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# HOPE and DREAM: A Two-Clinic NICU Follow-up Model

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## Abstract

**Objective—**The natural extension of inpatient-focused neonatal neurocritical care (NNCC) programs is the evaluation of long-term neurodevelopmental outcomes in the same patient population.

**Clinical Design—**A dedicated and collaborative team of neonatologists, neonatal neurologists, neuropsychologists, neurosurgeons, physical medicine and rehabilitation physicians, and psychologists are necessary to provide personalized medicine, developmental assessments, and parental education for NNCC graduates. To achieve this goal, we devised a two-clinic follow-up model at Children's Wisconsin: HOPE (Healthy Outcomes Post-ICU Engagement) and DREAM: Developmentally Ready: Engagement for Achievement of Milestones) clinics. Those infants with significant neurologic diagnoses attend DREAM clinic, while all other high-risk neonatal intensive care unit (NICU) infants are seen in the HOPE clinic.

**Conclusion—**These clinic models allow for a targeted approach to post-NICU care, which has improved family engagement and perceptions of value.

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Authors' Contributions

K.C. and S.C. served as the primary writers and editors of the manuscript. S.A., E.F., A.F., A.H., J.J., I.K., J.K., L.M., and S.S., all played an active role in the two-clinic model described in this manuscript. In addition, these authors contributed to the writing and editing process.

Conflict of Interest

None declared.

**Keywords**

neonatal neurocritical care; high risk; long-term follow-up; multidisciplinary care model; value; care

One in every 10 infants is born prematurely in the United States.[1] Throughout the past 30 years, significant medical advances in the field of neonatology have decreased mortality in this population, yet this has not been accompanied by a reduction in morbidity.[1–4] This overall improvement in survival of infants at the earliest gestational ages has led to a cohort of children at high risk for significant medical and developmental problems. In the 1990s, the American Academy of Pediatrics (AAP) highlighted the developmental challenges premature infants face and emphasized the importance of neonatal intensive care unit (NICU) follow-up programs.[5–10] A National Institute of Child Health and Development workshop held in 2002 helped define the target patient population who may benefit most from NICU follow-up. This target population included infants born at ≤32 weeks and/or ≤1,500 g and follow-up clinics began to focus on providing family-centered comprehensive outpatient care. Over the past 20 years, NICU follow-up programs have consistently provided outpatient services to premature infants. However, the AAP has expanded its NICU follow-up recommendations to include infants with special needs, those with medical technology requirements, those with anticipated early death, and infants at risk because of family issues.[7] This programmatic expansion highlights the importance of growth and developmental care beyond the walls of the NICU.

Infants with neurologic compromise are a specialized population with increasing survival beyond the NICU.[11] In 2008, a multidisciplinary subspecialized team of providers at the University of California San Francisco (UCSF) operationalized a neonatal neurocritical care (NNCC) service dedicated to brain-focused care of sick newborns with primary neurologic diagnoses or those at risk for secondary neurologic compromise.[11–13] This NNCC program involves comanagement by neonatology and pediatric neurology, education efforts for nurses and providers, and an approach to standardizing care practices for infants with neurologic injury. Given the shift in neonatology practice from solely increasing survival of critically ill infants to improving neurodevelopmental outcomes and quality of life, the development of a NNCC program was timely.[12] Glass et al published their UCSF NNCC patient outcomes as of 2010 revealing that 25% of all NICU admissions required specialized neurologic care such as neonatal medical and nursing expertise, neuromonitoring, neuroimaging, and neurodevelopmental care.[11,14,15] Diagnoses included perinatal asphyxia, neonatal seizures, congenital cerebral malformations, intraventricular hemorrhage, and cerebral infarcts with an overall mortality of approximately 20% in both term and preterm patients.[11,14,15] Since Glass et al published these patient-specific findings, neurocritical care has become an integral part of NICUs across the globe. Studies by Mulkey and Swearingen and Bashir et al have demonstrated the impact of having a neonatal neurologist involved early in NICU care leading to improved seizure detection and management with a multidisciplinary neurocritical care team.[16,17] These publications have led to the formation of the Newborn Brain Society, a collaborative group of international neurologists and neonatologists with the shared goal of improving brain-focused care (https://newbornbrainsociety.org). From meetings of the

Newborn Brain Society, our level IV academic NICU formed our own neurocritical care program in 2017. We designed this program upon the pillars of clinical service, education, research, and quality improvement.

The natural extension of the inpatient-focused care of NNCC programs is the evaluation of long-term neurodevelopmental outcomes in this patient population. Traditionally, these patients with neurologic injury were seen in spaces designed for premature infant follow-up care. Glass et al remarked that many infants in the UCSF NICU NNCC service are enrolled in a well-established NICU follow-up program but inconsistently receive follow-up with a neurologist or rehabilitation specialist as part of a multidisciplinary visit.[11] To address this gap, our NNCC program aimed to develop a coordinated interdisciplinary approach to NICU follow-up, bringing together the previously separated outpatient service lines all working toward maximizing physical health and neurodevelopmental outcomes. This interdisciplinary approach includes specialists from neonatology, neurology, neuropsychology, neurosurgery, physical medicine and rehabilitation, psychology, and therapy services.

## Two-Clinic NICU Follow-up Model

A culture shift is necessary to address the neurologic, developmental, and medical needs during thefirst 1,000 days after NICU discharge.[18] A dedicated and collaborative team of neurologists, neonatal developmental specialists, and developmental therapists is necessary to provide personalized medicine, developmental assessments, and parental education for NNCC graduates. To achieve this goal, in 2019, we devised a two-clinic follow-up model at Children's Wisconsin: the HOPE (Healthy Outcomes Post-ICU Engagement) and DREAM (Developmentally Ready: Engagement for Achievement of Milestones) clinics. Children's Wisconsin is a 70-bed, level IV NICU with approximately 800 admissions per year. Of those admissions, 1 in 10 has a primary neurologic diagnosis. This number underestimates those infants with neurologic conditions since many NICU patients have a primary diagnosis of prematurity rather than their neurologic diagnosis. Those infants with significant neurologic diagnoses requiring NNCC care while in the NICU attend DREAM clinic, while all other high-risk infants are seen in the HOPE clinic. Utilizing a nursing triage system, patients are identified for each clinic by their complete diagnoses prior to NICU discharge. Both clinics provide a layer of support for infants and their families that complement the primary care clinic and subspecialist involvement. In addition, both clinics aim to prepare high-risk infants for optimal transition to the school system. Both HOPE and DREAM providers perform developmental testing using similar tools to identify early features of neurodevelopmental disorders.

The DREAM clinic enrolls patients with diagnoses including but not limited to neonatal seizure, hypoxic ischemic encephalopathy, and grades III and IV intraventricular hemorrhage (Table 1). These diagnoses place infants at the highest risk for long-term neurodevelopmental impairment, and therefore, necessitate expertly coordinated medical services and neurodevelopmental follow-up through school age. DREAM clinic visits occur at 3, 6, 12, 18 months, 2, 3, and 5 years of age. Visits 3 months through 2 years occur according to the child's adjusted age if born premature. Clinic

visits are staffed by an interdisciplinary team of neonatologists, neonatal neurologists, neuropsychologists, neurosurgeons, physical medicine and rehabilitation physicians, and psychologists. Additional clinic support services are provided by a nurse coordinator, social worker, and clinical dietician. Developmental testing in the DREAM clinic is performed by a psychometrist with oversight from a pediatric neuropsychologist who understands the impact of neonatal brain injury on development and cognitive function in this specialized patient population. Clinical psychologists with expertise in early childhood assessment may play a similar role at other institutions. Neurodevelopmental assessments include the Bayley Scales of Infant and Toddler Development, Fourth Edition (Bayley) at 12 months and 2 years of age, with transition to the Wechsler Preschool and Primary Scale of Intelligence, Fourth Edition testing administered at 3 and 5 years of age if clinically appropriate. At the 3- and 5-year visits, developmentally appropriate neuropsychological (i.e., visual motor integration and attention) and school readiness measures may be administered. At all clinic time points, parents complete a measure of adaptive functioning, and at 2 years of age, the Modified Checklist for Autism in Toddlers (M-CHAT) is administered for autism screening. In addition, at 3 and 5 years, parents complete measures of emotional, behavioral, and social functioning to assist in screening for psychiatric disorders such as depression, anxiety, and attention deficit/hyperactivity disorder. Rather than focusing solely on developmental catch-up by 2 years of age, clinic providers educate families on their child's developmental trajectory and develop personalized goals for future growth and development. If at any time point, the clinical and developmental evaluation is less concerning than anticipated and more routine NICU follow-up is adequate for the patient's needs, seamless transfer to the traditional NICU follow-up clinic (HOPE clinic) may occur. In addition to the developmental assessment, a clinical psychologist meets with families to address emotional or behavioral concerns and overall family functioning. This includes healthy sleep habits, family interactions, coping of early developmental concerns, and maternal mental health screening in the child's first year of life.

The HOPE clinic enrolls the traditionally followed NICU patients similar to follow-up clinics designed in the early 1990s. Unlike in the early follow-up era, the HOPE clinic continues the NICU's multidisciplinary care model with specialized neonatology, developmental, nursing, and therapy providers. Infants born at ≤32 weeks and/or ≤1,500 g are followed up in the HOPE clinic. In addition, infants with complex medical diagnoses listed in Table 1 are followed up in this clinic. Mirroring the key developmental time points of the DREAM clinic, patients are evaluated 6, 12, 18 months, 2, and 3 years. Graduation from the HOPE clinic occurs after the 3-year visit, when developmental catch-up in anticipated and testing for preschool readiness is performed. To achieve standardized developmental testing between the two complimentary follow-up clinics, Bayley evaluations are performed at the 12-month and 2-year HOPE visits by a certified examiner. All patients in the HOPE clinic receive neurologic and developmental screening by a neonatologist or pediatrician using the Hammersmith Infant Neurological Examination and Capute Scales: Cognitive Adaptive Test/Clinical Linguistic & Auditory Milestone Scale assessment tools when a Bayley evaluation is not administered. These screening assessments allow for easy referral to neurology or neuropsychology and the DREAM clinic if further evaluation is

warranted. The HOPE clinic focuses on the developmental assessment and refers patients for early intervention services such as physical, occupational, and speech therapy.

In this two-clinic follow-up model, we provide a family-centered and clinical work space that promotes patient and family comfort while optimizing multiple providers seeing patients in one visit. This model provides proximity to diagnostic areas and allows opportunities for clinical team collaboration. As this two-clinic model aligns with the Children's Wisconsin mission to deliver innovate high-quality patient care, extramural funding has not been required for stainability. While the cost of follow-up needs to be acknowledged, the cost of inaction for the patients with severe brain injury in the DREAM clinic is difficult to measure and may be even greater.[19]

## Impact to Date and Discussion

Since their implementation, NICU follow-up programs have aimed to provide family-centered care and support services for these infants while ensuring optimal growth, development, and behavioral outcomes.[20] However, multiple follow-up clinic sites have reported a significant downturn in enrollment with first visit no-show rates between 10 and 30%, and subsequent attrition rates between 10 and 70%.[21,22] Prior to the establishment of the HOPE and DREAM complimentary NICU follow-up clinics, a study by Swearingen et al reported a 2-year lost to follow-up rate of 62% of premature infants at the Children's Wisconsin traditional neonatal follow-up clinic.[21] Social disparities and surrogate markers of low socioeconomic status drove this elevated clinic attrition rate, likely reflecting the barriers to care that result in inequalities of the urban community served. In addition, Swearingen et al speculated that families who perceived consistent value in follow-up clinic appointments were more likely to attend over time. Based on these findings, optimizing derived value in every NICU follow-up visit became the mission of the two-clinic model.

Since the HOPE and DREAM clinics were opened in July 2021, 1,614 visits (1,369 HOPE and 245 DREAM) were scheduled (Table 2). Our current no-show rate for the first year of this two-clinic model is 10.7% (12.0% HOPE and 3.3% DREAM). In 2019 and 2020, prior to the two-clinic model, 1,014 and 832 NICU follow-up clinic visits were scheduled, respectively. The no-show rates for these years were 27 and 25%. We speculate that the striking improvement in follow-up clinic attendance can be attributed to several quality improvement efforts in place. These interventions include an in-person introduction to the clinic by our triage nurse prior to NICU discharge, better communication by either the HOPE or DREAM clinic coordinator during the transition home period, and a focus of each clinic visit on what matters most to the family. Taking family feedback into consideration, changing the focus of developmental messaging from a "report card" to a personalized plan for growth has improved family engagement and perceptions of value. One mother of a patient cared for in the DREAM clinic remarked, "they have truly helped me grow as a mother of a medically complex child. All I see for the future is hope and amazing things for my beautiful son!"

## Conclusion

The evolution of neurocritical care in the NICU requires refocusing and reimagining long-term follow-up care that is brain centered and value driven. Any NICU has the tools to accomplish this goal. Identifying and triaging infants receiving neurocritical care in the NICU and enrolling them in the multidisciplinary DREAM clinic is a novel approach to post-discharge care. This clinic model allows for a personalized approach, specialized developmental assessments, and parental education specific to neurologic diagnoses and their impact on childhood outcomes. After 1 year of DREAM clinic operation, appointment timeslots were doubled due to consistent family engagement. While the DREAM clinic provides a follow-up environment for NICU graduates at highest risk for developmental delays, the traditional model of NICU follow-up in the HOPE clinic remains crucial. Together the HOPE and DREAM clinics occur in harmony to provide the best and safest care for Children's Wisconsin NICU graduates.

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**Key Points**

- Infants with neurologic compromise are a specialized population with increasing survival.
- Interdisciplinary NICU follow-up brings together previously separated outpatient service lines.
- Our novel clinic model allows for specialized developmental assessments.

**Table 1**

HOPE and DREAM clinics criteria for referral prior to NICU discharge

| HOPE clinic | DREAM clinic |
|---|---|
| Birth weight <1,500 g | Neonatal seizures |
| Gestational age ≤$32^{0/7}$ wk | Grades 3–4 intraventricular hemorrhage |
| Persistent pulmonary problems (BPD) or oxygen therapy at the time of discharge | Cystic periventricular leukomalacia |
| Intrauterine growth restriction (>2 standard deviations below the mean for >1 parameter) | Hydrocephalus (acquired or congenital) |
| Diffuse periventricular leukomalacia | Hypoxic ischemic encephalopathy (with or without therapeutic hypothermia) |
| Elevated bilirubin levels requiring an exchange transfusion | Congenital neurologic abnormalities |
| Prolonged (>1 wk ± diazoxide/SolCarb) and/or severe symptomatic hypoglycemia | Severe hypoglycemia with MRI changes ± seizures |
| Severe congenital or acquired infections (positive blood cultures with pulmonary compromise, DIC, or shock) | Neonatal stroke |
| Infants with intrauterine drug exposure requiring hospitalization for therapy >30 d | CNS infections with meningitis or encephalitis |
| Infants with complex congenital heart disease | Infants with complex congenital heart disease with documented brain injury |
| Any other infant with complicated NICU course requiring >3 mo hospitalization at the discretion of the medical team | Any infant who required neurologic and/or neurosurgical services while in the NICU, or at the discretion of the medical team |

Abbreviations: BPD, bronchopulmonary dysplasia; CNS, central nervous system; DIC, disseminated intravascular coagulation; DREAM, Developmentally Ready: Engagement for Achievement of Milestones; HOPE, Healthy Outcomes Post-ICU Engagement; MRI, magnetic resonance imaging; NICU, neonatal intensive care unit.

**Table 2**

Follow-up visits scheduled and no-show rate before and after establishing the two-clinic model

| | Prior NICU follow-up model | | Two-clinic model, July 2021–June 2022 | | |
|---|---|---|---|---|---|
| | **2019** | **2020** | **HOPE** | **DREAM** | **Total** |
| Clinic visits scheduled | 1,014 | 832 | 1,369 | 245 | 1,614 |
| No-show rate | 27.0% | 25.0% | 12.0% | 3.3% | 10.7% |

Abbreviations: DREAM, Developmentally Ready: Engagement for Achievement of Milestones; HOPE, Healthy Outcomes Post-ICU Engagement; NICU, neonatal intensive care unit.