



We are all connected; we mutually support, teach, learn from, and enrich one another.

—Heidelise Als.

Supporting Closeness – Building Relationships, COINN 2024

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Introduction

In May of this year, Aalborg, Denmark, became a hub of international expertise as 275 passionate nurses from 28 countries convened. Their mission was to showcase groundbreaking work and exchange insights at the forefront of newborn care. Amidst the picturesque landscapes of Denmark, these dedicated professionals explored topics through vivid oral presentations and a rich display of poster presentations. Illuminating the event were keynote addresses tackling pivotal global issues in newborn care and neonatal nursing, underscoring the urgency of their shared mission. The overarching theme, "Supporting Closeness – Building Relationships," echoed the core principles of the NFI and NIDCAP Philosophy, resonating deeply with attendees. Throughout

the conference, a diverse array of sessions explored the nuances of developmentally supportive care, highlighting the relentless pursuit of excellence in nurturing the most vulnerable members of our society.

The organizer was The Council of International Neonatal Nurses (COINN) which is an international organization comprised of approximately 16 national organizations and over 4000 individual members. COINN's vision is "unifying neonatal nurses globally" with a mission "to promote excellence in neonatal nursing and health outcomes for the infants and families nurses serve and to act as an international leader in development of professional standards of neonatal nursing."

Many NIDCAP Trainers and NIDCAP Professionals attended the conference and presented their work on developmentally

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NIDCAP Professionals and Trainers at the COINN Conference

focused topics. These were consistent with the conference themes and reinforced the focus of the NIDCAP Federation International (NFI).

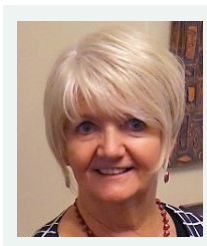
Key Themes

What struck us at this conference was the disparity between the developed world and the developing world. We were presented
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Editorial

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Spreading the Word



In this edition, we explore the multifaceted challenges confronting healthcare professionals as they care for hospitalized newborns and their families. The global crisis of infant mortality persists, particularly pronounced in developing nations where the shortage of nurses exacerbates the situation.

Considering these pressing concerns, it becomes imperative to explore avenues for support and collaboration.

Livia Nagy Bonnard's narrative underscores the influential role parents can play as advocates, as she shares her work to enhance newborn care in Hungary. Additionally, Sophia Gerassis sheds light on the enduring impact of siblings' experiences in the Neonatal Intensive Care Unit (NICU), offering valuable insights into familial dynamics during such challenging times.

The commendable growth of the NIDCAP Federation International (NFI) is an inspiration, with Fatima Clemente exemplifying exceptional leadership in advancing NIDCAP

and developmental foundation programs. Indeed, strong leadership is the cornerstone of NFI's important work, as evidenced by the collaborative efforts of two NIDCAP Training Centers in Denmark, extending their global reach.

Bindu George's account offers a glimpse into the commendable initiatives underway in Qatar, showcasing developmental care strategies and the requisite training to support them effectively. The dissemination of such initiatives underscores the expanding influence of NFI, as it endeavours to elevate the standard of care for hospitalized newborns worldwide, while simultaneously bolstering its professional membership.

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with a stark global contrast where the decrease in nurses, such as in Africa was directly related to an increase in deaths in one-to five-year-olds. This has huge implications for poaching of staff from these countries to fill gaps in the failing systems in the developed world. It also made us think about the global reach of the NFI and ways that we as an organisation could help in these countries. It certainly calls for further discussion.

The conference presented many opportunities for the pro-motion of developmental care practices and education, and it became clear how many of these strategies could be simply used in some African systems as well as other depleted areas such as India, SE Asia and Eastern Europe.

Keynote Presentations

An informative session was given by Joy Lawn, Professor of Maternal, Reproductive and Child Health at the London School of Hygiene & Tropical Medicine (LSHTM). Dr Lawn spoke on the topic Every Newborn Everywhere: How Can We get Neonatal Nurses Everywhere.

She explained that while most women in Africa now deliver their babies in health facilities, these hospitals lack the life-saving technologies, equipment, and trained staff that are

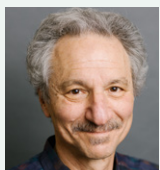
necessary to manage preterm babies and newborns in distress. Over one million newborns die annually, 75% from preventable causes.

Together, South-East Asia and sub-Saharan Africa account for 79% of the global burden of neonatal mortality. Evidence has shown the importance of specialised neonatal nurses to improve the chances of newborns' abilities to survive and thrive. Yet, the global shortage of nurses was also estimated to be 5.9 million of whom 89% are needed in low to middle income countries (LMIC) where the burden of neonatal mortality is particularly high (See Fig 1, p.4).

The availability and international distribution of nurses were a focus of the presentation by Howard Catton the CEO of the International Council of Nurses (ICN). He is committed to ensure that the ICN effectively represents nursing worldwide, advances the nursing profession, promotes the wellbeing of nurses and advocates for health in all policies. He painted a sobering picture where nursing is heading for a crisis with an estimated shortage of 5.7 million by 2030. He explained the high international mobility of the workforce as approximately 1 in 8 nurses are working in a country other than where they were born or trained.

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Editorial Board



Jeffrey R. Alberts, PhD, is Professor of Psychological and Brain Sciences at Indiana University -- Bloomington (USA). Jeff is also a NIDCAP Professional and blends his lab studies with similar research at Cincinnati Children's Hospital Medical Center.



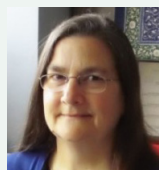
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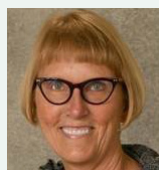
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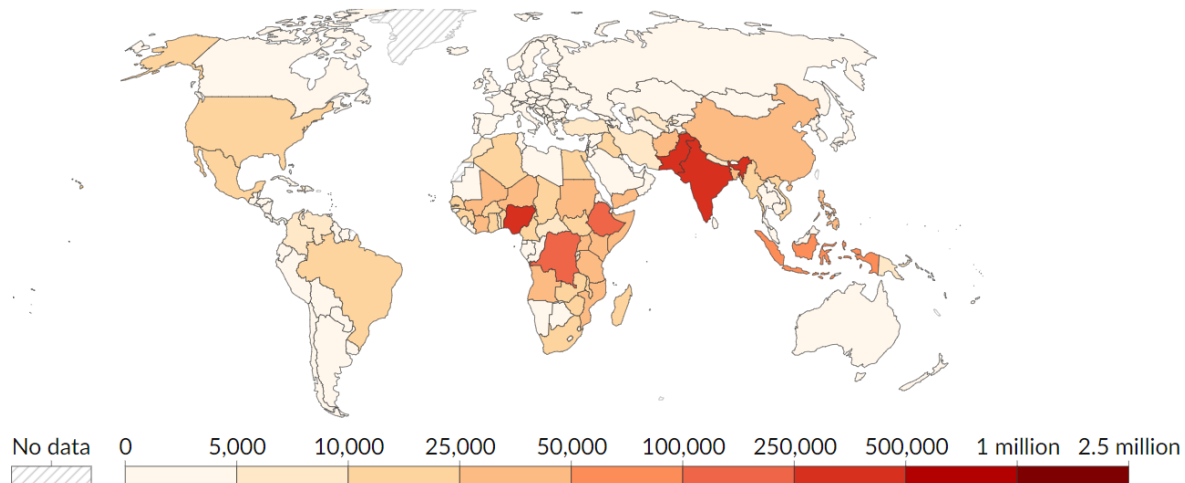
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Figure 1: Global distribution of neonatal mortality (source UN Inter-agency Group for Child Mortality Estimation (2023))

Number of neonatal deaths, 2021

The estimated number of neonates – babies under 28 days old – who die each year.

Table Map Chart



The projected nursing density in 2030 raises many concerns. Countries in Africa and Southeast Asia have a critical shortage which impacts on health care and the infant survival rates. Countries in southern Europe and eastern Mediterranean have a challenge to increase the number and influence of nurses in these countries.

What does this mean for the NFI? As we recruit more nurses into NIDCAP Training and FINE Education we have a good opportunity to promote their work and their unique contributions to infant and family centred care. A strength is the partnership with parents and the NFI could promote this role-modelling to other countries. In Figure 2 on page 5, the target countries are easily identified in the reds, pinks and lighter blue.

The power of parents was showcased in the opening address by Livia Bonnard Nagy on the role of parents in the NICU and beyond. Livia is the co-founder, vice-president of Right(s) beside you - Hungarian patient organization, Fellow, EFCNI - European Standard of Care for Newborn Health, NIDCAP Member of Family Advisory Council, FINE (Family and Infant Neurodevelopmental Education) Faculty member in Hungary. Her impressive biography and her emotive presentation captured the audience as she led us on her journey, as the mother of an extremely low birth weight infant. She shared with us how the experience of having a preterm infant still affects her family's life, as she was not allowed to stay at the hospital or visit. Particularly distressing was that she received no help with breastfeeding, parenting skills or with questions she had about her baby. She suggested using the parents as painkillers – be allowed to be present – to use the senses –

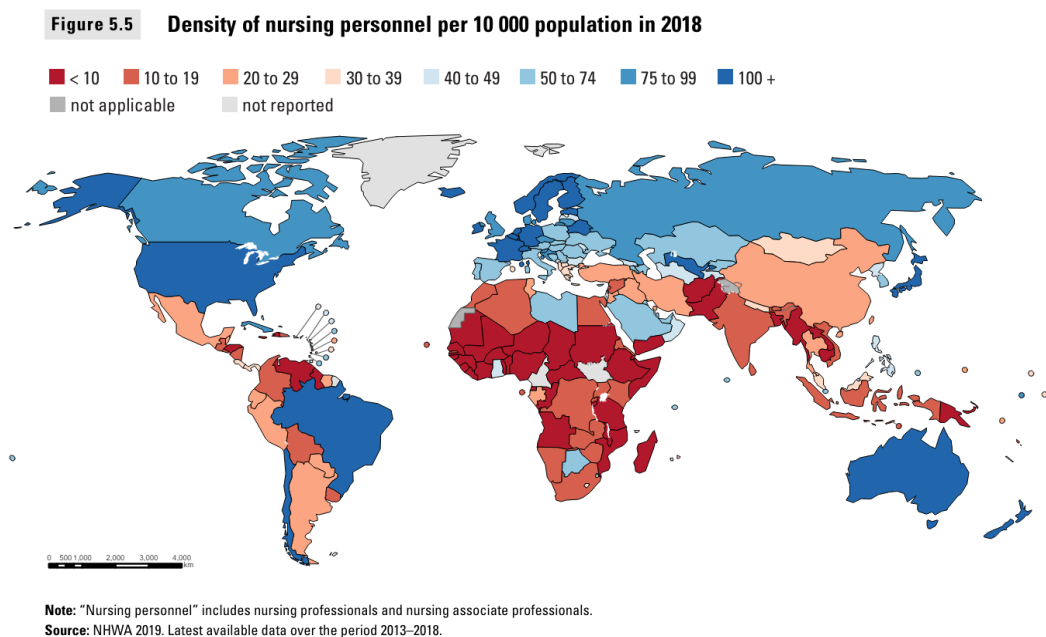
touch my baby, smell my baby, hold my baby. She shared with us that 18 years later she is still a NICU mom, and despite many challenges her son is ultimately happy. From her experience she was driven to improve the education of all health care professional in Hungary. Her work has improved conditions for other families by educating nurses and starting FINE Training for parents, an innovative program. This keynote presentation provided an emotive start which put what we as neonatal nurses do into perspective.

Developmental Care Themes

The COINN 24 conference was very inspiring on multiple levels. From a supportive developmental perspective there were several interesting and challenging presentations. For us, the challenge was to be present at all five parallel sessions, as there were many presentations under this theme. Here are a few selected presentations.

Supporting Parent-Infant Closeness in Clinical Care by Anna Axelin from Turku, Finland. Anna reminded us of the importance of giving the best opportunities to support parents and infants to be together. She described the three steps of the path of parent-infant closeness in clinical care. Maternity care - do we support parental prenatal attachment and development of co-parenting, Delivery – do we support immediate skin-to-skin and initiating breastfeeding, and Newborn care – do we practice Family Centered Care (FCC) skin-to-skin care (SSC), couplet care, home care. She reinforced the need for support as attachment starts before delivery, maternal-fetal attachment, and how bonding and attachment are very important for the development of the infant-parent relationship.

Figure 2: Projection of nursing personnel density (source ICN State of the World's Nursing 2020)



Stina Klemming, NIDCAP Trainer from Sweden, presented a summary of the anticipated global impact of Kangaroo mother care (KMC) and potential death prevention annually. The current impact of KMC is anticipated to prevent 10,000 global deaths, add the impact of scale up implementation prevents 150,000 deaths, further add the impact of community initiated KMC prevents 250,000, then add impact of immediate KMC research and the death prevention is 400,000. A global target for prevention is to distribute KMC with an implementation strategy to all countries. The NFI is in a position to endorse and promote current skin-to-skin programs and resources. The NFI Kangaroo-a-thon is a start and perhaps next year each NIDCAP training centre could partner with a hospital in a developing country as a strategy of global outreach. With the figures above this could be a worthwhile collaboration.

Sofia Augoustakis from Rigshospitalet, Copenhagen, Denmark, presented her research on the *Duration of infant-parent skin-to-skin contact In Neonatal Wards: A Danish nationwide cross-sectional survey*. This study has highlighted the importance to measure some of the care we provide, we know caregiving has a great impact on parent-infant bonding and brain development.

Nadine Griffiths, Senior NIDCAP Trainer from Sydney, Australia, presented her poster on the *Development of a screening process for parent depression and stress after discharge from a surgical NICU*. Her team found a multidisciplinary standardised screening protocol was feasible and effective in establishing referrals to services for families at risk. Her find-

ings that 24% of mothers and almost 42% of fathers reported depressive symptoms suggest screening should be extended to all families discharged from a NICU. This was one of many groundbreaking poster presentations at the conference.

In the session Sleep and Neuroprotective Care, Jannie Haaber, from the Danish NIDCAP Training and Development Center, Copenhagen, DK and Tenna Gladbo Salmonsén, from the Danish NIDCAP Training and Development Center, Aarhus, Denmark opened with the presentation *Burden of care – a fact – or is it?* They took us on a short journey of the importance of brain development, development of the senses and the impact of the environment; how daily procedures and daily care can be an explosion of sensory stimulation and the crucial need for positive sensory regulation, and parental involvement. They reminded the audience of the importance of being able to identify the infants' sleep and awake states to know when the infant is ready to interact, and with reference to Heidelise Als, why it is so important to be present and observe to understand the infants behaviour.

Another aspect of parental involvement in pain management was from Alexandra Ullsten, music therapist from Sweden, who told us about parent delivered lullabies, when the infant is skin-to-skin before, during and after a procedure. It is exciting to follow the study SWEpap, which is an RCT. Further the presentation was a part of a workshop – Building relations to stop pain in the NICU with several presentations about pain management. Marsha Campbell Yeo from Halifax Canada underlined the importance of having parents actively engaged in pain management. Among other things, she told us about a



International COINN participants

website Parenting Pain Away, which was developed to support parents and their families to feel confident to cooperate with health professionals in reducing their infants procedural pain. Bonnie Stevens, from Toronto Canada talked about implementation of pain management in newborn/preterm infants and how difficult it is but also how crucial it is to prevent pain and stress. In this discussion, she added the need for system changes requiring management level decisions to prevent pain and stress in newborn and preterm infants.

An expert panel of speakers provided insight into the *Care Of The Extremely Preterm Infant < 25 weeks*. We heard speakers from Japan, Miki Konishi, Akiku Kuroda, Ylva Blomqvist and Victoria Karlsson from Sweden. It is important to focus on this group of infants since they are immature, vulnerable and there are different ways to practice care. Reflections from the session included having a "Tiny Baby Unit" within the NICU to keep knowledge and practice to a few very dedicated nurses. 'The Tiny Baby Collaborative' – an international research group comprised of clinicians and researchers dedicated to improving the lives of children born at ≤ 23 weeks' gestation and their families foster collaboration and mutual learning among hospitals with exceptional outcomes for the most premature neonates. The goals are to identify and conduct research to improve care for the most premature neonates and their families. They share data on outcomes and practices among participating centers, and to compile evidence- and expert-based guidance related to the care of infants ≤ 23 weeks' gestation. The overall impression is that there is a need to share knowledge about the smallest and most vulnerable infants from the very beginning of life.

Neonatal Palliative Care was presented by Alex Mancini Schmidt from the UK. There was an emphasis on the importance of consistency between national guidelines (national network) concerning end of life or palliative care. The goal is to help parents when everything is uncertain and continue to develop the ability to observe what each infant needs in this very special situation.

During the workshop, '*Fathers in the NICU*', the speakers Anne Brødsgaard and Mette Petersen from Denmark and Francine de Montigny from Canada gave us valuable insight as to why it is important to have a greater focus of fathers, when their infant is in the NICU. We need to make the fathers/partners feel important and remember to ask, what they need, and acknowledge the importance of both parents in the infants life and the process 'to become parents'. Peer to peer support is worthwhile, father support groups are an example. In Denmark a national study is The SUPPORTED study – SUPPORT for first-time fathers of preterm infants in Early parenthood. We await the results.

Call to Action

Attendance at this conference has triggered many issues that we feel the NFI may consider as we move forward with NIDCAP across the globe. Three issues stood out for us: the power of skin-to-skin on closeness and brain development, the global issues threatening newborn care and survival in developing countries, and the need for a universal education program for developmentally supportive family and infant care.

Becoming an advocate for newborn care in Hungary

Livia Bonnard Nagy, Co-founder, vice-president Right(s) beside you Association (Melletted a helyem Egyesület), EUPATI (European Patients' Academy on Therapeutic Innovation) Fellow

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Undertaking an observation during FINE 2

When did my 'patient expert' journey begin? Probably during my nursing education in the early 1990s, I was fortunate enough to try myself out in intensive care with all of the beauties and challenges within. But 10 years later I became a 'naïve patient'. I never thought there could be such a deep, gut-wrenching, paralysing pain in every part of my body. I thought, this can't happen to me, I can't give birth early, way too early. Many women have thought that and sadly, many will continue to think that until the unthinkable happens.

I remember standing in the hallway of the deserted maternity clinic in the evening. The smell of chemicals, a distant baby crying, snippets of conversations, a typical obstetric setting. In my hand I clutched the day's breastmilk. As I stood outside the neonatal intensive care unit (NICU) door I tried to recall how I got there.

I was a Hungarian mom and lived happily in the French-Swiss border, close to Geneva with my French husband and 7-year-old little girl. I was pregnant with our second child. A 31-year-old mother, who did not smoke, nor drink, with a previous healthy pregnancy and a natural, uncomplicated pregnancy and birth.

During the 25th week of my pregnancy, my gynaecologist authorized one last flight: he let me go for a two week vacation to take my daughter to visit our family in Hungary. Two days

before our return to France I became unwell. First, I had a headache, then my legs and arms got heavy and swollen, all of a sudden, I was feeling extremely tired and I dragged myself into the closest hospital. I had pre-eclampsia.

Memories that triggered action

I remember the emergency doctor who explained to my frightened husband, who was then 1300 km away from us, on the phone, what was happening to his wife and his unborn son. They would have to deliver the baby immediately. My son was born in the 27th week of pregnancy and weighed 890 grams at birth. I remember the moment when my son was born. I saw his tiny feet as a neonatologist was running away with him as he had no signs of life. My husband rushed to us from France. I will always remember the first time we met our son around 24 hours after his birth. I tried to prepare myself for the sight of my son, but you cannot prepare for this. Five days after his birth, the hospital released me and I had to leave my baby there. Alone. I was devastated.

The NICU door will haunt me for the rest of my life. I was afraid of what was waiting for me behind that door. For the next 14 weeks, I stood in front of that door twice a day and pressed the bell. Would they open quickly, or would I need to wait? If I had to wait, was it because something was going wrong on the other side of the door? Was it my son?

The doctors came by and often said some cliché like 'two steps forward, one step back' and then they left me alone. The visiting time for each infant was 20 minutes, twice a day. I insisted on calling the NICU every morning at the same time, I had my daily rituals. Every day I wrote down every little detail in his baby journal, and also added one photo for every day. If anything happened, I knew I needed memories. I needed to prove his existence. Often, I found myself NOT looking at my baby BUT at the monitors.

I tried to think that this is not my son, to avoid getting too attached to him. I did not want to feel any pain, if he would not make it and he died. Although everybody tried to convince me that I had to be happy as I had survived, I blamed myself for his preterm birth. I was a mother of two children, but what was the reality? One of them was 1300km away from me and the other one was locked down in a NICU, where I had to ask permission to see him. I couldn't be a mother to any of my children, it was torture. I felt invisible in the hospital. The doctors and nurses were overworked and did not have time to support a mother who was depressed. I had no psychological help. Each nurse cared for between six and seven infants in incubators, and there were one-two neonatologists each shift.



After discharge

At that time, I was confident and felt that my baby was in good hands. Never, not for one minute did I question that my son and I did not receive the best treatment and care. Now, in hindsight, I know how dangerous this situation was. I remember the exact day and the exact hour when my son started to breathe without any machine. At that moment he was born a second time, but I was not there. They told me on the phone. The moment when I could hold

him in my arms for the first time is equally unforgettable. He was then 12 weeks old.

There must be a better way

Eighteen years ago he went through traditional, and unfortunately outdated, non evidence-based neonatal care. I had two visits for 20 minutes each a day to be with my baby, who was I was told was 'ready' to be visited. I could only look at him, I had to ask permission even to touch him or take a picture of him. The main reason was: as they say: to avoid infection. I imagined I had a biological bomb, planted in my head from the first moment I set foot at the NICU and it went on for 14 weeks. I was afraid to kiss my own child for a year. I did not let anyone to touch him beside his father and sister for a year! They were giving formula milk to my baby as my breastmilk dried up very quickly because of my stress, and misleading information. He received good old cluster care where his sleep cycles, pain and stress were ignored, he was positioned on his back without any support for his shoulders, legs or knees while he was in the incubator.

Then one morning, the staff told me I could take my son home. All of a sudden, he was lying there next to me in the bed, a little two-kilogram baby, who was on monitors only few hours before. I felt completely incompetent and did not dare to sleep for weeks. I was his monitor during the night: Is he still breathing? How on earth could the NICU staff think I could possibly take care of this baby? Is it really my baby because I still don't feel it. And I knew about attachment and bonding as

I already have an eight year old daughter. After my son got out of the NICU, I felt many things, but I missed the most important feeling: I did not feel like his mother. I felt more like a nurse and did not let anyone near him. When I fed him, I was wearing the green NICU uniform and a mask for weeks. We didn't receive any diagnosis, only 'this child got away with it'. No diagnosis means no prognosis it means go home and have a happy life.

It took another two and a half months before we both could take a flight to go home, back to France. We learned that the French and Swiss social system are extremely weak and do not have enough information or a good adviser so it is easy to slip out of the social system. During follow-up nobody took my worries, my comments seriously. My son's development was extremely slow. We were followed in three different countries, but there was no consistency.

Becoming an advocate

It took me two and a half years to learn how to become the voice of my child, to stand up for his rights and stand up for my rights as a mother. They kept repeating, he is an extremely preterm BOY, why am I so impatient?

After two and a half years we finally got a diagnosis. My son has periventricular leukomalacia (PVL) and cerebral palsy (CP), which equals a mentally and physically disabled child. Therapies came in line, some were useless, some dramatically improved my son's development day by day and changed the quality of his and my family's life. Some were recommended by the neurologist, some by the pediatrician. I received ideas from the parent group, from the internet, and Google doctor became my best friend. At the beginning I did not question the scientific evidence of any of the interventions, most of them largely expensive and not paid or reimbursed by health insurance. Results were coming little by little. My son started to walk and talk around the age of five, he became relatively independent and managed his daily routines. Feeding was always an issue, and still is. If he finished his food, I doubled the portion. The first 10 years of his life this was my 'mothermeter'. He started school in a special class and continued his studies in a special school adapted to his handicap. So, I had to give up my job, I became a full time social assistant to navigate between medical appointments, therapies, interventions, school, finance and insurance.

What does it take to become a dedicated advocate and create the Right(s) beside you Association for premature babies in Hungary? It took a traumatic birth and NICU experience with an extreme premature baby who weighed barely 600 grams in the first week and who, has to live with the consequences of his early arrival for the rest of his life.

It took a minimum of one neonatologist (special admiration to Dr. Csaba Nádor) who believed that with good patient-centered and family integrated care you can protect the brain and neurodevelopment of these babies. There needs at least one NICU nurse who believes that by involving parents, even better care can be provided and the baby will leave for home with



18 years later

competent parents. Our association was founded in September 2015 with the aim of bringing together in a unique way doctors, health professionals, decision makers and NGOs representing parents of premature babies to ensure that every baby born prematurely or sick has the best possible chance of survival with the best possible quality of life. To give everything I didn't have 18 years ago, up-to-date, evidence-based information about premature birth-related diseases, professional help and social support.

Call to action

As developmental care was NOT part of the nursing curriculum, the association strongly advocated to establish the FINE

(Family and Infant Neurodevelopmental Education) training as a basic education in every level III NICU in Hungary. With the help of volunteer neonatologists, 'veteran parents' whose child was born extremely preterm, we fully translated the educational materials and organised the trainings. These parents have been helping the international trainers, initially as translators, and now themselves involved in training part of the faculty. Along the way we learned how to get finance for the training and we started to collaborate with industry partners. We have learned how to climb back through the window of the decision-makers when we are thrown out the door. There was a need for an evidence-based handbook specially for NICU nurses. We translated the Neonatal Nursing Care Handbook by Carol Kenner and Judy Wright Lott. We started to advocate for the NICU nurses as we faced huge challenges, how to implement neurodevelopmental care on a daily basis. Closed-system workplaces are typically teams that deal with life-and-death situations. Their work, and the success of their work, depends on everyone knowing exactly what to do, and in what order - they are maximally interdependent. We had to be aware of their mental health state and the workload they faced day by day.

During these 18 years I have heard lots of stories from families like mine – throughout EUROPE and around the world. We are not a special unique case. During these years I learned a lot about the neonatal practices at both domestic and international levels. Finally, I dare to say out loud: my son did not get the best practice in Hungary. France and Switzerland failed during follow-up. Was my son the unfortunate little boy who was born in the wrong country, in a wrong city or in a wrong NICU? Was it my fault I couldn't become a COMPETENT mother for my son, to stand up for his right and advocate for him correctly?

Today we know, I know that 'every care is brain care', every touch and word has lifelong consequences and we have to protect the brain of every preterm baby, but I wish I knew back then....



Mission

The NFI improves the future of all infants in hospitals and their families with individualized, developmental, family-centered, research-based NIDCAP care.

Adopted by the NFI Board, June 29, 2022

Vision

The NFI envisions a global society in which all hospitalized newborns and their families receive care in the evidence-based NIDCAP model. NIDCAP supports development, enhances strengths and minimizes stress for infants, family and staff who care for them. It is individualized and uses a relationship-based, family-integrated approach that yields measurable outcomes.

Adopted by the NFI Board, October 20, 2017

Fatima Clemente MD

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Heidelise Als has profoundly influenced my professional and personal life. Thank you for being my mentor and inspiration ...

"We are all connected; we mutually support, teach, learn from, and enrich one another" Heidelise Als

I was born in the beautiful city of Porto, Portugal, a city steeped in history and culture. However, my early years were spent outside of Porto and were incredibly rich and varied in experiences as I traversed the globe alongside my family. My "*globetrotting journey*" was a result of my father's career as a military officer, which took my family to different places, allowing us contact with diverse cultures, languages, and traditions. This period of my childhood left a lasting imprint on me and shaped my future perspective on life. It has not only broadened my horizons but also shaped my values, emphasizing the importance of empathy, understanding, and interconnectedness in our global community.

I graduated in Medicine at the University of Porto and began working as a doctor at São João University Hospital. In my professional journey as a doctor, this multicultural foundation has proven to be an invaluable asset. It has enhanced my ability to collaborate and work in diverse environments. So as a young paediatrician, I had the curiosity and desire for varied experiences that led me to have opportunities beyond the familiar confines of Porto as I undertook several months of hospital internships in London and Paris.

Like any young doctor, I was drawn to state-of-the-art technologies that could enhance patient care. The latest advancements on mechanical ventilation captivated my attention in the first years of my career.

My Introduction to NIDCAP

In the nineties, attending the French Paediatric Society Meeting in Reims, France, I chanced upon a workshop presented by an enthusiastic team from the University Hospital of Brest, led by Professor Jacques Sizun. The topic presented, *New Approach to Caring for Infants*, promised a shift in perspective toward understanding the language and behaviour of babies, with a focus on their development and family, caught my interest. This moment was really a "*touchpoint*" and marked a true turning point in my professional and personal journey. It challenged conventional medical approaches by placing a spotlight on infants' behaviour and families, understanding of the infant's needs, and involving the family in the care process.

Reading infant behaviours was really a new concept for me, and this paradigm shift made a profound change in my



Fatima Clemente with NIDCAP founder Heidelise Als

approach to neonatology. Embracing the principles introduced by the Brest team, I began to view each newborn not just as a medical case but as a unique individual with their own language. The emphasis on family involvement also became a cornerstone, recognizing that the well-being of the infant is linked to the support and understanding provided by their family. This new philosophy of care not only revolutionized my professional practice in neonatology but also had a strong effect in my personal life.

Bringing NIDCAP to Portugal

As I continue my journey as a neonatologist, the lessons learned in France remain embedded in my practice. The fusion of cutting-edge technology with a compassionate, family-centered approach has become the hallmark of my commitment to the well-being and development of every newborn under my care. With Madalena Pacheco RN, a young neonatal nurse and now the Head Nurse of our NICU, we shared a common enthusiasm for enhancing our understanding of NIDCAP principles. Together, and with the support from Hercília Guimarães, Professor of Pediatrics and Chief of Department of Pediatrics - Faculty of Medicine of Porto University, Neonatology Service Director, we began our NIDCAP journey in Portugal.

We successfully secured a scholarship from the Calouste Gulbenkian Foundation to fund NIDCAP training which

allowed our team to travel to Boston and had the privilege to meet Professor Heidelise Als and Dr Nikk Conneman. In the year 2008, I was certified as a NIDCAP professional along with Madalena Pacheco RN, Carla Castro RN and Ligia Silva RN, neonatal nurse specialists and the first NIDCAP nurses certified in Portugal. Our team has expanded, now with eight NIDCAP professionals and six more in training, bringing together dedicated professionals who share our passion for enhancing the well-being of newborns and their families.

With the support of Dr Graciela Basso, who was crucial in the implementation and integration of NIDCAP care at the Neonatology Unit level and at the hospital system level, and even at the national level in Portugal. With her vast experience and knowledge, she supported the training of our team and its expansion. We realized our dream in 2015: the inauguration of the São João NIDCAP Training Center. This Center became a place where our team's commitment to improving care for infants and families in Portugal could develop. Each member brought a unique set of skills and dedication to the table, contributing to a collaborative and supportive environment focused on the NIDCAP approach to newborn care.

The Future for Developmental Care and NIDCAP

Our shared team vision extended beyond NIDCAP professional certification – it was about continuous improvement in the care provided to newborns and their families. So, for the past few years, São João NIDCAP Training Center has an important goal: the education in NIDCAP foundation courses like Foundation for Infant Neurodevelopmental Education (FINE), providing the pathway for NIDCAP Training and certification. In our Portuguese experience with the multidisciplinary training of many professionals in the NICU team with FINE training, it is the fundamental step to establish the foundations for NIDCAP training. It's essential for the team to "speak" the same language and to understand the process of a changing care philosophy under the synactive theory. Through this approach, we intend to meet the evolving needs of the Portuguese hospitals and NICU professionals.

In the last three years with the financial support of the Portuguese Parent Association, we have trained on Developmental Care and NIDCAP foundation with FINE 1 and 2 more than 700 NICU professionals across all Portugal, 17% of them are neonatologists. This multidisciplinary participation has an important impact on neonatal care in Portugal, emphasizing the importance of individualized, family-centred approaches.

Another of our goals for the future is to initiate basic training in Africa in Portuguese-speaking countries: Angola, Mozambique, Guinea-Bissau, and Cabo Verde. The online training has opened a window of opportunity for decreased costs and the ability to reach more distant hospitals. Family-centered care is not a reality in hospitals in Africa. The need for families to be in the units 24/24h, to support breastfeeding, kangaroo care, and to support parents in caregiving, is crucial

for the survival of premature babies. We intend to integrate developmental care through Portugal's exchange programs that already exist with these countries.

Rewarding Experiences

My most successful professional experience is working with professionals from different Portuguese NICUs and sharing their journey in learning the language of the infant, caring for the infant, and partnering with families. It is a true privilege for me! Each time, I am grateful to be able to work with excellent and motivated professionals who aim to improve their skills to meet the needs of families and their babies.

In a period where we are experiencing a global crisis in national healthcare systems, where hospital resources are often directed towards other more technical aspects, it is surprising that we have so many individual requests for FINE courses and NIDCAP training. This demonstrates the recognition of the importance of developmental care and the need for ongoing skill development to meet the demands of families and infants in increasingly complex situations like cardiac and surgical pathologies that often require specialized care but also special attention to developmental issues due to the complexity of their conditions to optimize outcomes. Working with hospitalized infants can be challenging yet immensely rewarding.

Effective communication and collaboration among multidisciplinary teams is essential. Therefore, as we work together providing the NIDCAP approach to comprehensive care, the individual needs of each infant and family are considered. It is not an easy task but remains one of our goals in our NICU in Porto.

Advice for those doing NIDCAP Training:

- *Be open-minded!* Think of neonatal care from a global perspective and be ready to learn new concepts. You will move from a traditional task orientated model of care to one built on relationships that uses a reflective process. NIDCAP emphasizes an individualized approach to newborn care, it can be really challenging, but it will certainly be very rewarding.
- *Build Relationships!* NIDCAP training encourages positive relationships, collaboration and communication among care providers, families, and other stakeholders such as scientific societies, Parents associations and Universities involved in the newborn's care.
- *Seek Mentorship!* Mentorship from your trainer but also from experienced NIDCAP professionals and other trainees. They can provide guidance, feedback, and support as you navigate the complexities of implementing NIDCAP principles in practice.
- *Continuously reflect on your practice!* Seek opportunities for improvement. You are not alone on this journey. You are part of a Global community that is organized within the NIDCAP Federation International. You can participate

in different NFI committees. You can share your skills and experiences and be part of workgroups, supporting the growth of our organization. Take the initiative and contact the chairs of each committee. You'll find the contacts on the NFI website.

- *And finally, Be Patient with Yourself!* Implementing NIDCAP care takes time and practice. Be patient with

yourself as you develop your skills and understanding. Remember that every interaction with a newborn is an opportunity for growth and learning. Remember it is a journey, and it requires time, but also dynamism and determination. Build a team that supports each other.

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Column Editor: Debra Paul, OTR

The presence of siblings in the Newborn Intensive Care Unit is encouraged and recommended by the Standards for Newborn Care and parent organisations. Sibling support programs in the NICU have a vital role in implementation of Individualized Family and Infant Developmental Care. Siblings are an important part of a family's experiences and Sophia's story illustrates how the experience of having a sibling in the NICU can influence one's life and impact career choices.

How being a NICU sibling influenced my life

Sophia Gerassis

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I was two years old when my sister Dimi was born on Mother's Day, critically ill and premature at 30 weeks gestation with a 500-gram tumour in her chest. I would spend time with my family in the Newborn Intensive Care Unit (NICU) although I don't remember this. I grew up as a sibling to a baby that was in the NICU, and over the years I found it hard watching my sister in pain and the trauma she and my parents faced. It was very challenging in those early years of my sister's life. My parents spent many hours at the hospital, and I stayed with my aunty and grandparents, who gave me a lot of support. While I was growing up, the experience of sharing Dimi's history made me stronger in a way. I needed to be there for her, especially when I could see that she was worried and scared. After Dimi was discharged from the NICU she needed to go to the Children's Hospital for follow up blood tests and scans till she was six years old. I would usually go with mum and Dimi and remember how scared Dimi would be. I was extremely protective of my little sister, and we were inseparable. As we got older, the bond we had continued. I am proud of Dimi, and we have a good relationship, although she is two years younger, we are still very close.

As I grew older my parents became involved in fundraising for the NICU and hospital. I was very grateful to be involved as it taught me to be appreciative and that raising awareness of the work of the NICU is important. Other people get to see what my family went through and the important role NICUs play. My Mum fundraises a lot and she shares Dimi's story to give other families hope.

I have been actively involved with fundraising. Mum has encouraged us to give back to the hospital. As a family we have organised a successful Gala Dinner in 2016 and other fundraising events, and we also wrap and deliver gift packs for Mother's Day, Father's Day, Christmas, NIDCAP Day as well as take part as a family in the annual Race for Grace bike marathon. My parents attend the annual Grace Gala and my sister, and I have also attended two of them. I think my life has been entwined with the NICU, the doctors, nurses and therapists.

Bringing our story to life

In 2023, I graduated from year 12 high school at All Saint's

Grammar in Sydney. For my subject of Visual Arts, I had to complete the theory of various influential artists and a practical of a series of major works based on a theme.

I created a series of oil paintings to portray the trauma faced by my family because of my sister's complicated birth. My family was informed in the NICU my sister had a 10% survival rate, leaving them in an extremely vulnerable and emotional state.

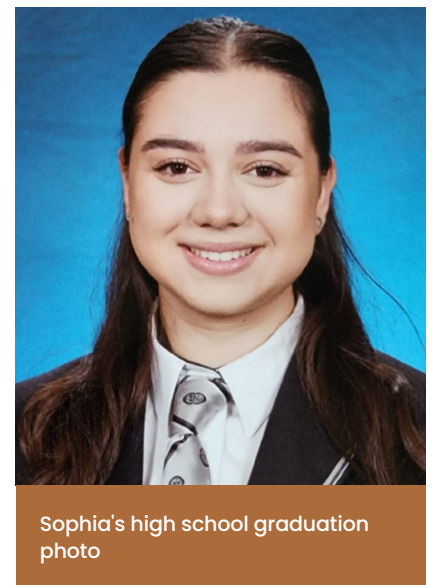
These emotionally charged artworks serve as a testament to my family's challenging and unforgettable experience, with the aim to raise awareness of the severity of this situation. Through this body of work, I sought to evoke a poignant blend of vulnerability and hope, capturing the transformative journey of my younger sister.

The first canvas shows my sister just after surgery – this was her worst point. It draws out vulnerability and is confronting to capture the audience. My intention is to show people the power of faith.

The second canvas shows people that from a bad situation things can get better – it portrays hope and faith. I wanted to raise awareness that without the NICU the situation would have been different.

The third canvas shows me and my sister. She is getting better on the road to recovery. It is very special as it shows me and her connecting on the road home.

While the genesis of my art is rooted in personal experience, various artists have influenced my creative practice. Among them, Alyssa Monks (<https://www.alyssamonks.com/>)



Sophia's high school graduation photo



Canvas 1



Canvas 2



Canvas 3

stands as a significant inspiration. Her profound artworks capture the essence of vulnerability and intimacy in the human experience, navigating the disquieting spaces of emotional distress. Drawing from the same medium, I have endeavoured to emulate Alyssa Monks' painting style, melding realism with a confrontational subject matter, thereby attempting to forge a powerful connection with the viewer.

The paintings not only offer a glimpse into my family's perseverance through our personal journey but also serve as a catalyst for broader discussions about the challenges faced by families in similar situations.

The power of storytelling through art

I found when my art was on display people don't say much – maybe they are in a state of shock. However, when they read the story, they seem to understand.

The three pieces took me nine months to complete. While I was painting, it brought back feelings and emotions. It also brought back emotions for my mother which I found was very touching. It was hard to balance all my studies during my final year of school. I had to meet a deadline with my bodies of work which needed to be submitted for Higher School Certificate marking. I also needed to allow time to study for my upcoming exams. It was difficult but I am proud of myself for being able to complete and achieve great results.

Creating connections through art

I would like people to see things from a sibling's perspective and to be aware of the effect the experience and the trauma can have on a sibling. For me it resulted in a strong connection between me and my family to the NICU (Grace), that's why we fundraise and are passionate about making a difference in the lives of others.

I want people to feel a connection to the artwork. They may not have had the same experience, but they can appreciate those who have.

My message to other siblings of NICU babies is to have hope and be there for them. In the end, with lots of love, patience and with all the amazing medical help, everything will be okay.

You must have strength. I also think it is important for siblings to be present in the NICU, so that the family is whole during that stressful time.

I am now about to embark on my career. I started at Macquarie University in February 2024 where I have enrolled in a double degree of Speech & Hearing Sciences and Psychology. This is a four-year course with an additional two years for a Masters in Speech Therapy, a total of six years. My sister was seeing a speech therapist when she was younger, and I became interested in Speech Therapy. Ultimately, I would love to work with children and help them overcome their speech issues. Helping others makes me happy. I was also looking at courses that would not be taken over by Artificial Intelligence in the next few years, as well as courses in demand. I am hoping eventually to have my own practice.

Painting is a hobby, and I will keep doing it as I enjoy it and it helps me relax. I have attended art classes since I was six years old and now teach art to other children. I have also sold a few of my creations. My favourite works are my series of major works – called Tiny Miracles – named after Mum's organisation. It was very personal – links into my sister who was tiny and also our miracle!



Sophia painting

Words from my sister

“Seeing the paintings made me feel special and honoured that Sophia did her major works on me and my difficult start to life. It made me feel different and the way it affected my family. My sister Sophia is very special to me, more than just my sister, she is an inbuilt best friend. I want to keep doing things for the hospital and keep a connection as they saved my life and also save the lives of other babies every day.”

Words from my mother

“It was emotional watching Sophia paint. I am very proud and impressed with her work, even more so because of the strength and maturity she showed during the whole process. It has shown me that Sophia felt strongly about the subject and her connection to Dimi. As a two-year-old, Sophia always sat quietly with Dimi in the NICU. It was important for her to be there, so we were all a family together.”



Sophia's family contributing at fundraising event for the NICU

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Global Perspective on Developmental Care in Qatar

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The State of Qatar is in the Middle East and occupies the northeastern coast of the Arabian Peninsula. The capital is Doha. The population of Qatar is nearly 3 million people, and the country is home to over 100 nationalities, of which around 15% are Qatari citizens and the rest are expatriates. Islam is the official religion of the state, but followers of different religions live in Qatar. Arabic is the official language of the country and English is a widely spoken second language.

Healthcare standards in Qatar are generally high. Over the last ten years, there has been substantial investment in maternal and child health. The leading public non-profit healthcare provider, established by the government, is Hamad Medical Corporation (HMC), which offers family-centered maternity care. The HMC runs a network of hospitals, community clinics, ambulance services, and a home healthcare service. The HMC is accredited by the Joint Commission. It also has the Primary Health Care Center (PHCC), which runs 27 regional centers across the country. There are a wide range of private healthcare options. Approximately 70% of the population use the publicly funded system, which is available to all regardless of nationality. Around 30% access healthcare through the private sector.

There are five maternity hospitals with 32,000 newborn deliveries annually, 99.5% are hospital deliveries and 10% are premature births. The neonatal mortality is 4.28/1000 births. Perinatal and maternal mortality rates in Qatar are comparable to most high-income countries. The consanguinity rate is around 54%. There is one tertiary Neonatal Intensive Care Unit (NICU) offering cardiac and life-saving surgeries, two additional Level 3 NICUs, four Level 2 neonatal units caring for babies less than 32 weeks, and six Level 1 neonatal units (primary care).

Qatar's developmental care practices and NICU initiatives focus on a holistic approach to patient well-being. They emphasize the integration of the cultural sensitivity of the region and respect the values and beliefs of families in Qatar. Parental awareness of the benefits of family-centered care and parental partnership in caregiving in a hospital setting is still evolving in the region. Majority of staff have no formal training in developmental care provision, and developmental care practices are not standardized across the neonatal units. Majority of units do not offer 24-hour access to NICU parents.

The NICU

The Sidra Medicine Hospital is a Women and Children's hospital and academic medical center. It employs more than



4,000 highly trained multidisciplinary clinical and support staff representing over 95 nationalities. The staff are drawn by an ambitious vision to care for women and children and to partner with parents in their child's health care delivery.

The NICU at Sidra Medicine, which opened in 2018, is the only tertiary NICU in Qatar. It is staffed with a 35-member medical team. There are 150 nurses, dedicated NICU allied health professionals, pharmacists, and social workers, and training for doctors (Fellows and Residents). This is a referral hospital for high-risk pregnancies, infants who have life threatening illnesses, and/or rare congenital problems. Care is extended to critically sick infants, those with complex illnesses, and preterm infants from the viability threshold of 23 weeks

gestation. Hence the NICU's acuity is generally very high. About 40% of infants are born elsewhere and referred for conditions requiring specialist care. The NICU has 42 NICU cots spread over two floors in all single-family rooms conducive to delivering family-centered care. The average length of NICU stay is 29 days.

There is a multinational-multicultural global staff community with varied developmental care knowledge and training. Over the last five years, the staff knowledge gaps, staff-parent cultural-linguistic barriers, and the organizational challenges of a relatively new and diverse NICU were tracked. Protocols have been established, introducing multiple quality initiatives, and delivering staff training in developmental care.

Working Towards a Standard of Individualized Developmental Care

There has been continued efforts to improve the outcome of newborns and to provide standardized individualized developmental care. In 2022, the former Division Chief, Dr. Charlotte Tscherning, initiated Family and Infant Neurodevelopmental Education (FINE 1) for all NICU staff. In 2023, a selected nine-member multidisciplinary team (MDT) of a neonatologist, neonatal nurse practitioner, physiotherapist, speech-language therapist, respiratory therapist, and four neonatal nurses were FINE 2 certified. Since 2023, a collaboration with Newborn Individualized Developmental Care and Assessment Program (NIDCAP) professionals abroad has promoted key concepts of NIDCAP. Ongoing efforts continue for staff education, professional development opportunities, and attendance at international conferences for exposure to the latest evidence-based Infant and Family Centered Developmental care (IFCDC) practices.

The parents and families in the NICU are multicultural and multinational with a wide range of socioeconomic and linguistic backgrounds. Parental involvement in care is highly varied in this region due to family and job commitments. Also, awareness and appreciation of IFCDC is still evolving, as most families are used to the traditional concept of the nursing-medical team being the caregivers. Many families rely on private nurses and/or nannies to help with care of their infants. Also, patient complexity and critical illness in a tertiary NICU often makes it is very difficult for parents to bond with their infant.

Parents are seen as their infants' natural care givers. The focus is on enabling parents to be confident, knowledgeable, and independent caregivers. Parents are welcomed around the clock and there is an inclusive rounding policy, and a 24-hour interpreter service to tackle linguistic barriers. Parents are encouraged to be involved in their infant's care. They are supported to achieve parenting skills in routine caregiving and in recognizing their infant's needs. Parent-tailored education is delivered. The discharge process and parental education commences at admission.

Paramount importance is given to optimizing parental psycho-social support and well-being. The NICU is staffed

with two dedicated social workers who meet every family within a few days of admission. Palliative care and bereavement support is provided. Onsite Women's Mental Health Team expertise is available too.

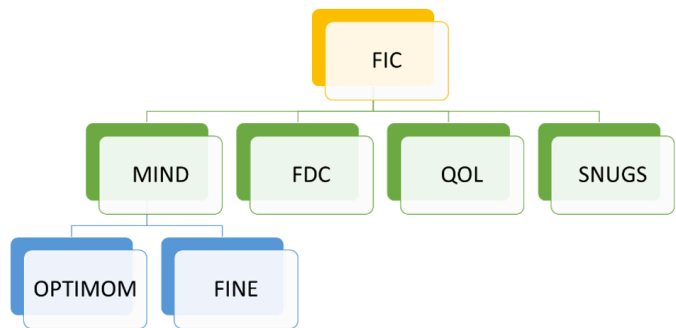
Developmental Care Initiatives

The core MDT of over 100 members (Medical, Nursing, Allied Health, Health Assistants, Social Workers, Lactation consultants, Administrative Staff, Parent Support Professionals), called 'Family Integrated Care' (FICare), works together to promote and practice evidence-based IFCDC. It seeks to reduce the disparity between the intrauterine environment and the NICU and to optimize the potential for optimal outcomes for patients and families.

The team created clear guidelines and introduced multiple quality initiative (QI) projects (Figure 1). 'Managing Infant Neuro Development' (MIND) is a QI focusing on bridging gaps in developmental care. It seeks to optimize positioning and nesting, increase the number of babies enjoying skin-to-skin care, attend to focusing on environmental noise and light exposure minimization, minimizing pain and stress, promoting infant-driven, cue-based, positive safe feeding practices, increase the number of babies receiving breastmilk at discharge, work towards a Baby-Friendly hospital, and commence infants on Mother's Own Milk (MOM) within 6 hours after birth (OPTIMOM QI).

NIDCAP concepts are recently being implemented by the FINE QI. They include components incorporating bedside behavioral observations into the care of babies, supporting regulatory behaviors, individualizing care, developmentally supportive handling, protecting baby's

Figure 1: Quality Initiatives Implemented at Sidra Medicine NICU For Optimizing Developmental Care.



- Managing Infant Neuro Development (MIND)
- Family-Centered Discharge Care (FDC)
- Optimizing Mother's Own Milk (OPTIMOM)
- Quality Of Life (QOL)/ Palliative care group
- Sidra Neonatal Unit Group Support (SNUGS)
- Family And Infant Neurodevelopmental Education (FINE)

sleep states, promoting cluster care individualized to each infant, swaddled weighing and bathing, creating awareness of the benefits of reading and talking to babies, and incorporating all these into routine care.

A Parent-Peer Support Group called 'Sidra Neonatal Unit Group Support' (SNUGS) was started. This group offers culturally sensitive support for parents of patients who share common experiences. It also serves as a platform for delivering parent education on IFCDC practices. Parental feedback is regularly sought and is considered an important, valuable parameter for continuous improvement.

The palliative care QI, 'Quality of Life' (QOL), offers supportive care to families of patients in the final phase of a terminal illness as well as focusing on comfort and quality of life of infants with complex illness. The team identifies and meets with families to discuss palliative plans, to support decision-making incorporating traditions and customs into care, and to promote emotional well-being.

An MDT called 'Family-Centered Discharge Care' (FDC) developed a family-centered discharge process that starts from admission. It focuses on timely and safe discharge practices, and incorporates parent tailored education and preparedness for discharge. Weekly MDT meetings were implemented to discuss progress and to highlight barriers to be addressed. A weekly list of babies for upcoming discharge, the 'NICU Graduate' list, is generated to ensure timely completion of pre-discharge tasks. At discharge, every baby is congratulated and presented with a NICU Graduate certificate.

Family-Centered and Developmental Care Resources, Recognitions, and Celebrations

There are a range of family-centered bedside tools aimed at improving parent-staff communication and communicating progress to parents. These tools include: the What's Up Patient Care Board, the Train-To-Home, and the Care Team card.

Recently, we introduced multidisciplinary bedside developmental rounds. These rounds focus on promotion of bedside family-centered tools, partnering with parents in bedside care, and bedside staff education.

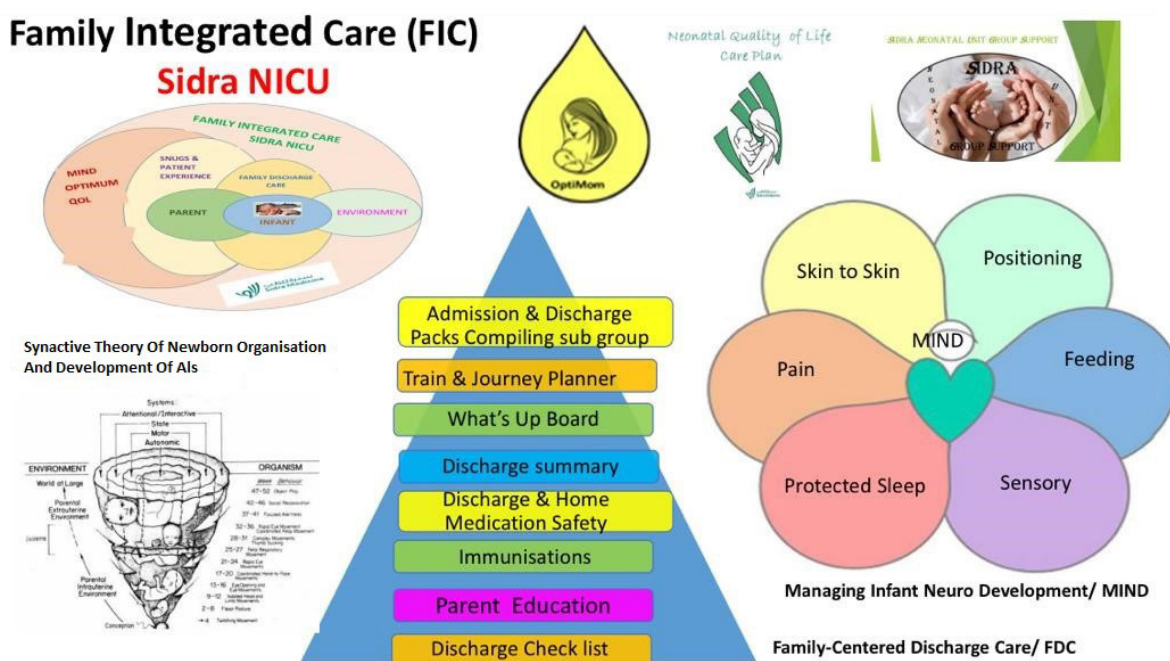
We have been observing Breastfeeding Awareness week, International Kangaroo Care Awareness Day, Pain Awareness Week. We promote best practices in each of these areas. We also celebrate special NICU days, including Mother's Day, Father's Day, and 100th NICU days with parents-families. World Prematurity Day is well celebrated every November 17th.

Weekly protected educational sessions, staff study days, and orientation for new staff to address the challenge of high nursing staff turnover, is ongoing to ensure optimal quality of developmental care.

Assuring and Evaluating Developmental Care Quality

By continuously monitoring practices and QIs, the NICU data shows successful implementation of the QIs. There has been gradual improvement in parental engagement and awareness of the benefits of parental caregiving. Staff and parent feedback and anecdotes ascertain improved experiences and satisfaction with the QIs.

Figure 2: A synopsis of the SIDRA NICU IFCDC Quality Initiatives over last 5 years.



Well-established post-discharge monitoring pathway and follow-up clinics for high-risk infants (HRIF clinic) have been implemented. During these clinics, a multidisciplinary team assesses the neurodevelopmental progress of vulnerable newborns with standardized developmental assessment tools. Additionally, every infant discharged from the NICU is reviewed at the NICU Discharge Clinic. This is reassuring for the parents and improves a safe discharge process. There is no community support post-discharge. NICU Palliative Clinic support is offered to parents of infants being discharged on 'Do Not Resuscitate' (DNR) plan and Bereavement Clinic support is available for families of deceased NICU patients.

Ongoing Integration of IFCDC

We continuously work to encourage parents to actively participate in their infant's care journey and to increase our professional expertise. Areas for improvement are identified. Challenges are continuously addressed.

Funding for educational activities, staff training and resources for optimization of developmental care is provided internally by the organization. These efforts are immensely supported by the Divisional Chief, Professor Samir Gupta, and leadership.

There is emphasis in the importance of investing in these practices for the long-term improved outcomes of infants.

Weekly protected educational sessions, staff study days, and orientation for new staff to address the challenge of high nursing staff turnover are ongoing to ensure optimal quality of developmental care. There is additional emphasis on research endeavors, the aim is to collaborate with the local Neonatal Network and with international institutions.

There is a commitment to improve and grow in the provision of standardized IFCDC practices, to use any potential opportunities in this area, and to liaise with NIDCAP professionals to maximize NIDCAP-individualized, developmentally oriented care.

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NICU FINE 2 Certified Professionals, *Sidra Medicine, Doha, Qatar*

Rhyme & Reflect

Diane Ballweg, MSN, Developmental Specialist at WakeMed Hospital in Raleigh, North Carolina, USA

A Sleepy Request in the NICU

BUZZ, BANG, BEEP

*Hey, I'm trying to sleep!
This noise, as studies agree, makes me not as
well as I could be.
Undisturbed sleep helps me grow from head to
toe, you see.*

WHIZ, WONK, WHAM

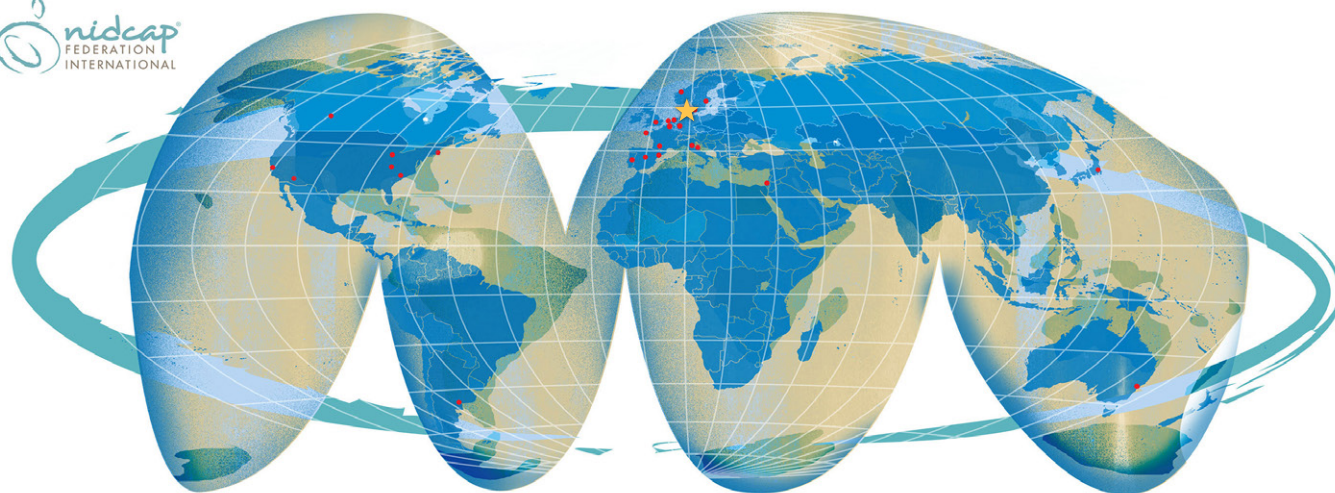
*Who do you think I am?
Healthy and big? Not born too soon? Not easily
disturbed? Eat beans with a spoon?
Alas, that's not me, as you know, so help me
sleep, develop, and grow.*

SLAM, SPLASH, SQUALL

*I am small, and that's not all.
I may be sick, with the ick.
With bunches of blam, boom, jibber-jabby, I don't
sleep, and I feel crabby.*

PLUNK, POP, PITTER-PATTERS

*Heidi taught us that everything matters.
In the NICU I dwell, and I'm not so big or so well.
I need sleep, light and deep, so please, not a
peep while I sleep!
Thank you!*



Danish NIDCAP Training and Development Center, Aarhus

Tenna Gladbo Salmonsens, RN, MScN, NIDCAP Professional, Co-director, and Eva Jørgensen, RN, NIDCAP Trainer.

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The Danish NIDCAP Training and Development Center, Aarhus, was established in 2015 as the first NIDCAP center in Denmark. The center is located in the Central Region of Denmark, hosted by Child and Adolescent Medicine, Aarhus University Hospital in affiliation with the neonatal intensive care unit.

Our journey towards implementation of developmental supportive care, in our Level 3 neonatal intensive care unit (NICU) at Aarhus University Hospital, started in 2005 with NIDCAP training by senior NIDCAP Master Trainer Agneta Kleberg followed by lectures and bedside education of staff by Eva Jørgensen. In 2006, Hanne Aagaard, and Eva Jørgensen were certified as NIDCAP professionals. In addition to continued implementation and education in our unit and in Denmark, we founded a national NIDCAP network in 2006, together with NIDCAP professionals in Denmark, to share experiences and to support each other implementing NIDCAP. In 2009, Hanne Aagaard received her Ph.D. degree from Aarhus University with the title: Preterm Mothers Experiences, Self-esteem and Support. In the establishment of the training center in Aarhus, we were supported by senior NIDCAP Master Trainer Agneta Kleberg and APIB Master Trainer Deborah Buehler and in 2015, Eva Jørgensen was certified as a NIDCAP Trainer. Hanne is now Professor in Neonatal Nursing at Lovisenberg Diaconale University College, Norway.

In our NIDCAP Training Center, the primary objective is to encourage the implementation of developmental supportive



Map of Denmark showing the central region highlighted in rust color.

care for the growth and well-being of newborn infants and their families. Our vision is to support and empower families, and support the multidisciplinary team overall in achieving this goal. Our approach involves initiating Newborn Individualized Developmental Care and Assessment Program (NIDCAP) education and Family Infant Neurodevelopment Education (FINE) within our own NICU, the Pediatric Units caring for newborns without the need for intensive care, the Maternity Unit, and the Labour ward (midwives). We disseminate this educational outreach to local hospitals by theory and protocols for handling both elective procedures and urgent interventions in newborn care. On a global scale, Eva Jørgensen, our Center's NIDCAP



Part of the Aarhus NIDCAP Team

Trainer, contributes to the development of Standard of Care plans for the European Foundation for the Care of Newborn Infants (EFCNI).

We offer FINE Level 1 training to all newly hired nurses as a part of the introduction program, and they are in the following months supported by structured NIDCAP bedside guidance with an increased focus on the autonomic system, feeding and attention to the infant's behavior. This is a part of the overall implementation strategy.

Our goal is for all nurses and doctors to complete FINE level 2 training, we are on our way – although it will be an ongoing process. FINE 2 is important to support the overall level of developmentally supportive care. It gives a broader understanding of Al's Synactive Model of Infant Development and a more consistent language among health-professionals across all levels of experience. Furthermore, and very importantly, it strengthens the communication with parents.

A FINE 2 certified nurse says: *"The experience of a professional quality improvement - and thus a significant professional*

satisfaction - has contributed to a great personal fulfillment." Further she says, *"The FINE 2 educational program has also contributed to enhancing the dialogue with parents."*

A doctor says, *"Observing the infant and families from the bedside during medical procedures, feels like having just been given eyes and ears for the first time in our own Unit! What you see cannot be unseen."*

Our team is growing.

The team at the Danish NIDCAP Training and Development Center, Aarhus and our NICU at Aarhus University Hospital has great support from our multidisciplinary leadership. We are currently four NIDCAP professionals and further three are in training. We are proud of having a family-representative, who also has had a strong connection to the national parent organization, as a member of the steering group for the NIDCAP Training Center. It expanded our perspectives, when talking about collaboration with parents.

Collaboration

In close collaboration with the newly established Danish NIDCAP Training and Development Center, Copenhagen, we have developed a non-pharmacological standard operational procedure for a study.

The key focus is a structured observation of the infant's comfort and provision of supportive care before, during and after a procedure. We aim to implement the protocol for any medical procedure in the NICU and all clinical research, that involves manipulation or interventions at the patient level. A dedicated nurse is responsible for environmental preparation, supportive positioning, observation of the infant's communication signs, and pacing the task accordingly to ensure minimal challenge, discomfort, and a pain-free procedure for the infant. Collaborating with parents, the nurse prepares the infant through environmental modifications such as adjusting light and noise, maintaining warmth, and providing supportive bedding. Continuous communication between the nurse and other team members provides an environment to support the infant during the procedure.

More research to come.

While increasing the critical number of NIDCAP and FINE certified staff, we have also fertilized the ground for creating new knowledge. We plan to compare the need for pharmacological intervention on the comfort of the infant and parents during and after predefined procedures using the standard operating comfort procedure described previously, with no standardization procedure.

Patient-Centered Learning

The support of the infant starts with understanding how we as NIDCAP professionals, can provide an environment and comfort for the baby. In addition, to empower families to become involved in their infant's daily care and feeding, and to support

them during medical examinations and procedures. NIDCAP Professionals work clinically at the cot side with parents and other health professionals, showing them their observations, reflections and supporting them to see clearly the behaviors of the baby. This enables the family and healthcare professionals to gain knowledge and skills and apply this to the care of the infant. Bedside observations provide insights into the infant's response and needs. This hands-on learning approach is crucial for developing a thorough understanding of developmental supportive care in our Unit. It Improves communication skills, decision making in care, and collaboration with parents, and promotes multidisciplinary teamwork in support of the infant's development.

This statement by a nurse supports our work. *"Through increased awareness and understanding of the NIDCAP approach, I have been able to optimize and structure the environment,*

enabling me to effectively support each child with individually tailored care and nurturing. The enhanced skills have resulted in an experience of being able to fulfill my core responsibilities in a much more qualified manner."

The team at Danish NIDCAP Training and Development Center, Aarhus:

NIDCAP trainer: Eva Jørgensen, RN

Training center director: Tine Brink Henriksen, MD, Professor, Consultant Chair, PhD

Training center co-director: Tenna Gladbo Salmonsén, RN, MScN, NIDCAP professional.

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Danish NIDCAP Training and Development Center, Copenhagen

Jannie Haaber RN, Intensive care nurse, NIDCAP Trainer and Director of the NIDCAP Training Center and Porntiva Poorisrisak PhD, Consultant Neonatologist, APiB Professional, Co-director of the NIDCAP Training Center

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The Neonatal Intensive Care Unit (NICU) in Copenhagen was the first NICU in Denmark. It is also the largest NICU and the only level 4 unit in the Country.

Our NIDCAP journey in Copenhagen began in late 1990 when nurse specialist Janne Weis and nurse Dorthe Mai were introduced to NIDCAP. Before then we had a developmental and family centered care group of dedicated staff who worked with family focused care, minimal touch, and early discharge. Dorthe Mai was a leader in implementing hospital-assisted home care after early discharge in Denmark. The first family in Denmark to use early discharge was in 1997 provided by Dorthe Mai and the home care team from our unit.

In the year 2000, Janne Weis and Dorthe Mai became NIDCAP professionals with Agneta Kleberg as their NIDCAP Trainer and mentor. A new friendship and lifelong partnership were established with Agneta Kleberg. Her dedication and contribution as a person and as a professional have had a very positive and important impact of the strategy, vision, and goals for our NICU and NIDCAP journey.

In 2005, we went from an open bay unit to two family rooms with one parent bed next to the infant. It was a significant step towards more family centered care and strengthened the partnership between the healthcare professionals and the family. This move facilitated the families to be actively involved in the care for their infants, enabled shared decision-making and more individualized care plans for the infant and the family.

Over the years the NIDCAP team expanded Janny Hoegh

and Jannie Haaber, two nurses who became NIDCAP professionals. Janne Weis completed her Ph.D on Family focused and guided conversations using a semi structured conversation form with a focus on partnership. This represented a huge milestone in the unit's journey towards enhancing Family Centered Care in practice.

NIDCAP certificated unit

Becoming a NIDCAP certified unit in 2015 was undoubtedly a significant achievement and a testament to the unit's commitment to provide high-quality individualized developmental care for infants and families. The accomplishment was a culmination of years of dedication, hard work and support and engagement from the leadership. Without leadership support it wouldn't have been possible. The NIDCAP Nursery Program with its 121 points is a comprehensive evaluation framework that provided a structured approach for identifying areas of improvement and setting of new goals for enhancing care for infants and families. It enabled us to recognize the units existing strengths. Celebration of our achievements, both big and small, is very important for boosting the morale, enhancing teamwork, and maintaining motivation for providing high quality care. We continue to celebrate in our daily work.

In 2020, the unit was re-certified in the NIDCAP Nursery Program. Re-certification is a lifelong commitment and an ongoing evaluation and reflection of how we take care of infants, families, and each other. Now and in the future. The NIDCAP

Nursery Program and guidelines will be used in preparation for our new Childrens Hospital - Mary Elizabeth Hospital- for Children, Teens, and Expecting Families for Children.

Since 2015, the unit has had an interdisciplinary NIDCAP group, consisting of a team of experienced healthcare professionals all working to support development care in a family centered way. The group is led by Jannie Haaber (RN, NIDCAP Trainer) and Porntiva Poorisrisak (Neonatologist, APIB Professional). Since 2020, the NIDCAP team has had a parent consultant, who first of all is mother of a preterm infant and also works in her professional life as a family advisor for families with preterm infants. Our parent consultant is member of the advisory board in the Danish Organization for Preterm infants and their families. Inclusion of a parent consultant in the NIDCAP group together with a parent consultant in the leader group of the unit, reflects a commitment to prioritizing the family's needs and experiences. Hopefully contributing to more responsive and compassionate care for infants and their families during their stay in the unit.

Becoming a NIDCAP Training Center

NIDCAP Nursery Certification was the first milestone reached in preparation to become a NIDCAP Training Center.

The designation as a NIDCAP Training Center signifies a recognition of the unit's commitment to be role model for other healthcare professionals and a responsibility to share knowledge and expertise both within and beyond our own NICU. By offering education and training our unit now has the possibility and responsibility to empower healthcare professionals to integrate NIDCAP into their own practice- to improve wellbeing, development and outcomes for infants and families.

Leadership support and involvement is crucial for a successful implementation of becoming a NIDCAP Training Center. And luckily there has been a huge support from the leaders of the unit and the Hospital. Support to ensure resources, to address barriers proactively and to inspire and motivate staff being a part of the journey and pride of the achievement as a team.

In 2019, Jannie Haaber started as a NIDCAP trainer in training and Porntiva Poorisrisak became a APIB Professional in training at the same time as suggested and supported by Agneta Kleberg. The decision to have Jannie and Porntiva work together on APIB training was a strategic move, groundwork for their future leadership roles within the NIDCAP Center. Of course, again with great support from Head of Department Morten Breindahl and Head Nurse of Department Sanne Allermann Beck who are the Medical and Nursing directors in the NIDCAP Center, Jannie Haaber is Director and Porntiva Poorisriak is Co-Director of the Center.

During the process of becoming a NIDCAP trainer and APIB Professionals Jannie and Porntiva had a very close collaboration with Nikk Conneman, NIDCAP and APIB Master trainer and Pernilla Stenman (NIDCAP Trainer in training at that time) from Lund in Sweden. Having supportive partners throughout the journey has undoubtedly enhanced the experience, made

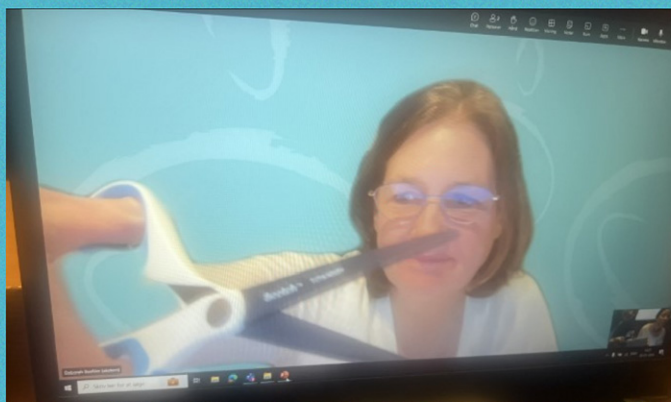


NIDCAP Team

possibilities for feedback, reflection and provided encouragement to keep on. A partner in crime is very important throughout the journey to become a NIDCAP trainer and to establish a NIDCAP Center. Sharing, caring and exchange.

In August 2023, we reached the milestone to become a NIDCAP Training Center where Jannie finished as NIDCAP trainer and we could celebrate having two more NIDCAP Professionals in the unit- Laerke Johanne Bager and Maria Clemenn Kaas, two intensive care nurses.

The Center was officially opened on 26 January 2024, the same day celebrated with a conference day. All NICUs in Denmark and collaborative pediatric units at the hospitals were invited. There were 130 healthcare professionals from all over the country and the NIDCAP team from Lund/Malmö attended. With fantastic speeches from Agneta Kleberg, Nikk Conneman, Stina Klemming and Deborah Buehler the participants were enriched with an understanding of NIDCAP, architecture of brain, brain protection, the importance of keeping family together and support skin to skin contact from the very beginning. Agneta received a well-deserved standing ovation for her tremendous work, her expertise, passion, and impact on countless infants, families, and professionals she has trained. At the end of the day the ribbon was cut and the Danish Center NIDCAP Training and Development Center,



Becoming a NIDCAP Training Center



Copenhagen was officially opened. Afterwards we celebrated with music, champagne, and cake.

Collaboration

For several years there has been a Danish NIDCAP center in Aarhus with Eva Joergensen as NIDCAP trainer and Tenna Samuelsen and Tine Brink as directors. Having a national NIDCAP center nearby should not be undervalued and makes opportunities for support, shared learning and collaboration in joint projects and initiatives that can have significant impact locally and nationally. Already we have worked together describing non-pharmacological approach for LISA (Less Invasive Surfactant Administration) procedure as part of a PhD project. We are looking forward to more future interventions or project together.

Education, projects, and research

As mentioned, being a NIDCAP Certified unit and a Center we are committed to being role models.

In the beginning of April, the nurse leadership were the first group in the unit to complete Family Infants Neurodevelopmental Education (FINE 1). FINE 1 will be an obligatory part of the nurse's development and training program in the unit. In spring 2024, the interdisciplinary leadership, Jannie and Porntiva will make plans for FINE and NIDCAP education in the unit. We are looking very much forward to collaborating with other units and hospitals in the future.

Qualitative improvements and research is a high priority in the unit:

During the last year we have established group sessions for mothers, fathers and families which are provided once a week. All group sessions are supported by members of the NIDCAP group. There has been fantastic feedback from parents and families.

A new protocol for Golden Hour, day and week has been made for extreme premature infants and a new protocol for skin-to-skin contacts for the youngest born before GA 25 weeks.

We also are in the beginning of working structurally on how to keep families together with CPAP treatment at the delivery room to prevent hospitalization. We begin with the latest preterm and full-term infants.

NIDCAP member Ragnhild Maastrup, RN, PhD and IBCLC specialist has a leading role in our Neonatal Interdisciplinary Research. Ragnhild has undertaken and still does research about preterm infants and breastfeeding.

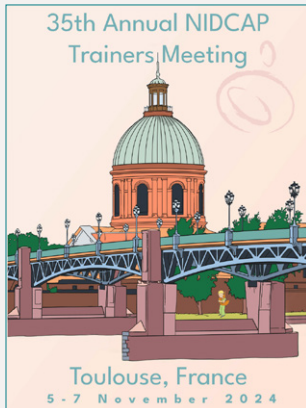
In the NIDCAP group we have at the moment three nurse PhD students. Rikke Steenkjaer has focused on pediatric delirium. She and the team are researching non-pharmacologic interventions in line with NIDCAP principles to prevent and manage pediatric delirium in critically ill children aged 0-17 years. International PICU experts agreed on a bundle of interventions such as developing daily structure, adjusting light exposure according to the time of day, scheduling time for sleep, providing eyeglasses and hearing aids if appropriate, and family involvement.

Joan Neergaard Larsen and team are researching couplet care, keeping families together. The project aims to prepare for a couplet care intervention in 2026, when all neonatal, paediatric, and obstetric departments at our hospital will relocate to the new Mary Elizabeth's Hospital. The new hospital will have single-family rooms with the ambition of keeping families together.

Mette Petersen has just recently been admitted as PhD student. This PhD project is a national intervention study aiming to support first-time fathers (FTFs) of preterm infants in early parenthood. The title of the PhD project is *Development and process evaluation of a family healthcare intervention supporting first-time fathers of premature infants admitted to a neonatal unit and their transition to everyday life at home.*

All above mentioned are just a few of initiatives we have been or are working on. Our future goals will continuously be to provide the best possible care and treatment for infants and families- thanks to NIDCAP and the network, all the dedicated staff in our unit, trainers, inspiring people, and research.

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The 35th Annual NIDCAP Trainers Meeting

NIDCAP: Systems Integration at Local, Regional and National Levels

November 5-7, 2024

Centre de Congrès Pierre Baudis
11 Esplanade Compans Caffarelli
Toulouse, France

Hosted by the French NIDCAP Center, Toulouse
(By invitation only)

Annual NFI Membership Meeting

November 5, 2024

Time TBA

Centre de Congrès Pierre Baudis

11 Esplanade Compans Caffarelli

Toulouse, France

(Members may also attend via Zoom)



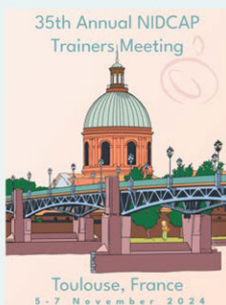
OPEN ONE-DAY CONFERENCE

Thursday, November 7, 08:00-18:30 CET

Centre de Congrès Pierre Baudis
Toulouse, France
Hybrid Meeting

SPEAKERS

Deborah Buehler, PhD
Adrien Tacquet
Naïs Baschet, MD
Delphine Druart, RN
Monique Flierman, MSc
Aurélien Guillou, RN
Peggy Laurant, RN
Kelly Janssens, RN, RM, LC
Pierre Kuhn, MD
Charlotte Bouvard
Debra Paul, OTR
Charlotte Tscherning, MD
Dorothy Vittner, PhD, RN, FAAN



SAVE the DATE

12^{èmes}
Journées
Francophones
NIDCAP

Open One-Day Conference

**NIDCAP: Systems Integration at
Local, Regional and National Levels**

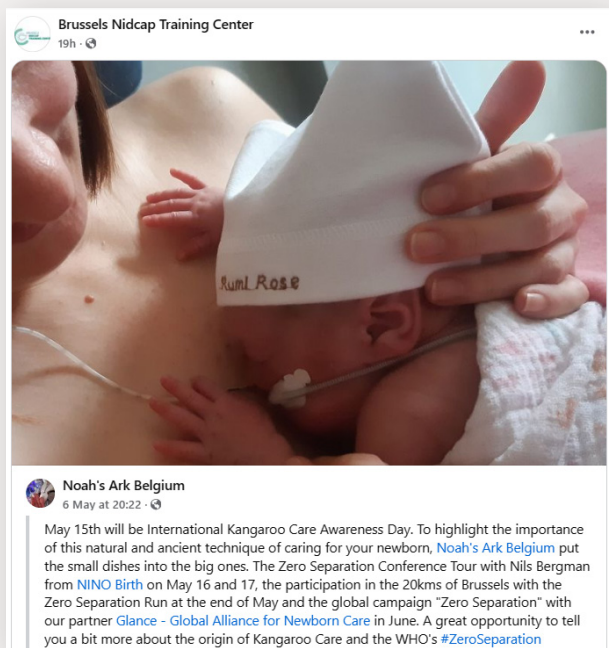
This conference is being held on the last day of the 35th Annual NIDCAP Trainers Meeting and the first day of the 12^{èmes} Journées Francophones NIDCAP. The purpose of the meeting is to equip the learner with the knowledge to provide high level and evidence-based, developmentally supportive care to hospitalized infants and their families.

Visit our conference page for details:

nidcap.org/7nov2024

NIDCAP Training Centers – Facebook Pages

The NIDCAP Training Centers have been active promoting their work on Facebook. Kangaroo Day and World NIDCAP Day were celebrated. We also have three new NIDCAP Professionals and an outreach program for developmental care.




Nicola Mangiapia
a day ago · 🌐

Today is World KANGAROO THERAPY Day. It's the "skin to skin" practice between mother and child. Every year a healthy care practice for the well-being of the premature newborn is confirmed.

MY Lobster 🍤 <https://www.nurse24.it/.../la-canguro-terapia-nei-neonati...>
Nidcap France NIDCAP Federation International EFCNI SIN INF Società Italiana di Neonatologia Infermistica SIN - Società Italiana di Neonatologia

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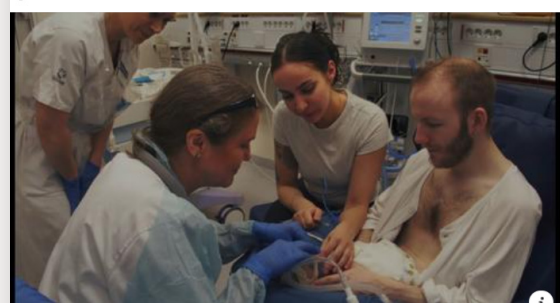
👍 17

👍 Like 💬 Comment

Nidcap Sweden
Yesterday at 11:08 · 🌐

New video from Skånes Universitetssjukhus about ROP screening examination in parent's knee with skin-to-skin contact before and after. The parent can co-regulate the child and provide the best support through potentially stressful and painful experiences through their body and hands, their scent, their voice and their ability to sense the child's needs. What procedures do you do in skin-to-skin contact?
#skintoskin #kangaroocare #kangaroocareday
https://youtu.be/w6tva0OhA9E?si=omAp3Y_JmpOlvYKE

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YOUTUBE.COM

Ögonbottenundersökning av tidigt födda barn med användning av vidvinkelkamera och i förälderns knä

👍 8 9 shares

👍 Like 💬 Comment ➦ Share

Nidcap Portugal

Nampula, Mozambique 🇲🇵


The mission "Healthy and empowered women: the key to healthy children and generations" is going on until May 24th.

Health professionals have set off for Mozambique to expand knowledge and provide mother-child support to the community of Nampula. 🙌

With the participation of Nurse Florbela Neto, NIDCAP professional and Fine trainer 🙌🙌

Florbela Neto
NEONA... See more

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health4moz.org 4h
Adicionado a 66ª mi... > ✕

Formação Mulheres Saudáveis Empoderadas

FLORBELA NETO
Enfermeira especialista em Saúde Infantil e Pediátrica / Neonatologia

Sophia Nidcap Training Centrum
20 March · 🌐



MARCH 20th
2024
nidadcap
nidadcap.org
30 Training Centres Worldwide
voice of the newborn
Changing Lives... Care for Newborns & Their Families

Nikk Conneman
20 March · 🌐

Happy World NIDCAP day!!!

NIDCAP TRAINING CENTERS

AMERICAS

North America

CANADA

Edmonton NIDCAP Training Centre

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OCEANIA

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SWEDEN

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MIDDLE EAST

ISRAEL

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