

Developmental Observer

The Official Publication of the NIDCAP® Federation International



The key is zero separation.

– Björn Westrup, MD

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Björn Westrup, MD, PhD

DOI:10.14434/do.v15i2.34360

Interviewed by Pierre Kuhn, MD, PhD



Profile

B jörn Westrup is a visionary and an influencer who, together with Agneta Kleberg and the Karolinska NIDCAP Team, has spread the philosophy of developmental care throughout Sweden

and Scandinavia over the past 25 years. From my point of view, Björn has played an extraordinary role in the development of Infant and Family Centred Developmental Care (IFCDC) and NIDCAP across Europe and Worldwide. When I met him for the first time in 2009, I was very impressed by his strength of conviction and persuasion, the finesse of his understanding of NIDCAP and his involvement in research in IFCDC. I had the chance to be warmly welcomed for more than one year in Stockholm where I had the opportunity to "breathe" and "smell"

NIDCAP and Mother Infant Couplet Care from the inside, especially at Danderyd, KI Hospital where Björn was the Head of Department for many years. I realized how resilient and skilled he was to carry system change and to succeed in the implementation of NIDCAP and parental involvement as primary caregivers. This experience contributed a lot to change my perception and vision of what perinatal care can be. Björn is *a sensitive and endearing person, also very experienced in facilitating working groups.* I learned a lot from his sense of consensus and balance while working with him as co-chair of the EFCNI Topic Expert Group on IFCDC. It has been a great privilege for me to collaborate with him in a very friendly and supportive atmosphere. Björn is also a great epicurean who knows at best how to enjoy great moments of friendship! We have many things to learn from your past and continuing journey, Björn. Thank you very much for sharing your story with us.

Profile - Bjorn Westrup PhD, continued from p.1

Björn Westrup is a paediatrician and neonatologist with a PhD. He was a senior consultant in neonatology and the director of the Karolinska NIDCAP Training and Research Center at Astrid Lindgren Children's Hospital, Karolinska University Hospital since its start in 1999. It was the first NIDCAP Center in Europe and has played a leading role in the development of other European centers. Dr. Westrup was also a member of the NIDCAP Federation International's first Board of Directors. He has pioneered the development of Infant & Family Centered Developmental Care (IFCDC) and Mother-Newborn Couplet Care (MNCC) in Europe. Björn organised a unique meeting in Sweden with the Karolinska NIDCAP team. The Stockholm Conference on Ultra-Early Intervention is an internationally renowned and acknowledged meeting in Sweden dedicated to ultra-early intervention in IFCDC. He has been and is still very involved in research in that field and especially in immediate skin-to-skin contact in preterm infants after birth with the aim to avoid separation of infants from their mothers and fathers. Björn has also chaired the topic expert group dedicated to IFCDC of the European standard of care from the European Foundation of the Care of Newborn Infants (EFCNI).

PK: When and how did you get interested in developmental care?

BW: During my first rotation into neonatology in the paediatric residency program. The hospital was a small county hospital in Falun in the forest area of Sweden and was quite old fashioned and had just started allowing parents into the paediatric units. Parents were not allowed in the neonatal unit. I saw the importance of parents. A senior colleague and head of the Paediatric Public Health Program fought for parents to be allowed in the neonatal unit. He set me a challenge as a junior doctor to get parent's involved in their infant's care. I started to observe different infant behaviours when the parents were present. Towards the end of 1989 I attended a conference organised by Professor Hugo Lagercrantz at the Karolinska where Heidelise Als was an invited presenter. I was intrigued with the combination of natural science and behavioural science. This gave me some theoretical context to explain what I had seen.

On return to my unit, I mentioned this to a clever young neonatal nurse, Agneta Kleberg, who was enthusiastic about the concept. I arranged for funding and brought Agneta to Boston where we were both introduced to NIDCAP and APIB. Actually, we had just asked for a visit but were instead offered a four-day introduction of both NIDCAP and APIB – a surprising visit but that later proved be very instrumental for the development of NIDCAP in Sweden and Europe. Heidi was wise and strategically savvy as always.

PK. Could you tell us more about your NIDCAP journey?

BW: When we returned to Sweden, I realised that, at that point, there was not sufficient scientific evidence to a general

recommendation for implementing NIDCAP and we needed more research before starting the program.

A prospective phase-lagged observational study was commenced during NIDCAP Training of myself and Agneta. Data was collected for the control infants during Agneta's and my training phase. After a wash-out period with staff training we prospectively recruited the NIDCAP infants and parents. The main findings of the three-year follow-up was a difference in behaviour in the NIDCAP cohort. There were fewer internalising problems and better parent child interactions in the NIDCAP group. We found no short-term benefits.

When Hugo Lagercrantz in 1994 heard about our study in Falun, he invited us to Stockholm to conduct a randomised controlled trial on NIDCAP as part of our PhD programs.

At the same time, we continued to consolidate the NIDCAP based care in Falun, which took a lot of energy. Agneta wrote the Swedish Handbook on NIDCAP which was also translated into Norwegian. She was a fantastic tutor and implementor.

Nevertheless, it was a great challenge to promote NIDCAP as it was quite controversial, and many professionals in the neonatal community in Sweden and internationally were quite sceptical. However, more parents were included in their infant's care and were very positive. In addition, we had important and continuous support of two professors Hugo Lagencrantz from Stockholm, and Nils Svenningson from Lund.

Despite the sceptic, we were not discouraged and continued. There was a gradual acceptance, however it is still not in all units in Sweden.

Today NIDCAP and/or FINE is practiced in 15 units across Sweden. FINE has been very well received and it led to more NIDCAP Training. I believe the development of FINE has been crucial for IFCDC and NIDCAP. We see more people interested in NIDCAP.

PK: Can you summarise why NIDCAP is essential to you?

BW: Firstly, it is very attractive to organise the care according to a framework that incorporates natural, behavioural sciences and theory of systems change. Secondly, the core pillars are ethical for sensitive care based on the infant's own voice and behaviours, and thirdly, the short- and long-term research results show positive effects on both child health and development and parents wellbeing and mental health.

PK: Can you tell us how you see Infant Family Centred Developmental Care and NIDCAP – Are they the same?

BW: IFCDC is a generic term for a framework of newborn care that incorporates the theories and concepts of neurodevelopment, neuro-behaviour, parent-infant interaction, parental involvement, breastfeeding promotion, environmental adaptation, and change of hospital systems. It is based on the leading-edge work of Als and her colleagues in the NIDCAP Federation International (NFI) and Brazelton and on the World Association for Infant Mental Health Declaration of



FIGURE: Global Perspective of Infant and Family Centered Developmental Care

Developed by Bjorn Westrup and Kaye Spence for the NFI - work in progress

Infants' Rights. The core pillars of IFCDC are sensitive care based on infant behavioural communication and cues gives the infant a voice and is beneficial for brain growth, parent engagement supports parental wellbeing and infant development, and customised adaptations of the NICU environment and hospital system as a whole. IFDC is more descriptive and general in terms of ethics and legal benefits. Whereas NIDCAP is a philosophy and a caregiving approach that has a training program, so far, is the only program that includes all aspects of IFCDC. The work of Als and the NFI has greatly influenced on the concept of IFCDC and will surely continue to play a significant role in its future development.

PK: Are there other programs that are part of IFCDC?

BW: Yes, there are many and some quite specific. For example, breastfeeding, and skin-to-skin care are important components of IFCDC. There are also more specific programs. However, NIDCAP is the most developed and research based. [Figure 1] As far as I have understood, FiCare (Family Integrated care) is for example a program for parental involvement more, and in

itself not a program that supports the whole idea of IFCDC. In contrast, the Close Collaboration with Parents program include most of the components of IFCDC, especially the behavioural part and parental involvement.

PK: Can you tell us how you became involved in the EFCNI Standards and how important they are to you?

BW: These standards are very important tools to initiate change and improve the quality of care in Europe and beyond. Most importantly they are multi-disciplinary. They are going to be revised regularly and the expert groups have started inviting comments and recommended changes. It is important to acknowledge that the initiative for the standards was taken by parent organisations under the broad umbrella of EFCNI. The standards were written in collaboration with parents and endorsed by professional and scientific societies in Europe. Standards are playing a role globally.

The US Design Standards and IDC Standards are complimentary to the European standards, and I strongly believe the collaboration between the two groups will continue. **PK:** What about the WHO study on immediate SSC with preterm infants: Could you summarize the scientific rationale for us?

BW: The rationale is that 20 million babies are born worldwide annually with a need for neonatal care. We cannot only focus on high income countries. We need to turn to countries with high mortality in low-birth-weight infants globally. If we want to make a difference, then we need to consider the low- and middle-income countries. My experience at the Karolinska and through my lifelong experience with IFCDC and NIDCAP makes me realise it is beneficial with early skin-toskin contact for small vulnerable infants. In collaboration with Nils Bergman from South Africa, we undertook observational studies to improve short term health outcomes in low- and middle-income countries to increase survival. One finding was better stabilisation at birth. It took eight years to convince the WHO and the Melinda and Bill Gates Foundation to fund the study in Nigeria, Malawi, Ghana, Tanzania, and India. The target group were infants born between 1000g and 1800g.



NIDCAP Care in the Moment

A mother's presence - The Netherlands

We planned to recruit 4000 maternal/infant pairs. However, the data safety and monitoring board stopped the trial after 75% recruitment due to a statistical benefit in the intervention group, see:

WHO Immediate KMC Study Group et al. Immediate "Kangaroo Mother Care" and Survival of Infants with Low Birth Weight. The New England Journal of Medicine, 2021, 384, (21): 2028-2038. doi:10.1056/NEJMoa2026486

PK: What do you see as the challenges and barriers for implementing early skin to skin for infants over 1000g?

BW: There needs to be a lot of training and support for immediate skin-to-skin. The key is Zero separation – keeping infants and their mothers close both physically and psychologically. It necessitates a very strong collaboration with obstetrics in order to provide medical care for the mother while she stays in the NICU – Mother-Newborn Couplet Care (MNCC) in Mother-NICUs. However, you need to have strong leadership to set the goals and change professional attitudes through training and education. We also need changes in NICU design as well as ensuring quality care for mother /infant dyad.

PK: Is immediate skin to skin challenging?

BW: It is very challenging, and it will take decades before there is a general implementation across countries and globally. I would like to finish with a positive outcome. Following on from our and other studies, the government in India have issued a directive to re-build all the NICUs, that is over 1000 units. The goal is to accommodate mothers close to their infants as well as implementing developmentally supportive care. Moreover, WHO will in 2022 publish a general recommendation of immediate and continuous KMC for all sick or small newborn babies.

It will take many years to ensure Infant- and Family-Centered Developmental Care including Newborn Couplet Care for all – however we have made an important start.

PK: Has NIDCAP affected your personal life?

BW: It helped me enormously in my clinical work as a neonatologist, it makes it much easier to assess the condition of the newborn and its family and understand their needs. NIDCAP makes the work more interesting and rewarding. My NIDCAP work and involvement in training and research is the foundation of my engagement in WHO global research scale-up project of KMC. Also, it has been very important for my own scientific journey. On a personal level, I am not so sure that my own family members are convinced that I am successful in relationship-based and not task-oriented behaviour - but it hopefully has helped.

PK: Thank you very much Björn for your time and kindness during this interview and also for all the incredible work you have done for the care of vulnerable preterm infants and their families.

DOI: 10.14434/DO.V1512.34359

Editorial



The world being in a pandemic has made us re-think the way we do things and has challenged us about what is normal. One thing for certain is that the NIDCAP community has gone to great lengths in meeting the challenges and we hear of new innovations to the NIDCAP Training. An example is the training

occurring in Rwanda and in this issue, Patrick Manibaho tells us about their efforts with NIDCAP Training by distance.

We learn about Björn Westrup and his brilliant work over several decades, Sylvie Mingy enlightens us on the achievements of the French NIDCAP Training Center in Brest. With such inspirational people, the NFI can be proud of its members. The science and art of feeding newborns is explained by Erin Ross and Marjorie Palmer, in addition Brenda Tarka provides a way of helping babies feed.

Finally, we are taken on a parents journey of the highs and lows of intensive care in Japan. It is important for all health care professionals to learn from and about cultural practices in different countries.

Last month we saw the celebration of NIDCAP through World NIDCAP day. Jennifer Degl writes about the celebrations and encourage us to think about next year. It is important that we continue to celebrate the achievements of the NFI and the membership.

Kaye Spence AM

Senior Editor – Developmental Observer Adjunct Associate Professor / Clinical Nurse Consultant Australasian NIDCAP Training Centre / Sydney Children's Hospitals Network / Western Sydney University / Australia

Cover photograph of Lara from Sydney, Australia used with permission.

Editorial Board



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Sandra Kosta, NFI Executive Director of Administration and Finance, has been an Associate Editor for the *Developmental Observer* since 2007. As a Research Specialist at Boston Children's Hospital, Sandra has co-authored several papers on the effectiveness and long-term outcomes of NIDCAP Care.









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Column Editor: Debra Paul, OTR

Losing a loved one is never easy, especially when the loss is a baby. In this story, we hear from the NIDCAP Trainer that worked with a family as they cared for their baby who was born very premature, and the impact of helping the baby's parents learn how to read their son's behavioral language and provide him support. Following the loss of their son, the baby's mother sent a letter of gratitude to the staff in the newborn intensive care unit and shared how the individualized and developmentally sensitive care their son received profoundly influenced their experience, They described what NIDCAP meant to his family and how it changed their perspective of an intensive care setting. The comforting words that this mother provided to the staff in her letter also challenged staff to expand the NIDCAP work throughout their country so that other babies and families can benefit from this family centered, evidenced based approach to developmental care.

NIDCAP from a Parent's Perspective: An Open Letter from a Family

Kanako Uchimi, NIDCAP Trainer and Author/Translator

DOI: 10.14434/DO.V1512.34361

asahiro was born at 22 weeks gestation at the Tokyo Metropolitan Bokutoh Hospital and weighed about 400 grams. Immediately after his birth, Masahiro developed respiratory distress with poor lungs and became seriously ill and needed Nitrous Oxide gas and respiratory support. Masahiro was his parents' first child, and every day they were with their son, they gently touched Masahiro and talked to him affectionately.

Miwa and Teruhisa, Masahiro's mother and father, were able to read Masahiro's behavioral cues so well. During one skin-to-skin care, as Masahiro rested on Miwa's chest, she sensed, based on his expression, that his pain and distress had eased. Likewise, when Teruhisa held him for skin-to-skin, Masahiro's eyes would open, his face would shine, and he appeared delighted with the experience of being close to his father. It was as if Masahiro was enjoying the attention.

Shortly after six months, and Masahiro's half-birthday, it was with great sadness that his parents said goodbye to their son who embarked on an eternal journey in April 2021. Following Masahiro's passing, Masahiro's mother, Miwa communicated to our staff, "Thanks to everyone, we have become a family". These words provided me with a little relief as everyone who had cared for Masahiro was filled with great sadness for his parents. Later, we received a letter from Masahiro's family addressed to our hospital staff. I would like to now share the letter Masahiro's family sent us as it provided us with a great deal of courage and energy. *To everyone at Tokyo Metropolitan Bokutoh Hospital NICU Dear Doctors and Nurses,*

For medical professionals, I presume that the days will continue to be unrelenting.

I am full of respect and gratitude to everyone who is working hard every day in the midst of anxiety and great tension. Thank you again.

Thank you to everyone for taking care of our son Masahiro while he was in the newborn intensive care unit. I was able to complete the forty-ninth day of the memorial service^a without delay.

It seems that the six months spent in the NICU were short, but I think it is more than enough time for our family. Masahiro did his best. The six months my son was alive was in the midst of widespread fear of COVID-19 infection.

I think there were various difficult decisions in the hospital, such as protecting the bond between parents and children and protecting the safety of everyone involved. Under such circumstances, you allowed us to visit our son 24 hours a day, encouraged active skin-to-skin care, and provided care that was close to our hearts until the very end.

Every day, everyone was thinking and discussing what was the best that could be done at that time. You listened sensitively to the words of our family and worked together to provide care and treatment. And above all, you treated Masahiro and our family with love. I'm really grateful. Thank you very much.

We cherish the growth record with photos that you gave me as well as Masahiro's diary that we wrote together and value. Thank you for the many messages you wrote while you were so busy. It is an important treasure for us.

FAMILY VOICES





Without each and every one of you, we wouldn't have had six months with Masahiro.

Ma-kun. Ma-kun ...

I still can't forget how hard he responded to many calls. We laughed and rejoiced together in Masahiro's small changes and growth, and thanks to everyone, our first child-rearing became fun and happy. I can't heal my sadness and pain, but when I remember your faces, it still makes me feel better! I am really grateful to have met all of you.

I can't forget how you understood the feelings of a newborn premature baby and how to respond to them. In the midst of all the confusion, your voice and actions towards my son served as a model for us, and each word brought us closer to our baby.

I was really surprised to find that facilitated tucking and skin-to-skin care also gave Masahiro the best experience that we could imagine. Putting my hands in the incubator all day and talking to my son, singing a lullaby, and so on. Thank you for watching over Masahiro with warm eyes.

One day, I learned that "NICU is not just a place to treat." I understood that the NICU is a place to help families learn about their baby's responses and language as well as their child's development and on-going care. I remember feeling relieved as until then I thought it was special place to treat baby illness in every way. I was very happy to feel that nurses are not only for treatment, but also for helping us raise our children.

I think situations will vary depending on the baby and family, but please continue to be a friendly place that is



Masahiro's team

supportive of the premature baby and family. And we hope that the efforts of NIDCAP will be taken for granted throughout Japan in the future. We look forward to seeing how you continue to you create an ideal environment for babies' development, care and growth.

Best regards, Miwa June 2021

a This is a Japanese custom. The memorial service will be held 49 days (7 weeks) after death. The day of the final decision on whether to go to heaven is 49 days after death.

NOTE: The below is the mother's letter in original format.

【家族コラム原稿案】

まさひろくんは22週、四百数十グラムで、私たちの病院で生まれました。 彼は生まれた直後から肺の状態が悪く重症でした。NOガスと呼吸器のサポートをず っと必要としていました。ご両親にとって初めてのお子さんで、毎日、まさひろく んに手で優しく触れ、優しく語りかけてくれました。そして、ご両親は彼のしぐさ を読み取れるようになりました。

あるときのカンガルーケアでは、ママの胸の上で彼の表情は安らぎました。そして 彼の痛みや苦痛が和らいでいることをママは察知しました。パパのときは目も口も 開けて表情が輝き喜んでいました。それはまるでアトラクションを楽しんでいるか のようでした。

ハーフバースデーを迎えて間もなく、 2021年4月、永遠の旅に出た優裕くんとの 別れは大きな悲しみでした。しかし、優裕くんのお母さんが「皆さんのおかげで私 たちは家族になれました」とおっしゃってくださったことに、大きな悲しみの中で 少しの安堵感を覚えました。後日、私たちの病院スタッフへご家族からお手紙をい ただき、私たちは大きな勇気とエネルギーをもらいました。そのお手紙をご紹介し ます。

墨東病院NICUの皆様へ

拝啓

NIDCAP TRAINERS MEETING 2021

医療関係者の皆様にとっては、まだまだ気の抜けない日々が続くことと推察いた します。

日々、不安と大きな緊張感の中、尽力されている皆様には、心から尊敬と感謝の思 いでいっぱいです。今日もありがとうございます。

息子、優裕の生前中は大変お世話になりました。四十九日の法要も滞りなく済ま せることができました。

NICUで過ごした6か月は短いようですが、私たち家族にとっては十分過ぎる時間 であるようにも思います。よく頑張ってくれましたから。

息子の生きた6か月はまさにコロナの感染への恐怖が広がる中にありました。

院内では親と子の絆を守ること、関わる人すべての安全を守ることと、いろいろ難 しい判断があったと思います。

そんな中で、24時間の面会を許可してくださったり、積極的なカンガルーケアを実施してくださったり、私たちの心に寄り添ったケアを最後の最後まで行ってくださいました。

その時できる最大限のことを皆さんが日々考え、話し合ってくださっていたこと。 家族の言葉に敏感に耳を傾け、連携してケアや治療に力を尽くしてくださったこ と。

そして何より、優裕と私たち家族に愛情をもって接してくださっていたこと。

本当に感謝の思いでいっぱいです。ありがとうございました。

皆さんからいただいた写真付きの成長記録や皆さんと書き綴った優裕ダイアリーも そのひとつです。忙しい中、たくさんのメッセージをありがとうございました。大 切な宝物です。

皆さんお一人おひとりなくして、優裕との6か月はありませんでした。

まーくん。まーくん…。

たくさんの呼びかけに、一生懸命こたえる姿が今でも忘れられません。

小さな変化や成長に一緒に笑い、喜び合ってくださり、私たちにとって初めての子 育ては皆さんのおかげで楽しくて幸せなものになりました。

まだまだ悲しみやつらさは癒えませんが、みなさんの顔を思い出すと今でも元気が 出ます!

皆様との出会い、本当に感謝しています。

早産で生まればかりの赤ちゃんの気持ちをどう汲み取り、どう接したらよいのか。

とまどいの中、皆さんの赤ちゃんに対する声かけや行動は私たちのお手本となり、 言葉の一つひとつが赤ちゃんとの距離を縮めてくれました。

ホールディングやカンガルーケアも、私たちが想像する以上に、赤ちゃんにとって 最高の時間を与えられるということも実感し、本当に驚きました。

保育器に一日中、手を入れて話しかけてはウトウトしたり、子守歌を歌ったり…。 そんな姿も温かい目で見守ってくださり、ありがとうございました。

「NICUは治療する場ではありませんよ」とある日、教わったこと。

NICUは家族とともに赤ちゃんの子育てを手助けする場所なんだ、と理解しました。それまでは病気をあらゆる方法で治療する場所で特別なんだと思っていただけに、気持ちが和らいだことを覚えています。そして、皆さんが一緒に子育てを手助

けして応援してくださっているんだと感じ、とてもうれしかったです。

状況は赤ちゃんやご家族によっても様々だと思いますが、これからも赤ちゃんや ご家族に寄り添った優しい場所であり続けてください。

そして、NIDCAPの取り組みも、今後、日本中で当たり前に取り入れられる ことを私たち家族も願っています。赤ちゃんの心のケアと、成長と発達のために理 想的な環境づくりを今後も期待しています。

敬具 2021年6月 優裕の父、母



Masahiro with his mother, Miwa



Mission

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

Adopted by the NFI Board, July 1, 2019

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



World NIDCAP Day

Jennifer Degl, MS Family Representative - NFI Board Member

DOI: 10.14434/DO.V1512.34369

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appy 20th Anniversary to the NFI! We sure know how to celebrate as can be seen by the multitude of events hosted by our members throughout the month of March in concert with our 3rd annual World NIDCAP Day.

March 20th was exceptional this year. So many of our members celebrated World NIDCAP Day in their hospitals with activities, parties and some even made specially designed NIDCAP themed cookies. Several bridges and buildings across the globe were glowing in teal to help us spread awareness about the NIDCAP practice so that we can continue to share it with more hospitals, babies, and families.

One event that we are especially proud of is our first ever World NIDCAP Day Virtual Gala. It was no small feat to pull off such an event. Many members of the NFI Advancement Committee and others worked tirelessly to plan each portion of the gala. One member of the

"The compelling stories from Africa and Japan conveyed the true meaning of NIDCAP while reminding us all that the NIDCAP practice is truly a global one."



gala planning team that deserves special recognition is Sandra Kosta. Sandra seemed to work around the clock to make sure the event went off without a hitch and it worked. There were many presentations from several NFI members from all over the globe. The compelling stories from Africa and Japan conveyed the true meaning of NIDCAP while reminding us all that the NIDCAP practice is truly a global one. Our family presentation was also quite beautiful. Latoshia Rouse's family story was a true gem. Hearing her story while seeing her beautiful children play in the background shows us how important the NIDCAP practice is and the impact it makes on babies and families.

Our gala was full of prizes as well. Attendees were invited to bid on several different gift packages, including books authored by our members, developmental care tools such as the Zaky, and oneon-one conversations with our NIDCAP experts including, Drs. Heidelise Als, Jane Holmes Bernstein, Nikk Conneman, and Graciela Basso. The lucky winners have been notified.

Let's not forget to mention the inauguration of the newly opened Lund-Malmö NIDCAP Training and Research Center in Sweden that occurred during the Swedish Conference on Ultra-Early Intervention. This event was March 24, 2022, and many of our own NFI members gave presentations including Dr. Heidelise Als, Dr. Deborah Buehler, and more. We are so happy to have yet another training center open.

Thank you to each and every one of you who attended an event or shared it with your colleagues, donated your hardearned money, celebrated in your hospital, or just wore teal to help us spread the word about NIDCAP during the month of March. We are thankful for you!

Is it too early to start World NIDCAP Day 2023?

Predictability of Neonatal Sucking for Later Developmental Outcomes

Marjorie Meyer Palmer MA, NLP, CC-SLP, Neonatal/Pediatric Feeding Specialist, Speech-Language Pathologist, Founder/Director, NOMAS® International

DOI: 10.14434/DO.V1511.33788

s early as 1974, it was reported that a deviant suck was a sign of neurological issues.¹ Hill and Volpe reported in 1981 that, difficulty with neonatal sucking has been described as an early indicator of neurologic abnormalities.¹ Typical sucking in the infant has been well described in the literature. It is generally accepted that, in the preterm infant, the immature pattern is characterized by short bursts of three to five sucks followed by a pause of equal duration. In the term infant, there is a continuous sucking burst of 10-30 sucks per burst with an average ratio of one suck-one swallow-one breath.² In both cases, the infant is comfortable with coordinated respiration while feeding occurs effortlessly.

When an infant is unable to coordinate sucking, swallowing, and breathing in a rhythmical and comfortable fashion, the suck pattern presents as disorganized.³ In this case it is usually caused by the infant's inability to maintain adequate respiration while also sucking and swallowing. Such infants may experience apnea or oxygen desaturation during feeding.⁴ If feeding persists, the infant may show signs of stress such as finger splay, head turning, widening of the eyes, extension of the limbs, arching backward, or any of the many other behaviors indicative of distress. It is important for the feeder to recognize these signs of stress in the infant, to respond quickly to alleviate the cause of stress which will calm the infant, and to assure feeding is a pleasurable experience.⁵

The Neonatal Oral Motor Assessment Scale (NOMAS) is a tool designed to assess neonatal sucking and distinguish between disorganized and dysfunctional feeding. A recent study reported that infants who lack coordination of suck-swallow-breathe and who also experience stress during feeding, as based on the NOMAS, have a longer transition time to full oral feedings than those infants who are not stressed during feeding. Infants with a disorganized suck who are stressed take 22 days to transition to full oral feedings, while those with no stress can transition in six days.⁶

Dr. Xianhong Zhang and colleagues in the Department of Neonatology at the Children's Hospital of Chongqing Medical University in Chongqing, China used the NOMAS to identify abnormal sucking patterns in moderately and late preterm infants and to ascertain the relationship between these patterns and neurodevelopmental outcome at six months corrected age. This study did not enroll infants with neurologic disorders, so no infants were classified as having a dysfunctional suck. Infant feeding was classified as either normal or disorganized based on the NOMAS. The researchers reported that infants who demonstrated stress signs per the NOMAS, that is, incoordination of suck, swallow, and respiration which result in nasal flaring, head turning, and extraneous movement, along with arhythmical jaw and tongue movements, were at risk for adverse neurodevelopmental outcomes at six months corrected age.⁷

In addition to infants who present with both a disorganized suck and stress per the NOMAS, it is also possible to predict later developmental outcomes for infants who present with a dysfunctional suck.8 This suck pattern can be identified by abnormal movements of the tongue and jaw that occur during active sucking and that are never typical. These movements include the lack of a central tongue groove compared to a cupped tongue with a central tongue groove. The tongue instead presents as either flattened/flaccid with an absent tongue groove or is retracted with the posterior tongue humped against the palate.⁸ During a dysfunctional suck, the jaw may demonstrate an excessively wide excursion pulling the tongue away from the nipple and interrupting the intra-oral seal that is formed between the tongue and the palate. Another characteristic of a dysfunctional suck occurs when the jaw is unable to make an adequate downward movement due to a restriction of movement at the temporal-mandibular joint that inhibits smooth downward movement of the jaw. This restriction is secondary to the posterior humping of the tongue against the palate. In all cases when a dysfunctional suck is diagnosed, there is a neurological issue that has been identified or soon will be identified.⁹ These may include diagnoses such as, grade III intraventricular hemorrhage (IVH),9 periventricular leukomalacia (PVL), perinatal hypoxic ischemic encephalopathy (HIE), seizure disorder, hydrocephalus, meconium aspiration, meconium staining, congenital anomalies, placenta abruptio with decreased muscle tone, chromosomal abnormalities, and neonatal encephalopathy of unknown etiology, to name a few. It has been reported that in addition to an association with dysfunctional sucking, severe IVH negatively impacts the suck-swallow-breathe rhythm. The independent effect of neurological injury in the form of IVH on early neonatal feeding coordination suggests that a closer analysis of feeding may reflect and predict neurological sequelae.9

Early diagnosis of the neonatal suck pattern is important because of the complexity of the neuronal network needed to suck and neuroplasticity in infancy. Because of this, the skill of sucking has the unique ability to give insight into areas of the brain that may be damaged either during or before birth.¹⁰ In 2009, it was hypothesized that a standardized instrument for neonatal sucking could offer a cost-effective early screening tool for preterm infants at greatest risk for developmental delay,¹¹ and the NOMAS provides such a tool. The NOMAS can be administered at the bedside within two to three minutes by the trained examiner observing a routine feeding offered by the assigned caregiver in the intensive or special care nursery. The examiner first observes the non-nutritive suck during the first burst, first pause, and second burst to rule out sensory conditions such as habituation and perseveration. This is followed by a two-minute observation of nutritive sucking starting once the nipple is adequately and properly placed in the infant's mouth. The number of sucks per burst and the type of pattern (continuous or burst-pause) is observed and recorded. A disorganized sucking pattern occurs when an infant exhibits too much variability in the number of sucks per burst (sucking bursts have between 5-10 sucks per burst), or the infant demonstrates an inconsistent suck-swallow-breathe ratio. The NOMAS may also be used for breast feeding infants but will require the examiner to spend more time observing the infant because of the variability of flow that occurs with breast feeding.^{12,13}

NOMAS-based assessments for neonatal feeding performance have been considered helpful tools to predict neurodevelopmental outcome at six and 12 months corrected age.¹⁴ The NOMAS has been identified as the only neurobehavioral assessment that specifically measures preterm sucking behavior.¹⁵ Slattery reports in a review article that, early sucking and swallowing measures predicted neurodevelopmental outcome in later infancy in five of the six studies reviewed.¹⁶ Thus studies show that sucking and swallowing disorders in early infancy serve as potential markers of neurodevelopmental problems and abnormal sucking patterns may reflect neurologic developmental issues in preterm infants.¹⁷

The NOMAS provides predictability for later developmental outcomes for both disorganized and dysfunctional sucking patterns and is a screening tool that can be administered by observation at the bedside by a trained examiner. Trained examiners demonstrate reliability in the administration and scoring of the NOMAS to distinguish between disorganized and dysfunctional sucking patterns to assure the subsequent intervention strategies, therapeutic techniques, and treatment plans are appropriate. Currently there are NOMAS Licensed Professionals in 46 U.S. States and 40 foreign countries.

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Letters to the Editor

I really like the new layout of the Developmental Observer - my compliments for all the work and the professional appearance. There is a lot of content and I like the use of quotes from people in between the articles.

> - Monique Oude Reimer Sophia NIDCAP and APIB Training Center

It was really a pleasure to read the article written by Jeff Alberts and his review regarding "The effect of gentle human touch during endotracheal suctioning" from the last issue of the DO. I really like the way he analysed it. It is not only his excellent English and the ability to write in an interesting way, but it is the way he sees and thinks about the subject. I was amazed how he referred to my review. I would like to express my thanks.

> – Ita Litmanovitz Israel NIDCAP Training Center

> > Continued on p. 18

Supporting Oral Feeding in Fragile Infants: Introduction to SOFFI®

Erin Sundseth Ross, PhD, CCC-SLP President, Feeding Fundamentals, LLC

DOI: 14434/DO.V1512.34364

upporting Oral Feeding in Fragile Infants (SOFFI®) is a comprehensive approach to feeding preterm infants and infants with medical comorbidities within the hospital setting and after discharge. It is based on observation of the capabilities of the baby at different neurodevelopmental stages and on caregivers consistently responding appropriately. SOFFI® uses the concepts of the Synactive Theory as the foundation for observations, and interventions are based on developmentally supportive care concepts. What is unique about SOFFI® is it focuses on the neurobehavioral development of feeding, with the neonatal intensive care time period considered as the foundation for all later eating development. The goal of SOFFI® is to ensure positive eating experiences, based on infant behavioral communication, with the overall goal of improving feeding outcomes in-hospital and after discharge. In a recent post-discharge pilot study of healthy preterm infants who did not exhibit feeding problems while in the NICU, 42% experienced some type of feeding problem.¹ This is consistent with a review article by Pados and colleagues that revealed the overall prevalence of problematic feeding after NICU discharge and before four years of age was also 42%.² Many programs designed to improve feeding outcomes within the NICU only consider outcomes to discharge. SOFFI® is the only feeding program that has research supporting improved outcomes both within and after discharge from the NICU.³

Initially certified in NIDCAP in 1993, I have focused on the problem of feeding in NICU settings and the poor feeding outcomes in this population. My experience working in both the NICU, starting in 1990, and in the Pediatric Feeding Clinic led me to wonder whether good intentions within the NICU setting were contributing to feeding problems, even though the feeding problems did not reveal themselves until after discharge. Over time and with more insight into the neurodevelopmental aspects of learning to eat, it became clear that many professionals do not consider post-discharge outcomes. Infants begin eating reflexively and they discharge from the NICU while eating is still reflexive.

SOFFI[®] teaches that negative feeding experiences from birth through when the infant is eating volitionally are the reason many infants develop feeding problems once home. If an infant is uncomfortable, out of breath, pushed along, in pain, or overwhelmed every time they eat, they develop ways to avoid eating. In fact, this is a wonderful example of Classical Conditioning. Infants learn to escape and avoid eating,



On-going consultation in the SOFFI method

and have low appetite, because eating has been paired with repeated aversive experiences. Infants do communicate their experiences during feedings, yet feeders often ignore these signs either out of ignorance or out of a desire to help the baby learn to eat and go home. Most literature and staff focus on getting infants to eat sooner and to go home sooner. Few focus on eating with better skill with a goal of developing long-term enjoyment of eating. Quality leads to quantity and one doesn't have to be sacrificed for the other. SOFFI® was developed initially to educate local nursing staff and it has grown into an international training program.

SOFFI® has been used as the training framework for several published studies and abstracts.³⁻⁵ These studies have shown it is an effective intervention model for preterm infants as well as term infants who are ill, the same populations typically seen within hospital NICUs. Statistically significant improvements in outcomes at discharge were shown in these studies, yet more importantly, no adverse effects occurred despite changing the focus to quality feedings. Unique to SOFFI®, significant improvements were found after discharge, including fewer infants who 1) demonstrated feeding problems overall, 2) required feeding therapy, 3) vomited, and 4) arched.³ One study showed that

more infants with significant co-morbidities who discharged home with a nasogastric tube for supplementation transitioned to full oral feedings by three to five months corrected age.⁵

SOFFI[®] educates the trainee on the importance of parental involvement in feeding and infant care in general, and covers learning theory, including the Synactive Theory and Classical Conditioning. All experiences are framed within the concept of homeostasis. By understanding the infant's communication and responding appropriately to their needs, repeated negative feeding experiences are avoided. This helps the infant build the skills for eating and the desire to eat. Parents are the primary feeders from the beginning, and breastfeeding is emphasized as the best and most biologically expected way to feed the infant. Most infants in the United States will be both breast and bottle-feeding at hospital discharge. Bottle-feeding is associated with more physiological challenges during feedings, so bottle-feeding strategies are provided in SOFFI[®] training.

"Feeding is the 'last barrier' to discharge because it requires infants to be able to do everything else"

SOFFI® offers in-depth information on the development of feeding. Infants are developing the neurological and motor ability to eat all through the preterm period. Feeding is the most complex activity they will learn to do. Feeding is directly tied to maturation, and research repeatedly shows the average age for reaching full oral feedings is 36.5 weeks gestation, plus or minus two weeks. By understanding the developmental nature of feeding and the influence of medical comorbidities, asking infants to do something too challenging can be avoided. Infants develop within windows of time, which is often forgotten with eating. Many health professionals want all preterm infants to eat by 32-34 weeks, and often infants are pushed to eat by 36 weeks. The literature is full of articles that suggest infants who are still hospitalized at 36 weeks are behind. In fact, half of infants who are developing typically would be still working on feeding. SOFFI[®] training brings the concepts of neurodevelopment, learning, and infant behaviors together to teach trainees how to observe and evaluate feedings, and then how to improve feeding experiences. The methodology uses the neurodevelopmental framework of the Baby Regulated Organization of Systems and Sucking (BROSS®).6 All interventions are evidence-based, developmentally appropriate, and family-centered. Interventions begin well before oral feeding attempts. Staff use algorithms for decision-making, and families learn to be co-regulators of their infant during feedings. A parent education program is currently being piloted as well.

SOFFI[®] is used for preterm and term infants, hospitalized or at home, with or without medical comorbidities. Nurses and therapists who work with these infants in the NICU and after discharge are the primary disciplines trained, although dietitians, lactation consultants, physicians, and nurse practitioners have also completed training.

SOFFI[®] is used by hospitals to change feeding cultures and by healthcare professionals supporting eating development in infants. As one example, all NICU staff within a large hospital are completing training across a two-year period. The focus is on training as well as system issues with both bedside caregivers and leadership. This hospital is collecting infant, parent, and staff outcome data to explore how changes in the bedside feeding culture improves outcomes.

Feeding is the "last barrier" to discharge because it requires infants to be able to do everything else, all at the same time. It is naturally the last thing they develop, and when the development of swallowing, airway protection, the gastrointestinal system, and the respiratory system are all understood, the complexity of eating is respected. Feeding is so challenging because of the neurological and physical development of the infant. The protective swallowing mechanisms and the physiologic, motor, and behavioral state systems are still developing. When feeders don't know how to observe and respond appropriately during feedings, infants can be exhausted, cough, choke, gag, experience decreases in heart rate and oxygen saturations, or shut down. By training feeders to not only see with new eyes, but to respond appropriately to the communication of the infant, the goal becomes supporting positive experiences within the current development of the infant. Additionally, a shared language and philosophy can be taught to the family who are the most important people in their infant's life and should be the primary feeders. What healthcare professionals teach, and model is what the parents learn. If parents are taught to ignore their infant's behaviors and to focus on the task of feeding enough volume, the challenges during feedings continue well after discharge. SOFFI® shifts the trajectory of feeding to develop a strong foundation for life-long eating. References

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The Impact of NIDCAP on the Infant, Family and Society



7, 8, & 9^{**} October 2022

Seminaris Hotel Bad Boll / WALA Bad Boll, Germany

Hybrid Meeting

Hosted by NIDCAP Germany, Training Center Tübingen

(Full meeting attendance is by invitation only)

* Friday, October 7, 2022

One Day Symposium, Open to All, See Details Below

** Sunday, October 9, 2022 Membership meeting

FEDERATION INTERNATIONAL voice of the newborn	act of NIDCAP on the Infant, Family a One Day NIDCAP Symposium at WALA 7 October 2022 10:00-17:15 CEST	nd Society Universitätsklinikum Tübingen		
Session I - NIDCAP and the individual	Session II - NIDCAP and the family	Session III - NIDCAP and society		
 10:00 Welcome & Introduction Deborah Buehler, PhD, President, NIDCAP Federation International Christian Poets, MD, PhD, Director, NIDCAP Germany, Training Center Tübingen 10:15 Plasticity of the preterm brain in response to environmental stimuli - O. Jenni 11:00 Plasticity of the preterm brain in response to injury - I. Krägeloh-Mann 11:45 Translating data on brain development into practice - J. Sizun 12:30 Lunch break 	 13:30 Psycho-Neonatology: Working with parents, preterm infants and staff. Development of former preterm infants 20 years later - K-H. Brisch 14:15 The NICU experience of parents: Translation into practice - E. & F. Pfeiffer 15:00 Break 	 15:30 Putting the infant on the political agenda - S. Mader 16:00 Steps for implementing NIDCAP on a national level - D. Haumont 16:30 How can health care professionals influence the political agenda to improve newborn care? Translation into practice K. Janssen 17:00 Reflections – Heidelise Als, PhD, Founder, NIDCAP Federation International, Inc. Director, National NIDCAP Training Center, Boston, MA 		
Oskar Jenni, MD, Director, Developmental Pediatrics, University Children's Hospital Zürich, Switzerland Ingeborg Krägeloh-Mann, MD, Professor, Pediatric Neurology, University Children's Hospital Tübingen, Germany Jacques Sizun, MD, Medical Director, Neonatal Department, Centre Hospitalier Universitaire de Toulouse, France	Karl-Heinz Brisch, MD, UnivProf. at the Paracelsus Medical Private University (PMU), Salzburg, Austria Elena & Frieder Pfeiffer, Parents of a prematurely born infant	 Silke Mader, Chairwoman of the Executive Board and Co-Founder of European Foundation for the Care of Newborn Infants (EFCNI) Dominique Haumont, MD, Neonatal Unit, Saint- Pierre University Hospital Brussels, Belgium Kelly Janssens, RN, Midwife, Breastfeeding and Lactation Consultant IBCLC, NIDCAP Trainer, University of Leuven, Belgium 		
Attend the One Day NIDCAP Symposium Wala Heilmittel GmbH, Dorfstr. 1, 73087 Bad Boll/Eckwälden, Germany More details and reaistration information here:				

in Person *or* Virtually...

nidcap.org/7oct2022-nidcap-symposium

SCIENCE DESK

Not an Exclusive Club Anymore

Dalia Silberstein, PhD, RN, NIDCAP Trainer

Israel NIDCAP Training Center, Meir Medical Center, Israel

Target Article: The culture of research communication in neonatal intensive care units: key stakeholder perspectives. Jennifer Degl , Ronald Ariagno, Judy Aschner, Sandra Beauman, Wakako Eklund, Elissa Faro, Hiroko Iwami , Yamile Jackson, Carole Kenner, Ivone Kim, Agnes Klein, Mary Short, Keira Sorrells, Mark A. Turner, Robert Ward, Scott Winiecki, Christina Bucci-Rechtweg and International Neonatal Consortium. Journal of Perinatology, 2021,41:826–2833. https://doi.org/10.1038/s41372-021-01220-5

y childhood home in faraway Montevideo was a three-minute walk from the large and fancy National Golf Club. Access to the club and lawns was banned for non-members. On Sundays, however, the club would open its gates to the public, and city residents were allowed to stroll the fine grass extensions and enjoy the gift of a huge urban green area. As a child, I spent many Sundays exploring each and every corner of that seemingly immense green paradise. Nevertheless, for me, golf clubs remain emblems of exclusivity, elusiveness and unapproachability.

The first words of the target article¹ title signal the topics of concern: "culture", "research" and "communication". Generally, we think "research" in neonatology involves the creation, dissemination, and application of scientific knowledge. In this case, it is scientific knowledge for the benefit of babies receiving care in a Neonatal Intensive Care Unit (NICU). But what does "culture" have to do with such science?

Our target article is authored by seventeen individuals, along with a Workgroup of the *International Neonatal Consortium*. Degl and colleagues take us on a look into NICUs scattered across the world and enable us to see some of the workings through three different sets of eyes. Each set of eyes belongs to a distinct group essential to the care of premature or medically fragile infants: neonatologists, neonatal nurses, and parents of babies that received care in a NICU. Other professions could have been included, but some important lessons were learned from just these three.

The data reported in the article came from a survey constructed systematically by a broad-based group using a stepwise consensus methodology. After a comprehensive literature review, the survey designers highlighted an important set of relatively unaddressed research issues: (i) preterm infants are routinely exposed to drugs that have not been adequately researched (for dosage, effectiveness, safety); (ii) investment in neonatal therapeutics tends to be low, and therefore lags persist in the study of new and existing drugs for newborns, as compared to other populations; (iii) there is a huge need to facilitate the conduct of neonatal clinical trials; and (*iv*) the participation in this kind of trials is perceived by many as potentially risky, burdensome for parents, as well as ethically challenging.

Then, with cloud-based software, the group administered an elegantly constructed survey to members of each "stakeholder group", which yielded 323 respondents (52 neonatologists, 188 neonatal nurses, and 83 parents of NICU graduates) from NICUs around the world (see Table 1 in the article for demographics). They produced an article that is readable, with thoughtful discussion of results, supported by helpful data.

The results revealed differences in perceptions of the research process, research knowledge and its appli-

cations. How could this be among groups united by a common cause? A surprising number of parents were never or rarely offered meetings with the neonatal team caring for their baby - a setting where it would be natural and effective to share and explain research knowledge as part of the decision-making process. NICU parents have special forms of knowledge pertinent to research training and education programs, and yet, they were almost never consulted or included. Over 80% of the physician respondents felt that existing medications are insufficient to meet the medical needs of NICU patients; they cite unsatisfactory off-label use of medications, in untested dosages for babies. Parents and even neonatal nurses are relatively unaware of these shortfalls and the need for reform and quidance in appropriate pharmaceutical research. There were numerous other important revelations about the perception of research protections across the participant groups. Significantly, there was great unanimity across the groups, in support of the principle that research should be an important component of a NICU's work.

The strengths of this report stem from the salient trends that are highlighted in it and reflected upon in the discussion. Indeed, Degl et al. provide a mind-opening perspective. Various questions are inspired by their article. How have we not contemplated and discussed these issues? Why have we been unaware of some of the real challenges? What other summits have yet to be conquered in neonatal care that we have not even attempted yet?

Clearly, neonatal research is needed, as is its broadly-based dissemination. A NICU's caregiving culture, along with family-centered developmental care, needs continued implementation and fine-tuning. In such a cultural context, input into new research directions will arise. Degl et al. preview some new and needed research questions. While the paper raises a variety of topics for reflection and action, I would like to address two extensions of the ideas in the target article that inspired me.

Envisioning a path beyond informed consent

While we can celebrate recent advances in patient involvement in medical research, parental involvement in *neonatal research* seems to be evolving more slowly.² Informed consent is one aspect of neonatal research in which parental involvement is formally pursued. Since the '70s parents have been asked to give permission for their babies to be involved in clinical research. Notably, the procedures for informed consent rarely have received input from the principal stakeholders, i.e., parents of NICU graduates.³

Janvier et al.² dig into the process of "informed consent", beyond signing an agreement to participate. They emphasize the need to integrate parents in the review of procedures for informed consent and describe instances in which parental input improved how parents were approached for participation of their infants in research. They also identify further ways in which parents can be be integrated – from setting research priorities to analyzing and presenting results. Bourque et al.4 echo and extend these messages in their discussion of activities performed by

resource parents in neonatology, and outline those activities where resource parents may be integrated to optimize research. Shen and collaborators⁵ note that researchers tend to restrict parental input to "later" stages of research, after the study focus has been finalized. They too, provide recommendations for engaging parents in research, and strongly advocate for the enhancement of research that is acceptable and relevant for the population it is intended to serve.

Visibility and clarity of researchrelated information

Degl et al.¹ advocate for involving the "natural stakeholders" (namely, nurses and families) in NICU research in all stages of the research process. They see neonatal nurses as a crucial interface between families and neonatal research endeavors.

I emphasize the potential of increased parental involvement, as I believe parents in the NICU remain especially in need of advocacy. Fragile infants have fragile parents. But such parents are accessible and responsive. It is with great respect and admiration that we read a family's testimony published in the most recent Developmental Observer,⁶ illustrating vividly how straightforward the enrollment process can be when a study's objectives resonate with the values and potential benefits they envision for their child. Nevertheless, families might also experience profound dilemmas regarding enrollment.³

Appropriately, we professional caregivers – each of us in our diverse roles – should be constantly aware that information that is clear and obvious to us is not necessarily so for families. Degl and colleagues identified the need for guidance in communicating with parents (and with nurses) about clinical trials, noting that education about research underlies effective communication more generally.

Ouestions about "what should we talk about with families?" often concern me, as there is much we need to discuss during an infant's hospitalization. How much information can be handled by a parent in the NICU? It may seem daunting to add discussions of research to the topics we already address with families in the NICU. Here is a major lesson of "The Culture of Research Communication ...": communicating about research brings benefits. We move beyond the old and well known informed consent, towards a broader approach that advocates for parental involvement and engagement of a dramatically different kind. There are myriad benefits. Parents are empowered to parent. Staff are united and integrated. Barriers are broken. Inclusion reigns over exclusion.

Final thoughts

Where do we go from here? As a relatively young discipline, Neonatology has promising opportunities ahead. Research is needed to support and enhance neonatal clinical practices. In recent years, we have witnessed how the increasing involvement of parents in their infant's care improves the care we deliver in the NICU.

Neonatal research may be our next "port of entry" into the advancement of our collaboration with families. This path is being envisioned for us by others.^{1,2,5,7} Imagine a culture of care that strives for more collaborative relationships among all the involved parties. Recall many of the parents you have known; dream of their involvement in redesigning research documents, developing research materials, prioritizing research topics, supporting recruitment and collection of data, coauthoring scientific articles, taking part in research committees, co-presenting at professional meetings (see Pyramid of Complexity, presented in Figure 1 in Janvier at al., 2019).²

Envision inclusiveness and collaboration, both in caregiving and in research. There is a view that can elevate and respect aspects of exclusivity. At times, "exclusivity" implies refinement or the privilege of high quality. But Degl and colleagues clarify the toll of exclusivity. At its root, exclusivity implies *exclusion* – denial of access. The future is already knocking at our doors. It is time. The exclusive golf club should be fully opened to all.

Acknowledgements: I am grateful to Jeff Alberts, PhD, for his thoughtful and invested support in the editing and organization of my manuscript. And to Ita Litmanovitz, MD, for suggesting thought-generating bibliography for my writing.

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Does Caffeine Use Support Suck/Swallow/Breathe Coordination at Breast and Bottle, and Lead to an **Earlier Discharge?**

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DOI: 10.14434/DO.V1512.34362

o preemie babies need their "cup of coffee" each day to improve feeding skills at breast or bottle when they are adjusted to 34 weeks gestation or above?

Caffeine is a common pharmacologic treatment for apnea, and for extremely premature infants who are born at 24, 25, 26 weeks gestation,¹ continuing caffeine may be just what the doctor ordered. Just like you and I need our coffee in the morning to function, does an extremely premature infant benefit from their "coffee" through their daily dose of caffeine through the adjusted age of 34-37 weeks? This is the time they are working on coordination of suck/swallow/breathe, improved intake and maintaining stable vital signs during feeding experiences at the breast or bottle.

Research shows that caffeine affects respiration in the following ways: increased minute ventilation, improved carbon dioxide sensitivity, decreased periodic breathing, and decreased hypoxic depression of breathing.²

If a baby maintains the intervention of caffeine while setting the foundation for feeding skills, would they be able to maintain stable vital signs, improve organization of behavior, and improve intake in a shorter amount of time? Therefore, decreasing time spent in the hospital?

The literature also shows that caffeine is safe and effective, but the therapeutic window for use has not been established. Eichenwald³ suggests that a baby be free of apnea/bradycardia events off positive pressure for five to seven days or at 33-34 weeks PMA. But could the baby continue caffeine support while



working on suck/swallow/breathe coordination at breast and/or bottle, which may begin around 34 weeks PMA? If babies are given the support of caffeine during this time, when an additional activity, such as breast and bottle feeding, is being presented, it may improve the positive experience of feeding and lead to improved intake and the main goal of full oral feeding for discharge home.

Infant bottle feeding.

The transition to oral feeding requires that a baby demonstrates physiological stability. To assist the infant, we need to understand how they maintain optimal oxygenation during oral feeding and how they can self-regulate their oxygen status.4 Swallowing momentarily interrupts breathing, which requires work for organization with the suck/swallow/ breathe pattern. Could caffeine support the organization needed to achieve full oral feeds more quickly?

Many authors discuss the use of caffeine with suggestions to be proactive, rather than reactive to apnea episodes at rest and during oral feeds. Some suggest that caffeine may be needed longer for the extremely premature infant to support the developing lung. It is discussed that the common practice is to discontinue caffeine between the 33-34 PMA. It was noted that apnea still occurs and is not trivial in the 35-39 PMA. It is suggested that continuing caffeine past 35 weeks is a possible treatment plan that could have a significant clinical impact. However, physicians seem reluctant to keep an infant on caffeine past 34 weeks with concern that it may delay discharge. It may be possible that staying on caffeine longer could in fact, speed up discharge. If de-saturations are closely observed and recorded, the need to extend the use of caffeine will become

"Swallowing momentarily interrupts breathing, which requires work for organization with the suck/swallow/ breathe pattern."

evident. If the medication was not discontinued until three to five days post last incident of a desaturation, the baby has support while feeding, and could in fact discharge from the unit sooner avoiding the need to prolong hospitalization to monitor for desaturations to ensure that the baby is stable.

Caffeine's favorable effect on cardiorespiratory physiology in stabilizing systemic and cerebral hemodynamics and its capacity to mitigate hypoxic respiratory depression may play a part in neuroprotection.⁵ Kumar and Lipshultz⁵ suggest that the therapeutic window for caffeine will need continued research to understand the favorable outcomes that may be achieved for premature infants.

Dabin² discussed the wide variation in discontinuing caffeine, and the need for more studies to assist with the balance of avoiding apnea episodes and delaying discharge if caffeine is not discontinued soon enough.

Along my journey as an Occupational Therapist in the NICU, I had the privilege of working with two wonderful premature babies born at 24.6 weeks gestation and 24.4 weeks gestation. They were similar weight, 715 grams, and 760 grams. Both needed oxygen support and caffeine support. My focus was on the caffeine support and how it may assist with improved success with breast and bottle feeding.

Baby A, was born at 24.6 weeks gestation and had caffeine discontinued at 36.3 weeks. At that time, we only expected the baby to attempt to bottle feed every other feeding due to respiratory effort made during feeds, and difficulty with completing his feeds. He always seemed to need to "catch his breath" and would take 35-70% of his feeds, but remember, he was only trying to nipple feed every other feeding. He was too tired the rest of the time.

Baby B, was born at 24.4 weeks gestation and had the caffeine discontinued at 37.6 weeks gestation. Baby B was able to take advantage of the benefits of caffeine for 10 days longer than Baby A. At the time that the caffeine was discontinued for Baby B, he was consistently taking above 50% of his feeds and was bottle feeding on a cue based schedule and showing an appropriate coordination of suck/swallow/breathe.

Baby A was discharged home at 42.5 weeks and had a gastrostomy tube placed due to the inability to maintain enough energy to complete oral feeds. Baby B was discharged home at 40.5 weeks, taking full oral feeds.

When looking back at the journeys of these two babies, it may have been advantageous for Baby A to continue caffeine longer as he continued to improve with breast and bottle feeding skills. It may have assisted him to have a better foundation for coordinating suck/swallow/ breathe during feeding if the discontinuation of caffeine was considered when the baby was above 35 weeks corrected age, on cue based feeds, and taking 50% or more of each feeding orally. And, most importantly, continuing caffeine if the baby had experienced any desaturations or bradycardias in the last three to five days.

Further studies would benefit outcomes and help to establish guidelines for using caffeine and considering feeding skills and intake at the time of discontinuing the support that caffeine offers.⁶ A solution may be in correctly and efficiently charting and recognizing a desaturation and/or bradycardia and keeping a close eye on the baby's stability when nipple feeding and at rest.

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Letters to the Editor (continued from p.11)

Thank you for the new look issue of the Developmental Observer. I particularly enjoyed the first article "NIDCAP from a Parent's Perspective" - it's incredible to hear that baby Benjamin was a week old before he was even put in his bed! And the way the NICU/health system is set up to have them progress to a family room and the neonatal home care is inspirational.

Catherine Piasini
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NIDCAP TRAINING CENTERS WORLDWIDE



French NIDCAP Center, Brest

Sylvie Minguy (RN NIDCAP trainer Brest France) NIDCAP Trainer

The University Hospital of Brest is in the Brittany region of France, in the westernmost department of the Finistère. There are approximately 2200 births each year in the maternity department, which is the only Level 3 maternity department that can receive children and newborns needing critical care including extremely preterm infants.

The Neonatal and Pediatric Intensive Care Unit of Brest has 12 beds open to children from 0 to 15 years of age with medical or surgical needs. A large majority of admissions are premature newborns. Approximately 400 newborns are admitted each year in our different units, including about 100 very preterm babies born between 24 and 32 weeks gestational age.

Our intermediate and special care nursery has a capacity of 18 beds divided into two sections. Six intensive care beds and twelve intermediate care beds. Since 2007, six intermediate care beds have been relocated to the maternity unit. When the nursery was established, we named it 'Koala Unit' as it is not a true 'Kangaroo Care' service. Indeed, even if the parents are close to their baby, they do not perform skin-to-skin contact 24 hours a day.

The Road to NIDCAP

The arrival of NIDCAP in Brest was a process and great collective adventure. In the 1990s due to advances in perinatal medicine, the mortality of preterm infants, especially those with a gestational age of less than 30 weeks, decreased significantly. These infants were hospitalized for several weeks in the NICU. During this hospitalization, preterm infants were cared



NIDCAP Brest team

for in an inadequate environment for the harmonious development of the brain – sudden separation from their parents, noise, pain, unusual positions, frequent handling, and early, excessive, and often inappropriate stimulation.

We were faced with increasingly important problems, for which we did not have satisfactory solutions that were applicable to all infants. Infants were uncomfortable, and sometimes stressed and in pain. Pain was diagnosed on the basis of the infant's behavior, and it was often difficult to determine its severity and differentiate it from stress.

Respiratory morbidities, such as bronchopulmonary dysplasia leading to prolonged ventilatory support, were difficult for the infant, their family, and for caregivers. Increasingly, frequent questions arose within the medical and paramedical team about the medium and long-term future of these very premature infants. What would be the impact of this "We were missing the overarching theme which was determined ultimately thanks to an internet search carried out by Dr Jacques Sizun in 1996. One night while on call, he read the word 'NIDCAP' for the first time and it suddenly seemed obvious to him: 'If it exists, that's really what we need!'"

environment on the developing brain? What would be their achievements and at what pace? What were their chances of getting into school? Their psychological future? Their behavior in everyday life?

Families were present in the NICU more often but were finding it difficult to know their infant. The hospital pediatricians or private doctors who followed these former premature babies reported to the hospital teams that the parents absolutely did not know their infant upon discharge from neonatology and intensive care. It was as if the parents had never been involved in the care and development of their baby during hospitalization.

Various programs were set up at that time within the hospital and the intensive care unit to improve the care of babies and their families. Skin-to-skin techniques were used, even for the mechanically ventilated children.

In 1993, a study on noise, conducted by nurses, led to a change in practice that reduced the noise level in the neonatal unit. Between 1993 and 1998, instructions for additional examinations, in particular biological examinations, fell by 70% in the neonatology unit. This process of change led to a reduction in orders of systematic, painful, and non-essential examinations, all accomplished without compromising the safety of the infant.

In 1997, there was a lot of work done on pain within the entire pediatric department of the hospital. No invasive procedure such as intubation, placement of a chest tube, placement of a catheter was performed without analgesic cover. Unfortunately, this coverage was not always completely effective.

Between 1996 and 1998, 80% of the department's nursing staff benefited from training in the sensory awakening of full-term newborns and in massage techniques. The caregivers thought they could relieve the infants with massages but quickly realized that some infants did not tolerate massage at all.

Parents were increasingly present in the service. They were admitted to the units, but they were excluded at certain times, during rounds, whether medical or nursing, and especially during care. They remained mere visitors.

It was difficult for families to find their place with their infants due to a lack of autonomy, but also due to a lack of privacy. Parent/infant contact was difficult and only possible when the caregiver wanted it.

The siblings or the grandparents could visit the baby only when the infant had stayed in the unit for a long time. Developmental care techniques were used only after medical stabilization of the infant. There were different attitudes between different caregivers and between different units.

The Arrival of NIDCAP

All these reflections and the desire to change our practices fostered the implementation of NIDCAP. It appeared to us that rather than focusing and acting on an isolated environmental factor, a more global modification of the structures and organization of care was necessary.

We were missing the overarching theme which was determined ultimately thanks to an internet search carried out by Dr Jacques Sizun in 1996. One night while on call, he read the word 'NIDCAP' for the first time and it suddenly seemed obvious to him: 'If it exists, that's really what we need!'

From that night on everything moved very quickly. We needed to inform the teams, find funding, convince the hospital directors, find a trainer in the United States.

Dr Jacques Sizun, Dr Nathalie Ratynski and the Nursing Staff Director at the time, Ms Catherine Mambrini, flew to Denver, Colorado to participate in a NIDCAP training session conducted by Dr Joy Browne. They returned to Brest a few days later with a new perspective on the infants in the unit. Several meetings later, five nurses came to support the team. In just over two years, thanks to Joy's guidance, these seven professionals became NIDCAP certified (five nurses and two physicians). Jacques thought that the work stopped there, in reality it was only beginning.

'The child and his parents are at the center of care. Caregivers gravitate around.'

Now that the theory had been absorbed and understood by the core team in the unit, it was time to disseminate the program across the services and influence change within the system without being too "pushy"! Little by little the premises, the realization and the organization of the care, the relationships with the infants, with the parents, and between professionals had effected a real paradigm shift and inspired the establishment of a new philosophy of care:

Quickly, the demand for the formation of new NIDCAP training centers appeared. The French NIDCAP Center, Brest opened in 2004 directed by Dr Jacques Sizun and co-directed



Team of resuscitation and neonatology caregivers at the 20th anniversary celebration of NIDCAP in Brest.

Parents and former premature children came to share their stories and the impact of NIDCAP on their hospitalization.

by Dr Nathalie Ratynski, who became the first French NIDCAP trainer.

Observations in the unit were conducted mainly by Nathalie and periodically by other trained nurses. In 2005, a nurse coordinator position in developmental care was created. From then on, all infants born before 33 weeks and their parents were able to benefit from individualized NIDCAP monitoring. This position makes it possible to maintain cohesion between the numerous services, but also to establish links with external services specializing in the care of vulnerable infants. That same year, Dr Heidelise Als spent a few days in Brest to officially inaugurate the first French Training Center. Outstanding! The program continued to promote NIDCAP in Brest and throughout France and Europe. A training center opened in Brussels.

In 2007, the French NIDCAP Center, Brest hosted the 18th Annual NIDCAP Trainers Meeting in Combrit, Brittany, France and invited Professor Sunny Anand, an internationally renowned neonatologist for his research work on neonatal pain. In 2011, the first French-speaking NIDCAP days were organized in Brest. Since then, every year, these sessions take place in one of the French or Belgian centers with staff trained in NIDCAP and in the past few years for those with FINE 2. These allow the opportunity for beautiful reflections and reunions around a different theme each year.

NIDCAP progress in Brest continued with the training of additional NIDCAP Professionals. At the beginning of 2013, I, Sylvie Minguy, became the second NIDCAP trainer, guided by Agneta Kleberg and Deborah Buehler.

Over time, the two trainers expanded their training efforts and obtained authorization to provide new training such as FINE 2 and the SOFFI program. A little later, Jacques Sizun and Isabelle Olivard became NBO trainers with the help of Yvette Blanchard. These three training programs are very successful among French teams.

Expansion of NIDCAP

As the demand for NIDCAP training grew, the second French NIDCAP Training Center opened its doors in 2017 in Toulouse. In January 2020, Jacques Sizun and Nathalie Ratynski left Brest Hospital to join Toulouse Hospital. Dr Jean-Michel Roué took over the directorship of French NIDCAP Center, Brest which now has six NIDCAP Professionals, two of whom are working full time in the unit. This time is shared between the various trainings, the NIDCAP follow-up of children and their families and the coordination with the outpatient follow-up services for vulnerable children. The training of new NIDCAP Professionals is being planned.

We work in close collaboration with the French NIDCAP Center, Toulouse and organize regular meetings. We distribute the training according to requests, availability, and the geographical location of the requesting centers. There is a frequent exchange between trainers and trainers in training. Indeed, two new NIDCAP trainers guided by Delphine Druart will be operational in France in the near future.

Although it has not always been easy, over the past twenty years the program has continued to grow. We have evolved enormously and integrated all the techniques of developmental care into the organization of care, always keeping in mind to place the infant and his family at the heart of the system. It seems to me that if, at the beginning of NIDCAP implementation, we had been told that system-wide changes would take place during these years, we would not have believed it!

Achievements

Among many, two great moments enriched the process of setting up the NIDCAP program in Brest and provided even greater motivation to all the teams:

After several months of hard work in 2011, the intensive care and neonatology departments obtained NIDCAP Nurs-

ery Certification. This work carried out by all the units of the Women-Mothers-Children Department of the hospital has brought about a common dynamic and made it possible to continue the dissemination of the NIDCAP philosophy to all the units.

During the NIDCAP Nursery Certification visit in December 2010, the expert site visitors, Karen Smith, MSN, James Helm, PhD and Roger Sheldon, MD pointed out the strengths of the unit. They highlighted:

- The quality of care provided to newborns: One of the best among all the units visited by them.
- The quality of relationships between caregivers, infants, and families with mutual respect
- Single room architecture.

Another great moment was the big event in 2018 organized to celebrate the 20th anniversary of the implementation of the NIDCAP program. Supported by the hospital directors' board, we were able to organize two memorable days of events for all the teams.

The first day was devoted to children and their families with make-up workshops, clown shows, a music concert, and a

gigantic snack. It was an opportunity for parents, children, and professionals to meet and celebrate. The demand was so great, we were unable to accommodate everyone.

The second day brought together professionals from different units and peripheral hospitals in the region, as well as many parents and representatives of the "SOS Préma" parents' association with whom we have been working closely for 15 years. Parents and former premature children came to share their stories and the impact of NIDCAP on their hospitalization. Among them, Morgane, born at 25 weeks, and her mother, came to tell their journey, sometimes difficult but so moving, from a little girl born at 25 weeks to a brilliant student in foreign languages at the University. Morgane and her family were featured in my "advanced practicum" during my NID-CAP training 20 years earlier!

During these days, we also had the chance to welcome Joy Browne for a conference on the role of parents in neonatology services. It was a real joy to see Joy back in our department!

In addition, several nurses and doctors from the resuscitation and neonatology units spoke to the evolution of their daily work with children and their families. We said to each other as we left "Rendez-vous for the thirty year anniversary!!"



Just one final story... On May 1, 2022, Benoit, the father of Gabin who was born in Brest in May 2020 at 26 weeks gestation, sailed across the Atlantic Ocean in an amateur transatlantic race, 'Cap Martinique'. All skippers sailed under the logos and colors of a cause near and dear to their hearts. Gabin's father chose to sail under the colors of NIDCAP in recognition of the care of his baby, but also of his family during his hospitalization! The NFI sent him the logo that was displayed on the sails of his boat throughout the crossing, from La Trinité-Sur-Mer, Brittany, France to Fortde-France, Martinique.

Thus, the NIDCAP adventure continues for all!

I was present for the start of the race on May 1st in La Trinité-sur-mer. Here are some photos of the event.

Global Perspective on Developmental Care - Rwanda

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DOI:10.14434/DO.V15I2.34367

R wanda is one of the smallest countries in Africa, bordered by Uganda, Burundi, Tanzania and Democratic Republic of Congo. It is known as the Land of a Thousand Hills with a population of 13,477,805. It has been 27 years since Rwanda came out of one of the most devastating genocides in world history. After the 1994 genocide against Tutsi, Rwanda started from scratch to rebuild the health system destroyed. The strengthening of the health system in Rwanda is a foundation for socio-economic support and the cornerstone of the country's renewal.

The Rwandan health sector is a pyramidal structure and consists of three levels: Primary, Secondary and Tertiary (as shown in the diagram below).

Overview of Rwanda Decentralized



Rwanda currently operates a well-functioning, decentralized public healthcare service system. It is comprised of 1700 health posts, 500 health centers, 38 district hospitals, four provincial hospitals and eight referral hospitals, including two Teaching Hospitals. Rwanda also has a vibrant private health services sector, comprised of two general hospitals, two eye specialty hospitals, 50 clinics and polyclinics, eight dental clinics, four eye clinics, and 134 dispensaries.

All public facilities transfer the patients following the pyramidal structure seen above. Private facilities may refer to any level of the private or public health system. Referrals depend on the condition and needs of the patient.

Among 50 hospitals of secondary and tertiary levels, 49



Patrick Manibaho, RM, Marie Louise Uwimana, RM, and Jean Damascene Ndahayo, MD

have newborn intensive care units. They follow a referral flow depending on the health conditions of the newborn. In Rwanda, 12% of babies are born prematurely. Newborn mortality rate is 16 per 1000 live births and 30% of newborn deaths are caused by preterm birth complications.

Rwanda has worked to reduce neonatal mortality through newborn survival initiatives, with a National Neonatal Care Protocol and the establishment of neonatal care units (NCUs) in every public hospital to care for sick and small newborns. Through the efforts to improve care for sick and small newborns, more preterm and/or low birth weight (LBW) babies are surviving into childhood, yet there is poor health, nutrition, and developmental outcomes among children born preterm and LBW at one to three years in rural Rwanda.

High rates of developmental delay (52.6%) exist for infants. This is most significant among children born prematurely and/or LBW (67.5%) when compared to children born at term ages at age two to three years (51.1%).¹

Developmental Care

The Ministry of Health and Partners in Health have created the Pediatric Development Clinic with support from UNICEF and specialists from Boston Children's Hospital. The interdisciplinary program is intended to improve health outcomes for babies at risk of death or developmental delays. It is the first program of its kind in Rwanda.

The clinic started in April 2014 in Rwinkwavu District Hospital and has since expanded to four Districts: Kayonza, Kirehe, Rutsiro and Musanze. The clinic allows health care providers to follow infants after they go home, through regular clinic appointments and community-based support. The program features a weekly nurse-led clinic at health facilities, social supports such as food and transportation money for vulnerable families, and training for staff members in caring for high-risk infants through simple interventions. High-risk families are identified by social workers and receive home visits and community-based support as well. The program also is linked with electronic medical records systems to improve care and tracking of patients' outcomes.

NIDCAP in Rwanda

To bring NIDCAP into Rwanda, Heidelise Als, PhD (National NIDCAP Training Center, Boston) collaborated with two experienced NIDCAP Trainers, Natalie Wetzel, RN (NIDCAP Germany, Training Center Tübingen) and Maria López Maestro, MD (Hospital Universitario 12 de Octubre NIDCAP Training Center, Spain). These NIDCAP Trainers have started to train our team at Ruhengeri Referral Hospital (RRH). Given the travel restrictions due to the SARS-COVID-2 pandemic, the training is being conducted online. At this time, our team of NIDCAP Professionals in Training at RRH consist of two registered midwives (Patrick Manibaho, RM, Marie Louise Uwimana, RM) and two medical doctors (Deborah Makasi, MD and Jean Damascene Ndahayo, MD).

Zoom meetings, recorded videos and bedside live streaming during observation are the preferred ways to conduct successful training. Workshops are scheduled based on availability of trainers and trainees, often twice a month. The NIDCAP Observation write-ups are sent via email for feedback. A reflective session occurs via zoom for review of the NIDCAP reports.



Deborah Makasi, MD

The NIDCAP observation is conducted in collaboration with NICU staff and family members. Healthcare professionals communicate in English. However, the communication with family members is done in Kinyarwanda, the main language spoken in the community.

The team is looking forward to achieving certifications as NIDCAP Professionals. Our longterm plan is to continue our training to become NIDCAP Trainers-in-Training and ultimately have a training center in Rwanda. Our goal is to train our fellow caregivers in hospitals across the country. Our group represents the first Sub-Saharan African hospital to receive NIDCAP training.

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Developmental Observer

The official publication of the NIDCAP Federation International published on-line three times a year. © 2022. The statements and opinions contained in this publication are solely those of the individual authors and contributors and not necessarily of the NIDCAP Federation International. Articles from the *Developmental Observer*, duly acknowledged, may be reprinted with permission. Please contact us at: *developmentalobserver@nidcap.org*.

Contributions

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

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ISSN: 2689-2650 (online)

All published items have a unique document identifier (DOI)

NIDCAP ON THE WEB

NIDCAP Training Centers - Facebook Pages

The promotion of NIDCAP on Facebook continues with new pages being added. Over the past few months, we have seen these pages promote conferences, seminars and support sessions, helpful information, new publications, achievements, and celebrations of NIDCAP. Please visit these sites and explore other information and achievements to help you celebrate NIDCAP.



NIDCAP ON THE WEB





Nidcap Sweden

28 April at 06:21 · 🚱

Finally! The Immediate Parent Infant SKIN-TO-SKIN Study, IPISTOSS, is published. Infants born preterm have improved cardiorespiratory stabilization when cared for in SSC with a parent immediately after birth. This may be the desirable standard of care for very

The NFI NIDCAP Blog offers observations from many different perspectives on NIDCAP and its implementation, such as NIDCAP and APIB training, Nursery Certification, the science behind the approach, the family experience with NIDCAP, the NFI, and much more. We encourage you to visit the NIDCAP Blog and to leave comments for our bloggers and our NIDCAP community in general. If interested in becoming a guest blogger please contact Sandra Kosta at <u>sandra.kosta@nidcap.org</u>.

NIDCAP BLOG NIDCAP.org

Sophia Nidcap Training Centrum

11 March · 🚱

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