

# NEONATOLOGY TODAY

News and Information for BC/BE Neonatologists and Perinatologists

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Jul. 5, 2013; Munich, Germany  
www.munich-neocon.com

#### The Munich International Conference Improvement of Neurodevelopmental Outcome in Neonatology

Jul. 6, 2013; Munich, Germany  
www.munich-neocon.com

8th International Neonatal Nursing Conference 2013 - COINN 2013  
Sep. 5-8, 2013; Belfast, Northern Ireland  
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## The Hemodynamic Effects That Delayed Umbilical Cord Clamping Has on Premature Infants

By Ross Sommers, MD; Judith Mercer, PhD, CNM

The optimal timing for umbilical cord clamping following birth is undetermined. Although there is no particular justification for immediate cord clamping (ICC), it has become the standard of care. The most pressing defense for ICC in preterm infants is the rapid availability of the infant for resuscitation. Yet recent studies have identified advantages in delay in cord clamping (DCC) or cord milking. One advantage is the decreased rate of intra-ventricular hemorrhage among preterm infants without differences in Apgar scores or levels of resuscitation.<sup>1</sup> One hypothesis for this finding is that DCC provides a stabilizing increase in cerebral blood flow. Serial measurements of blood flow in the Superior Vena Cava (SVC) by ultrasound doppler is a technique one can use to explore this hypothesis.<sup>2</sup>

Approximately half of the fetal cardiac output (CO) of the fetal-placental circulation is present in the placenta at any given point in time, while only 8-10% of the fetal CO passes through the lungs. Immediately at birth, the CO to the newborn lung must increase to 45% so that functional respiration can be established. DCC provides the increased fetal-placental blood transfusion necessary to support this transition and may prevent hypovolemia in other organs. It is estimated that ICC in preterm infants prevents the addition of 20 to 30 ml/kg of blood.<sup>5</sup> Lowering the infant below the introitus speeds this transfusion, while raising the infant above the level of the pla-

centa decreases the volume of transfusion. An additional important factor in this transfusion is the reservoir of stem cells present in umbilical cord blood that can differentiate into endothelial, mesenchymal, and haematopoietic precursors. Given the potential of these cells to repopulate over extended periods of time, they may offer a continuing benefit beyond the newborn period.<sup>6</sup>

*"The optimal timing for umbilical cord clamping following birth is undetermined. Although there is no particular justification for immediate cord clamping (ICC), it has become the standard of care."*

DCC allows for transfusion of whole blood, not just red blood cells. A meta-analysis of preterm infants with DCC identified a 5 mg/dl mean difference in hematocrit.<sup>7</sup> Blood pressure in premature infants is dependent upon multiple variables including cardiac stroke volume, heart rate, and systemic vascular resistance. Although studies have failed to identify an association between DCC and increased

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References: 1. Barrett-Reis B, et al. *Pediatrics*. 2000;106:581-588. 2. Erickson T, Gill G, Chan GM. *J Perinatol*. 2012:1-3. 3. Lawrence RA, Lawrence RM. *Breastfeeding: A Guide for the Medical Professional*. 6th ed. St. Louis, MO: Elsevier Mosby, Inc; 2005:147.

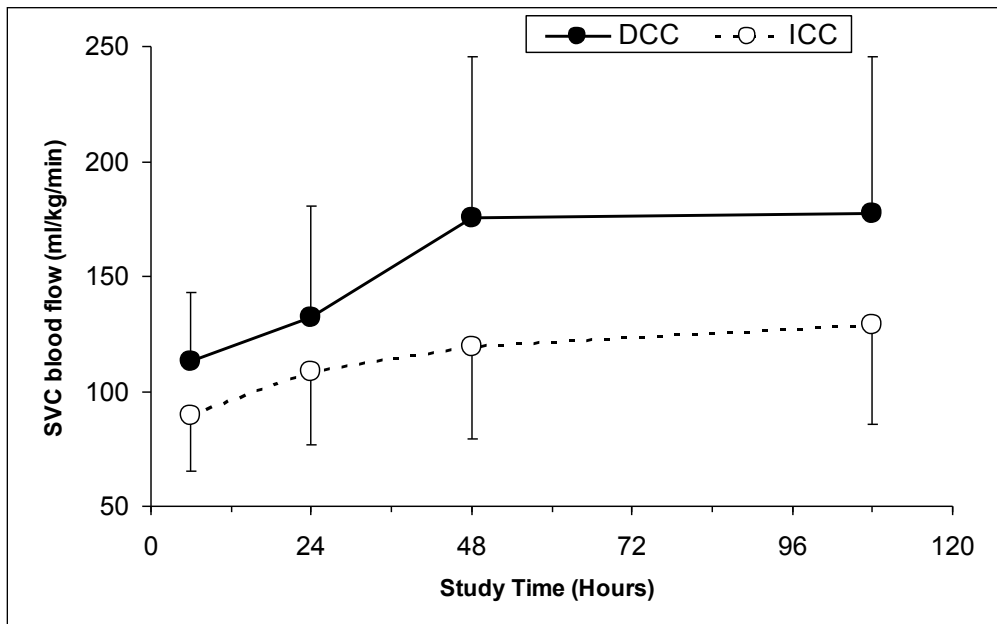


Figure 1- SVC blood flow over the course of the study, Mean ± SD. (ANOVA: groups,  $p=0.002$ ).

blood pressure,<sup>8</sup> we recently identified an increased cardiac stroke volume in the right ventricle at 48 hours of life without differences in heart rate or blood pressure.<sup>2</sup>

Depriving premature infants of fetal-placental blood volume may lead to such detrimental consequences as hypovolemia, hypotension, and end organ hypo-perfusion. However, DCC has been found to decrease the incidence of intra-ventricular hemorrhage (IVH) (16% for DCC compared to 29% for ICC), a significant benefit for premature infants.<sup>8</sup> Preliminary findings also suggest that DCC is associated with improved neurodevelopmental outcomes.<sup>9</sup>

Due to its safety profile and ease of bedside use, ultrasound doppler technique is frequently used to quantify hemodynamic measurements during the transition period following preterm birth. One new exciting use of this technology is the measurement of blood flow in the Superior Vena Cava (SVC), considered a measurement of “systemic blood flow.”<sup>3</sup> SVC flow is not subject to the effects of fetal shunts such as a patent ductus arteriosus (PDA) or a patent foramen ovale (PFO). Low blood flow in the SVC following preterm birth is a significant predictor of the development of large grade IVH.<sup>4</sup> Given the decreased IVH rates<sup>1</sup> and increased systemic blood volume<sup>5</sup> associ-

ated with DCC and its potential hemodynamic benefits, one logical explanation is that DCC is associated with increased SVC flow.

In order to test the hypothesis that DCC is associated with increased SVC flow, we completed a prospective randomized study of 51 infants with an average gestational age of 28 weeks who underwent four ultrasound examinations over the first 5 days of life. Premature infants randomly assigned to the DCC group had significantly higher SVC flow over the study course (Figure 1). Furthermore, the differences in SVC flow between the DCC and ICC groups at 48 and 108 hours (53 and 54 mL/kg/min, respectively) were greater than at 6 and 24 hours (26 and 23 mL/kg/min), suggesting that the effects of DCC persist beyond the immediate postnatal period in which IVH frequently occurs.<sup>2</sup> It is likely that the higher SVC blood flow in the DCC infants is the result of increased blood volume received by the infants.<sup>5</sup> In addition, DCC allows the infant’s heart to adjust to ex-utero cardiovascular physiology more gradually.

In an observational non-randomized study of 30 infants with an average gestational age of 26.5 weeks, Meyer et al. identified greater SVC flow values at 24 hours for 13 infants with DCC (median value 91 ml/kg/min) compared to 17 infants with ICC (me-

dian value 52 ml/kg).<sup>10</sup> SVC blood flow values at 24 hours of the infants exposed to DCC were 70% greater than those of the infants exposed to ICC. These differences were greater than the 20% difference between the DCC and ICC groups that we observed.<sup>2</sup>

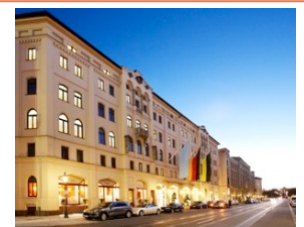
A third recent randomized study evaluated the hemodynamics of umbilical cord milking following preterm birth. After delivery, the infant was placed below the level of the placenta and approximately 20 cm of umbilical cord was milked 2-3 times towards the infant before being clamped. Fifty infants with mean gestational ages of 25 weeks were enrolled, and seven measurements of SVC flow were taken over the first three days of life. Small, but significant differences in SVC blood flow (10-15ml/kg/min) at the 6 and 12 hour exams only were identified.<sup>11</sup> Given the minimal difference in SVC flow at these two intervals, and the lack of overall findings between the two groups,<sup>11</sup> it appears that cord milking does not have as robust an impact on SVC flow as delayed clamping does.<sup>2, 10</sup>

Many neonatologists are recommending the adoption of DCC in premature infants as the standard of care based on the benefits identified in the meta-analyses. Others argue for more evidence before recommending a change in practice. More data will soon be available as there are several randomized control studies underway. At the University of Oklahoma (NCT00579839), 200 infants of gestational age 24 to 34 weeks underwent DCC for 30-35 seconds. Another (NCT00818220), from the University of Rhode Island and Women & Infants Hospital of Rhode Island, consists of DCC for 45

**“If results from these studies provide further evidence of the benefits of increased fetal-placental blood transfusion after delivery, DCC or umbilical cord milking may become the standard of care for premature infants.”**



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**Improvement of Neurodevelopmental Outcome in Neonatology**  
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**and the Pre-Conference Workshop:**  
**The Amplitude-integrated EEG (aEEG) in Neonatology**  
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Howard Kilbride, MD  
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Division Director, Neonatology

seconds in 210 premature infants of gestational ages 24 to 32 weeks. There is an ongoing multisite randomized study of DCC in premature infants in Australia that has a projected enrollment of over 1000 infants with follow-up to 18 months. A randomized control study from the University of California at San Diego (NCT01434732) involving cord milking in infants less than 32 weeks gestational age is nearly complete—the primary outcome is SVC flow at 6 hours of life. If results from these studies provide further evidence of the benefits of increased fetal-placental blood transfusion after delivery, DCC or umbilical cord milking may become the standard of care for premature infants.

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# Highlights from 2013 NEO: The Conference on Neonatology

By Alan R. Spitzer, MD and Rosemarie Ugalde

As one of the premier meetings in newborn medicine, *NEO: The Conference for Neonatology* attracts a wide range of healthcare professionals from across the country and abroad who seek a dynamic scientific conference where they can expand their clinical knowledge as well as their professional network.

The roots of this conference are steeped in a tradition of excellence. Originally titled, *Management of the Tiny Baby Conference*, this meeting ran for an impressive 28 years, and was recognized as one of the legendary conferences in Neonatal Medicine. Over the last seven years, we have continued to honor this program's commitment to educational excellence on a much grander scale through the formation of what is now known as *NEO: The Conference for Neonatology*. It is my great pleasure to share some of the highlights from the 2013 meeting, and provide you with a preview of the 2014 conference, in this issue of *Neonatology Today*.

Since its debut in 2007, *NEO* has consistently provided its audience with a high-level, evidence-based program which uniquely addresses both the cutting edge and the practical aspects of Newborn Medicine. After each conference, we solicit feedback from participants via a detailed evaluation process. A meticulous review of these responses allows us to continually build on our previous success by crafting an educational program which is tailored to fit the current needs of the Neonatal-Pediatric community. Each year the *NEO* Planning Committee, comprised of distinguished faculty from the Neonatal-Perinatal community, assembles an agenda which speaks to the cur-

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***“As one of the premier meetings in newborn medicine, NEO: The Conference for Neonatology attracts a wide range of healthcare professionals from across the country and abroad who seek a dynamic scientific conference....”***

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rent and most critical issues facing clinicians involved in the practice of Newborn Medicine. Educational sessions are led by world renowned experts recognized for their particular knowledge of these clinical topics.

The 2013 *NEO Conference* was no exception, nor were the additional meetings which preceded this unforgettable program. As in prior years, educational activities began on February 20<sup>th</sup> with a pre-conference day designed to provide attendees with an introduction to quality improvement techniques, and an overview of the quality improvement components of Maintenance of Certification (MOC). Moderated by Drs. Dan Ellsburly and Robert Ursprung, two of the leading figures in Neonatal CQI, this year's session included: presentations which addressed overall MOC requirements, recommendations for reducing: catheter associated infections, necrotizing entero-



colitis and retinopathy of prematurity and much more. Ideally suited for clinicians who seek a foundation for developing solid quality improvement initiatives, record attendance included neonatologists, advanced practitioners and nurses from across the country.

On February 19<sup>th</sup>-24<sup>th</sup>, we also hosted *Specialty Review in Neonatology*. Considered by many to be the leading national review of its type in the country, numerous neonatologists, residents, fellows and advanced practitioners attended this outstanding fundamental pathophysiology course in Neonatal-Perinatal Medicine. This year's meeting featured an Automated Response System (ARS) which proved to be a great benefit for both faculty and attendees. Instructors utilized this technology to assess the audience's knowledge of each topic presented and participants utilized it to effectively engage in the question and answer exercises designed to fine tune their knowledge of critical subject matter. ARS will be available again at the 2014 *Specialty Review in Neonatology*. SR attendees have numerous opportunities to interact with NEO attendees and industry sponsors during exhibit hall hours and evening events.

The 2013 NEO: *The Conference for Neonatology* commenced on February 21<sup>st</sup> and ended on February 24<sup>th</sup>. Major themes included the latest developments in critical areas such as: respiratory support, fetal evaluation and testing, pharmacology and therapeutic interventions, ethical considerations in the NICU, neonatal nutrition and complications of NICU care. Participants benefited from the interactive presentations which allowed them to engage in discussions with key speakers as well as their peers.

For those of you eager to access conference information through your hand held device, we did not disappoint. This year we introduced a mobile device app which enabled registrants to quickly and conveniently look up lecture times, locations, exhibit hall hours and other pertinent details found in the official agenda and pocket guide. For the second consecutive year, and in an effort to accommodate the growing presence of our international audience, we offered simultaneous translation of the meeting in Spanish. Both these features were hugely successful, and will be available to our guests at the NEO conference in 2014.

One of the most popular and highly anticipated events at this meeting is the *Legends of Neo-*



natology Gala Award Ceremony which honors those who have made significant contributions to the care of the critically-ill neonate. On the evening of February 22<sup>nd</sup> 2013, I had the privilege of inducting Lilly M. Dubowitz, MD, Jeffrey Maisels, MD, and Jen-Tien Wung, MD, into the Neonatology Hall of Fame for their accomplishments in the areas of gestational age

and neurological assessment, neonatal jaundice and respiratory care, respectively. Friends, family and colleagues looked on as examples of their extraordinary work were displayed and commemorated in front of a captive audience of their peers.

NEO also serves as the perfect backdrop for clinicians and delegates from commercial organizations, hospital and academic institutions to engage in discussions regarding products and services available to the pediatric community. This year participants interacted with repre-



representatives from close to 50 companies during the daily Exhibit Hall hours and while attending approved industry sponsored symposiums. We welcome their participation this coming February, and are grateful for their support of our commitment to educate the medical community.

*NEO: The Conference for Neonatology* will take place at the Hilton Orlando Bonnet Creek, February 20-23, 2014, and is on track to be better than ever. Top luminaries from the neonatal world - active in both patient care and clinical research - will gather at *NEO* to share



thought-provoking commentary. For attendees this is a wonderful opportunity to earn CME/CNE credit hours while collectively celebrating the advances which have been made in this specialty and explore solutions for the challenges that lie ahead.

***“NEO: The Conference for Neonatology will take place at the Hilton Orlando Bonnet Creek, February 20-23, 2014, and is on track to be better than ever.”***

In addition to the first-class presenters and the myriad of benefits described above, a topnotch conference team is ready to assist you with all your meeting needs prior to the event and on-site while you interact with expert faculty, industry leaders and valued colleagues.

As a reminder, *NEO* is run alongside another preeminent meeting described above; *Specialty Review in Neonatology*. Clinicians preparing to take the 2014 board certification exams and/or those who would like to strengthen their general knowledge of neonatal-perinatal medicine will find this intensive and comprehensive review to be an invaluable learning tool.

Anyone involved in the care of neonates would be hard-pressed to find such a multitude of high-quality educational opportunities all under one roof. I hope you will join us in Orlando the week of February 20-23 for an unforgettable educational experience.

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INOMAX® is a vasodilator, which, in conjunction with ventilatory support and other appropriate agents, is indicated for the treatment of term and near-term (>34 weeks) neonates with hypoxic respiratory failure associated with clinical or echocardiographic evidence of pulmonary hypertension, where it improves oxygenation and reduces the need for extracorporeal membrane oxygenation.

Utilize additional therapies to maximize oxygen delivery with validated ventilation systems.

**Reference:** 1. Data on file. Hampton, NJ: Ikaria, Inc; 2013.

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- INOMAX is contraindicated in the treatment of neonates known to be dependent on right-to-left shunting of blood
- Abrupt discontinuation of INOMAX may lead to increasing pulmonary artery pressure and worsening oxygenation even in neonates with no apparent response to nitric oxide for inhalation

**Please see Brief Summary of Prescribing Information on adjacent page.**

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## Brief Summary of Prescribing Information

### INDICATIONS AND USAGE

#### Treatment of Hypoxic Respiratory Failure

INOMax<sup>®</sup> is a vasodilator, which, in conjunction with ventilatory support and other appropriate agents, is indicated for the treatment of term and near-term (>34 weeks) neonates with hypoxic respiratory failure associated with clinical or echocardiographic evidence of pulmonary hypertension, where it improves oxygenation and reduces the need for extracorporeal membrane oxygenation.

Utilize additional therapies to maximize oxygen delivery with validated ventilation systems. In patients with collapsed alveoli, additional therapies might include surfactant and high-frequency oscillatory ventilation.

The safety and effectiveness of INOMax have been established in a population receiving other therapies for hypoxic respiratory failure, including vasodilators, intravenous fluids, bicarbonate therapy, and mechanical ventilation. Different dose regimens for nitric oxide were used in the clinical studies.

Monitor for PaO<sub>2</sub>, methemoglobin, and inspired NO<sub>2</sub> during INOMax administration.

### CONTRAINDICATIONS

INOMax is contraindicated in the treatment of neonates known to be dependent on right-to-left shunting of blood.

### WARNINGS AND PRECAUTIONS

#### Rebound Pulmonary Hypertension Syndrome following Abrupt Discontinuation

Wean from INOMax. Abrupt discontinuation of INOMax may lead to worsening oxygenation and increasing pulmonary artery pressure, i.e., Rebound Pulmonary Hypertension Syndrome. Signs and symptoms of Rebound Pulmonary Hypertension Syndrome include hypoxemia, systemic hypotension, bradycardia, and decreased cardiac output. If Rebound Pulmonary Hypertension occurs, reinstate INOMax therapy immediately.

#### Hypoxemia from Methemoglobinemia

Nitric oxide combines with hemoglobin to form methemoglobin, which does not transport oxygen. Methemoglobin levels increase with the dose of INOMax; it can take 8 hours or more before steady-state methemoglobin levels are attained. Monitor methemoglobin and adjust the dose of INOMax to optimize oxygenation.

If methemoglobin levels do not resolve with decrease in dose or discontinuation of INOMax, additional therapy may be warranted to treat methemoglobinemia.

#### Airway Injury from Nitrogen Dioxide

Nitrogen dioxide (NO<sub>2</sub>) forms in gas mixtures containing NO and O<sub>2</sub>. Nitrogen dioxide may cause airway inflammation and damage to lung tissues. If the concentration of NO<sub>2</sub> in the breathing circuit exceeds 0.5 ppm, decrease the dose of INOMax.

If there is an unexpected change in NO<sub>2</sub> concentration, when measured in the breathing circuit, then the delivery system should be assessed in accordance with the Nitric Oxide Delivery System O&M Manual troubleshooting section, and the NO<sub>2</sub> analyzer should be recalibrated. The dose of INOMax and/or FIO<sub>2</sub> should be adjusted as appropriate.

#### Heart Failure

Patients with left ventricular dysfunction treated with INOMax may experience pulmonary edema, increased pulmonary capillary wedge pressure, worsening of left ventricular dysfunction, systemic hypotension, bradycardia and cardiac arrest. Discontinue INOMax while providing symptomatic care.

### ADVERSE REACTIONS

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice. The adverse reaction information from the clinical studies does, however, provide a basis for identifying the adverse events that appear to be related to drug use and for approximating rates.

Controlled studies have included 325 patients on INOMax doses of 5 to 80 ppm and 251 patients on placebo. Total mortality in the pooled trials was 11% on placebo and 9% on INOMax, a result adequate to exclude INOMax mortality being more than 40% worse than placebo.

In both the NINOS and CINRGI studies, the duration of hospitalization was similar in INOMax and placebo-treated groups.

From all controlled studies, at least 6 months of follow-up is available for 278 patients who received INOMax and 212 patients who received placebo. Among these patients, there was no evidence of an adverse effect of treatment on the need for rehospitalization, special medical services, pulmonary disease, or neurological sequelae.

In the NINOS study, treatment groups were similar with respect to the incidence and severity of intracranial hemorrhage, Grade IV hemorrhage, periventricular leukomalacia, cerebral infarction, seizures requiring anticonvulsant therapy, pulmonary hemorrhage, or gastrointestinal hemorrhage.

In CINRGI, the only adverse reaction (>2% higher incidence on INOMax than on placebo) was hypotension (14% vs. 11%).

Based upon post-marketing experience, accidental exposure to nitric oxide for inhalation in hospital staff has been associated with chest discomfort, dizziness, dry throat, dyspnea, and headache.

### OVERDOSAGE

Overdosage with INOMax will be manifest by elevations in methemoglobin and pulmonary toxicities associated with inspired NO<sub>2</sub>. Elevated NO<sub>2</sub> may cause acute lung injury. Elevations in methemoglobin reduce the oxygen delivery capacity of the circulation. In clinical studies, NO<sub>2</sub> levels >3 ppm or methemoglobin levels >7% were treated by reducing the dose of, or discontinuing, INOMax.

Methemoglobinemia that does not resolve after reduction or discontinuation of therapy can be treated with intravenous vitamin C, intravenous methylene blue, or blood transfusion, based upon the clinical situation.

### DRUG INTERACTIONS

No formal drug-interaction studies have been performed, and a clinically significant interaction with other medications used in the treatment of hypoxic respiratory failure cannot be excluded based on the available data. INOMax has been administered with dopamine, dobutamine, steroids, surfactant, and high-frequency ventilation. Although there are no study data to evaluate the possibility, nitric oxide donor compounds, including sodium nitroprusside and nitroglycerin, may have an additive effect with INOMax on the risk of developing methemoglobinemia. An association between prilocaine and an increased risk of methemoglobinemia, particularly in infants, has specifically been described in a literature case report. This risk is present whether the drugs are administered as oral, parenteral, or topical formulations.

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# Digital Scrapbooking as a Standard of Care in Neonatal Intensive Care Units: A Three-Year Update

By Muhammad Subhani, MD, MBA

The census of most Neonatal Intensive Units (NICUs) is comprised of premature infants or infants with congenital problems who require a prolonged length of stay. The dramatic improvement in survival for the sickest and tiniest of infants has allowed parents to take their babies home in most cases. Increasing use of digital photography has allowed parents to capture the roller coaster ride moments of their infant's stay, but adds up as an additional chore for them.

In response to the wish list of parents staying at Ronald McDonald's House in Amarillo, Texas, our NICU started a program in the 2007 of taking pictures of those infants whose parents were staying there, from their birth until discharge or in some unfortunate cases of expiry.

Through a generous grant of \$8500 by the Ronald McDonald House of Amarillo ([www.rmhcofamarillo.org](http://www.rmhcofamarillo.org)), the program of picture taking later became the standard of care with the addition of scrapbooking, offered to all admitted infants. Although a detailed description for the program could be found in the already published manuscript titled "Digital Scrapbooking as a Standard of Care in Neonatal Intensive Care Units: Initial Experience" in *Neonatal Network*, Volume 31, 3, pages 162-168, May/June of 2012, the program can be summarized as a combination of taking pictures from birth, sometimes even from delivery room until discharge or expiry at any point during their stay where it was deemed necessary, in addition to various predefined milestones, then creating a digital scrapbook on a laptop. At discharge or expiry, parents receive the pictures and the scrapbooking project on a CD. Readers are advised to review the original manuscript for a better understanding of the entire process of digital scrapbooking.

The following description summarizes our experience with this innovative program for about three years duration, with a hope that other units could easily initiate this program with substantially lower cost and sustain this program with better results. Since its inception on August 3, 2010, our unit has served 843 infants.

## Positive Experiences First

Parents simply could not thank the unit enough for this great gift of pictures on CD. The Stedje family had an initial loss at 25 weeks prior to the introduction of this program. It was followed by 25-week triplets. One of the triplets also did not survive. The family received a separate CD for all three infants and was able to look at the

photos at their home after a few months of discharge. As per mother, Erika: "Scott and I were finally able to sit down tonight and look throughout the pictures on the CD. We cried tears of joy while looking at each pic. It was great to see how far they have come. Receiving that CD was the best gift anyone could have given us and we thank you so much!!"

Some parents, who had their babies delivered in another neonatal intensive care unit only two blocks away from our unit, shared their preference of using our unit for this additional benefit to some nursing staff, if given the choice by their insurance carrier. As per our discharge planner Jennifer Daily, "Even when the parents seem frustrated in some cases of delay on the day of discharge, their mood changes dramatically with CD." The parents are very appreciative of getting the CD free of charge. A set of Lightscribe™ CD and the CD cover costs approximately ninety cents, all together which could easily be covered in the unit's supplies budget. Engraving two best photos of the infant with their given name, date of birth, weight and length on the CD itself by Lightscribe™ technology takes approximately 15-20 additional minutes, but the unanimous twinkling response by the parents for this professional look is simply priceless.

Another perceived benefit for this project is the addition of an interactive avenue between the nursing staff and the parents. The "awe" moments of captured memories by a nurse, whether it was the first touch by the parent or first bath, decreases the barrier between the nursing staff and the parents, which in turn has increased the trust placed by the parents in nurses, as they often perceive nurses going above and beyond their usual caring for their infant.

The nurses remain the backbone of taking pictures, but the greatest sense of support and relief, even though infrequent, in our unit comes from some volunteers, also known as "Cuddlers," the same people who provide the service of holding the babies, including the skin-to-skin. The majority of "cuddlers" are retired females who take it upon themselves to either come at extra times or extend their regular visitation hours for capturing photos of all the infants on their day of visitation. One of the volunteers, a middle-aged school teacher by profession, is the mother of one of our 25 weeks extremely premature and sick infants. She became a volunteer just for capturing photos. Attempts to entice some local photographers, amateurs and photography students to capture photos in some of their spare time, has not been fruitful so far.

## However, There Are Some Concerns

Although every infant is supposed to have at least some pictures, in some cases there were none, except the very first picture taken of the name and date of birth for identification purpose. The majority of them were babies who had a very short length of stay for conditions like suspected sepsis or delayed transition, although some had stayed for a while. The main reason for this omission was non-initiation of enrollment, which was traced back to the combination of new nurses, unit health clerk and short staffing. In a hectic situation of multiple simultaneous admissions and deliveries, getting an additional permit signed for this project was low on their priority list. If possible, the inclusion of digital scrapbooking in the general consent form for admission for the NICU could alleviate this issue.

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Discrepancy in the number of pictures was another issue. Infants whose parents were more vocal in "asking" the nursing staff for taking "more pictures" of their infant's got a better share of photos, even with shorter length of stay in contrast to parents with language barriers. The nursing staff felt awkward in commu-

nicating their desire for taking photographs, even when there was an opportunity to do so, mainly because of language barriers. These problems have been gradually rectified with continued reinforcement by charge nurses during their daily huddle sessions, and discussion during monthly meetings, usage of interpreters and even other available parents for communicating with parents who could speak the same language.

The biggest disappointment for the author, however, has been the lack of interest by parents for accomplishing the digital scrapbooking where parents have the capability to write a digital diary as often as they could, and then decorate it according to their likeness with associated photos. All parents, except a few, felt hard-pressed with the lack of available time with their sick infants, especially when touch was restricted to avoid overstimulation. It was, therefore, no surprise that the unanimous answer by parents for not doing this activity was, "I would rather spend time with my baby in skin-to-skin touch, changing diapers or taking temperature than doing scrapbooking."

Surprisingly, the ones who utilized it created masterpieces with their creativity. They were mostly teenage single mothers or young married couples. The best scrapbook created was by a teenage single mother whose 25-week infant stayed for couple of months. The parents, who did not attempt scrapbooking were, however, extremely receptive, and appreciative of author's proposition that volunteers be utilized to write their thoughts on a plain paper diary and later transcribe that diary for scrapbooking or, depending upon the available time, input it directly into the computer. Unfortunately, the same "cuddlers" who did a great job in capturing photos, shared their lack of interest in doing the journaling part. In the author's opinion, the combination of their age group being in the sixties and their possible lack of computer experience may have deterred them from the computerized journaling. High school or college age students who routinely volunteer at hospitals for various reasons seem to be panacea for this. Strict hospital rules, including confidentiality, however, pose significant hurdles for this age group, at least in our hospital. In addition, these personnel could make themselves available only on weekends or occasionally late night due to their academic obligations. A good alternate would be recruitment of some volunteers who enjoy traditional scrapbooking, and then train them for the digital version which should not take more than an hour.

Although we started our project with about \$8500 almost three years ago, we have learned that it could be done at a much lower cost. For an average sized 30 beds, \$2000 would be considered a reasonable amount including initial supplies. Current point-and-shoot cameras (POS) for around \$200 could do a reasonable job, considering what we are accomplishing with our Nikon D60 cameras

with their associated lens. Another big improvement that has evolved over time is placement of each infant's SD (secure digital) card at the bedside in the folder of their chart. This activity saves time previously lost in sorting the required card from the rest of the cards stock. It also prevents accidental placement of the SD card in the plastic cover of another infant's card. At present, we have two cameras that serve six rooms for our bed capacity of 32. Ideal situation would be the availability of one camera in each room locked in a safe place, ready to take picture by pulling out the SD card from infant's chart folder.

Creation of two DVD's or digital presentations remains on the "To Do List" for the author. One would include the process of initiating and maintaining the entire process of digital scrapbooking for nursing and ancillary staff. The other is aimed specifically for the parents about the "How To" for scrapbooking. It is strongly believed that they would significantly shorten the time required for training new nurses and ancillary staff and augment the interest of parents for scrapbooking.

In short, the experience of the digital scrapbooking has been extremely rewarding for the author and the entire unit. Not only it has set us apart from all other units, it continues to build eternal bonds of friendship between neonatal staff and parents of our patients by sharing unforgettable memories of the most vulnerable times in their infant's life. Any NICU unit staff determined to make this wonderful program part of their daily routine is welcome to contact the author for personal discussion at [subhani@yahoo.com](mailto:subhani@yahoo.com).

### Happy Scrapbooking!

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# "Welcome To Holland"

By Emily Perl Kingsley

This brief essay by Emily Perl Kingsley, was sent to us by the parent of a child with Down Syndrome. We reprinted it in February of 2009, and wish to share it again with our readers, because it poignantly expresses feelings of many parents who have children with chronic neonatal and cardiac health problems.

"Welcome to Holland"© 1987 by Emily Perl Kingsley.

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo. David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after



Emily and Jason Kingsley

you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away, because the loss of that dream is a very, very significant loss.

But, if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

NT

Emily Perl Kingsley

Emily Perl Kingsley has been a writer for Sesame Street since 1970. Her son, Jason, who is now 38 years-old, was born with Down Syndrome in 1974.

Kingsley has written over 20 children's books, and has been awarded 19 Emmy Awards for her work on Sesame Street. She is up for another this year. In October 2008 she received a special award from the U.S. Department of Health & Human Services in recognition of her work including individuals with disabilities on Sesame Street.

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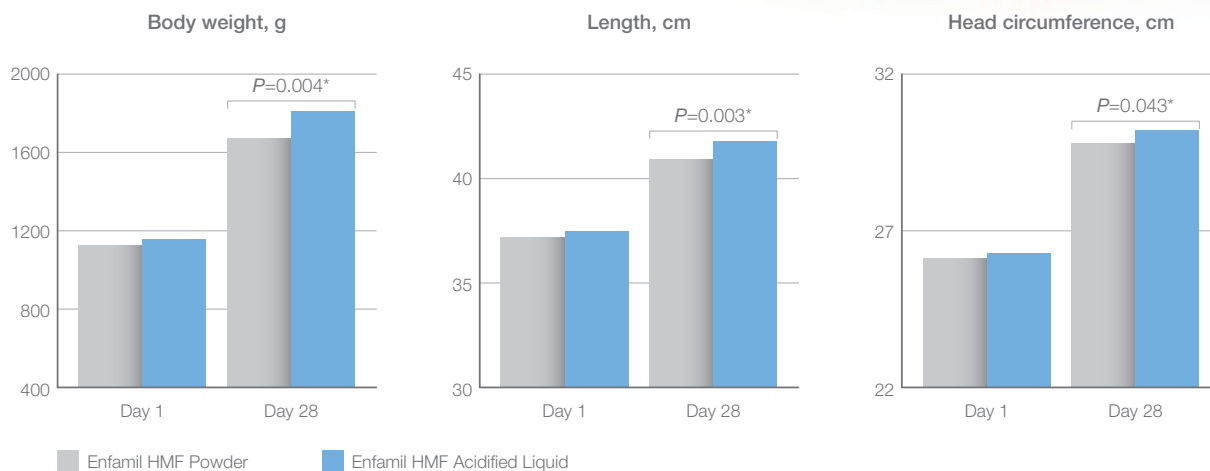
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