neonatal care academy

NCA JOURNAL

INNOVATION FOR NCA MEMBERS – CLINICAL NEWS AND FACTS

EDITION 3

THERMOREGULATION · HEARING SCREENING · BRAIN MONITORING · JAUNDICE MANAGEMENT · NEONATAL ACCESSORIES

EDITORIAL

Dear Readers,

Welcome to the latest edition of the NCA journal. At NCA, our vision is to partner with the expertise and experience of KOLs and clinicians worldwide, to deliver high quality educational content.

Our education delivery stretches across an on-line format, eSeminars, and In-person workshops and courses through our host of many events worldwide in the areas of Newborn Brain Injury, Family Centred Care, Jaundice Management, Hearing and Vision screening and more.

One of the Hot Topics in Neonatology today is FAMILY CENTRED CARE – this edition of the NCA journal will focus on issues surrounding this area, including Live Video Streaming, Working in Partnership with professional organisations such as EFCNI to enhance Family Experience, delivering Family Centred Phototherapy, and understanding the impact of hearing loss and early identification of this on families.

Don't forget to check back regularly on the NCA website for new updates – and follow us on social media to keep abreast of the many interesting educational activities being experienced around the world.

We wish you an interesting read and very much look forward to meeting you in person at one of our upcoming courses.

JUDY MOORE
Director of Medical Education and Training, Natus Medical Incorporated

COMBINING FORCES FOR PRETERM BABIES – THE EUROPEAN FOUNDATION FOR THE CARE OF NEWBORN INFANTS

EFCNI european foundation for the care of newborn infants

SILKE MADER. Chairwoman and Co-Founder EFCNI

IMPACT AND WORK OF EFCNI

The European Foundation for the Care of Newborn Infants **(EFCNI)** is the first pan-European organisation and network to represent the interests of preterm and newborn infants and their families. It brings together parents, healthcare experts from different disciplines, and scientists with the common goal of improving long-term health of preterm and newborn children.

In 2008, EFCNI was founded to improve the situation for preterm infants, ill newborn infants and their families, and to unite families over geographical and cultural boundaries to speak with one strong, growing voice. Before, parent organisations already existed in several, but not all European countries; cross-country coordinated activities and international exchange was lacking. Thanks to the work and empowerment of EFCNI, today, parent organisations for preterm infants exist in nearly all European countries playing an important role in:

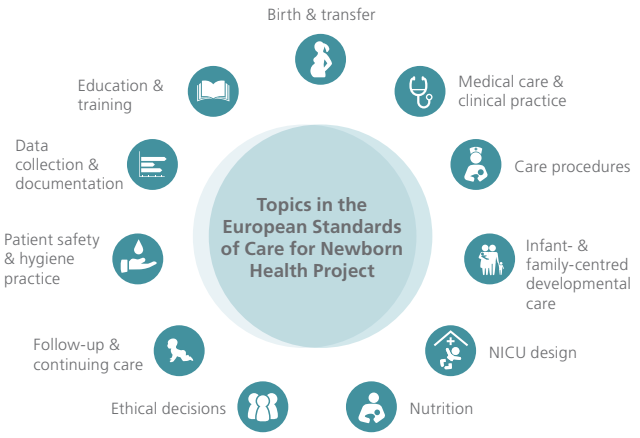
- providing a platform for affected families, sharing important information, and creating a network
- raising public awareness for the topic
- carrying out policy work and linking with healthcare professionals

WORLD PREMATURITY DAY

The pan-European cooperation began at a meeting in Rome in November 2008. Following EFCNI's invitation, 25 representatives from 18 nations came together to discuss options and goals for working together. During this trailblazing meeting the decision was made to initiate an official day for preterm infants worldwide. The date, 17 November, was chosen because of the personal story of loss and hope of one of EFCNI's founders. In 2018, about 120 countries celebrated World Prematurity Day and about 200 purple lightings of landmarks were captured.

ABOUT THE EUROPEAN STANDARDS OF CARE FOR NEWBORN HEALTH PROJECT

EFCNI is dedicated to improving the full spectrum of care by ensuring the best possible prevention, treatment, care and support, and promoting and protecting the right to the best start in life for every baby. Amongst others, EFCNI's project – the *European Standards of Care for Newborn Health*, is a milestone project for ensuring European-wide harmonised treatment for all infants. The *European Standards of Care for Newborn Health* project aims to address the disparities in provision and quality of care existing in Europe by developing reference standards, which are covering the most important topics associated with preterm birth and neonatal morbidity. These European standards are intended to be used as a source for a national development of respective binding and implemented guidelines, protocols, or laws (depending on the local situation).



Besides medical topics, the project also addresses topics such as infant- and family-centred developmental care. The Topic Expert Group on infant – and family-centred developmental care focuses on newborn care that is centred around the infant and the infant's family and their close supporters in order to support optimally the infant's health and development. The strategies for implementing this approach are based on supporting the unity of infant and parents, i.e. family access and integration into all care, early bonding, shared-decision-making, and parental involvement as the primary caregivers.

It is an absolutely unique project, as for the first time, such recommendations have been initiated by a patient organisation and, working hand in hand with healthcare professionals, parents (representing the little patients – preterm and ill infants) have been involved in every step in setting up this new framework. Developed over five years through the voluntary commitment of about 220 renowned international healthcare experts, patient representatives and further stakeholders, the newly launched standards are supported by more than 170 healthcare professional societies and parent organisations. In the course of the launch of the standards, the *Lancet Child & Adolescent Health* even issued a full editorial on the topic (see link).

http://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(18)30369-9/fulltext

In 2017, the project was awarded one of the most innovative Landmarks 2017 by the initiative Germany – Land of Ideas. The project was made possible thanks to the voluntary contribution and commitment of the project members and the financial support by the project industry partners AbbVie, Baxter, Nestlé Nutrition Institute, Philips Avent, Philips, and Takeda. Thanks to Dräger for supporting the project from 2013 till 2015 and to Shire for supporting the project from 2014 till 2018.

The complete European Standards of Care for Newborn Health, the Call to Action (in 20 languages) and further materials are available for download on the website *https://newborn-health-standards.org*

ABOUT THE GLOBAL ALLIANCE FOR NEWBORN CARE (GLANCE)

GLANCE is the first global network to represent the interests of babies born too soon, too small or too sick and their families. Initiated and coordinated under the umbrella of EFCNI, GLANCE aims at including parents, from all parts of the world to exchange knowledge and experience. GLANCE aspires to decrease the burden of afflicted families and their preterm and sick newborns to let them thrive beyond survival.

The objective of GLANCE is to gain insiders knowledge about the actual needs of families with sick or preterm born babies in regions and countries beyond the realm of Europe and to take effective actions of support.

For more information about EFCNI please visit: *https://www.efcni.org*

THE ROLE OF REMOTE VIEWING ON FAMILY CENTERED CARE IN THE NICU

DR SADHANA CHHEDA, MD FAAP. El Paso Children's Hospital Texas.

The NICU experience is a distressing period that can have lifelong consequences. Parents faced with their newborn's admission into the NICU endure a particularly difficult experience that may include parental anxiety, depression, and post-traumatic stress. Factors contributing to the parent's psychological state are their dependence on caregivers, the rules of the NICU and the uncertainty about their child's prognoses. The separation of parents from their baby and the inability to share their baby with other family members combined with these parental mental health issues can adversely affect the parent-baby relationship resulting in adverse outcomes for the babies social and emotional development as well as their behavioral and cognitive functioning. This separation may render the NICU graduate at risk for abuse and maltreatment following hospital discharge. Also paramount to a long term healthy family relationship, is the sibling-infant bond, and the NICU experience has also been shown to affect brothers and sisters.

Family centered care (FCC) is an approach to medical care that acknowledges that optimal health outcomes are achieved when family members play an active role in providing emotional, social and developmental support. FCC has been endorsed by the AAP and many other health organizations. Utilization of FCC in the NICU has been shown to decrease length of stay, improve maternal well-being, enhance infant-parent attachment and improve long term outcomes for the baby.

There are many aspects to FCC including but not limited to the physical design of the NICU, parent education, breastfeeding support, kangaroo care, sibling support, photography, staff training and policies supportive of parental involvement. Technology can play a role in FCC and can be especially helpful when families are distant from the NICU. The recent use of web-cameras has been shown to play an important role in virtual visitations and can strengthen FCC.

El Paso Children's Hospital (EPCH) is in a unique situation. It is the only Children's hospital in West Texas (serving a 250 mile radius of Texas and New Mexico); on the USA-Mexico Border and serves one of the largest military bases in our county (Fort Biggs). All mothers deliver in other hospitals and then the baby is transferred to the NICU at EPCH for care. Parents (and extended family members) may be a long way from the NICU, especially military fathers that are deployed overseas or families that are unable to cross the border. Thus in 2013 a grant was obtained from the Foundation to purchase the NICVIEW Camera System.

The NICVIEW provides a secure video stream over the Internet that parents and family members can use to see their new addition. All video & information is secured with up to 256-bit SSL encryption. EPCH NICU issues user names and passwords, and authorized parents have access only to their child's bed. No protected health information is stored on this system and this system operates outside of the hospital's servers. Individual cameras and/or accounts can be disabled at any time. Viewing times are completely customizable to meet the needs of the NICU. Although there have been challenges with the implementation of this project in the areas of nursing staff acceptance and integration into the NICU, technological and mechanical issues and family centered care challenges, overall the outcome has been positive with 80%

of the staff concluding that this service benefits family and more than 80% of families surveyed expressing satisfaction. Review of geographical data has shown logins from most of the states in the USA & several countries outside. Families have also found unique ways to utilize this service. A few examples include reports of mothers watching their babies at home while pumping to facilitate breast milk expression, families watching together with young siblings as teaching and bonding moments and yet others have aimed the camera on themselves while holding the baby so deployed fathers can view both members of the family.

Success of a distance patient viewing program depends on support of NICU staff and though webcams cannot replace parental presence, they can provide an effective way for families and their support persons to connect with the hospitalized baby.

THE POSITIVE IMPACT OF NEWBORN HEARING SCREENING… ONE FAMILIES' STORY

SAMUEL MANI. Clinical Application Specialist, Natus Medical Incorporated. APAC.

This touching story began with a request for the Natus clinical application team to demonstrate the ECHO-SCREEN® III infant hearing screener at a private Women and Children's hospital in southern India. The hospital is a well-known birthing center in the region, but little was known to them on the subject of newborn hearing screening and its importance.

(ABR) screens, across a lifespan of patients from infancy through adulthood – making the tool not only an infant screener, but also a surveillance screener with multiple applications (ex. pre-school screening, loud working environments, etc.).

It was important to demonstrate the simplicity of the screening procedure, and the doctor told us

50 % of infants with significant hearing loss have no family history or risk factors[1]

A discussion was held with the doctor regarding early identification and the impact on outcomes of children with actual hearing impairment. Solutions for screening program needs was highlighted by the flexibility of the ECHO-SCREEN III as a device with the capacity to perform both otoacoustic emission (OAE) and auditory brainstem response about a baby girl born 3 weeks earlier. The delivery was uncomplicated and the mother and baby went home 2 days after delivery with no issues or concerns. Within a week of discharge, the father called the doctor suspecting his new daughter could not hear. He commented that she did not respond to loud sounds nearby – like loud conversation or loud music. The baby was brought to the hospital for follow-up; however without access to infant hearing screening technology, the doctor could not alleviate the parents' concerns or conclude anything about the baby's hearing status. The parents were asked to wait for a few more weeks. With no choice, they reluctantly went home where their anxiety continued to grow over the unknown status of their daughter's hearing.

The doctor was obviously still concerned about this family so when it came time to demonstrate the ECHO-SCREEN III, the doctor called them. They immediately brought their daughter back to the hospital. They were clearly very upset after 3 long weeks agonizing over the situation, not knowing one way or another if there was a problem. The father was adamant his precious baby could not hear, but mom refused to accept it and repeatedly said that her little girl would be normal very soon. A clear and detailed explanation of infant hearing screening methodology and the meaning of pass/refer results was provided. The parents immediately gave their consent to conduct the hearing screen on their baby.

An OAE screen was performed on each ear. Unfortunately, a REFER result was returned on both. The mother was visibly distressed by the results, but after additional discussion with the parents, they soon realized how fortunate they were that they had discovered the potential problem at an early stage, as now a detailed audiologic diagnosis could be made, and early intervention program(s) could be initiated if needed, to support this infant and her family moving forward.

Fifty percent of infants with significant hearing loss have no family history or risk factors.[1] It is well documented in the literature that early identification (by 1 month of age), diagnostic audiologic evaluation (by 3 months of age) and early intervention (by 6 months of age) for infants with hearing impairment significantly improves outcomes. Late identified children demonstrate permanent changes in brain development, have a negative impact on their emotional development, show delays with development of speech processing ability and late or unidentified Hearing Impairments can lead to lifelong difficulties with reading.[2]

The story described above impacted this specific Indian family in a very positive way where early detection helped them identify a potential hearing impairment, and therefore seek early diagnosis and intervention. The child, if indeed confirmed with hearing loss, now has the potential to receive appropriate treatment and track right along with her normal hearing peers in terms of her language development.

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INTEGRATING DEVELOPMENTAL AND FAMILY CENTRED CARE INTO THE NICU

JUDY MOORE. Msc. Neonatal Sciences, MCGI. ANNP, RGN. Director of Medical Education, Natus Medical Incorporated

Developmental care provides a framework in which the neonatal environment and care processes are modified and structured to support the individual medical, psychosocial and developmental needs of the preterm infant and family. Reports indicate that developmental care may also have significant benefits for parents and providers of neonatal care.[1] The components of developmental care can be combined into a model of care, individualized to each infant. Individualized developmental care has been reported in relation to a number of outcomes including:

1. increased physiological stability;
2. fewer and less severe intraventricular haemorrhages;
3. fewer days of ventilatory support;
4. lessened use of exogenous surfactant and total parenteral nutrition;
5. quicker progression to full enteral feeding and improved weight gain.

The brain of preterm infants is still immature and rapidly developing in the neonatal period. However, neonates in the intensive care environment are exposed to an abnormal environmental milieu, repeated invasive procedures, prolonged illness and separation from parents and family. This intense sensory impact adversely affects maturation and organisation of vision, hearing, sleeping pattern, growth and consequently neuro-development and long-term outcomes of the child. For parents of preterm infants, the neonatal experience exposes them to a multitude of stressors and negative emotions, such as anxiety, guilt, helplessness and depression. The highly technical environment, as well as the appearance and behaviours of the premature infant, frequently lead to disruptions in assuming the parental role and a diminished quality of parent-infant interactions. These early problems may contribute to prolonged difficulties with parenting and place premature infants at risk for further cognitive, emotional, behavioural, and developmental problems.

Caregivers can apply an easy to assume range of strategies to positively impact this neuro-development and family/infant attachment. Some of these are discussed here:

LIGHT AND NOISE ABATEMENT

Guidelines recommending reducing noise levels, using adjustable lighting alongside procedural lighting as well as the implementation of light/dark cycles to aid the development of circadian rhythms have been developed. Light reduction can be easily achieved by covering incubators, and using dimmable lighting at the bedside. Noise abatement is also easily achieved by keeping all monitor alarms low, reducing voice levels, but more significantly, as shown in a recent study, the use of Ear Muffs applied to the sickest infants can significantly improve their physiological status and outcomes *(Neonatology Today, Volume 7/Issue 2 2012)*

PARENTAL/FAMILY ATTACHMENT AND BONDING

Several studies have revealed that parents with an infant in the NICU experience depression, anxiety, stress, and loss of control, and they vacillate between feelings of inclusion and exclusion related to the provision of health care to their neonate. Nursing interventions that promote positive psychosocial outcomes are needed to decrease parental feelings of stress, anxiety, and loss of control. Interventions need to focus on family-centred and developmentally supportive care, and Kangaroo Care is actively used in this aspect. It is often difficult for the family to be present at all times on the NICU and be with their infant 24/7 – one way of helping families deal with separation issues is to provide live video streaming at the bedside to any internet enabled device, so that parents and families can feel connected to their infant at all times. (For more information please visit *www.nicview.natus.com*)

One way of helping families deal with separation issues is to provide live video streaming.

These premature infants born between 23 and 32 weeks' gestation spend 2 to 4 months growing and developing outside of their mothers' wombs.

They leave the quiet, dark, painless intrauterine environment much too early and enter a world filled with bright lights, noise, painful stimuli, and separation from their parents. Their immature organs are required to function long before they are ready. In addition, various organs, especially the brain, are exposed to toxic effects of medications and therapies that can interfere with normal development and function. It is no wonder that many of the tiniest premature infants, exposed to repeated aversive sensory input during the early months of brain development, are plagued with sensory integration difficulties in later life. Delivering developmental care to premature infants requires a particular state of mind on the part of the entire health care team and can positively impact outcomes.[3]

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YOUR NEW BABY IS HERE! – THE COLORING BOOK

COME JOIN US AS WE SHOW YOU ALL THE WAYS WE HELP BABIES GET STARTED IN LIFE.

The neonatal intensive care unit (NICU) can be a confusing place for siblings of a preterm or sick baby. To support you in your family centered care model, we have developed the Natus Coloring Book, which is geared towards helping siblings understand what is happening in the NICU and to be a part of the family care approach.

Children can join the Natus BABY as he takes the opportunity to answer basic questions about the baby's care and allows siblings to understand in a gentle way through situational coloring. The colored pages can be used to decorate the baby's bedspace and help foster the sibling bond or as a memento once the baby goes home!

https://neonatalcareacademy.com/new-baby-coloring-book/

ENHANCING FAMILY EXPERIENCE DURING PHOTOTHERAPY TREATMENT

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neoBLUE® blanket
LED PHOTOTHERAPY SYSTEM

Jaundice is a common diagnosis in the Newborn Population with ~60% of all term infants developing hyperbilirubinemia[1]. From this, group, ~8-10% require treatment, but unless pathological or demonstrating extremely high bilirubin levels, these infants generally do not require NICU admission.

Numerous studies have reported that the length of stay (LOS) for childbirth has been steadily decreasing in recent decades, in an effort to decrease costs and demedicalise pregnancy, but this can lead to increase in hospital readmission with ~50% of neonatal readmissions attributed to jaundice management[2]. Lain et al (2015)[3] demonstrated infants born <38 weeks gestation, and discharged between days 0-2, were 9 times more likely than those born >39 weeks with LOS 3-4 days, to be readmitted for jaundice management. In addition, Young et al (2012)[4] demonstrated Feeding problems (41%) and Jaundice (35%) as the most frequent cause of hospital readmission in first 28 days of life with estimated mean cost of $4548 per re-admission. From the perspectives of parents, physicians, and payers, an unplanned, unexpected readmission within a few weeks after discharge of an ostensibly healthy newborn from a WBN is an undesirable event, especially when Term infants with basic physiological jaundice can easily be cared for in community settings utilizing fibre optic phototherapy blankets.

AAP clinical practice guidelines strongly support the recommendation that clinicians promote and support breastfeeding for jaundiced infants. Encouraging Breastfeeding is important in Jaundiced infants. Skin-to skin contact is the natural 'habitat' for human infants.[5] When separated from this contact, infants' stress hormone levels increase, and they cry. By providing phototherapy on the mother's chest, this stress response can potentially be avoided. Fibre-Optic Blanket Phototherapy can help to continue exposure to therapeutic light, increase infant comfort and satisfaction whilst at the same time promote bonding and attachment during feeding and kangaroo care.[6] A case report published in Pediatrics[7] reflecting this common clinical scenario in neonatal medicine described a technique for providing phototherapy while maintaining evidence-based practices, and found that effective phototherapy treatment can easily be achieved, within a Family Centred framework, even if infant is extremely jaundiced, and that this approach can assist clinicians in providing best-practices and family-centred care.

Home phototherapy can be a feasible, safe, and effective alternative to in-hospital photopheraphy

There are many studies examining the feasibility and safety of Home phototherapy. Vora (2013)[8] made a retrospective medical record review of consecutive readmissions with a diagnosis of hyperbilirubinemia to two hospitals, from January 2010 to September 2011. Data were collected on birth demographics, weight changes, intervening medical visits, feedings and elimination and demonstrated In 21 months, 176 infants were readmitted to two NICUs for management of hyperbilirubinemia. Their preliminary data suggested that a large number of infants are readmitted for hyperbilirubinemia and that nearly 1/4 of them may benefit from home management. They found that discharge bilirubin values when compared to the AAP threshold were a better predictor of bilirubin upon readmission than the isolated values or even the bilirubin risk zone.

Other studies have examined the effect of readmission to hospital for jaundice treatment, on parents, and how home phototherapy treatment can help reduce parental stress and increase parental satisfaction with care in this circumstance.[9] **Parents prefer home Fibre optic blanket phototherapy** to inpatient treatment and where pathological jaundice is not considered, home phototherapy can be considered as a suitable strategy for treatment.

Many facilities have implemented protocols for Home Phototherapy treatment, and many have very similar inclusion criteria for selection of the appropriate infants and families to consider this. An example of such criteria include:[10]

- The infant is otherwise ready to be discharged from the hospital
- The infant is eating, voiding and stooling well and is alert
- A primary liver disorder is not the cause of the elevated serum bilirubin
- The total serum bilirubin is less than 20-22 mg/dL in term infants, or less than 18 mg/dL in pre-term infants
- Follow-up evaluations will be done by the physician or by home nursing visits

In conclusion, home phototherapy can be a feasible, safe, and effective alternative to in-hospital phototherapy for otherwise healthy, jaundiced infants with motivated and capable parents when implemented with risk assessed protocols, and provide significant cost savings when compared to in-patient treatment.

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