-chair for the Colorado Special Education Advisory Committee (CSEAC) at the annual CSEAC retreat this past summer. She was appointed to CSEAC in April 2011 and is serving a six-year appointment as a parent representative from Congressional District 2.

CSEAC is a state-level committee mandated by federal and state law. The purpose of this committee is to provide input and assistance to the State Board of Education, advise the State Director

of Special Education, to advocate and promote communication, collaboration and partnership among educational service providers, children/youth, parents and administrators, and to serve as a liaison between parents of children with special needs, local educational agencies and the Colorado Department of Education.

Since joining CSEAC, Debra has served on the Communications Subcommittee as well as the Mental Health Ad Hoc Subcommittee. She will serve as a Co-chair elect for a year and will officially assume her role as Co-chair for CSEAC beginning in July 2014 through July 2016.

## Jacques Sizun, MD, Nathalie Ratynski, MD



Congratulations to Jacques Sizun, MD, Director of the French NIDCAP Center and Nathalie Ratynski, MD, NIDCAP Trainer at the Medical School, Université de Bretagne Occidentale and University Hospital Brest, France. Jacques and Nathalie have published a French book entitled “L'enfant né prématurément.” This book explains to parents how early family-centered, individualized care is important for the future of their preterm infant.

Every year in France, 50,000 premature babies are born; this represents 6-8% of all births. Technological advances in recent decades have increased their survival, but the long-term development, especially neurological, remains a matter of concern for parents and professionals. The NIDCAP approach to care or “developmental care” seeks to change the environment so that sensory stimulation and rhythms of care are tailored to the capabilities of these fragile infants, and parenting long ignored, becomes essential to



the cherishing and nurturing of these infants.

“L'enfant né prématurément” is based on the contents of Drs. Sizun's and Ratynski's lectures, workshops and training since the beginning of their NIDCAP “journey” in Brest. ISBN: 978-2-343-01995-6 • November 2013 • 134 pages

<http://www.editions-harmattan.fr/index.asp?navig=catalogue&obj=livre&no=41722>

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## Silke Mader receives “Prix Courage”



Congratulations are offered to Silke Mader, founder and chairwoman of the European Foundation for the Care of Newborn Infants (EFCNI). She was awarded the “Prix Courage” on November 5, 2013, by the public-service German television broadcaster ZDF television program, “ML mona lisa,” and the French beauty brand, Clarins. The award recognizes the efforts of exceptional women who work tirelessly to help ill or underprivileged children. Silke received this award for her work to bring together all professionals who can make a difference and improve

the conditions of infants born prematurely. She advocates for high-quality prevention methods, treatment and care in the hospital, as well as long-term follow-up and continuing care. Silke joins a group of illustrious women who have had their notable work recognized in the past.



# NFI-NIDCAP Nursery Certification Program (NNCP)

## Applicants and Interest Grows for NIDCAP Nursery Certification



Erasmus MC-Sophia Children's Hospital, Rotterdam, The Netherlands

This has been an exciting year for NNCP. Significant progress has been made, and interest has developed, as nurseries around the world have taken the initiative to embark upon the process of NIDCAP Nursery Certification. A short description of applicant progress and increased interest in this learning and evaluation process is provided below.

### Current NNCP Applicants:

- **Scandinavian NNCP Applicants**, one in Denmark and one in Sweden have submitted NNCP Applications: Parts I and II for NNCP Review. If the NNCP Site Review Teams determine that the applications are

complete, NNCP Site Visits will be scheduled in the near future.

- **French NNCP Applicant** has submitted NNCP Application: Part I in October, 2013. After review of this submission the Applicant was invited to submit NNCP Application: Part II and supporting documents (i.e., site scored Nursery Assessment Manual and the Nursery Assessment Manual: Provision of Evidence).
- **Italian NNCP Applicant** is currently working toward submission of NNCP Application: Part I.

### Interest in NNCP:

- **The Kingdom of Saudi Arabia** has recently expressed interest in learning more about NNCP. Their NIDCAP Trainer recently provided a presentation on NIDCAP Nursery Certification to them in April of this year.
- **Another NIDCAP Training Center in the United States** has recently requested more information regarding NIDCAP Nursery Certification and is seriously considering embarking on this journey.

For information on eligibility requirements and the NNCP Nursery Certification process, please see: [www.nidcap.org](http://www.nidcap.org); and/or contact Rodd Hedlund, MEd, NNCP Director at: [nncpdirector@nidcap.org](mailto:nncpdirector@nidcap.org) or 785-841-5440.

## Elected Officers of the NIDCAP Federation International 2013–2014

**President:** gretchen Lawhon, PhD, RN, CBC, FAAN

**Vice President for Administration:** James Helm, PhD

**Vice President for Organizational Advancement:**

Deborah Buehler, PhD

**Treasurer:** Gloria McAnulty, PhD

**Secretary:** Sandra Kosta, BA

**Assistant Treasurer:** Sandra Kosta, BA

### Additional Directors:

Jeffrey Alberts, PhD

Heidelise Als, PhD

Vicki Batkin Bjornson

Nikk Conneman, MD

Rita Cummings, MA

Mandy Daly

Silke Mader

Kathleen VandenBerg, PhD

apply it in the provision of many tiny episodes of care; in brief moments of interaction; in everyday opportunities for support; in hours of work and reflection; and during days, evenings and nights of striving to do better.

The journey toward NIDCAP Nursery Certification would not have been possible without the vision and support of our NICU's leadership including: Professor Tzipi Dolfin, MD, former Head of the Neonatal Department; Ita Litmanovitz, MD, current Head of Neonatology; Khoolood Shabita, RN, NICU Nurse

Manager; and Anat Shapsa, RN, former NICU Nurse Manager.

As we look into the future, we are aware of the persistence and commitment involved in promoting transformation, maintaining change, and striving for excellence. Our gradual steps toward becoming one of the NFI's NIDCAP Training Centers around the world are certainly a constructive way to keep the good work going. As we move forward in this path, we would feel honored to more formally share and expand our experience and knowledge to other newborn nurseries in our region.

A MOTHER'S STORY Continued from page 4

*opportunity, but I didn't anticipate how profoundly it would shape my thinking. I have since attended a workshop by Dr. Jean Clinton (How Love Builds Brains) and another by Dr. Bruce Perry (Designing Trauma-Informed Services for Children and Families) on how trauma and neglect affects brain development. The information they shared reinforced for me the tremendous importance of those first months in the world... when the brain is 'wiring' pathways that will be used for all the higher brain function to follow. I never know how long each of the infants that I am caring for will stay, and I can't prevent the sometimes questionable and occasionally tragic decisions that are made for them once they leave our home. However, while they are with me, I can use NIDCAP to better respond to each infant and provide an environment that supports their healthy brain development. The foundation of self-regulation is an asset they will take with them wherever they go from here.*

*Thank-you for all you are doing on behalf of infants and the families who love them, A grateful Foster Mom.*

*PS: I 'googled' Dr. Browne, which led me to [www.wonderbabiesco.org](http://www.wonderbabiesco.org). On that site's 'Resources' link, among other great material, I found this quote in the article 'Early Experiences Can Alter Gene Expression and Affect Long-Term Development' from the Center on the Developing Child, Harvard University:*

*'The experiences children have early in life--and the environments in which they have them---shape their developing brain architecture and strongly affect whether they grow up to be healthy, productive members of society. This growing scientific evidence supports the need for society to re-examine the way it thinks about the circumstances and experiences to which young children are exposed.'*

*I got goose bumps and think I may have heard choir music in the background. Preach it, brothers and sisters!"*

Exactly thirteen weeks after I met this amazing baby girl, Molly was moved to a foster-to-adopt home. I expected the change of environment and caregiver would cause her to temporarily lose some of the ground that she had gained and it did, but once hearing Molly's story, her new parents were very willing to implement the same approach of introducing change in segments, eliminating as many other stressors as possible, and waiting for her to self-regulate before taking the next step. It took about two weeks before they felt she was ready for that next step, which was welcoming her older sibling into their family as well! After a brief honeymoon phase, her sibling (who was exposed to a very chaotic environment until six months of age) is acting out in quite a robust fashion, but Molly, now six months herself, seems to be taking it in stride, as would her namesake, the "Unsinkable Molly Brown."

SUPPORTING FAMILIES Continued from page 9

*"I think that once you form the relationship and you have the continuity of care, then you develop that trust and respect with those families and then, they are more apt to tell you what they need."*

**Conclusions**

This study illustrates that relationships between healthcare providers and newly immigrated families in the NICU are complex and nuanced, and hence fragile. We assert that in the global world in which we currently practice, there is an obligation to systematically amplify the cultural competence of healthcare providers and NICU organizations. We call for greater awareness

of culturally competent care, and more research on interventions that will show benefits to families in the NICU.

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National NIDCAP Training Center  
email: [gloria.mcanulty@childrens.harvard.edu](mailto:gloria.mcanulty@childrens.harvard.edu)

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**Sandra Kosta, BA**  
National NIDCAP Training Center  
email: [sandra.kosta@childrens.harvard.edu](mailto:sandra.kosta@childrens.harvard.edu)

### Jeffrey Alberts, PhD

Professor, Psychological and Brain  
Sciences, Indiana University  
email: [alberts@indiana.edu](mailto:alberts@indiana.edu)

### Heidelise Als, PhD

NIDCAP Founder, Past President 2001-2012  
NIDCAP Senior Master Trainer  
APIB Master Trainer  
Director, National NIDCAP Training Center  
email: [heidelise.als@childrens.harvard.edu](mailto:heidelise.als@childrens.harvard.edu)

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Marketing/Business Development  
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St. Andrews, Scotland

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Family Representative, Dublin, Ireland  
email: [mandy.daly@yahoo.co.uk](mailto:mandy.daly@yahoo.co.uk)

### Silke Mader

Family Representative, Munich, Germany  
Founder, European Foundation for the Care of  
Newborn Infants  
email: [silke.mader@efcni.org](mailto:silke.mader@efcni.org)

### Kathleen VandenBerg, PhD

NIDCAP Master Trainer  
Director, West Coast NIDCAP and  
APIB Training Center  
email: [vandenbergek@peds.ucsf.edu](mailto:vandenbergek@peds.ucsf.edu)

### Rodd Hedlund, MED

Director  
NIDCAP Nursery Certification Program  
NIDCAP Trainer  
email: [nncpdirector@nidcap.org](mailto:nncpdirector@nidcap.org)

## NIDCAP TRAINING CENTERS

by order of establishment

### National NIDCAP Training Center

Boston Children's Hospital and Brigham and Women's Hospital  
Boston, Massachusetts, USA  
**Director:** Heidelise Als, PhD  
**Contact:** Sandra M. Kosta, BA  
**email:** [nidcap@childrens.harvard.edu](mailto:nidcap@childrens.harvard.edu)

### Sooner NIDCAP Training Center

University of Oklahoma Health Sciences Center  
Oklahoma City, Oklahoma, USA  
**Co-Director:** Andrea Willeitner, MD  
**Co-Director and Contact:** Eleanor (Bunny) Hutson, RN  
**email:** [bunny-hutson@ouhsc.edu](mailto:bunny-hutson@ouhsc.edu)

### West Coast NIDCAP and APiB Training Center

University of California San Francisco  
San Francisco, California, USA  
**Director and Contact:** Kathleen VandenBerg, PhD  
**Associate Director:** Deborah Buehler, PhD  
**email:** [vandenbergek@peds.ucsf.edu](mailto:vandenbergek@peds.ucsf.edu)

### Carolina NIDCAP Training Center

WakeMed, Division of Neonatology  
Raleigh, North Carolina, USA  
**Director and Contact:** James M. Helm, PhD  
**email:** [jhelm@wakemed.org](mailto:jhelm@wakemed.org)

### Colorado NIDCAP Center

University of Colorado Denver  
School of Medicine and The Children's Hospital  
Aurora, Colorado, USA  
**Director and Contact:** Joy V. Browne, PhD, PCNS-BC, IMH (IV) Mentor  
**email:** [joy.browne@childrenscolorado.org](mailto:joy.browne@childrenscolorado.org)

### St. Luke's NIDCAP Training Center

St. Luke's Children's Hospital  
Boise, Idaho, USA  
**Co-Director:** Beverly Holland, MSN, RN, NE-BC  
**Co-Director and Contact:** Karen M. Smith, RNC, BSN, MEd  
**email:** [smithka@slhs.org](mailto:smithka@slhs.org)

### Karolinska NIDCAP Training Center

Astrid Lindgren Children's Hospital at Karolinska University Hospital  
Stockholm, Sweden  
**Director:** Björn Westrup, MD, PhD  
**Contact:** Ann-Sofie Ingman, RN, BSN  
**email:** [nidcap@karolinska.se](mailto:nidcap@karolinska.se)

### French NIDCAP Center

Medical School, Université de Bretagne Occidentale and University Hospital  
Brest, France  
**Director:** Jacques Sizun, MD  
**Co-Director and Contact:** Nathalie Ratynski, MD  
**email:** [nathalie.ratynski@chu-brest.fr](mailto:nathalie.ratynski@chu-brest.fr)

### Sophia NIDCAP Training Center

Erasmus MC-Sophia Children's Hospital  
Rotterdam, The Netherlands  
**Director:** Nikk Conneman, MD  
**Co-Director and Contact:** Monique Oude Reimer, RN  
**email:** [nidcap@erasmusmc.nl](mailto:nidcap@erasmusmc.nl)

### Centro Latinoamericano NIDCAP & APiB

Fernández Hospital  
Fundación Dr. Miguel Margulies and Fundación Alumbrar  
Buenos Aires, Argentina  
**Director and Contact:** Graciela Basso, MD, PhD  
**email:** [basso.grace@gmail.com](mailto:basso.grace@gmail.com)

### UK NIDCAP Training Centre at St. Mary's

St. Mary's Hospital  
Imperial College Healthcare NHS Trust  
London, England  
**Director and Contact:** Inga Warren, Dip COT, MSc  
**email:** [inga.warren@imperial.nhs.uk](mailto:inga.warren@imperial.nhs.uk)

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

University of Illinois Medical Center at Chicago  
Chicago, Illinois, USA  
**Director:** Beena Peters, RN, MS  
**Contact:** Jean Powlesland, RN, MS  
**email:** [jpowlesl@uic.edu](mailto:jpowlesl@uic.edu)

### NIDCAP Training and Research Center at Cincinnati Children's

Cincinnati Children's Hospital Medical Center  
Cincinnati, Ohio, USA  
**Director:** Whitney Brady, MSN, RN  
**Contact:** Linda Lacina, MSN  
**email:** [nidcap@cchmc.org](mailto:nidcap@cchmc.org)

### The Brussels NIDCAP Training Center

Saint-Pierre University Hospital  
Free University of Brussels  
Brussels, Belgium  
**Director:** Dominique Haumont, MD  
**Contact:** Delphine Druart, RN  
**email:** [delphine\\_druart@stpierre-bru.be](mailto:delphine_druart@stpierre-bru.be)

### NIDCAP Norway, Ålesund Training Center

Ålesund Hospital, Ålesund, Norway  
**Director:** Lutz Nietsch, MD  
**Contact:** Liv Ellen Helseth, RN  
**email:** [nidcap@helse-mr.no](mailto:nidcap@helse-mr.no)

### The Barcelona-Vall d'Hebron NIDCAP Training Center Spain, Established 2011

Hospital Universitari Vall d'Hebron  
Barcelona, Spain  
**Director and Contact:** Josep Perapoch, MD, PhD  
**email:** [jperapoc@vhebron.net](mailto:jperapoc@vhebron.net)

### Hospital Universitario 12 de Octubre NIDCAP Training Center

Hospital Universitario 12 de Octubre  
Madrid, Spain  
**Director:** Carmen Martínez de Pancorbo, MD  
**Contact:** María López Maestro, MD  
**email:** [nidcap.hdoc@salud.madrid.org](mailto:nidcap.hdoc@salud.madrid.org)

### St. Joseph's Hospital NIDCAP Training Center

St. Joseph's Hospital and Medical Center  
Phoenix, Arizona, USA  
**Co-Directors:** Bonni Moyer, MSPT and Marla Wood, RN, MEd  
**Contact:** Windy Crow  
**email:** [stjosephnidcap@dignityhealth.org](mailto:stjosephnidcap@dignityhealth.org)

### Italian Modena NIDCAP Training Center

Modena University Hospital, Modena, Italy  
**Director:** Fabrizio Ferrari, MD  
**Contact:** Natascia Bertonecelli, PT  
**email:** [natafili@yahoo.com](mailto:natafili@yahoo.com)

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