

35 Years of Neonatal Follow-up In Rhode Island

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Advances in perinatal and neonatal medicine including the use of antenatal steroids,¹ and magnesium sulfate,² more aggressive delivery room resuscitation, surfactant,³ prophylactic indomethacin,⁴ improved ventilatory techniques⁵ and nutritional management⁶⁻⁸ have significantly improved survival rates of preterm infants.^{9, 10} These improvements have been most notable for infants born with **extremely low birth weight (ELBW < 1000 grams)** and at the limits of viability (22-24 weeks).^{11, 12} This improvement in survival has resulted in an increasing prevalence of infants at risk for neurodevelopmental impairments and infants with special health care needs. In response, there has been an emergence of specialized follow-up care programs at tertiary care centers in the United States that provide enhanced transitional care and post-discharge care, and ongoing assessments. All fellowship training programs in Neonatology in the United States must have a follow-up program for training fellows that monitors the outcomes of **neonatal intensive care unit (NICU)** graduates.

VERY LOW BIRTH WEIGHT (VLBW) SURVIVORS IN RHODE ISLAND

Data from **Women & Infants Hospital (WIH)** is consistent with increased survival of our smallest and most vulnerable infants. Infants considered at the limits of viability are born at 22 to 24 weeks of gestation. Although the Academy of Pediatrics does not recommend active resuscitation of infants at 22 weeks gestation, it is recommended that physicians consult with families to develop a plan about the level of intervention for infants born at 23 to 24 weeks. Figure 1 shows the increase in the number of live births and survivors for these most immature infants of 23 to 24 weeks gestation in Rhode Island from 1990 to 2007. In 1990 there were 16 live births of infants of 23-24 weeks gestation and 7 survivors. This number increased to 38 live births in 2007 and 20 survivors. Increasing numbers of infants are being discharged on monitors, oxygen, special formulas,

medications, and gastrostomy tube feeds. These infants with special health care needs and their families benefit from the support of staff knowledgeable about the needs of high risk infants.

The Neonatal Follow-up Program at Women and Infants has been providing supplemental care to high risk infants since 1974. Initially infants seen in the Follow-up Program had been cared for in a 20-bed Special Care Nursery at the old Providence Lying-In Hospital. In 1984 the NICU was expanded to 41 beds when the hospital moved to its current site at 101 Dudley Street. Since that time the number of infants born at WIH and cared for in the NICU has increased, with a current daily census of almost 70 being cared for in the new 80-bed single room NICU. The mission of the Follow-up Program is to provide a continuum of specialized clinical care for graduates of the NICU, to monitor specific quality indicators, and to conduct prospective, longitudinal outcome studies including descriptive studies, interventional studies, as well as local and multicenter clinical trials.

CRITERIA FOR FOLLOW-UP AT WOMEN & INFANTS HOSPITAL

Infants routinely scheduled for follow-up include premature infants weighing less than 1500 grams at birth, infants of any birth weight with neonatal compli-

cations that place them at developmental risk including **intraventricular hemorrhage (IVH)**, **bronchopulmonary dysplasia (BPD)**, **periventricular leukomalacia (PVL)**, asphyxia, meningitis, congenital malformations and infants discharged on cardiorespiratory monitors or oxygen. Definitions of subgroups of high risk infants seen are shown in Table 1.

The number of visits per year has increased from approximately 200 in 1974 to over 1268 in 2009, and the number of staff has increased from 3 (physician, psychologist, and nurse) to 17 (4 pediatricians including a medical director, 2 psychologists, nurse practitioner, a social worker, a **Rhode Island Parent Information Network (RIPIN)** parent consultant, an occupational therapist, a pulmonologist, 2 nutritionists, a manager, a business representative, a chart coordinator, and a data analyst). Staff provide comprehensive multidisciplinary assessments.

Referral Process

Infants are primarily referred to the Follow-up Program from the NICU. In addition, **Early Intervention (EI)**, primary care providers, visiting nurses and parents may refer for growth, neurologic, developmental or behavioral concerns. Visits are scheduled from birth to adolescence, as indicated. High risk NICU graduates who move to Rhode Island from other parts of

TABLE 1. Common Definitions of Patients Seen in Neonatal Follow-up Program

Premature - any neonate born before 37 completed weeks of gestation. (37 weeks or less.)

Low birth weight (LBW) - birth weight less than 2500 g

Very low birth weight (VLBW) - birth weight less than 1500 g.

Extremely low birth weight (ELBW) - birth weight less than 1000 g.

Micro premie - any neonate whose birth weight is less than 750 g.

Chronological Age - The age of the infant based on the number of weeks or months since the actual date of delivery.

Corrected Age - The age of the infant calculated from the expected date of delivery. It may also be calculated by subtracting the number of weeks of prematurity from the chronological age. For example, an infant born 6 months ago with a gestational age of 28 weeks (3 months premature) has a chronologic age of 6 months and a corrected age of 3 months.

Small for gestation - weight <10th % for gestation

Threshold of viability - 22-24 weeks gestation

the country may also be referred for specialized follow-up. Informed consent for study involvement is obtained when indicated.

Age of Assessment

For premature infants born prior to 34 weeks gestation, corrected age (time since mother's expected date of delivery) is used for assessments of growth, development and nutrition in the first 30 months of life. Chronologic age (time since birth) is used thereafter. In contrast, immunization schedules are always based on chronologic age regardless of gestational age at birth. Infants with special health care needs (such as home oxygen or apnea monitor, feeding issues, or neurologic injury/illness) are seen within 1 month of discharge and followed closely thereafter. Stable VLBW infants are seen for standard visits at the corrected ages of 3, 7 and 18 months, and then at the chronological ages of 30 months and 5 years. School age assessments are also completed on children who are participating in long-term studies or special programs. For example, adolescents in the Indomethacin IVH Prevention Trial are currently being assessed at 16 and 18 years of age.

Type of Assessments

The Follow-up Clinic provides medical management for graduates of the NICU. Infants with medical problems such as apnea of prematurity, obstructive apnea, BPD, reflux and failure to thrive, are managed longitudinally until the problem is resolved or well controlled. Infants with more complex medical issues are referred to specialty clinics.

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Growth

Both appropriate-for-gestational age and small-for-gestational age VLBW infants are at increased risk of growth failure post discharge. Weight, length and head circumference are routinely collected longitudinally. Input is provided by the

staff nutritionists and recommendations made to the family and primary provider. Infants with significant growth failure are referred on for further assessment and possible candidacy for growth hormone.

NEURODEVELOPMENTAL OUTCOMES

Premature infants are at increased risk of cerebral palsy (CP), hearing loss, vision impairments, developmental delays, cognitive impairments and learning problems. Early identification is imperative so that appropriate referrals can be made to support the optimal development of these children.

Rates of CP in ELBW infants in RI range from 9-12%. The most common form of CP in this population is spastic diplegia, accounting for 40% to 50% of all cases, followed by spastic quadriplegia, and hemiplegia. Although CP is the most well known and potentially most disabling motor abnormality associated with prematurity, preterm infants more often have less severe differences in their neurologic development including difficulties with fine and gross motor coordination. During the first year of life transient findings of abnormal tone and movement are common in the motor development of VLBW infants. Infants with suspect or abnormal neurologic findings benefit from EI services.

While much less common than motor disabilities, rates of neurosensory disabilities are higher in ELBW infants than the general population. Unilateral or bilateral blindness rates in Rhode Island are usually about 1% of ELBW infants. Milder visual impairments including myopia, strabismus, and lack of stereopsis (depth perception) occur more frequently. Hearing impairment benefiting from amplification occurs in about 1-3 % of VLBW infants.

The most common impairment seen in VLBW and ELBW infants at 18 and 30 months is cognitive impairment, defined as scores that are more than 2 standard deviations below the mean on standardized cognitive testing. At school age 50% of former VLBW children will need some type of resource or special education supports.

The Follow-Up Program provides neurodevelopmental assessments and management. Neurosensory, neuromotor, behavior, and developmental assessments are completed on all infants at each visit. Developmental assessments include the follow-

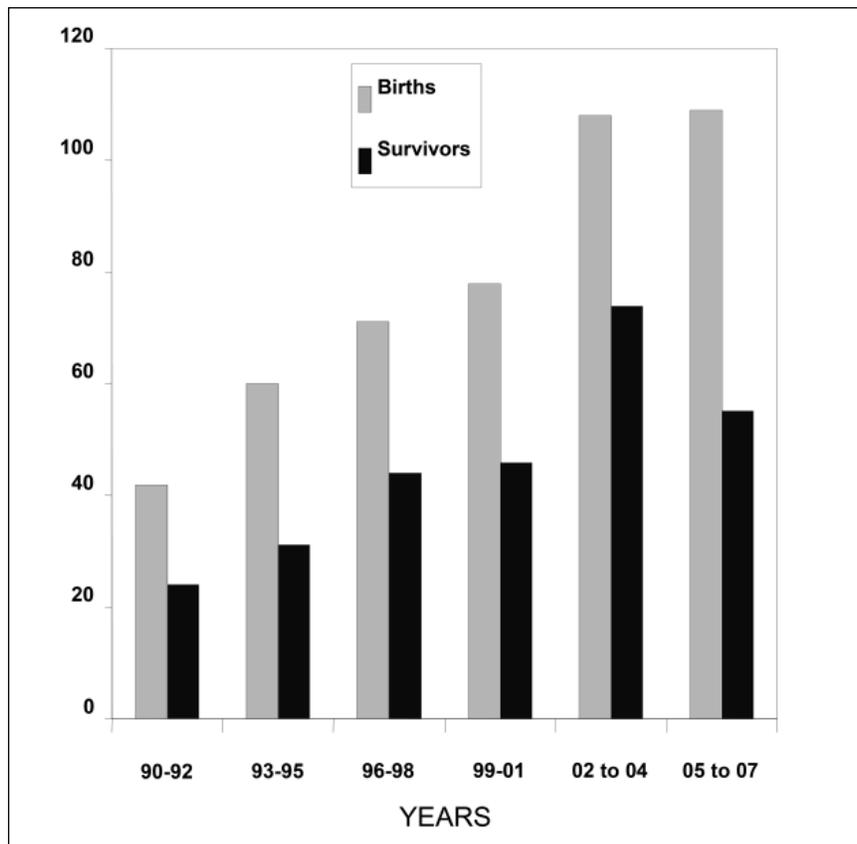


Figure 1. Number of live births and surviving 23 to 24 week gestation infants at Women & Infants Hospital by birth cohort.

ing: Cognitive, Language (Receptive and Expressive), Gross Motor, Fine Motor, Behavior (Internalizing and Externalizing and Adaptive Behavior), Executive Functioning, Memory, Achievement and Phonological Processing. Referrals are made to EI and the Department of Education as needed.

Feedback

Results with recommendations are provided to parents at the end of each follow-up visit. A summary letter with findings and recommendations for appropriate supplemental support services including specialty services and early intervention within the community is sent to the primary provider.

Teaching

The Follow-up Clinic is heavily committed to teaching fellows, residents, and medical students. In addition, visiting nurse practitioner students, fellows and physicians from other institutions and countries spend time in the clinic.

Data Base

The Neonatal Follow-up Program maintains a comprehensive data base of neonatal characteristics, neonatal outcomes, and post-discharge outcomes. This data is used for in-house monitoring of outcomes and is a quality indicator for management in the NICU. Long term outcomes are considered important because of a known disconnect between neonatal outcome and post-discharge outcome.^{13,14} The most demonstrative example of this was the use of high doses of ambient oxygen in the management of respiratory distress which through long term follow-up studies was associated with the subsequent diagnosis of retinopathy of prematurity with significant vision impairment or blindness.^{15,16} The program has both data entry staff for collection of neonatal and follow-up data, and a data analyst.

Transition Home Care

In 2006-2007 with the support of March of Dimes, CVS Charitable Trust, and the Department of Pediatrics, the Follow-up Program expanded services to provide comprehensive health integration services for infants considered at highest risk. The primary objective was to provide enhanced parent education, seamless support, and specialized infant services closely linked to the medical home (primary provider) during the first 6 months after discharge.

Nationally, 50% of ELBW infants are rehospitalized by 18 months of age. The objective of the enhanced services was to achieve fewer rehospitalizations and improve outcomes. Data collected from 2007 to 2008 indicate a significant decrease in the number of infants rehospitalized.

In summary, the Women & Infants Neonatal Follow-up Program plays an important clinical role to guarantee that all VLBW and high risk NICU graduates receive appropriate transition care, assessment and referral for community services as needed after discharge. In addition, ongoing surveillance of annual neonatal and post-discharge outcomes of high risk infants within an ever changing NICU environment permits the systematic monitoring of quality indicators and an audit of NICU interventions. In a 2004 publication comparing neurodevelopmental outcomes or death of ELBW infants cared for in the 12 centers of the NICHD Neonatal Research Network, our NICU had the lowest rates of cerebral palsy and the lowest combined outcome of any neurodevelopmental impairment or death.¹⁷ Data such as these provide the evidence for changes and innovations in management that result in the continual improvement in acute NICU care, survival of premature infants, and in long term outcomes for Rhode Island's NICU graduates.

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Disclosure of Financial Interests

The authors and their spouses/significant others have no financial interests to disclose.

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