

# Extremely Low Birth Weight NICU Graduate Supplement to the

## *Critical Elements of Care for the Low Birth Weight Neonatal Intensive Care Graduate (CEC-LBW)*

Available at: <http://www.medicalhome.org>

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This supplement to the *Critical Elements of Care for the Low Birth Weight Neonatal Intensive Care Unit (NICU) Graduate (CEC - LBW)* was developed by literature review and consultation with experts working with this population. The document is intended to provide an overview of the long-term special needs of the extremely low birth weight (ELBW) NICU graduate. Although such infants can experience a wide range of life-threatening neonatal complications, this supplement specifically addresses post-NICU care of ELBW infants who: 1) experienced the usual complications associated with extreme prematurity and/or extreme low birth weight, and 2) were discharged home in a relatively healthy condition.

The ELBW infant has selected health and neurodevelopmental risks that require more than standard well-child care throughout childhood and adolescence. Information in this supplement is designed to educate and support health care providers, parents, third-party payers, and policy makers interested in the care of ELBW infants and children.

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## Extremely Low Birth Weight NICU Graduate Supplement

### Suggestions for Using the ELBW Supplement:

1. Read the **Introduction**. This section contains a concise profile of the health and neurodevelopmental concerns specific to the ELBW infant.
2. Use the sections **Health Outcomes, Major Neurodevelopmental Sequelae, and Minor Neurodevelopmental Sequelae** as a reference for more specific information.
3. Use the **Health and Neurodevelopmental Surveillance Grid, Appendix 1**, as a quick reference (see CEC-LBW for instructions in its use with LBW). The health and neurodevelopmental surveillance recommendations on this grid should be carefully considered for the ELBW population.
4. Consult the **Table on Health and Neurodevelopmental Surveillance for ELBW, Appendix 2**. This table highlights high priority health and neurodevelopmental surveillance issues that should be carefully considered during well-child appointments with an ELBW infant or child.

### Glossary of Terms Used in the ELBW Supplement:

<b>BW</b>	– Birth Weight
<b>LBW</b>	– Low Birth Weight (2500 grams or less)
<b>VLBW</b>	– Very Low Birth Weight (1500 grams or less)
<b>ELBW</b>	– Extremely Low Birth Weight (1000 grams or less)
<b>Micropreemie</b>	– Birth weight 800 grams or less (some studies use 700 or 750 grams)
<b>CEC - LBW</b>	– Critical Elements of Care for the Low Birth Weight NICU Graduate

## INTRODUCTION

The extremely low birth weight (ELBW) premature infant is an infant born at 1000 grams or less (2 pounds 3 ounces), generally before 28 weeks gestation. This subpopulation of NICU graduates requires extra vigilance by the primary care provider and other health providers, with attention to medical sequelae and developmental surveillance/screening. Survival rates for infants born at ELBW are 85%. Micropreemie ELBW infants (501-750 grams birth weight, generally between 23 and 25 weeks gestation) have a survival rate of greater than 50%.<sup>1,2</sup> The average hospital stay for the ELBW infant is 100 days.<sup>3</sup> It is particularly important to provide support for the transition from the hospital to home and to assure heightened medical and developmental follow-up. This includes tracking of health and neurodevelopmental status such as newborn hearing screening, retinopathy of prematurity exams, feeding, nutrition and growth, and screening for learning disabilities throughout the school years.

Infants born at ELBW are at risk for the same health and neurodevelopmental problems as children born low birth weight (2500 or less grams). These problems are discussed in the original document "Critical Elements of Care of the Low Birth Weight NICU Graduate" (CEC - LBW). However, these adverse outcomes affect *greater percentages* of infants at the lower weights and often at *greater severity*, placing the ELBW infant at greater risk than the LBW infant. **Neurological, neurodevelopmental, neurosensory, and functional morbidities increase with decreasing birth weight.** Male gender is associated with increased neurodevelopmental morbidity. Poorer outcomes in the ELBW population are seen in infants who had:

- chronic lung disease,
- periventricular leukomalacia (PVL) and/or Grade III - IV intracranial hemorrhage,
- necrotizing enterocolitis requiring laparotomy
- steroids postnatally for chronic lung disease
- nosocomial infections
- retinopathy of prematurity.<sup>4,5</sup>

Ranges of surviving ELBW infants with moderate or severe disability start at 20-30 % for the heavier ELBW group (700-1000 grams BW) and are reported to be approximately 30% to 50% for

infants born at the limits of viability (less than 25 weeks of gestation). Many children demonstrate more than one disability – e.g. severe vision impairment, hearing impairment, cerebral palsy, mental retardation.<sup>5,6,7,8,9</sup> The bottom line is there are now more children with disability, because the overall rate of disability has remained fairly constant as the numbers of survivors have increased.

Parents, physicians and schools are seeing increased numbers of children presenting with the major and minor neurodevelopmental morbidities associated with prematurity. Some of these children have cerebral palsy, vision impairment, hearing loss, and/or mental retardation. As a group, they have lower IQ scores, lower achievement scores on standardized tests, and more difficulties with learning disabilities than their full-term peers. Approximately one-third of ELBW children have been reported to receive educational placements outside of the regular classroom.<sup>10</sup> VLBW children, which includes the ELBW population, show lower rates of high school graduation than normal BW children and are less likely to go to college than are full-term babies.<sup>11,12</sup> *It is important to note that, although parents of ELBW children report more frequent and more complex limitations of functioning than parents of term infants, both the parents and the ELBW teenagers themselves rate their quality of life as being fairly high.*<sup>13,14</sup> In addition, as therapies and interventions in the NICU continue to evolve and improve, the outcomes as children progress through childhood to adulthood may also improve.

The “take-home” message for the post-NICU management of the ELBW infant is that, given the high risk for the adverse sequelae of prematurity, *every ELBW infant needs extra-vigilant monitoring and early referral for concerns.* Many procedures that might be considered optional for larger LBW infants become essentially mandatory for the ELBW infant - including hearing assessment, close ophthalmologic follow-up, ongoing neurodevelopmental assessment, and assessment of school performance. ( See Appendices 1 and 2.)

## HEALTH OUTCOMES

Please see the information on Health Outcomes from the CEC - LBW for general information that also applies to the ELBW infant (in Appendix 3). Below is supplemental information about some of the sequelae seen in LBW infants but with special implications for the ELBW survivor.

### ***Newborn (PKU, etc.) Screening:***

It is currently recommended that a third newborn screening specimen be obtained on infants born at less than 1500 grams. Due to thyroid gland immaturity, medications, transfusions or other factors, ELBW infants can have a delayed onset of TSH elevation. The third screening test should be done at 4-6 weeks of age or just prior to discharge from the NICU. Results take 10 to 14 days and may not be available to the primary care provider until after discharge.

### ***Rehospitalization:***

ELBW infants have a higher rate of rehospitalization than term infants, especially during the first two years of life. Rates of 22-56% in the first year of life and 37-72% by two years of age have been reported. Fifty-eight percent (58%) of micropreemies have been reported to be rehospitalized in the first 18 months of life, with almost half having 2 or more admissions.<sup>15</sup> Rehospitalization is most frequently related to respiratory tract problems, including pneumonia, bronchiolitis, respiratory syncytial virus (RSV), and reactive airway disease. ELBW children with a history of chronic lung disease (CLD) are more likely than those without CLD to be readmitted and have longer inpatient stays. However, respiratory tract *infections* leading to hospitalization appear to occur at equal rates for ELBW children with and without a history of CLD.<sup>16</sup>

Admission for surgical repair of hernias or hydroceles is not uncommon. Other reasons for readmission include laser therapy for retinopathy of prematurity (ROP), acute gastroenteritis, ventriculoperitoneal shunt complications, seizures, strabismus surgery, and urinary tract infection.

### ***Immunizations:***

The ELBW population of infants is at risk of increased morbidity from vaccine-preventable diseases. Most immunizations should be given at full dose and on schedule by chronological age to the medically-stable preterm infant. The modification of the immunization schedule for the ELBW infant is the same as that for the LBW infant (see the AAP recommendations for immunization of preterm and LBW infants).<sup>17</sup> There is special information for influenza vaccine, RSV, and hepatitis B. ELBW infants, regardless of CLD status, may benefit from RSV prophylaxis [Palivizumab (Synagis)] during the RSV season up to 12 months of age. Infants with CLD may benefit from RSV prophylaxis up to 2 years of age. Please refer to the AAP recommendations for prevention of RSV infections.<sup>18</sup>

### ***Growth:***

As a group, ELBW infants grow poorly in early childhood and during this period tend to remain in the bottom quartile in weight.<sup>19, 20</sup> Of note, small head circumference (less than 3rd percentile) at one year of age or less is strongly associated with low cognition and learning disabilities at school age.<sup>21</sup> Growth of ELBW infants should be **plotted by corrected age** on the CDC growth charts (2000, downloadable at: [www.cdc.gov/growthcharts](http://www.cdc.gov/growthcharts)) or the preterm infant growth charts from the Infant Health and Development Project.<sup>22</sup> The CDC growth charts include body mass index beginning at 2 years of age. Optimal weight targets are 15 grams per day before due date, and 20-30 grams per day after due date, with primary emphasis on rate of weight gain, not on percentile placement on the growth chart. Optimal growth targets are 0.7 - 1.1 cm/wk of linear growth and 0.4-0.6 cm/wk head circumference growth. Infants who are not on a growth trajectory at least parallel to the normal curves are not growing satisfactorily and should receive further evaluation.

In early childhood, ELBW children continue to be smaller in weight when compared to normal BW peers. Catch-up growth for this population seems to come later and often does not occur until between 8 and 14 years of age. By 14 years, substantial weight and height gains are made. Adolescents

may still remain shorter and lighter than age-matched peers, but studies indicate that greater than 90% of these adolescents have weight and height in the normal range.<sup>23</sup>

### ***Breast Milk and Breast Feeding:***

Breast milk *may* be a protective factor for visual development, intellectual development, brain growth and cognition in all children.<sup>24, 25</sup> Given the extra risk for poorer cognitive outcomes in ELBW infants relative to normal BW and full term peers, it appears very reasonable to encourage breast milk feeding of this population. Preterm infants fed human milk, when compared to preterm infants fed formula, had higher IQ scores at 3 and 8 years of age.<sup>26</sup> In addition, for the ELBW infant there is evidence of increased epidermal and transforming growth factors (EGF and TGF-alpha) in mother's milk during the first postpartum month that has potential importance in healing effects on gastrointestinal mucosa.<sup>27</sup>

However, breast milk may be deficient in some nutrients needed by children born prematurely. *Fortification* with human milk fortifier may be necessary for a breastfed ELBW infant until 2.5 to 3 kg. Need for fortification with human milk fortifier post-discharge should be individualized; prolonged use is not recommended due to potential for inappropriate vitamin intake.

Some infants may need to continue calorie *supplementation* to breast milk (e.g., to 24 cal/oz); this may be accomplished by an addition of powdered formula to the breast milk. It is important to monitor growth carefully. Refer for consultation with a pediatric nutritional specialist as needed.

It takes a great deal of effort to initiate and maintain breast pumping and feeding breast milk to the ELBW infant in the NICU. Commendation and extra support should be extended to mothers who pursue and achieve this goal. Information is available to assist the family and physician in supporting breastfeeding the premature infant. (Pediatric Annals, May 2003 issue is entirely devoted to this topic.)

### ***Other Feeding Issues:***

The ELBW population is at high risk for feeding problems. Infants born under 32 weeks gestation had more immature feeding skills at term equivalent age when compared to infants born at 33 to 36 weeks gestation and to term infants.<sup>28</sup> Please see the CEC-LBW for further information under the section *Failure to Grow*.

### ***Osteopenia of Prematurity:***

The main cause of osteopenia of prematurity is inadequate calcium and phosphorus intake. VLBW, and even more so ELBW, infants are at risk for under-mineralized bone since the majority of calcium and phosphorus is accrued in the last trimester. This inadequate calcium and phosphorus state may be aggravated by or prolonged post-natally by long-term use of total parenteral nutrition (TPN) or use of non-preemie formulas or unfortified human milk. Certain medications can further impact bone mineralization, including corticosteroids and diuretics. Adequate vitamin D is also necessary for bone mineralization. VLBW infants may continue to have decreased bone mineral content that persists beyond one year of age.<sup>29</sup>

Attention to growth and vitamin/mineral status is important in determining formula choice or need for fortification of breast milk post-discharge. Some formulas may not optimize bone mineralization (e.g., soy formula). The observation that osteopenia of prematurity increased in LBW infants receiving soy protein-based formula lead to the American Academy of Pediatrics' conclusion that soy formulas should not be fed to LBW preterm infants.<sup>30</sup>

Assessment for osteopenia may include monitoring of alkaline phosphatase and serum calcium and phosphorus levels.<sup>31, 32</sup> Refer for consultation with a pediatric nutritional specialist as needed.

### ***Dental Issues:***

Dental enamel defects, such as hypoplasia, occur in about two thirds of VLBW children. Systemic illness, deficiency of calcium and phosphorus, and mechanical factors such as prolonged intubation in

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the neonatal period are contributory. Very preterm infants may have delays of tooth eruption, but usually have a full complement of teeth by two years of age. Dental examinations are currently recommended for all children by one year of age. Due to provider availability, this is difficult to achieve but remains a target goal for high-risk populations. The ELBW infant falls into a high-risk population; initial evaluation has been suggested at presence of 8 teeth or 2 years, whichever comes first.

### **Respiratory:**

ELBW infants suffer the same spectrum of respiratory problems and chronic lung disease that are seen in LBW infants (see CEC - LBW). There is an increased occurrence of re-hospitalization for respiratory illness in the ELBW child, especially during the first two years of life.<sup>16</sup> By adolescence, children with a history of ELBW and/or CLD have been reported to demonstrate respiratory health similar to that of normal BW peers, with no increased incidence of asthma or need for hospitalization.<sup>20</sup>

### **Sudden Infant Death:**

Infants with birth weights less than 1500 grams are much more likely to die of SIDS than controls.<sup>33, 34</sup> The association between prone sleeping and SIDS appears to be stronger in LBW infants than in normal BW infants.<sup>35</sup> There is evidence ELBW and VLBW infants are more likely to be placed to sleep in a prone position than larger LBW infants post-discharge. In the hospital, premature infants are often placed prone under close monitoring because it supports respiratory function. Babies are generally moved to the supine position in the weeks prior to discharge unless there is a contraindication. The AAP recommends supine as the preferred sleeping position for term and preterm infants.<sup>36</sup> Due to the ELBW infant's increased risk for SIDS it is important to discuss sleep position at well-child visits during the first months at home.

### **Cardiovascular & Hematologic Issues:**

ELBW infants may be anemic with hematocrits in the mid-20's when discharged from the NICU. Hematocrit, reticulocyte count and growth should

be monitored closely (every 2-4 weeks). If the infant is thriving and growing well, transfusion is not needed. However, if the hematocrit drops below 20 and reticulocytosis is inadequate, or growth is poor, transfusion should be considered.

Iron deficiency without anemia has been reported in 18% of ELBW infants at 12 months corrected age.<sup>37</sup> Blood pressure has been reported to be elevated in late adolescence in VLBW survivors.<sup>38</sup>

### **GI Sequelae:**

#### **Gastroesophageal Reflux Disease (GERD):**

The ELBW population is at risk for GERD. Many preterm infants of all weights first present signs of GERD *after* discharge from the NICU. Review of this topic can be found in the CEC - LBW.

#### **Hernias and Hydrocele:**

Hernias, both inguinal and umbilical, and hydroceles increase in incidence as birth weight decreases. The ELBW infant should be followed closely for resolution or potential complications of hernias and hydroceles. Surgical repair is often delayed until approximately 1 year of age. Educating the family about signs and symptoms that require medical attention should be included in the management plan.

#### **Hepatoblastoma:** <sup>39, 40, 41</sup>

Hepatoblastoma is a rare childhood embryonal malignancy. Reports in Japan have suggested a link between extreme prematurity and later development of hepatoblastoma. A rate of 0.5% has been reported among ELBW infants at one site. Age at diagnosis has ranged from 6-77 months. Both boys and girls are affected. Hepatoblastoma with unfavorable pathology and outcome appears to develop in ELBW children. Stage of tumor appears higher (i.e. more poorly differentiated) with associated poorer outcomes as gestational age decreases. It has been suggested that serum alpha-fetoprotein or abdominal ultrasound may be useful to detect early hepatoblastoma.

### **Exercise:**

Some children with a history of ELBW may experience deficiencies in aerobic and anaerobic

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performance, strength and coordination regardless of presence of pulmonary disease or neuromuscular problems. However, as a rule children born prematurely may engage in physical activities and competitive sports without limitation. Physical activity is encouraged for all children born prematurely to support skill development and to compensate for any possible effects on their coordination secondary to premature birth.<sup>42</sup>

### ***Car Seats and Car Beds:*** <sup>43, 44, 45</sup>

Positioning ELBW infants properly in a car seat can be difficult, particularly if the infant is still small at the time of hospital discharge. Most safety restraints currently on the market are designed for infants weighing 3.5 kilograms (7 pounds). Three manufacturers, Baby Trend, Safetyfirst/Costco and Evenflo, make a car seat model that is smaller. It is advised to select a car seat with: 1) a crotch strap distance of less than 5.5 inches from the seat back, and 2) a distance of less than 8 inches from the lowest shoulder strap position to the seat bottom.

A significant concern for car seat positioning of the ELBW infant is respiratory compromise. Premature and LBW infants are at greater risk for poor oxygenation in the semi-upright position in a car seat. AAP recommends that all infants born before 37 weeks gestation have a car seat check, including assessment for possible oxygen desaturation, before hospital discharge. Although infants must pass a car seat test prior to discharge, it is still recommended that the infant be closely monitored during travel, and if possible have an adult ride next to the infant in the back seat. For infants at risk of respiratory compromise, travel should be kept to a minimum.

**Car Seat Position:** All infants, including preterm infants, must ride in a rear-facing car seat until 12 months of age (corrected age for preemies) AND at least 20 pounds. If the vehicle seat slopes such that the infant's head flops forward, the car seat should be installed at a 45 degree angle (reclined halfway back). If needed, a roll of cloth or newspaper can

be wedged under the foot end of the car seat to achieve this angle.

**Infant Positioning:** The infant's buttocks should be against the back of the car seat. It is not permitted and is unsafe to pad a car seat behind the infant's back or under the buttocks. If there is additional space between the infant and the crotch strap (when buttocks are fully back), this space should be filled in to assure a snug fit and prevent slouching. A rolled blanket can be used for padding between the infant's crotch and the buckle. Blanket rolls can also be placed on either side of the infant for lateral support of the head and neck.

The position of the shoulder slot used for the shoulder strap must be at or below the level of the infant's shoulders. The harness should fit snugly and the chest clip positioned at the level of the axilla. A car seat with a tray or shield will initially be too big for LBW and ELBW infants.

Parents should avoid using bulky snowsuits or wrapping the infant in blankets. An extra blanket can be placed OVER the infant once positioned properly in the car seat.

See [www.aap.org/policy/01351.html](http://www.aap.org/policy/01351.html) (*Safe Transportation of Premature and Low Birth Weight Infants*) for illustrations of the various positioning recommendations described above.

**Car Beds:** Infants with documented desaturation, apnea, or bradycardia in a semiupright position should travel in a supine or prone position in an alternative safety device. While not crash-tested, car beds offer an alternative for infants with exceptional needs. Car beds are not as safe as car seats. Use of a car bed should be minimized and used only for absolutely necessary trips. Before transitioning from a car bed to a car seat, an oximetry test while positioned in the infant's personal car seat is needed.

## NEURODEVELOPMENTAL OUTCOMES

### MAJOR SEQUELAE

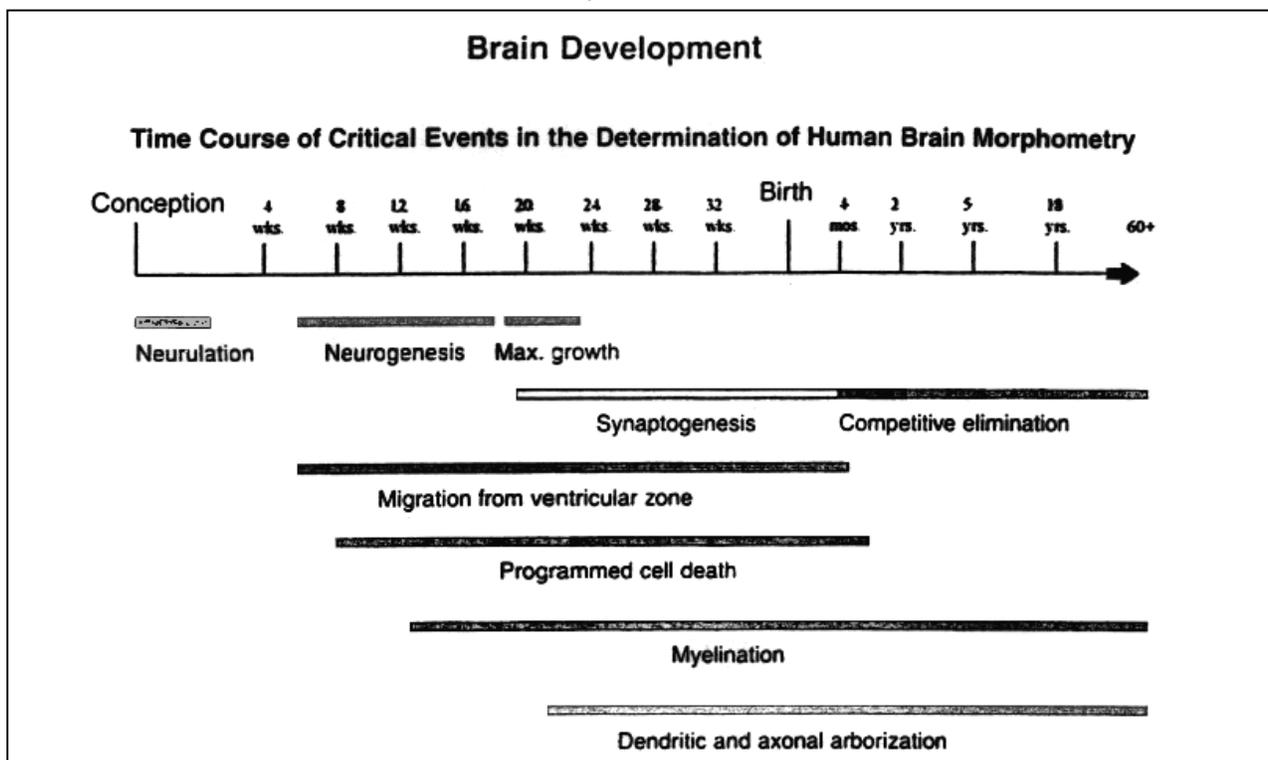
The major neurodevelopmental morbidities of ELBW infants are the same as for the LBW infant - mental retardation, cerebral palsy, seizure disorders, hydrocephalus, and neurosensory abnormality (visual or auditory impairment). These major adverse outcomes occur in approximately 20-30% of ELBW survivors, with infants at the limits of viability at greater risk.<sup>4, 8, 46, 47 48, 49, 50, 51, 52</sup> The incidence of major neurodevelopmental abnormalities has remained fairly constant as survival rates have increased over the past decades. Regular monitoring of neurodevelopmental progress and early referral for assessment and treatment of any concerns is important for this population.

If one looks at the differences in the gross brain structure toward the end of the second trimester versus term, as well as the neural maturation, migration, synaptogenesis, and myelination

occurring between 20 weeks and term (see Figures 1 and 2), it is not surprising that the brain is vulnerable to alterations in development and that adverse sequelae increase as gestational age at birth decreases.

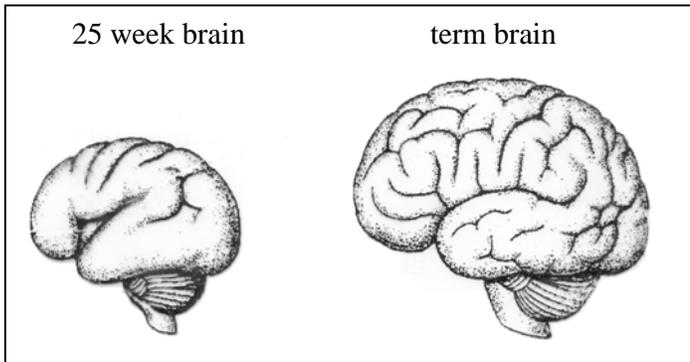
Most of the increase in cortical connections and complexity occurs after 25 weeks gestation. If infants born extremely preterm undergo imaging of the cerebral cortex at term-equivalent ages (38-42 weeks post-conceptual age), there is less cortical surface area and less cortical complexity than seen in normal infants born at term.<sup>53, 54</sup> Onto this maturational pattern, add insults such as hypoxia, intracranial bleeding, hypoperfusion, and the stress of handling in the NICU (to name a few), and the risk of poor outcomes becomes even more understandable. Brain MRI studies in preterm infants show about 4% cystic PVL and at term equivalent, 35-79% have non-cystic white matter injury, likely related to a combination of ischemia and infection. While cystic PVL shows strong correlation to later cerebral palsy, the clinical correlates of more diffuse white matter injury remain to be determined, but may be related to the spectrum of cognitive/behavioral deficits.<sup>55</sup>

Figure 1



Note. From "Images in Neuroscience," by J. Geidd, 1999, *Am J. Psychiatry*, 156(1), p. 4. © 1999 by *Am J. Psychiatry*. Reprinted with permission.

Figure 2



Note. From *The Developing Human, Clinically Oriented Embrology*, by K.L. Moore, 1973, Philadelphia: © 1973 by W.B. Saunders Company. Permission pending.

### **Cerebral palsy:**

Cerebral palsy (CP) has been diagnosed in 10 to 20% of ELBW infants with many studies in the 15% range even at the lowest birth weights.<sup>4, 5, 8, 9, 10, 19, 56, 57, 58, 59</sup> Thus, one in five to ten ELBW infants seen in a primary health care provider's office may have CP. This percentage remains essentially constant from infancy through adolescence. Because of this relatively high incidence, close monitoring of motor development and referral to a NICU follow-up program is recommended for all ELBW infants, with an initial visit usually occurring around 4-6 months corrected age.

Among ELBW infants, spastic types of CP are more common than the athetoid or ataxic types. Findings of Grade III and IV intracranial hemorrhage, ventriculomegaly, and presence of cystic PVL correlate strongly with later CP.<sup>60, 61, 62, 63</sup> Periventricular cysts occur in 4% of infants and are often identified in the first 3 weeks of life. However, there is increasing evidence of evolution of cysts beyond the first month of life and affected children may demonstrate visual and cognitive deficits as well as spastic diplegia or quadriplegia.<sup>64</sup>

Grades III and IV ICH occur in 11% of ELBW children; 44% of children with Grades III and IV ICH have disabling CP; and 45% to 85% of children with Grade IV ICH have MR and CP at school age.<sup>59, 60</sup> Ten percent of children with transient periventricular echodensities persisting for more than 7 days have spastic diplegia, and the risk and severity of spastic motor disability increases with persistent echodensities. Cystic PVL is found

in 5-26% of ELBW infants compared to 1-5% of infants over 1000 grams BW.<sup>59, 65</sup> Approximately 50% of children with cystic PVL have been reported to have CP at school age, with infants demonstrating 3mm or greater cystic lesions in the parieto-occipital periventricular white matter most at risk.<sup>66</sup>

### **Mental Retardation:**

Mental retardation (MR) is defined as impairment of adaptive function and a standardized intelligence quotient (IQ) of more than 2 standard deviations (SD) below the mean. This translates to scores below 68-70 on standardized cognitive tests (mean of 100, SD of 15 or 16 depending on the specific test used). Children with cognitive delay or MR are eligible for early intervention programs, specialized school programming and transition services during and after high school. Socioeconomic variables impact IQ scores, but the influence is less as birth weight decreases and as biologic risk takes on greater importance.

In early childhood years, low cognitive scores have been reported in 20% to 42% of ELBW children.<sup>4, 9, 46</sup> The percentage of infants with cognitive scores more than 2 SD below the mean has been reported to increase as gestation decreases. One group found 11% of 26-week gestation infants with cognitive deficiency on testing in early childhood, rising to almost 40% of infants born at 24 weeks gestation.<sup>58</sup> Others, looking at micropreemies (<750 g BW), found 28% of children with significant delay at 30 months corrected age.<sup>67</sup> However, summing up the heterogeneous literature on 22-26 week gestation survivors, Lorenz found in over 1500 children examined at a range of ages from 10 to 66 months there was a mean prevalence of 18.6% for impaired mental development.<sup>9</sup>

At school age, micropreemies are more than nine times more likely than full term controls to have an IQ under 70. Infants with birth weights between 750 gm and 1499 gm are over twice as likely as full term controls to have cognitive scores less than 70 (37%, 15%, and 6% in the <750 gm, 750-1499 gm, and term groups, respectively).<sup>68</sup>

In one follow-up study at 14 years of age, 20% of ELBW children have demonstrated IQ scores more than 2 SD below the mean.<sup>19</sup>

**Hearing Loss:**

ELBW infants are at increased risk for both neurosensory hearing loss and conductive hearing loss. All ELBW infants need to have brainstem auditory-evoked response newborn hearing screening performed before 1 month corrected age (if not by discharge). Further follow-up should occur as recommended by the audiologist or whenever there is any clinical or parental concern.

Hearing impairment severe enough to require hearing aids has been found in 1.5 - 9% of ELBW infants.<sup>8, 46, 50</sup> If one includes conductive hearing losses, incidence increases to 11% of ELBW infants affected.<sup>4</sup>

**Visual Impairment:**

ELBW infants are at particular risk for visual disabilities. *Blindness* has been documented in 1-7% of ELBW infants and is more prevalent in children with birth weights under 1000 grams than in larger infants.<sup>4, 8, 46</sup> Blindness predominantly occurs as a result of retinopathy of prematurity (ROP). ROP screening and intervention can reduce the incidence of post-ROP blindness. All ELBW infants need to be examined for ROP at 4 to 7 weeks post-delivery<sup>69, 70</sup> and re-examined until full retinal vascularization occurs or ROP regresses. Recommended timing<sup>93</sup> is as follows:

Gestational Age at Birth, wk	Age at Initial Examination, wk	
	Postmenstrual	Chronologic
24	31	7
25	31	6
26	31	5
27	31	4
28	32	4
29	33	4
30	34	4
31*	35	4
32*	36	4

\*If necessary.

Infants with severe ROP are candidates for laser therapy to attempt prevention of retinal detachment and blindness. In addition, children with a history of ROP are at risk for late retinal detachments (after 2 years of age) and visual field loss.

Other visual abnormalities also occur more frequently in the ELBW infant, such as decreased visual acuity, myopia, strabismus, glaucoma, and

visual field loss. Visual impairment is also common in children with severe cystic PVL.

Strabismus may be present with or without CP and with or without a history of ROP. It has been associated with white matter lesions in the occipital areas of the brain on MRI scans.<sup>71</sup> Strabismus was found in 12% of ELBW 18-month-olds.<sup>56</sup>

Amblyopia is reported in 3% of the general population and 3% of preemies without ROP, but increases to 26% in preterm infants with severe ROP.<sup>72</sup> Monitoring of eye alignment, red reflex, and acuity must be part of routine follow-up of the LBW infant. *Infants who demonstrate crossing of the eyes after 3-4 months corrected age should be referred to pediatric ophthalmology for assessment and, where indicated, treatment to prevent loss of vision.*

**Regular, long-term ophthalmologic follow-up, including eye examination at one and five years of age is recommended for all ELBW infants regardless of presence or absence of ROP.** In early childhood, 9% of ELBW infants had “some degree of vision loss”.<sup>4</sup> Myopia has been reported in 8-12% of ELBW children.<sup>56, 73</sup> Over 85% of preterm children who had ROP become myopic and 20% are myopic by one year of age.<sup>71</sup> Over 40% of ELBW children seen at 5 years of age have been reported to have some form of ocular disease - from blindness and reduced visual acuity to strabismus. Even children with no history of ROP who were ELBW had a 31% incidence of ocular disorders at 5 years of age.<sup>72</sup>

**Progressive Hydrocephalus:**

Hydrocephalus requiring shunt placement was noted in 4% of 18-month-old ELBW infants in the National Institute of Child Health and Human Development Neonatal Research Network (NICHD-NRN).<sup>4</sup> Head growth out of proportion to any catch-up growth in weight or length or genetic potential is an indication for further evaluation.

**Chronic Seizure disorders:**

Neonatal seizures occur in up to 20% of LBW infants. Chronic seizures were noted in 5% of ELBW infants at 18 months in the NICHD-NRN.<sup>4</sup> At secondary school age, 8% of ELBW adolescents were receiving medication for seizures.<sup>10</sup>

## **MINOR SEQUELAE**

### **General School Issues:**

Aylward states,  
“...of the children born at ELBW and VLBW who do not have major handicaps, mean *group* IQs fall in the borderline to average range, with the majority of studies suggesting low average scores being the mode. IQ scores are inversely related to birth weight. Although such IQ scores are assumed to allow adequate school functioning, when these children have to compete with classmates who are average or above, the level of IQ scores found in children born at VLBW and smaller does not necessarily translate into average school performance....[T]he array of potential problems found in the outcome of preterm infants mandates that assessment extend beyond traditional IQ and achievement testing.”<sup>67</sup>

Parents should be alerted to monitor their child's school performance closely and request referral for further academic and/or cognitive testing when concerns arise. Implications for school programming needs are high. By middle school age, ELBW children are 3 to 5 times more likely than full term children to have a learning disability. Sixty to 70% of ELBW children require special assistance in school. And in adolescence, the use of special educational arrangements or remedial resources is 8 to 10 times greater for the ELBW population over term controls.<sup>67</sup>

**Intervening early in school programming and providing educational supports are associated with the greatest improvements in school function for this population.**<sup>10</sup> *Remember that, despite an increased prevalence of the following difficulties, a considerable number of children in the ELBW population do not struggle with these problems and are doing well.*

### **Borderline Cognitive Development:**

Borderline cognitive development is defined as a score between one to two standard deviations below the mean on standardized cognitive testing (i.e. between 68-70 and 84-85, depending on the test used). As a group, ELBW children are at high risk of cognitive abilities in the borderline range or lower. There is an increased prevalence of IQ below 85 in the ELBW population compared to full

term controls. Although there has been some evidence of a continued increase in cognitive scores into adolescence, other researchers have shown poorer outcomes over time, especially in the micropreemie population.<sup>11, 74, 75</sup>

At about 20 months corrected age, 2/3 of ELBW infants score more than 1 SD below the mean on the Bayley II, with about half of those scoring in the borderline range.<sup>4</sup> At 32 months of age, 18%, 23% and 33% of children born at 26, 25, and 24 weeks gestation, respectively, show cognitive scores in the borderline range. These poorer outcomes showed a significant relationship with the presence of chronic lung disease, ICH or PVL, parental substance abuse, and high social risk.<sup>58</sup>

In early school years, fifteen to twenty percent of ELBW children have had to repeat a grade, 20% are in special education, and 40% to 50% need educational assistance.<sup>50, 59</sup>

By adolescence, ELBW children remain at significant educational risk with 30-50% receiving remedial assistance and/or having failed a grade. About half of ELBW children are reported to demonstrate IQ more than 1 SD below the mean at 14 years of age.<sup>10, 76</sup>

### **Learning disabilities:**

Infants born at the lowest birth weights are at the greatest risk of an identified learning disability, with increasing risk as birth weight decreases.<sup>19, 77</sup> In the micropreemie population, 50-70% of children with normal IQ have learning disabilities.<sup>67, 78</sup> Learning disabilities are not typically identified before third grade in the ELBW population. Many other disabilities related to academic performance are not detected until a child is even older.<sup>76</sup>

Some studies have indicated that, particularly in the more medically-compromised VLBW population through two years of age, motor and neurological function show improvement after early delays, but that cognitive and expressive language difficulties are more persistent.<sup>79</sup> By five years of age, ELBW children demonstrate deficits in “executive” behaviors which are thought to impact later learning (such as planning, sequencing, working memory, and inhibition).

By middle childhood, ELBW children have significantly lower indices of verbal comprehension, perceptual organization, processing speed and freedom from distractibility. In some studies, two-thirds of ELBW children meet criteria for learning disabilities in one or more areas. *Even with IQ measurement in the normal range* (greater than 85), almost half of ELBW children have an identified learning disability in one or more areas (compared to fewer than 1 in 5 normal BW controls).<sup>80</sup> Affected learning areas include: written output, arithmetic, reading, spelling, visual-spatial and visual-motor abilities, and verbal functioning.<sup>49, 50, 81, 82</sup>

### ***Attention Disorders:***

Teachers and parents rate ELBW and VLBW children as more inattentive and hyperactive — behaviors which appear to be explained by deficits in specific working memory and general intellectual delay.<sup>50, 83</sup> In one report, 23% of VLBW children met clinical criteria for ADHD (compared to 6% of classroom-matched, same sex, nearest birthdate controls).<sup>84</sup> In various studies, about 10% of ELBW adolescents have been reported to have ADHD<sup>67</sup>; thirteen percent of ELBW children have been reported to be receiving medication for ADHD at secondary school age.<sup>10</sup>

### ***Speech & Language:***

The incidence of communication, speech, language and articulation difficulties and/or delays is high within the population of ELBW infants. At 18 months of age, approximately 40% of ELBW children are reported to demonstrate speech delay.<sup>56</sup> By school records review between ages 12 and 15 years, 10.8% of ELBW children were identified as having impairments of speech and language.<sup>76</sup> Difficulties are seen in both expressive and receptive language, including poor articulation, difficulty with speech fluency, and weakness in vocabulary and word finding.

***Speech and language development should be closely monitored, especially between 1 and 2 years of age, prior to kindergarten, and during school years.***

### ***Neuromotor Disorders:***

The ELBW child is at risk for delayed performance of fine motor and gross motor skills. Close monitoring of motor skill development and physical endurance is recommended. *Consideration should be given to formal assessment of fine motor skills and gross motor skills prior to school entry* as limitations in these skills may negatively impact school performance and peer relationships. Activities to build motor skills, both fine and gross, should be encouraged throughout the lifespan.

Difficulties in visual-spatial skills and visual-motor skills are specifically reported and affect functional performance of handwriting and other fine motor manipulation skills. Limitations in visual motor function in ELBW children are associated with periventricular brain injury.<sup>85, 86</sup>

Gross motor coordination and motor planning are also areas of difficulty for ELBW children compared to normal BW peers. Delayed motor milestones, clumsiness, hypotonia, and difficulty controlling movement have been reported. About half of ELBW children (compared with 5-9% of the general population) have a developmental coordination disorder.<sup>87</sup>

In one study of 5-7 year olds, ELBW children demonstrated slower reaction time, lower motor coordination scores on standardized testing and, on a cycling task, lower maximum cycling speed and lower peak and mean muscle power performance than normal BW children.<sup>88</sup> In another study, adolescents with a birth weight up to 1250 grams continued to demonstrate impaired motor skills.<sup>89</sup>

### ***Neurobehavioral Development:***

Behavioral issues and social outcomes have been difficult to measure and have been less often addressed in follow-up studies of the ELBW population. However, a number of issues have been raised.

Parents have reported altered response to pain in their ELBW toddlers with decreased sensitivity to "normal bumps and hurts".<sup>90</sup> In addition, there have been reports at late-preschool age of higher rates of

## Neurodevelopmental Outcomes

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non-specific physical complaints with no known medical cause.<sup>50, 79</sup>

Conduct disorders, shyness, unassertiveness, withdrawn behavior, and social skills deficits occur more frequently in ELBW children than full term peers. The ELBW child may be seen by peers as more sensitive and isolated – behaviors in part modulated by neuromotor delays.<sup>50, 82</sup>

In middle childhood, 55% of ELBW survivors born in the post-surfactant era demonstrated clinically significant neurobehavioral impairment.<sup>50</sup>

At age 8-9 years, ELBW children, under conditions of cognitive assessment, demonstrated preference for easy tasks, distrusted their own abilities, reacted to failure unrealistically, and needed constant praise and encouragement.

At school age, depression, anxiety, difficulty with social interactions, and low self-esteem have been reported to be more frequent for VLBW and ELBW children than normal BW peers, with evidence of persistence into adolescence.<sup>79, 91, 92</sup>

## Appendix 1

### ***Health and Neurodevelopmental Surveillance Grid: Low Birth Weight ( $\leq 2500$ gms)***

The Health and Neurodevelopmental Surveillance Grid was developed for the *Critical Elements of Care for the Low Birth Weight NICU Graduate*. All children should have well-child care guided by the AAP “Recommendations for Preventive Pediatric Health Care” (<http://www.aap.org/policy/re9939.html>). This grid supplements those recommendations with important health and neurodevelopmental screening and assessment steps for LBW infants and children. It is designed to be useful as a chart insert in the child’s primary health care record. It provides the PCP with a quick reference of surveillance issues for the LBW infant or child during a well-child visit.

HEALTH & NEURODEVELOPMENTAL SUPERVISION GRID: LOW BIRTH WEIGHT																			
See CEC Sections II & III for more specific information	NICU	Infancy (Corrected ages through 2-3 yo)								Early Childhood				Late Childhood			Adolescence		
Medical Evaluation	D/C	1 mo	2 mo	3 mo	4 mo	5 mo	6 mo	9 mo	12 mo	15 mo	18 mo	24 mo	3 y	4 y	5-13 y per AAP schedule			13-21 y Annual	
NICU Discharge Plan <sup>1</sup>	•																		
Interim History	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			•	•
Growth (L/HT, WT, OFC) <sup>2</sup>	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			•	•
Nutrition/Feeding <sup>3</sup>	•	S	S	S	S	S	S	S	S	S	S	S	S	S	S			S	S
Vision <sup>4</sup>	O	S	S	S	S	S	S	S	S	S	S	S	•	•	5 Y	10Y	12Y	15 Y	18 Y
Hearing <sup>5</sup>	O	—	—	—	S	S	S	S	S	S	S	S	•	•	5 Y	10Y	12Y	15 Y	18 Y
Special Health Concerns <sup>6</sup>	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			•	•
Development/Behavior Assessment <sup>7</sup>																			
Temperament/rhythmicity <sup>8</sup>	S	S	S	S	S	S	S	S	S	S	S	S	S	S	S			S	S
Sensorimotor <sup>9</sup>	O	S	S	S	—	—	O	—	O	—	O	S	S	S	S			S	S
Language <sup>10</sup>							S	S	S	S	—	O	—	S	S			S	S
Cognitive <sup>11</sup>							S	S	S	S	S	S	—	O	S/O			S/O	S/O
Social/Adaptive Behaviors <sup>12</sup>		S	S	S	S	S	S	S	S	S	S	S	—	O	S/O			S/O	S/O
School Performance <sup>7</sup>														S/O	S/O			S/O	S/O
Family Support <sup>1, 13</sup>	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			•	•

Assure compliance with the American Academy of Pediatrics "Recommendations for Preventive Pediatric Health Care."

- = To be performed in primary care setting; referral as indicated.
- O = Objective; standardized testing; referral to appropriate specialist(s) as indicated.
- S = Subjective; by history or observation.
- O — = Assessment range with preferred age (symbol).
- = Emphasized developmental domain.

1. See AAP Policy Statement. "The Role of the Primary Care Pediatrician in the Management of High Risk Newborn Infants"<sup>reference 2</sup>; "Excerpts from Family Centered Care"<sup>reference 3</sup>; and "Hospital Discharge of the High Risk Neonate"<sup>reference 4</sup>

2. Record on standard growth charts or on premature infant grids using corrected age.

3. Referral to nutritionist, lactation consultant, feeding specialist or GI specialist as indicated.

4. Examination by an ophthalmologist prior to NICU discharge when indicated and again as recommended by ophthalmologist.

5. Screening BAER prior to NICU discharge. If not done in NICU, refer for BAER within 3 months. If failed, repeat within 3 months. Closely monitor for hearing loss (conductive or progressive neurosensory hearing loss may occur later); high risk groups should be retested every 6 mos. until 3 y.o. High Risk = Family history of early onset hearing loss, persistent pulmonary hypertension as newborn, s/p TORCH infection, s/p meningitis, hyperbilirubinemia requiring exchange transfusion.

6. Consultation with pediatric subspecialists as indicated.

7. Consider referral to early intervention program from birth to 36 months; transition to public school preschool program at 36 months as indicated. Age 6-18, refer for psychometric testing through school district or psychologist as indicated.

8. Subjective assessment of child's temperament and daily rhythms at each visit.

9. Standardized movement assessment recommended at approximately 4 to 6 months, 8 to 12 months, and 15 to 18 months corrected age.

10. Standardized communication assessment recommended at approximately 18 to 36 months corrected age.

11. Standardized cognitive assessment recommended at approximately 36 to 48 months of age.

12. Subjective assessment of social/adaptive behaviors at all visits. Standardized assessment at 36 to 48 months of age.

13. See "Excerpts from Family Centered Care..."<sup>reference 3</sup> Refer to appropriate local family support services as indicated. Coordinate referrals with insurance providers to maximize coverage for services.

If a child enters care for the first time at any point on the schedule, or if any items are not accomplished at the suggested age, the schedule should be brought up to date at the earliest possible time.

## Appendix 2

### Appendix 2 - Health and Neurodevelopmental Surveillance: ELBW ( $\leq 1000$ g)

Aspects of the ELBW infant's health and neurodevelopment deserve heightened attention and thorough assessment. The following table provides accessible identification of the health and developmental surveillance issues considered necessary for the ELBW infant and child. This table correlates with the *Health and Neurodevelopmental Surveillance Grid for the LBW* (Appendix 1) and the AAP's "Recommendations for Preventive Pediatric Health Care" (<http://www.aap.org/policy/re9939.html>).

Corrected Age	Important Health and Neurodevelopment Surveillance
Infancy - <b>0 - 1 month</b>	<ul style="list-style-type: none"> <li>▪ Determine results of third (or later) neonatal metabolic screen in early post-discharge period</li> <li>▪ Refer to pediatric audiology within first 3 months, if not previously documented, or for re-evaluation as indicated by previous audiology assessment</li> <li>▪ Refer to ophthalmology as indicated for follow-up of retinopathy of prematurity</li> <li>▪ Assess growth and nutrition; record on standard growth charts using corrected age</li> <li>▪ Evaluate family stress and parent-infant interaction</li> </ul>
Infancy – <b>3 - 4 months</b>	<ul style="list-style-type: none"> <li>▪ Examine for strabismus; refer to pediatric ophthalmology if present.</li> <li>▪ Assess growth and nutrition; record on standard growth charts using corrected age</li> <li>▪ Evaluate family stress and parent-infant interaction</li> </ul>
Infancy -- <b>4 - 6 months</b>	<ul style="list-style-type: none"> <li>▪ Refer for standardized movement assessment, assessment of muscle tone and movement quality</li> <li>▪ Assess growth and nutrition; record on standard growth charts using corrected age</li> <li>▪ Evaluate family stress and parent-infant interaction</li> </ul>
Infancy – <b>8 - 12 months</b>	<ul style="list-style-type: none"> <li>▪ Refer for standardized movement assessment, assessment of muscle tone and movement quality</li> <li>▪ Screen language, fine motor-adaptive and personal-social skills</li> <li>▪ Refer to an ophthalmologist comfortable with pediatric population for vision assessment</li> <li>▪ Assess growth and nutrition; record on standard growth charts using corrected age</li> <li>▪ Evaluate family stress and parent-infant interaction</li> </ul>
Early Childhood – <b>15 - 18 months</b>	<ul style="list-style-type: none"> <li>▪ Refer for standardized movement assessment</li> <li>▪ Screen other areas of development and social interaction</li> </ul>
Early Childhood – <b>18 - 36 months</b>	<ul style="list-style-type: none"> <li>▪ Refer for standardized assessment of speech and language skills</li> <li>▪ Screen other areas of development and social interaction</li> </ul>
Early Childhood - <b>36 - 48 months</b>	<ul style="list-style-type: none"> <li>▪ Refer for standardized assessment of cognition and social/adaptive skills, as well as screening for school readiness</li> <li>▪ Refer to an ophthalmologist comfortable with pediatric population</li> </ul>
Middle Childhood – <b>6 - 12 years</b>	<ul style="list-style-type: none"> <li>▪ Review academics, school performance, attention skills, behavior, peer relationships, self-esteem and coping skills</li> <li>▪ Refer for psychometric testing through school district or psychologist as indicated</li> <li>▪ Refer for follow-up with an ophthalmologist at 9-12 years of age</li> </ul>
Adolescence <b>13 – 21 years</b>	<ul style="list-style-type: none"> <li>▪ Review academics, school performance, attention skills, behavior, peer relationships, self-esteem and coping skills</li> </ul>

## Appendix 3 –HEALTH AND NEURODEVELOPMENTAL SUPERVISION FOR THE LOW BIRTH WEIGHT NEONATAL INTENSIVE CARE UNIT GRADUATE

Reprinted without footnotes from Critical Elements of Care for the Low Birth Weight Neonatal Intensive Care Graduate. For full CEC – LBW document, see <http://www.medicalhome.org>

### HEALTH OUTCOMES

As a group, low birth weight children experience more health problems than normal birth weight children, and require special attention to some aspects of routine well-child care.

**Immunizations:** The appropriate age for initiating most immunizations for the premature infant is in accordance with the chronologic or uncorrected age. There should be no alteration of vaccine dosage. The following exceptions apply:

#### 1. Influenza vaccine

- a. Family contacts and other caregivers of infants born prematurely and infants with other chronic conditions should receive influenza vaccine.
- b. For preterm infants in whom chronic respiratory tract disease develops, influenza vaccine should be administered annually in the fall once they have reached 6 months of age.

#### 2. Hepatitis B

Optimal timing of immunization for the preterm infant with a birth weight less than 2kg whose mother is Hepatitis B surface antigen negative has not been determined. Current AAP Redbook recommendations (2000) are to: 1) delay Hepatitis B immunization for this subpopulation until just before discharge from neonatal hospitalization if the infant then weighs 2 kg or more, or 2) until approximately two months chronologic age when other immunizations are given.

**3. Respiratory Syncytial Virus** – Infants born at 32 weeks gestation or less, even without CLD, may benefit from RSV immunoprophylaxis. See the AAP Policy Statement for RSV Prevention (Pediatrics 112(6): 1142-1146, 2003) or the latest edition of the AAP Red Book for the most current recommendations.

**Growth:** Many low birth weight infants with growth appropriate for gestational age (AGA) deviate

from expected growth curves during their neonatal hospitalization and during periods of chronic or acute illness. Some of these AGA infants remain under the 10th percentile in height and weight parameters beyond three years of age with gradual catch up to their genetic potential by 6-8 years of age or later.

In contrast, infants less than 10% birth weight, small for gestational age (SGA), often remain small. Prognostically, there is a greater chance of catch-up growth in an SGA infant with normal intrauterine head growth. Catch-up head growth usually precedes catch-up in length and weight and is generally seen between 36 weeks postconceptual age and 8 months. Very little catch-up growth occurs in head size after one year of age. Infants with chronic medical conditions may not experience catch-up growth until school age.

**Breast Feeding:** Full-term, premature, and SGA infants all benefit from breast feeding. Studies indicate that premature infants and SGA infants who are breast fed have a significant intellectual advantage (higher IQ scores) over non-breast fed peers.

**Feeding Issues:** Feeding difficulties may surface in the first days and weeks post hospital discharge. Many LBW infants have difficulty sending clear behavioral cues to their caregiver, lack endurance, and become easily overstimulated resulting in stress during the feeding for both the family and the infant. Nursing support or the assistance of a feeding specialist with expertise in infant feeding (often either an occupational therapist or speech therapist) may be indicated. These specialists can help optimize reading infant's cues, and review positioning and feeding techniques. Lactation consultants, particularly those familiar with LBW infants, may be helpful to breast-feeding mothers and infants. Additionally, parental comfort with infant feeding and knowledge of formula preparation must be monitored. Registered dietitians may be consulted for growth and nutritional assessment.

Among LBW infants experiencing a relatively benign NICU course, those most at risk of nutritional problems after discharge are infants with:

- Very low birth weight ( $\leq 1500$  g birth weight)
- Extremely low birth weight ( $\leq 1000$  g birth weight)
- SGA
- Feeding problems while in the NICU, which may include requiring extra time with lactation consultant
- Special formulas needed to sustain growth
- Parenteral nutrition  $> 4$  weeks
- Bronchopulmonary dysplasia or other respiratory compromise
- Anemia
- Neurological damage
- Short gut syndrome
- GE reflux

Infants with any concerns in the above areas warrant close monitoring of nutrition with weekly or twice-weekly weight checks until a satisfactory growth rate is established. If the growth is not adequate, assessment of cause should be made with consideration of referral to a pediatric registered dietitian.

**Failure to grow** (FTG) is the failure to grow at the expected rate, with a downward shift across growth channels on standardized growth charts. FTG is more frequent in the low birth weight infant, especially infants with cardiorespiratory problems, gastroesophageal reflux disease, and neurodevelopmental problems

The risk of FTG is increased in LBW children who start solids earlier than 4-6 months corrected age and with the early use of cow's milk (prior to 12 months corrected age) or lowfat milk prior to 2 years of age.

Additional factors to consider in a child who is failing to grow include: anemia, physiologic/metabolic disorders, oral and motor dysfunction, neurobehavioral differences, family stress, family dysfunction, potential child abuse or neglect, other chronic health problems.

Some LBW infants need special attention to choice of formula (e.g. need to continue on enhanced preterm formulas) and caloric density of formula for optimal growth to occur. It is also important to be alert to medical complications affecting feeding such as gastroesophageal reflux disease (GERD), short

gut, cardiorespiratory or neurodevelopmental complications including swallowing dysfunction and incoordination, and anatomic factors such as deep palatal grooves post-intubation. At times further evaluation such as feeding assessment, oral motor assessment, and/or radiographic swallowing study will be needed.

Transitions to semi-solids and from breast/bottle to cup should be based on corrected age and developmental readiness, **not** on chronological age. Developmental readiness for solid foods is signaled by the infant's interest in and reaching toward other family member's food, and good head control in the upright sitting position.

### ***Behavioral Organization/Self-Regulation:***

Clinical research by Brazelton, Als and others has impacted the understanding of the neonate's emerging physiological and behavioral adaptation to his environment. Als' individualized developmental care model describes the infant in behavior along three channels of communication: the autonomic system (breathing patterns, color fluctuation, tremors, startles), the motor system, (body tone, postural repertoire, and movement patterns), and the state organizational system (range, robustness, modulation, and patterns of transition states). This model states that infants can communicate their stress limits and levels of stability through their behavior and that infants are in continual interaction with their environment through these functional subsystems. Approach and avoidance self-regulatory behaviors can be documented for an infant. An observation of the infant through these systems can clarify the emerging behavioral organization of the infant and assist families in understanding their infant's signals. At discharge from the NICU and in the continuing months ahead it is beneficial to the LBW infant that his caregivers continue to take into account the still emerging organization and integration of these systems.

Caregivers can support the infant by:

- protecting the infant from environmental stimulation as needed
- reading the infant's behavioral messages
- promoting the infant's self-regulatory behaviors
- providing supportive positioning and handling
- gently encouraging the infant's orientation to visual and auditory stimuli as alerting emerges,

and planning daily caregiving routines around the times the infant is best able to cope with handling

**Gastroesophageal Reflux Disease:** GERD is more commonly seen in LBW infants than full term infants. Reflux may contribute to failure to grow adequately, chronic cough, choking, and aspiration causing setbacks in respiratory healing. GERD can cause recurrent aspiration, apnea and/or bradycardia, “feeding aversion”, anemia, otalgia, and dental erosions. Children often alter feeding patterns because of the inflammation and presumed discomfort associated with reflux esophagitis. Although GERD may be diagnosed prior to NICU discharge, it is important to realize that the first symptoms of GERD may not present until the initial weeks and months at home. In a LBW infant with persistent feeding difficulties, consider occult GERD. Attention to positioning after feedings, and adjusting the volume and frequency of feedings are helpful management strategies. Medical, and potentially surgical, treatment is available and should be considered with significant GERD. Diligent, ongoing medical management using motility agents and/or medications to reduce gastric acid may be necessary with subspecialist referral as needed.

**Anemia:** During the first year of life, low birth weight infants are at high risk for anemia, which leads to an increased risk of neurodevelopmental sequelae and failure to grow. Maternal iron stores are transferred to the infant during the last trimester of pregnancy. The more premature the infant, the fewer the iron stores available for erythropoiesis. In addition, iatrogenic blood losses from the neonatal hospitalizations are often quite significant and, if the infant required transfusion in the NICU, there is subsequent suppression of red blood cell synthesis. Iron supplementation for the LBW infant (2-4 mg/kg/day) should start by 2 months postnatal age rather than at 6 months, as recommended for the full term infant. Iron fortified cereals and formulas are not enough. Ongoing monitoring of hematocrit and/or hemoglobin is needed.

Parents are sometimes concerned about “constipation due to iron” and want to reduce their infant's iron intake. Constipation is usually of multifactorial etiology, with the most common cause being insufficient fluid intake. For problematic

constipation, a careful assessment, potentially including a nutritional consultation, should be performed.

**Respiratory:** Complications of intubation such as subglottic stenosis, tracheomalacia, vocal cord paralysis, laryngeal granulomas, longitudinal palatal grooves may adversely affect dentition, speech and hearing, and the incidence of middle ear disease. LBW infants may have chronic lung disease and may be discharged home on oxygen with the need to be monitored for adequacy of oxygenation and ability to be weaned from this supplemental oxygen. In addition, continuing attention should be given to preterm infant car seat fit and positioning.

The most common respiratory conditions found in this population are chronic lung disease, upper and lower respiratory tract infections, and otitis media. Children may present with rales, cough, retractions, stridor at rest, and/or prolonged expiratory phase of breathing. Children may later experience difficulty with decreased exercise tolerance. Respiratory compromise can continue in to young adulthood. Abnormal pulmonary function tests may be related to complications of neonatal respiratory compromise or familial factors.

Increased risk of infection due to environmental exposures (e.g., daycare) and household exposure to direct airway irritants (e.g., smoke from cigarettes, fireplace, or woodburning stove) are important considerations for this population. Infants born at 32 weeks gestation or less may benefit from RSV prophylaxis (see the AAP Policy Statement, the latest edition of the AAP Redbook or consult a pediatric pulmonologist for the most recent recommendations).

**Sudden Infant Death Syndrome (SIDS):** Prematurity and low birth weight are two of the consistently identified risk factors for SIDS. The National Institute of Child Health and Human Development SIDS Cooperative Epidemiological Study found infants born at less than 2500 grams to be five times more likely to die of SIDS and infants with birth weights less than 1500 grams eighteen times more likely to die of SIDS than controls. Maternal smoking during pregnancy increases the SIDS risk 3 to 4 times. For full-term infants the peak incidence of SIDS is between three and four months postnatal age. In the preterm population, the peak incidence of SIDS is at more than 43 weeks

postconceptual age for preterm infants of any gestational age.

SIDS is the most common cause of post-discharge infant mortality, although the incidence has been decreasing with increased attention to supine sleeping posture in infants. Recommendations for sleep position for some children with chronic lung disease, upper airway malformations, and GERD must be individualized and may require apnea or sleep studies to assist in decision making. Some preterm infants with apnea persisting to discharge are sent home on methylxanthines and an apnea monitor. While home monitoring may be used to document apnea, bradycardia, or hypoxia, there is no evidence these are associated with an increased incidence of SIDS. Further there is lack of evidence that home monitoring has any impact on SIDS prevention, including in the preterm population.

**Cardiac Complications:** In the rare child discharged home with a Patent Ductus Arteriosus (PDA), spontaneous closure may still occur up to 4-6 months post discharge. Continued monitoring for congestive heart failure and need for medical or surgical intervention is needed.

The use of umbilical artery catheters in the NICU patient is associated with an increased risk of thrombus formation, vasospasm, and occasionally, secondary hypertension in infants. Infant blood pressure is difficult to measure accurately because infants and toddlers are usually upset by the discomfort of the cuff and pressure of inflation. Accurate blood pressures may be easier to measure when the infant is in deep sleep in the parent's lap.

Right ventricular hypertrophy can be a complication of severe bronchopulmonary dysplasia and pulmonary vascular hypertension associated with hypoxemia. Systemic hypertension is seen in infants and young children with chronic lung disease and generally responds well to antihypertensive agents and resolves over time. Care of these infants goes beyond the scope of this document.

**Late Sequelae of Necrotizing Enterocolitis (NEC):** There is a 10-22% incidence of strictures/intestinal stenosis in children experiencing NEC. These infants usually present with a partial bowel obstruction or with failure to grow adequately with a peak incidence of this complication at 2-8 weeks after the acute episode. Some children will be discharged with a

surgical stoma site that requires proper skin care and monitoring for potential fluid and electrolyte imbalance with even mild gastrointestinal illness. Additionally, intestinal fistulas may occur. If a long segment bowel resection was necessary, short gut syndrome with attendant issues of malnutrition and growth failure, vitamin and mineral deficiencies (fat soluble vitamins, vitamin B12, zinc, calcium), or potentially late onset bacterial sepsis may require long term management.

**Hernias:** Inguinal and umbilical hernias occur more frequently in LBW infants than in full term infants. Along with screening for hernias as part of ongoing well child care, primary care providers should instruct the parents of premature infants in the signs and symptoms of hernias, especially an incarcerated inguinal hernia, and the differentiation between a hydrocele and an inguinal hernia. Guidelines on seeking medical attention should be reviewed with parents.

**Rehospitalization:** Rates of rehospitalization are greater for LBW infants than for the normal birth weight population, especially during the first year of life. The likelihood of readmission for the VLBW infant has been reported to be as high as 38%. After the first year rehospitalization rates fall to 10%. Surgical interventions for strabismus, otolaryngological procedures, and hernia repair are not uncommon. LBW infants/children have an increased number of rehospitalizations for pulmonary conditions such as reactive airway disease, respiratory syncytial virus (RSV) and other pulmonary infections. Respiratory complications often decrease after two years of age. Other hospitalizations may occur for specific organ system abnormalities such as cardiac defects or central nervous system complications.

**Dental Issues:** Children born prematurely have a high prevalence of dental enamel hypoplasia (62% in VLBW children, 27% in LBW). In addition to the adverse effects of systemic illnesses during the neonatal period, deficiency of calcium and phosphorus in the neonatal period is directly related to enamel hypoplasia of the VLBW child. Local factors such as laryngoscopy and endotracheal intubation have also been implicated in the etiology of enamel hypoplasia.

### Appendix 3

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Very preterm infants may have delays of tooth eruption, but by two years of age usually demonstrate a normal complement of teeth.

***Osteopenia of prematurity:*** During the last trimester there is a sixfold increase in fetal calcium and phosphorus accumulation. Osteopenia of prematurity may present clinically between the 6th and 12th postnatal week and is most commonly caused by inadequate mineral intake. Supplementation of human breast milk or attention to mineral content of formula is indicated.

Risk factors for developing osteopenia include total parenteral nutrition requirement for longer than 2 weeks, use of non-preemie formulas or non-fortified

human milk in the hospital, use of soy formula, and drug-nutrient interactions such as steroids and diuretics impacting calcium, phosphorus, and vitamin D metabolism. The disease is usually subclinical and is often an incidental finding on radiographs which may show metaphyseal changes, osteopenia, and fractures. Additional findings may generally include growth failure, dental enamel hypoplasia, widely split sutures, craniotabes, and perhaps pathologic fractures. Laboratory workup reveals normal serum calcium, low to normal serum phosphorus, and elevated plasma alkaline phosphatase activity. Regular radiographic studies may assist with diagnosis and follow up.

## Appendix 4

### **Indicators Associated with Sensorineural and/or Conductive Hearing Loss:**

**A. For use with neonates (birth through age 28 days) when universal screening is not available.**

1. Family history of hereditary childhood sensorineural hearing loss.
2. In utero infections, such as cytomegalovirus, rubella, syphilis, herpes, and toxoplasmosis.
3. Craniofacial anomalies, including those with morphological abnormalities of the pinna and ear canal.
4. Birth weight less than 1500 grams (3.3 lbs).
5. Hyperbilirubinemia at a serum level requiring exchange transfusion.
6. Ototoxic medications, including but not limited to the aminoglycosides, used in multiple courses or in combination with loop diuretics.
7. Bacterial meningitis.
8. Apgar scores of 0-4 at one minute or 0-6 at five minutes.
9. Mechanical ventilation lasting five days or longer.
10. Stigmata or other findings associated with a syndrome known to include a sensorineural and/or conductive hearing loss.

**B. For use with infants (age 29 days through 2 years) when certain health conditions develop that require rescreening.**

1. Parent/caregiver concern regarding hearing, speech, language, and/or developmental delay.
2. Bacterial meningitis and other infections associated with sensorineural hearing loss.
3. Head trauma associated with loss of consciousness or skull fracture.
4. Stigmata or other findings associated with a syndrome known to include a sensorineural and/or conductive hearing loss.
5. Ototoxic medications, including but not limited to chemotherapeutic agents or aminoglycosides, used in multiple courses or in combination with loop diuretics.
6. Recurrent or persistent otitis media with effusion for at least three months.

**C. For use with infants (age 29 days through three years) who require periodic monitoring of hearing. Some newborns and infants may pass initial hearing screening but require periodic monitoring of hearing to detect delayed-onset sensorineural and/or conductive hearing loss. Infants with these indicators require hearing evaluation at least every six months until age three years, and at appropriate intervals thereafter.**

**Indicators associated with delayed-onset sensorineural hearing loss include:**

1. Family history of hereditary childhood hearing loss.
2. In utero infection, such as cytomegalovirus, rubella, syphilis, herpes, or toxoplasmosis.
3. Neurofibromatosis Type II and neurodegenerative disorders.

**Indicators associated with conductive hearing loss include:**

1. Recurrent or persistent otitis media with effusion.
2. Anatomic deformities and other disorders that affect eustachian tube function.
3. Neurodegenerative disorders.

*Position Statement 2000 -Joint Committee on Infant Hearing, American Academy of Pediatrics.*

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