

Developmental Observer

The Official Newsletter of the NIDCAP® Federation International

NIDCAP Federation International (NFI)

Founded in 2001, the NFI is an international, non-profit membership organization. The NFI encourages the implementation of developmental care and assures the quality of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) approach in all intensive, special care and newborn nurseries around the world. The NFI serves as the authoritative leader for research, development, and dissemination of NIDCAP, and for the certification of trainers, healthcare professionals, and nurseries in the NIDCAP approach.

“Cherish your human connections: your relationships with friends and family.”

JOSEPH BRODSKY

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Our Family's Journey: A Story of Love, Hope, Faith, and Strength

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My husband, Jeff, and I are honored to share our story about love, hope, faith, and strength. These four concepts kept us going through some of the hardest and happiest days of our lives. We hope other parents and families find comfort and peace after reading our story. We feel this confirms that miracles do happen, and that even in the most difficult situations, strength and resiliency exist in all of us.



Jeff, Marnie, and Brinley

Our journey in the Mayo Clinic Newborn Intensive Care Unit (NICU) began after we welcomed our beautiful daughter, Brinley Grace Eveslage, into the world on July 14, 2015 at 12:32 pm. She weighed 5 pounds 11 ounces at 33 weeks gestation.

It was a groggy Monday after a busy weekend with a baby shower my awesome sister planned for us. I was uncomfortable after developing lower back pain. I didn't sleep much Sunday night and waddled into work. I planned to go home early and treat myself to a massage. How on earth was I going to survive another seven weeks? My coworkers planned a surprise baby shower so I stuck out the day. What I did not realize was that I was in active labor. I left the clinic, where I work as a medical social worker, to change clothes and to feed the dog, only to return to triage that evening. I was convinced I was not in labor; I did not feel a single contraction but something just felt off.

“Surprise, you are dilated to seven. You are having a baby.” Tears flowed down my face in fear as I knew it was too soon. I was given medication to try to stop delivery but I threw it up. Contractions progressed quickly and Brinley knew she needed to come out as, unknown to us at the time, her intestine twisted and ruptured before birth.

We were blessed with a smooth vaginal delivery. Brinley was swept quickly into another room where the neonatal team patiently waited. They, too, were surprised to see her with a blue and distended tummy. We expected a premature baby who would be healthy. Our world changed as the neonatologist quickly explained she needed exploratory surgery and to be moved to the NICU. We were able to meet her but could not hold her right then. She was beautiful with big eyes and was exploring the sound of our voices. We held her hand and wept with overwhelming emotion. Not

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Brinley in the newborn intensive care unit

a second was wasted as they made arrangements for me to be moved to the hospital at the Saint Marys campus of the Mayo Clinic to be near her in the NICU.

That evening, prior to her surgery, we met with the neonatologist and surgical team. We knew something was wrong and there was the chance there would be nothing left of her intestine to save. We sat in my hospital room while we waited for the news. To pass the time, a nurse instructed me on how to pump milk. I felt an overwhelming calm and stillness, repeating to myself that, "she came early for a reason. Everything has a purpose. She has to be okay. Please God let her be okay." I had faith that she had to make it through - and she did.

We were relieved they were able to save one third of her intestine. We knew she had a tough road ahead but were deeply grateful that our baby girl was still with us. We expected she would be on total parenteral nutrition (TPN) or intravenous feeding for the first two to three years of her life and stay in the NICU for three months or longer. She had an ostomy bag until she was strong enough for surgery to reattach her intestines at

around eight weeks. None of this mattered as long as she was okay. She was our miracle baby. We celebrated her life and had hope for the journey ahead.

The next three months were filled with joyous days as we watched her grow and become an amazing little person. Her strength and feistiness were apparent right away. She did whatever the doctors asked of her. We spent countless hours holding her, talking to her, reading to her, singing, and praying. I loved coming to the NICU to do kangaroo holding and allow myself time to rest with her. I cherished every second of it. One of the best days was when the gastrointestinal (GI) team gave the all clear to start dry nursing at two weeks. I had to pump first because her gut could not tolerate a large amount of milk at once. This meant so much because she wanted to eat so badly. She had been communicating her desire to eat; it was so hard not to feed her. The dry nursing allowed her to soothe herself naturally while bonding with Mama. It was great for both of us. She had a feeding tube with a slow constant drip until she was ready for bolus feedings and eventually a bottle at six weeks.

Life was also hard in the NICU. We had tough days watching her barely gain weight. We struggled with keeping her ostomy bag in place. At two weeks she was diagnosed with hydrocephalus or fluid on the brain. This was devastating news. I remember feeling as though I could not cope with this too. I did not want this for her. I had nothing in me but to sob. I will never forget this day. The social worker came to reassure me that I did have the strength; she normalized my grief response. These were comforting words from a colleague and friend. What I remember the most is sitting in silence with another mother as we sat and held our babies. We just cried. Knowing that she felt my pain and suffering was so comforting. She did not need to say anything, and frankly, we did not speak the same language. I didn't need her to say anything. Her presence in the room was enough. We all tried to respect each other's space and privacy. You don't have to say anything to each other - maybe a glance, a smile. We would say hello in passing in the hallways or the parking ramp, and maybe chat briefly. We got to know a few families with common medical struggles. We all knew this sucks. What is there to talk about? We knew so much about each other already without talking. Part of me knew I only had enough

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strength for myself and my family. I could not be a strong support to others too. Not right now.

How do you adjust to the challenges of NICU parenting? How do you support each other, yourself, and your child? We were surrounded by support from our family, friends, and co-workers. They cooked us meals, bought us gift cards, parking passes, started a fundraising page-you name it. They came to visit and filled Brinley's bedside with love. I documented her progress on the Caring Bridge webpage to keep everyone informed. This was all helpful, but my baby was not home with me. Nighttime was the most difficult. I left her alone in the care of someone else. I would wake up to pump, not to feed my baby. I found strength in focusing on the moment. This is what needs to happen for Brinley. I had to stop myself from thinking about what should be happening and what was "normal." This is our normal.

We quickly built a routine. My husband would come in before work. I would come in shortly after to spend the morning and catch rounds. Most days we got lunch together. I would update him on her progress. I would go home for a few hours to get things done and return in the late afternoon. We would eat dinner at home and return to spend the evening together as a family. This routine helped the days pass. We thanked God for his presence in our lives and dug deep to keep faith.

We built a strong relationship with many of the nurses and medical team. It helped to have consistent nurses, like Patty, that grew to know Brinley well - and us. They taught us first how to be a part of her caregiving and we quickly became independent in providing care to Brinley. We brought her own outfits to dress her and her own blankets, rather than the hospital's sleepers and blankets. You wouldn't think this mattered, but I felt like we were providing for her - we were her parents. I laundered her clothes and brought books from home, anything to help normalize the situation.

The NICU at Saint Marys had four open-bay rooms. Some of those rooms had two enclosed rooms within the open bay that were used for smaller or sicker babies. We were in both room types depending on Brinley's needs. In the open bay rooms it was difficult to have a small space with another family right next to

you. I craved alone time and peace and quiet. I dreamed about moving her to the Intermediate Special Care Nursery (ISCN). We advocated for this and at five weeks she moved into a beautiful nursery with large private rooms. It was a vacation from the NICU. She did well there, though it was different. We built relationships with new nurses and had the same medical team, and at the same time I missed the NICU nurses and wanted to celebrate Brinley's victories with them. They sat with us through some of the most difficult days. They were our NICU family.

Brinley did so well with feeding in the ISCN that she went off the TPN and was on full bottle feedings at seven weeks. She was approved for intestinal reattachment surgery a week earlier than expected. I had mixed emotions about this as it meant we would start all over with feeding; back to what seemed like starving my baby until she could get to full feedings. When we were finally able to feed her, I wasn't sure if I could do it again. I did not want to put her through it, and we would be back at the NICU. I was, however, also happy that she grew and was on track to having her intestines reattached. It was time to get rid of the ostomy bag.

Surgery went well. We celebrated that her intestine grew fifteen centimeters over the course of seven weeks. Her surgeon was impressed and had hope that she would have more intestines to absorb nutrition. We celebrated her first passing of gas and stool. This meant her gut was working. All of this positive energy is what kept us going. It felt good to be back at the NICU. We were home with our NICU family who knew us. The smell, the dim lighting, the coloring - everything about it was good. I did not realize it until we came back how important our nurses were to us. The relationship and understanding of our journey were so comforting.

It took four weeks for Brinley to handle feedings after surgery. She eventually went off the TPN with a combination of breast and bottle feedings with pectin and formula for extra calories. She finally went home at eleven weeks. She did not require the TPN for two to three years like her doctors thought she would. She really is a little miracle. Soon she will be two years old and is a happy, rambunctious toddler with spunk. She knows what she wants and likes, and is not afraid to let you know. We are forever grateful for her strength.

Our message to other families is to accept help from others. Make time for yourself. Eat, go home and sleep, exercise, talk to your spouse and make time for each other. Lastly, create your own normal. Make the best of this experience and the amazing medical team who are there to take care of you and your baby. This is your time to just be present with your little one. No laundry, cleaning, or cooking. Just be.

Our time in the NICU was some of the hardest and also most joyous days of our lives. We found strength to remain positive; we held onto *hope* and *faith* and flooded Brinley with love. There was no better place for us to be. We will never forget our time there and cherish the relationships we built with our care team. We look forward to seeing everyone at the annual summer NICU reunion.



Brinley at home

Preemie Project: Raising Awareness of Premature Birth Through Photography

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Erik and Andrea celebrate their special relationship

In the more recent past than I can believe, premature babies spent weeks and sometimes months alone in incubators, until finally they were deemed stable enough to be held by their parents who waited with bated breath for that single moment to be determined. Although the theoretical basis existed and the scientific research had begun, the actual practice of concepts like family-centered care and relationship-based care were in their infancy in some Newborn Intensive Care Units (NICU). How well your patient was doing and therefore how well your day was going was determined by numbers, measurements and calculations. As a novice nurse accustomed to working with adults, I instinctively looked for ways to connect with my tiny patients. Even then, a few years away from knowing much about NIDCAP and starting my NIDCAP training, I tried to take my time and observe the babies in my care, to watch and see what they might be trying to tell me, what they might need from me. I also certainly felt a strong sense of empathy toward the mothers, fathers and siblings, who were going through one of the most difficult, heart breaking experiences of their lives. Even

though our unit did not specifically have a system where nurses participated in primary care, many nurses did request to be assigned primarily to certain babies. Like me, they were looking for ways to connect and often saw the benefits of a primary care relationship for everyone involved. I usually cared for only one or two babies at a time and found it quite fulfilling to get to know the babies very well and to grow a relationship with their families, as this allowed me to better support them. In some cases, parents kept in touch and let me know how they and their children were doing at home. It always made me feel good to see the pictures of these little people, thriving, despite the obstacles they had to overcome. That is where I drew my strength to go back to work each day to support the families at the start of their journey.

As I look back over the last 16 years in the NICU, I think about the many special babies and their families with whom I have been honored to connect. Each and every one of them taught me something important: things I couldn't learn from books or classes and things that helped shape me into the nurse I am today.

Late last year, a local photographer, Ashley Sykes, started a fundraising project called the Preemie Project. The project began as a way to honor the story of her friend's premature baby celebrating his first birthday and then grew into one that would raise money and awareness for premature birth. Her amazing project is a celebration of the lives of many premature babies from the Edmonton, Alberta area. The project allowed families, and sometimes the children themselves, a chance to share their stories. I was surprised and excited when I was contacted by

“She allowed me as a mom to feel competent and confident in developing a relationship with my son who was two pounds and hooked up to more tubes and wires than you could imagine.”

Renee Lukie, the mother of a former patient, to participate in this project and pose for a photograph with her now 14 year old son who was born at 24 weeks. What an amazing way to celebrate his life, as well as our special relationship. Ashley's project documented the family's story, which I share here in its original format from Ashley Sykes' Premie Project blog post at <https://ashleysesphotography.com/>.

Name: Erik

Gestational Age: 24 weeks

Weight at birth and length: 976 grams and 35 centimeters long

Current Age: 14

Renee: We were told when Erik was born that he was born at the cut-off date for gestation and it was going to be a tough battle but he was feisty. Who knew such a small baby could be feisty, but they were right. The Christmas season was the hardest our family had ever been through, with a two year old at home and our little man in the hospital fighting for his life. On Christmas Eve, we received a phone call that he had an infection and that they were bringing the priest in to bless him as they were not sure he was strong enough to fight through the E-coli infection. These days were the darkest days of my life as a mother. I had hope and believed that a Christmas miracle could happen but my heart was breaking from the inside out. There was a lot of staff coming and going in Erik's care over the Christmas holidays which was very hard to cope with when seeking consistency during a difficult time. We requested a primary care team so that we could limit the number of different people on our team in supporting Erik and ourselves. This is where our Christmas miracle happened and Andrea Nykipilo came into our lives. She became Erik's primary nurse which meant when she worked she would be placed with him and a few other babies in our pod.

She has a gift. She allowed me as a mom to feel competent and confident in developing a relationship with my son who was two pounds and hooked up to more tubes and wires than you could imagine. She took the time to teach, support and listen each and every shift. When she worked nights she was always there to take my bedtime phone call and was honest with how he was doing since I had left and what to expect in the morning for rounds. She helped me with this first real bath and introduced us to kangaroo care which was vital in Erik's growth and development. She understood the importance of family and helped us with introducing and having a two year old in the NICU. She is our angel on earth and we are forever grateful for her. Erik came home at four months old weighing 4 pounds 11 ounces. He overcame many obstacles during this time including infections, complications, blood transfusions and various medications to help him grow and be as healthy as possible. The day we brought him home was so exciting and scary at the same time, knowing we wanted to be home but would miss the support of those who

had helped us along the way. We thought we had brought home a baby who was going to be perfectly healthy, however, within a couple of months Erik was showing us signs that something was wrong, and together with our amazing pediatrician, Dr Teoh, Erik was admitted to the Stollery Children's Hospital in Edmonton for further testing resulting in Erik having his first of three airway surgeries. We spent much of 6 months in and out of the hospital for surgeries and appointments for his feeding tube and medications. Erik was in the Pediatric Intensive Care Unit (PICU), Intermediate Care Environment (ICE) ward and pediatric wards for weeks at a time. Again the support was amazing and our days were filled with learning and understanding Erik's new reality with a chronic lung disease that affected his airway. There were several home care visits, emergency room visits, hospital stays and the need to rely on family from afar and new friends in our new community. It truly took a village to get us to where we are today.

Erik will be 14 years old next week. He is 5 feet 7 inches tall, 127 lbs. and has size 10 feet. He is witty, smart, loving and a true miracle. Every day I am thankful for all he has taught us and that he offers our family. He just got his report card and it makes my heart smile to see his teachers write what a great kid he is and how hard he works at school, the good grades are a bonus but not the icing on the cake for us. For the second year in a row, Erik's teammates from his hockey team have voted him assistant captain for his team. Erik is a quiet leader with a heart of gold. His health has really come along; we haven't had a hospital stay or visit since he was nine years old (touch wood)! He does have low tone and finds that his muscles work better once he is warmed up when on the ice. Being an active child has helped his development in so many ways. We are proud of our son and the young man he has become. He truly is a gift that we are so thankful for. The journey has been hard but I wouldn't change it for anything. I hope our story can give someone hope and know that there are better days ahead. They are not alone and that the community in the NICU is there to help and support you.

Andrea: I, too, am so very proud of Erik and very thankful to have his family's story interwoven in my story. I believe it is very important to share the human side of the very technical and often medically-focused area of newborn intensive care and hope it inspires others to find the connections with those around them in meaningful ways. To all the extraordinary nurses and other professionals out there taking the time to connect with babies and families, I applaud you. Know that you make an unbelievable difference to these families.

Blog credit and photo credit to Ashley Sykes Photography: <https://ashleysesphotography.com/> and the Lukie family for allowing me to share our story and photos.

Spontaneous Motility of Preterm and Full Term Babies

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It is now accepted that the central nervous system (CNS) produces an extraordinary repertoire of complex behaviors without any external stimulation. One of these consists of a number of specific motor patterns that can be observed in fetuses and preterm and full term babies.¹ Their central nervous systems are capable of producing a range of behaviors which also include very complex motor activities, among which General Movements (GMs) are the most frequently observed.² Contemporary neurological assessments consist of two types of items: those related to spontaneous behavior such as GMs and those related to elicited responses.

Since the 1970's Prechtl and his co-workers have focused their attention on the spontaneous movements of the fetus using ultrasound scans. They recognized that spontaneous movement could be distinguished in movements that were clearly constant in form and were therefore easily recognizable every time they occurred. Prechtl defined these sequences as "movement patterns". With the aid of ultrasound he was able to identify several fetal movement patterns such as startles, GMs, isolated limb movements, twitches, stretches, breathing movements, hiccups, yawns, head rotation, head flexion, sucking and swallowing movements, among others. The changes of fetal position in the uterus, which elicit fetal trunk rotation, GMs and alternating leg movements, characterize ontogenetic fetal adaptation and have an adaptive function during prenatal life.³

General Movements emerge as early as nine to twelve weeks postmenstrual age (PMA) and look complex and differentiated from the very first moment they appear (Table 1). There is an amazing continuity in the development of the prenatal motor patterns during the first two months after birth,⁴⁻⁵ with very few changes in the form and pattern of GMs despite the huge changes in the environment. The form seems not to be influenced by the intrauterine nor the extrauterine environment. GMs continue to be present during the whole preterm period and they are seen up to the age of five to six months post-term age (PTA). Thus the young nervous system of the fetus generates these movement patterns without being stimulated. In other words, GMs are endogenously generated. They reflect the spontaneous activity of the brain and are the most frequently occurring and the most complex motor patterns observed from birth up to five to six months PTA.

It is likely that GMs are produced by complex nervous networks, the so-called central pattern generators (CPGs) located in different parts of the brain and at various brain levels, but

TABLE 1. Fetal Motor Repertoire by Postmenstrual Age

10 Weeks	12 Weeks	14 Weeks	20 Weeks
Startles	Startles	Startles	Startles
GMs	GMs	GMs	GMs
Isolated arm movements	Isolated arm movements	Isolated arm movements	Isolated arm movements
Isolated leg movements	Isolated leg movements	Isolated leg movements	Isolated leg movements
Hiccup	Hiccup	Hiccup	Hiccup
—	Breathing movements	Breathing movements	Breathing movements
—	Hand-face contact	Hand-face contact	Hand-face contact
—	Head retro-flexion	Head retro-flexion	Head retro-flexion
—	Head ante-flexion	Head ante-flexion	Head ante-flexion
—	Head rotation	Head rotation	Head rotation
—	Stretch	Stretch	Stretch
—	Yawn	Yawn	Yawn
—	—	Sucking and swallowing	Sucking and swallowing
—	—	—	Eye movements

Table 1 reproduced with permission of Mac Keith Press¹⁰

especially in the higher parts of the medulla and in the brain stem. Breathing, sucking, chewing, eye movements, swimming, crawling and walking are other spontaneous motor activities that appear to be endogenously generated (i.e. generated without any recognizable external stimulus). The combination of these motor activities varies according to the ongoing behavioral states of the newborn baby. According to Prechtl's definition of behavioral states 1 to 5, during state two (active sleep), irregular breath-

ing, slow and rapid eyes movements and body movements are fired by specific CPGs. During state one1 (quiet sleep), regular breathing and the absence of eye or body movements reflect the different neural mechanisms that serve to actively inhibit (or modulate in the case of respiration) these motor activities from higher cortical and sub-cortical structures.

The assessment of GMs was standardized and validated in a tool designed for the assessment of spontaneous motor behavior of newborn babies by Prechtl and co-workers, during the late 1980's.⁵⁻⁷ This non-intrusive tool is based on the observation of spontaneous non-elicited movements of the newborn baby, either preterm or full term. Prechtl and co-workers demonstrated that GMs in particular are an excellent marker for early brain impairment and dysfunction.⁸⁻¹²

What are General Movements?

General Movements involve the whole body in a variable sequence of arm, leg, neck and trunk movements. They wax and wane in intensity, force and speed, and have a gradual beginning and end. Every body part starts to move with a sequence, which changes continuously and the movement spreads all over the body. In the same way, the movement sequence gradually decreases and the baby becomes restful. Rotation along the axis of the limbs and continual changes in the direction of movement make GMs fluent and elegant and create the impression of complexity and variability.⁹ Preterm age GMs are similar to those of the fetus: they are of large amplitude, often of fast speed and are frequently accompanied by lifting of the pelvis (Figure 1). At term age, they are smaller in amplitude and show the so-called “writhing” character that gradually disappears, while “fidgety” GMs emerge from six to nine weeks PTA.¹⁰⁻¹¹

Fidgety GMs are small movements of moderate speed and

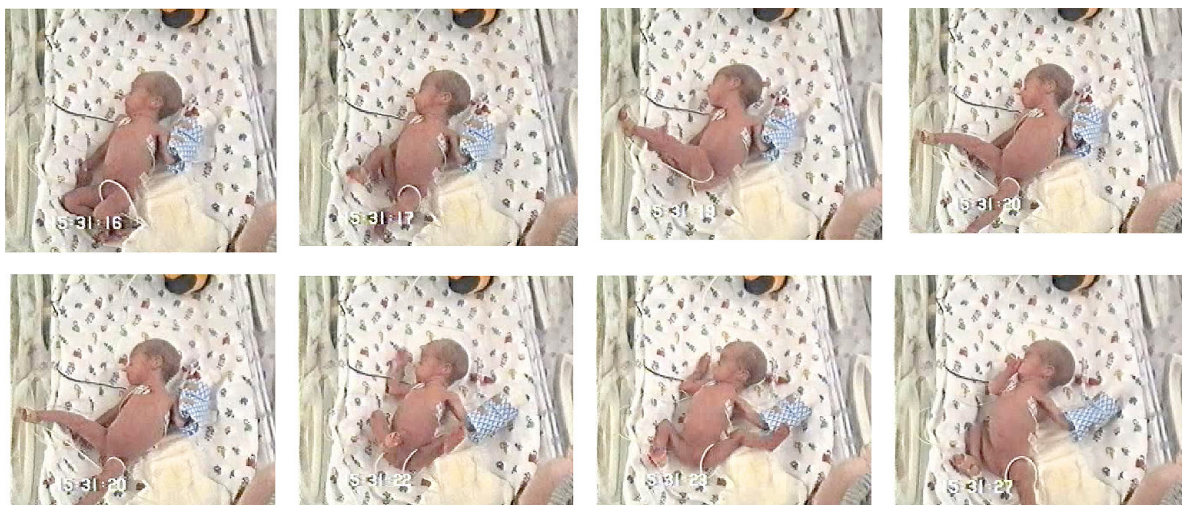
of variable acceleration of all body parts in all directions. They are observable when the baby is awake, except during fussing and crying. They may be seen as early as six weeks PTA and are typically observable starting from nine weeks PTA, lasting until twenty weeks PTA. Many other movements can be observed simultaneously with fidgety movements in healthy three to five month old babies, such as hand-hand contact, hand-hand manipulation, hand-mouth contact, foot-foot contact, fiddling, and leg lifting.¹⁰

Among the other movement patterns, the GMs are the most frequent, but also display the most complex pattern. It is likely their complexity makes them more vulnerable and therefore more sensitive to brain dysfunction. Brain lesions affect the quality rather than quantity of GMs, as has been demonstrated by various studies.⁸⁻¹² When the CNS is impaired, the GMs lose their main three characters: complexity, variability and fluency. There is only one exception to this rule: severe perinatal asphyxia is accompanied by a transient phase of hypokinesia: i.e. absence of recognizable GMs.

In the case of brain lesions, the three main patterns of GMs abnormalities are characterized as poor repertoire, cramped-synchronised or chaotic. Fidgety movements can be either abnormal or absent. Abnormal fidgety movements are exaggerated in speed and amplitude and are jerky.⁹

A poor repertoire GMs pattern is the most common abnormality and occurs during preterm, term and early post-term age. The sequence of movements of the body parts is monotonous and repetitive and the movements lack the complexity and variability seen in normal GMs (Figure 2). The predictive value of poor repertoire GMs is low because poor repertoire GMs can be followed by normal, abnormal or absence of fidgety movements. When abnormal GMs are followed by

FIGURE 1. Normal GMs: Example of a Variable and Complex Sequence of Normal GMs of a Preterm Baby



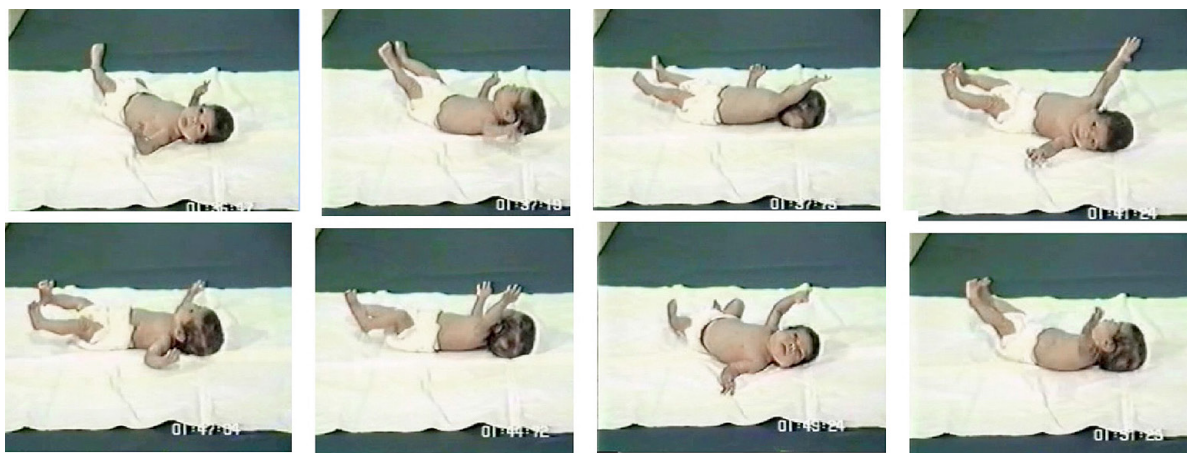
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FIGURE 2. Poor Repertoire GMs: Example of a Repetitive and Monotonous Sequence Within the Same GM of a Preterm Baby



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FIGURE 3. Cramped-Synchronized GMs: Example of the Synchronous and Cramped Character of GMs of a Preterm Baby



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normal fidgety movements, a recovery from brain lesions and a normal outcome are expected. When the fidgety movements are absent, on the contrary, cerebral palsy is very likely to occur. The absence of fidgety movements is highly predictive for later neurological impairments.¹¹⁻¹²

A cramped-synchronized GMs pattern is also a marker of severe GMs abnormality. Movements appear rigid and lack the normal smooth and fluent character. All limbs and trunk muscles contract and relax almost simultaneously (Figure 3). If this abnormal character appears early, persists for weeks and is accompanied and/or followed by no fidgety movements, the development of a spastic form of cerebral palsy is predictable.⁹⁻¹³

A chaotic GMs pattern is a rare abnormality. Movements of all body parts are abrupt, of large amplitude and occur in a

chaotic order. Babies with chaotic GMs often develop cramped-synchronized GMs a few weeks later. To provide a reliable assessment of GMs, the recording method must be standardized. The baby is videorecorded in supine, with bare arms and legs. During preterm age, it is necessary to collect at least three GMs for the reliable assessment of the spontaneous motility. After term age and older, five to ten minutes of optimal videorecording are enough to make the assessment. It may be advisable to save the videorecordings at the different ages in order to have the developmental trajectories of the baby.¹⁰

The diagnostic and prognostic assessment needs repeated longitudinal observations of GMs. The quality of GMs is repeatedly scored during the preterm, term and post-term period until about 20 weeks PTA to obtain the individual

Trajectory of a preterm baby born at 28 weeks postconceptual age. PR GMs in the preterm age, CS at term and early post-term age are followed by absence of fidgety movements and subsequent cerebral palsy.

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Generally, a baby is videorecorded every two or three weeks to have a reliable developmental trajectory.

Summary

Every year, the GMs Trust team provides standardized basic and advance GMs training courses, lasting three and a half days. The website for information is: <http://general-movements-trust.info/>

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Our Path to NIDCAP Nursery Certification

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Celebration in Valenciennes, France

The Department of Neonatology of Valenciennes obtained certification from the NIDCAP Nursery Assessment and Certification Program (NNACP) in 2016. Our journey began in 2005 when we started NIDCAP implementation, thanks to the training and benevolent support of Dr. Nathalie Ratynski from Brest, France. Our work was reinforced in 2011 by the creation of a nursery nurse advisor position.

Many changes in our neonatology service supported our path to NNACP certification. The opening of the Kangaroo Unit in 2005, along with the extensive skin-to-skin practice in all sectors of the unit including maternity, has proven advantageous. In addition to benefitting babies, widespread support has been offered to families coming from a socially vulnerable population. Furthermore, the maternity and neonatology departments received Baby Friendly Hospital Initiative (BFHI) certification in 2011. This was the first Level III center in France to receive this designation and was recertified in 2015. The BFHI certification process was a great opportunity to make invaluable improvements to support families. It also became a crucial tool for cohesion and positive dynamics within the obstetric and neonatal teams.

Consequently, in 2012 the team envisioned starting the

NNACP certification process, a path consistent with our philosophy. By means of several work groups and parental collaboration, the certification process involved the entire team and was supported by the hospital general management, care management and quality management. The process generated numerous reflections, leading to improvements regarding the parents' role in the unit and the care provided to babies.

Our hospital's visit from the NNACP site reviewers occurred in September 2016. Their visit was one of intense interaction, which allowed for review of the program criteria and resulted in certification!

As may be expected, the Neonatology Department continues working on improving the quality of care delivered to agree with the NIDCAP philosophy. Beyond the certification being an outstanding event in our history, it is also seen as a noteworthy stepping stone. Our hope is this second NNACP certification in France will be an important milestone towards the diffusion of NIDCAP within our Northern region and, furthermore, throughout the country. The inclusion of NIDCAP and of the BFHI processes in the next regional health plan is a short term measure that could contribute towards this initiative.

The Gold Standard for Excellence in Newborn Individualized Developmental Care

What All Newborn Infants and Their Families Deserve

Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), originated in 1984 by Heidelise Als, PhD, is the only comprehensive, family centered, evidence-based approach to newborn developmental care. NIDCAP focuses on adapting the newborn intensive care nursery to the unique neurodevelopmental strengths and goals of each newborn cared for in this medical setting. These adaptations encompass the physical environment and its components, as well as, the care and treatment provided for the infant and his or her family, their life-long nurturers and supporters.

Assessment of Preterm Infants' Behavior (APIB)

The Assessment of Preterm Infants' Behavior (APIB) (Als et al., 1982) is a comprehensive and systematic research based neurobehavioral approach for the assessment of preterm and fullterm newborns. The APIB provides an invaluable diagnostic resource for the advanced level clinician in support of developmental care provision in a nursery.

NIDCAP Nursery Assessment and Certification Program (NNACP)

The NIDCAP Nursery Assessment and Certification Program (NNACP) provides a comprehensive resource for the self-evaluation by a nursery system of its strengths and goals for integration of NIDCAP principles into all aspects of their functioning. External review and validation by the NFI may be sought when a nursery feels it has achieved this goal. Successful NIDCAP Nursery Certification, the ultimate goal, denotes distinction in the provision of a consistently high level of NIDCAP care for infants and their families, as well as for the staff, in a developmentally supportive environment. Nurseries that have achieved this recognition serve as a model and an inspiration to others. For information on eligibility requirements and the certification process please see: www.nidcap.org; and/or contact Rodd E. Hedlund, MEd, NNACP Director at: nnacpdirector@nidcap.org or 785-841-5440.



Mission

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

Adopted by the NFI Board, April 29, 2017

Vision

The NFI envisions a global society in which all hospitalized newborns and their families receive care and assessment 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.

Adopted by the NFI Board, April 29, 2017

Fatima Clemente, MD, Madalena Ramos, RN MSc, Hercília Guimarães, MD PhD

The São João NIDCAP Training Center, Centro Hospitalar de São João, Porto, Portugal

The first Newborn Intensive Care Units (NICUs) appeared in Portugal in the 1980's. An eight-bed NICU was established in the São João Hospital on July 5, 1983. There has been a very positive evolution in healthcare activity from the time the NICU service opened until the present day. One of the most important accomplishments of our unit is the emphasis on the special attention given to families. Since the beginning in 1983, parents have been encouraged to participate in the care of their newborns and to stay 24 hours with them, giving rise to empowered and informed families, and laying the foundation of developmental care in our unit.

São João Hospital is a University Medical Center, General Hospital providing a broad spectrum of pediatric subspecialties dedicated to the care of children and their families. It is located in northern Portugal, in the city of Porto, a beautiful river and seaside city. Our Unit is a 17 bed Level IIIC NICU that provides services to infants born in our hospital's maternity unit as well as infants transported from other hospitals in northern Portugal (25% of all admissions). This past year there were 417 admissions. The majority of infants are born near full-term age with complex genetic, surgical and cardiac health conditions. As a consequence, it is sometimes necessary to transfer preterm infants to other units due to a lack of beds.

The driving motivation of our journey toward NIDCAP was to understand and support infants and families, recognizing that parents are the most important persons in their infant's life and the infant's primary caregivers. Initially, Madalena Ramos applied and received a research grant from the Calouste Gulbenkian Foundation, an important Portuguese institution, to travel with a small group to Boston in 2002 and work with Heidelise Als, PhD, who developed the NIDCAP model.

One of the most important and fundamental steps for NIDCAP implementation in our unit was the participation of our NICU Director and Professor of Pediatrics at Porto University, Hercília Guimarães, as well as the NICU Nurse Director, Teresa Maia. They, too, traveled to Boston and participated in Professor Heidelise Als' introductory lecture and bedside training. This was a decisive milestone in our project. Our hospital leadership understood what NIDCAP was and the importance of its implementation in our hospital.

While in Boston, our team met another person who would play an important role in our NIDCAP journey: Nikk



Fatima Clemente, Teresa Maia, Ana Vilan, Nikk Conneman, Hercília Guimarães, Madalena Ramos, Carla Castro, Lúcia Silva, Josep Perapoch

Conneman, MD. Under his guidance and support, we continued the process that involved all of our NICU staff for the past 15 years. In 2008, Nikk certified two NIDCAP Professionals: Fatima Clemente, a physician, and Carla Castro, a nurse. Our hospital was very proud to have the first Portuguese NIDCAP Professionals and we had the commitment of all the hospital managers. Since 2008, four more staff have been certified, three nurses: Madalena Ramos, Lúcia Silva, and Florbela Netoand, and a psychologist, Sara Almeida. We also have an enthusiastic team in training, including six nurses, Cristina Araujo, Sandra Ribeiro, Branca Oliveira, Fatima Ferreira, Isabel Vieira, and Eugénia Fernandes, an occupational therapist, Lurdes Ribeiro, and two neonatologists, Gustavo Rocha and Susana Pissarra. In 2007, Fatima and Carla attended their first NIDCAP Trainers Meeting hosted by the French team in Combrit, Brittany. It was a starting point for us. We definitely wanted to be part of that family.

The unflagging support of the medical and nursing leadership allowed the developmental team to move forward and start dreaming about the possibility of opening the Portuguese NIDCAP Training Center in Porto. During this process, we had the privilege of having the support of an amazing person, Graciela Basso, MD. She was our NIDCAP and APIB Master Trainer and also our dear friend. Fatima began training in the Assessment of Preterm Infant Behavior (APIB) and achieved certification in 2014. She had the privilege of participating on an APIB team with the Trainers-in-Training of Madrid and Barcelona. Graciela guided us on a journey through many high points, yet also some challenges, culminating in the opening of the Portuguese NIDCAP Training Center on April 1, 2015. The beautiful ceremony mobilized our entire hospital and families as well.



Carla Castro, Eugénia Fernandes, Isabel Vieira, Madalena Ramos, Florbela Neto, Fatima Clemente, Graciela Basso

In addition to NIDCAP training in our own NICU, we began training with professionals in the cities of Évora, in southern Portugal and Lisbon. A key focus is always the educational and consultative support towards effective delivery of care in a neurodevelopmentally supportive, individualized, and family-centered framework. We found very enthusiastic and dynamic professionals in these hospitals, including Ana Malveira, Maria Franco and Carmo Silva, who comprised our very special first team of trainees. We have also taken the training across the Atlantic to Brazil. In addition, we had a rewarding experience bringing a shift from protocol-based to strategic process thinking

and from task-oriented to relationship-based care in a very different setting in Angola, Africa.

In 2017, we decided to advance further. Madalena Ramos started her journey to become APIB Professional and NIDCAP Trainer with Graciela. This step will open future possibilities for our NIDCAP Training Center.

We are very excited about what the future holds for our training center, in terms of both successes and challenges. São João NIDCAP Training Center will host the 29th Annual NIDCAP Trainers Meeting in October 2018. This will offer a timely opportunity to reflect on our center's development over the years and future strategies to improve developmental outcomes for infants and families by providing developmental services in the NICU, follow-up clinic and pediatric service. An additional challenge is to plan and prepare to achieve NIDCAP Nursery Certification.

In 2018, the construction of the new pediatric hospital will begin with a new unit for 27 newborns. This will provide a unique opportunity to plan and build a service according to our philosophy of developmental and family centered care with individual rooms for each baby and her or his family. This will be a dream come true, with the unconditional support of the director of the Pediatric Hospital, Professor Maria João Baptista, and the commitment of the clinic director of São João Hospital, Professor Artur Paiva.

All of our staff feels we have an opportunity and a duty to make a difference for infants and families in our NICU and beyond. The phrase of the NFI, "*Changing the future for infants in intensive care*", makes sense to all of us, and is our inspiration!



*Front: Graciela Basso, Sara Almeida, Florbela Neto
Back: Fatima Clemente, Madalena Ramos and Carla Castro*



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Conferences/Meetings

NIDCAP Trainers Meeting

Location: Chateau Lacombe, 10111 Bellamy Hill Rd NW, Edmonton, Alberta Canada

Date: October 21-24, 2017

Information: www.nidcap.org

SHINE, Zero to Three Annual Conference

Location: San Diego, California, USA

Date: November 29 – December 1, 2017

Information: www.zerotothree.org

Touch a Life, Impact a Lifetime: Neuroprotection in the NICU

Location: Children's Healthcare of Atlanta Office Park, Atlanta, Georgia, USA

Date: December 5, 2017

Information: www.choa.org

The 31st Annual Gravens Conference on the Physical and Developmental Environment of the High-Risk Infant

Location: Clearwater Beach, Florida, USA

Date: February 28 -March 3, 2018

Information: Bobbi Rose brose@health.usf.edu.

Video/Movies about NIDCAP

France: NIDCAP: à l'écoute des enfants prématurés

<https://www.youtube.com/watch?v=2ZXZa3B9xt8>

France: Les bébés prématurés du programme NIDCAP de l'hôpital des Enfants du CHU de Toulouse:

<https://www.youtube.com/watch?v=z957Tqvo6w>

Spain: Premios Hospital Optimista Proyecto NIDCAP

<https://www.youtube.com/watch?v=507eMgAxEp8>

Our Sponsors

The NFI thanks its first corporate sponsor, Sonicu, as well as its second corporate sponsor, Dr. Brown's. The generous support of these sponsors helps the NFI raise global awareness of the need for NIDCAP care and enhances opportunities to develop educational programs to broaden the reach of this care to more and more NICU professionals and the 'preterm families' they serve.



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Annual NFI Membership Meeting

Sunday, October 22, 2017
8:00AM – 10:00AM

Chateau Lacombe
10111 Bellamy Hill Rd NW
Edmonton, Alberta T5J 1N7
Canada



The 28th Annual NIDCAP Trainers Meeting

October 21–24, 2017

Chateau Lacombe
10111 Bellamy Hill Rd NW
Edmonton, Alberta T5J 1N7
Canada

*Hosted by the NIDCAP Training Center in
Development at Stollery Children's Hospital,
Edmonton*

(By Invitation Only)



NFI Celebrates World Prematurity Day November 17, 2017

About World Prematurity Day

Celebrated internationally on November 17th, World Prematurity Day (WPD) acknowledges the journeys of preterm infants and their families as well as raises awareness of the challenges faced by children born preterm and their families.



Purple is the symbolic color of WPD representing sensitivity and individuality, two of the characteristics of the premature infant.

Please Join Us

In honor of World Prematurity Day 2017 the NIDCAP Federation International (NFI) invites you to pay tribute to newborns, and to their families, nursery staff and hospitals around the world who provide essential NIDCAP care.

A popular way to spread the word is through the purple illumination of landmarks in your communities and the purple illumination of hospital websites. The National NIDCAP Training Center in Boston, Massachusetts has arranged for the lighting of the Zakim Bridge which is traversed by tens of thousands of people every day, and the NFI hopes that each training center will arrange for a similar marking of the day whether it be the lighting of a bridge, a government building, your hospital's website, your NICU's webpage, or your community's local newspaper (print or electronic version). Please consider contacting the programs in your communities that can execute such "illuminations".

Other suggestions for celebrating the day:

- Send the NFI's WPD [information sheet](#) to your local news agencies to inspire a story about preterm birth;
- Sponsor activities for the parents of preemies in your newborn intensive care units and/or your communities;
- Coordinate an educational workshop for your NICU staff on the sensitivities and individuality of preterm infants;
- Promote your activities using the [NFI's poster template](#) found on the NFI's WPD page.
- Share your WPD activities via your own social media and share on the NFI's social media:

We encourage you to mark World Prematurity Day in your own special way and to [share](#) these ideas with us so that we may help broaden NIDCAP's global reach.

Developmental Observer

The Official Newsletter of the NIDCAP®
Federation International

To download the *Developmental Observer*
please go to: nidcap.org



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NIDCAP On the Web



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 sandra.kosta@nidcap.org.

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Please visit the NFI's YouTube Channel to watch videos about NIDCAP (in 13 languages) and the NNACP. www.youtube.com/user/NIDCAPFI

NIDCAP TRAINING CENTERS

by order of establishment

National NIDCAP Training Center

Boston Children's Hospital and
Brigham and Women's Hospital
Boston, Massachusetts, USA
Director: Heidelse Als, PhD
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Sooner NIDCAP Training Center

(inactive)
University of Oklahoma Health
Sciences Center
Oklahoma City, Oklahoma, USA
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West Coast NIDCAP and APIB Training Center

University of California San Francisco
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Carolina NIDCAP Training Center

WakeMed, Division of Neonatology
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Colorado NIDCAP Center

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School of Medicine and The Children's Hospital
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Karolinska NIDCAP Training and Research Center

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Occidentale and University Hospital
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Sophia NIDCAP Training Center

Erasmus MC-Sophia Children's Hospital
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Centro Latinoamericano NIDCAP & APIB

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Edmonton NIDCAP Training Centre

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