Primary Care for Preterm Infants & Children

A CPQCC Provider Toolkit

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Executive Summary

Approximately 10% of births are preterm, and while there are regional and demographic variations, the high rate assures that pediatric providers will see significant numbers of preterm infants and children in their practices. Primary care pediatric providers are facing increasing time pressures as they balance providing quality clinical care, connecting with families, documenting in the electronic health record, and managing a practice. These providers need updated information readily available to them as they manage primary care issues for preterm infants and children.

Recommendations and guidelines for providing care for preterm infants and children come from a variety of national organizations including the American Academy of Pediatrics (AAP), the Centers for Disease Control (CDC), and the Advisory Committee on Immunization Practices (ACIP). The Primary Care for Preterm Infants & Children Toolkit combines many of the key recommendations in one easily accessible reference and helps inform pediatric providers when there are a variety of approaches to clinical presentations. The goal of the Toolkit is to support primary care pediatric providers as they care for preterm infants and children.

How To Use This Toolkit

The Primary Care for Preterm Infants & Children Toolkit serves as an easily accessible reference for primary care providers in a clinic setting. It can be viewed online or downloaded and printed. The Tip Sheet and Periodicity Chart summarize key information from the toolkit in two different two-page formats. A provider may choose to utilize either or both formats based on personal preference and practice needs.

We encourage NICUs to include guidance in their discharge summaries for primary care providers. The downloadable Tip Sheet can be used by NICUs as a starting point for developing their own customized Tip Sheet. The document can be used to develop a customized dot phrase or addendum to their usual discharge summary.

Disclaimer

The recommendations in this publication do not indicate an exclusive course of treatment or serve as a standard of medical care.
Introduction

This toolkit prepares the primary care provider with the skills and knowledge to care for preterm infants and children who are at increased risk for morbidity, serious illness, and hospitalization.

Prevalence of Preterm Birth

An estimated 15 million children are born preterm (<37 weeks gestational age) each year worldwide, with greater than 500,000 born annually in the United States. In 2018, the United States preterm birth rate was 10.02%. While this rate varies by geographic location and ethnic groups, overall it assures that preterm children make up a significant portion of virtually every primary care practice that provides care for children.

In 2018, the state with the lowest preterm birth rate was Oregon at 7.8%, and the highest was Mississippi at 14.2%. Other states with high rates included Louisiana 13%, Alabama 12.5%, and West Virginia 11.8%. Aggregate data from 2015-2017 looking at racial/ethnic groups showed the lowest rate of prematurity in the Asian/Pacific Islander population at 8.7%, followed by White 9%, Hispanic 9.4%, American Indian/Alaska Native 11.3%, and Black 13.6%.

Definition and Risks

Preterm infants and children are often medically complex and have been shown to require increased outpatient visits and hospitalizations. The World Health Organization (WHO) defines preterm as babies born before 37 weeks gestation. Using their terminology, an extremely preterm infant is born less than 28 weeks gestation, very preterm 28 to 32 weeks, and moderate to late preterm 32 to 37 weeks.

Common issues for these at-risk infants are poor weight gain, infections, respiratory issues, and neurologic abnormalities. Preterm infants who are small for gestational age (SGA), less than 28 weeks gestational age, or have bronchopulmonary dysplasia (BPD), intraventricular hemorrhage (IVH) grade 3 to 4, or necrotizing enterocolitis (NEC) have been shown to have higher rates of health care visits. One study found that infants born at 23 to 32 weeks gestational age had a mean of 20 outpatient visits in the first year of life compared to 12 outpatient visits for term infants without morbidities, with most visits occurring in the primary care setting. Preterm infants also have increased rates of rehospitalization during the first year of life with a 22% rehospitalization rate of infants <32 weeks GA in one study. In addition, increased rehospitalization rates persist through childhood and adolescence.

Primary care providers are responsible for health supervision and coordination of care for this high-risk population of preterm infants and children. This toolkit aims to assist primary care providers in the care of these infants and children by summarizing the current recommendations for many of the issues that are relevant in the primary care setting.
Monitor growth carefully, using the correct growth chart and adjusting for gestational age. Always support breastfeeding. If needed, supplement with post-discharge formulas specially formulated to meet the nutritional needs of preterm infants. Do not overfeed infants who gain weight rapidly after discharge.

It is crucial to monitor growth parameters in preterm infants and children, particularly in the immediate post-discharge period but also longer term throughout childhood. Preterm infants are at high risk for growth failure and nutritional deficiencies because of multiple factors including difficulty with feeding, food tolerance, and food absorption. In addition, some infants have increased metabolic demands due to comorbidities including bronchopulmonary dysplasia (BPD), cardiac issues, and neurological issues. Many infants have inadequate nutrition during their hospitalization due to illness and medical issues. However, there is evidence that weight gain in the post-discharge period is associated with obesity trends and may affect long term neurodevelopmental outcomes. Therefore, it is important to monitor for adequate growth and also to monitor for weight gain that is too rapid because of association with long term morbidities.

**Monitoring Growth**

Use the Fenton growth chart for preterm infants to maximum 50 weeks postmenstrual age (gestational age + chronological age). Use the WHO growth
The first step in monitoring growth requires using age-appropriate growth parameters and growth charts. The Fenton growth chart is most frequently used for preterm infants. It is based on 977 preterm infants in three North American cities and was subsequently revised and validated using data from 6 developed countries. The Fenton growth chart does not require age adjustment as the chart shows gestational age, for which the provider uses postmenstrual age (gestational age + chronological age). The Fenton growth chart can be used until 50 weeks postmenstrual age.

Both the American Academy of Pediatrics (AAP) and the Centers for Disease Control (CDC) recommend using the WHO growth chart for children 0 to 2 years of age and the CDC growth chart for children 2 to 20 years of age. Age should be corrected for prematurity until at least two years of age. The WHO growth standards are based on data collected between 1997-2003 on 8,440 children in 6 countries (Brazil, Ghana, India, Norway, Oman, and USA). These children were predominantly breastfed for the first 4 months of age and continued breastfeeding to one year. Selected children were healthy and living under conditions likely to favor achievement of full genetic growth potential. The CDC growth charts are based on data from the National Health and Nutrition Examination Survey (NHANES) data of children in the United States.

Post-Discharge Formulas

Consider using post-discharge formulas such as EnfaCare® and NeoSure® in infants <1800 grams birth weight and selected other high-risk infants.

Post-discharge formulas may be used for supplementation or feeding of preterm and very low birth weight (VLBW <1500 grams) infants when there is inadequate growth with breast milk alone. The post-discharge formulas that are most frequently used in the United States are EnfaCare® and NeoSure®, both 22 cal/oz. The contents of these formulas vary from the formulas for term infants in several areas including increased calories, protein, calcium, and phosphorus, which are known to be required in higher amounts for VLBW infants.

The amount and length of usage of post-discharge formulas are controversial, and recommendations vary considerably among geographic regions and institutions. Some studies have shown improved growth and brain growth with the usage of post-discharge formulas compared with standard formulas, but studies have not shown consistent results. In addition, there is growing evidence that breast milk provides similar growth and development to post-discharge formulas, and many do not currently recommend their usage if there is adequate growth with breast milk.

While all providers and families should be aware that specific recommendations vary and recommendations should be adjusted for each individual infant, some options for VLBW infants at discharge include:

1. Substitute post-discharge formula for breast milk 2 to 3 feedings per day
2. Fortification of mother’s milk with post-discharge formula powder to 22 or 24 calories for 2 to 3 feedings per day
3. Post-discharge formula to 22 or 24 calories with frequency determined by growth trajectory.

In addition, the question arises as to how long to continue post-discharge formulas. Again, each individual infant should be followed, but here are some general guidelines:

- BW>1800 grams: May not be necessary
- BW 1501-1800 grams: Up to 3 months
- BW 1001-1500 grams: Up to 6 months
- BW 751-1000 grams: Up to 9 months
- BW <750 grams: Up to 12 months

chart from 0 to 2 years. Use the CDC growth chart from 2 to 20 years. Use corrected age to adjust for prematurity until at least two years of age.
Follow-up After Discharge

See all infants within 48-72 hours of discharge from the NICU.

Preterm infants are at risk for growth failure after discharge, and most sources recommend a follow-up appointment within 72 hours of discharge from the NICU. The nutrition goals after discharge are to promote breastfeeding, provide appropriate nutrients, achieve a normal rate of growth for adjusted age, and avoid overfeeding.15

Some general guidelines to monitor growth are:
1. Provide follow-up within 72 hours after discharge from the NICU
2. Recheck every two weeks initially until stable weight gain is established
3. Continue to follow closely if taking post-discharge formula to monitor for too rapid weight gain
4. Use clinical judgment

Reflux

Reflux occurs in almost all preterm infants. Treatment with positioning or pharmacological agents is usually not indicated and may cause harm.

Gastroesophageal reflux (GER) is almost universal in preterm infants and usually occurs many times per day due to transient relaxation of the lower esophageal sphincter. Signs previously attributed to GER including desaturation, apnea, bradycardia, irritability, arching, perceived postprandial discomfort, feeding intolerance, or aversion have not been shown to be temporally related to the occurrence of GER. In addition, medications often used to treat reflux such as Histamine-2 (H2) receptor blockers (e.g. ranitidine, famotidine) and proton pump inhibitors (PPis) (e.g. lansoprazole, omeprazole) have not been shown to be efficacious in reducing GER. H2 blockers may be associated with adverse effects including increased incidence of necrotizing enterocolitis and late-onset infections. PPI use may be associated with gastroenteritis, pneumonia, and increased risk for childhood fractures.17 18

In most cases, treatment with positioning or pharmacological agents is not indicated and may cause harm. GER is considered a normal developmental occurrence that will resolve with time.17 Infants with anatomic abnormalities, recurrent pneumonia, or difficulty with feeding may be at higher risk for pathology that requires intervention.19

Vitamin Supplementation

VITAMIN D: Supplement infants with 400 IU of Vitamin D per day.

The AAP recommends 400 IU of Vitamin D per day in infants under 1 year of age to optimize bone health and prevent rickets. Due to low levels of Vitamin D in breast milk, all breastfeeding infants should be supplemented with 400 IU per day. All formulas in the United States contain at least 400 IU of Vitamin D per liter. Infants who are partially breastfed or taking less than 1 liter of formula per day should also be supplemented. 20

VITAMIN A: Vitamin A supplementation is not routinely recommended.

There has been controversy in the past as to whether preterm and low birth weight infants benefit from Vitamin A supplementation to prevent mortality and morbidity. A Cochrane study in 2016 did not find sufficient evidence to recommend routine supplementation, and there are no current recommendations for routine supplementation. 21
**IRON:** Supplement all preterm infants with iron unless they have received blood transfusions.

Most preterm infants should be supplemented with iron 2-3 mg/kg per day for the first 6 to 12 months after birth until the infant takes sufficient iron-fortified formula and complementary foods to provide sufficient iron.

Preterm infants are at high risk for iron deficiency anemia for several reasons including decreased iron stores at birth, the high rate of catch-up growth and its associated increase in blood volume, and iatrogenic depletion through blood testing during hospitalizations. Some studies have suggested that early iron deficiency in preterm infants may result in neurological abnormalities and effects on neurodevelopment.  

All preterm infants should have an iron intake of at least 2 mg/kg per day through 12 months of age. Recommendations include treating with iron supplements 2-3 mg/kg/day through 6 months of age or until the infant begins eating complementary foods or takes sufficient iron-fortified formula that supplies 2 mg/kg of iron. An exception would be infants who have received an iron load from multiple transfusions of red blood cells. There is no universal recommendation for performing laboratory tests for anemia in preterm infants. Timing can be guided by inpatient laboratory values prior to discharge. Another approach would be to consider checking for anemia in higher risk patients 4-6 weeks after discharge and as needed thereafter. Infants who are anemic should be treated with therapeutic doses of iron (4-6 mg/kg/day).
Follow general recommendations by chronological age except for special protocols for Hepatitis B Vaccine and Rotavirus Vaccine.

Preterm infants and children should be immunized with the routine immunization schedule without adjustment for gestational age or birth weight with the exception of Hepatitis B vaccine. Routine immunizations other than Hepatitis B vaccine have been shown to have adequate safety and antibody response. It is important to follow immunization status carefully in this population, as a recent study showed that preterm children had a lower rate of completed immunizations than full term children with over half who were under-immunized at 19 months and over one-third who were still under-immunized at 36 months.

**Hepatitis B Vaccine**

Follow special recommendations for infants <2000 grams because of diminished antibody response.

Hepatitis B vaccine has been shown to produce a diminished antibody response in low birth weight infants. Therefore the schedule and indications for infants <2000 grams have special considerations listed below.

**MOTHER IS HBsAg-NEGATIVE:**

- 1 dose within 24 hours of birth for all medically stable infants ≥2000 grams.
- For infants <2000 grams, administer 1 dose at chronological age 1 month or hospital discharge.
- A dose received by an infant <2000 grams AND <1 month of age does not count towards the primary series.

**MOTHER IS HBsAg-POSITIVE:**

- Administer Hepatitis B vaccine and 0.5 mL of Hepatitis B immune globulin (HBIG) (at separate anatomic sites) within 12 hours of birth, regardless of birth weight.
- For infants <2000 grams, administer 3 additional doses of vaccine (total...
of 4 doses) beginning at age 1 month.

- Test for HBsAg and anti-HBs at age 9-12 months. If Hepatitis B vaccine series is delayed, test 1-2 months after final dose.

**MOTHER’S HBsAg STATUS IS UNKNOWN:**

- Administer Hepatitis B vaccine within 12 hours of birth, regardless of birth weight.
- For infants <2000 grams, administer 0.5 mL of HBIG in addition to Hepatitis B vaccine within 12 hours of birth. Administer 3 additional doses of vaccine (total of 4 doses) beginning at age 1 month.
- Determine mother’s HBsAg status as soon as possible. If mother is HBsAg-positive, administer 0.5 mL of HBIG to infants ≥2000 grams as soon as possible but no later than 7 days of age.

### Immunoprophylaxis

Do not miss the opportunity to protect vulnerable children from Respiratory Syncytial Virus infections.

Palivizumab (Synagis®) prophylaxis is recommended for children who are at high risk of serious lower respiratory tract disease from Respiratory Syncytial Virus.

**PALIVIZUMAB RECOMMENDATIONS IN THE FIRST YEAR OF LIFE:**

The most common indication for palivizumab prophylaxis in the first year of life for children is for preterm infants born <29 weeks gestational age. It is also recommended for children born <32 weeks gestational age who required oxygen >21% for at least 28 days after birth. Other indications in the first year of life include hemodynamically significant heart disease and consideration for children with pulmonary abnormality or neuromuscular disease that impairs the ability to clear secretions.

**PALIVIZUMAB RECOMMENDATIONS IN THE SECOND YEAR OF LIFE:**

For children younger than 24 months, palivizumab prophylaxis is recommended for children who required at least 28 days of supplemental oxygen after birth and who continue to require medical intervention within 6 months of the start of the second

### Rotavirus Vaccine

Follow the routine schedule, but do not miss opportunities to administer the vaccine because it is usually not given during hospitalization. The first dose must be given between 6 weeks and 14 weeks 6 days of age, and all doses must be completed before 8 months of age.

Rotavirus vaccine is the other immunization that requires special consideration for preterm infants and other infants hospitalized in the neonatal period. The recommendations for rotavirus vaccine for preterm infants follow the standard recommendations. However, because it is a live vaccine that can be shed by the recipient in the stool after administration, it is not routinely administered during NICU hospitalizations in the United States because of concerns regarding nosocomial infections. Some NICUs administer the vaccine at hospital discharge.

In addition, rotavirus vaccine is unique among the routine vaccines in that it must be administered by a minimum age. The first dose of rotavirus vaccine must be administered before 15 weeks chronological age. Some premature infants are still hospitalized at this age and therefore miss the opportunity to have this vaccine. Others are discharged close to the maximum age for the first dose of 14 weeks 6 days and have a small window of opportunity to receive the vaccine. Administration of rotavirus vaccine should always be considered at the first outpatient visit after discharge. An infant can be given the first dose of rotavirus vaccine between the ages of 6 weeks and 14 weeks 6 days. All doses must be completed before the age of 8 months.
RSV season (supplemental oxygen, chronic corticosteroid, or diuretic therapy). It is also recommended for children who will be profoundly immunocompromised during the RSV season.

**GENERAL RECOMMENDATIONS FOR PALIVIZUMAB:**

Palivizumab may be administered up to 5 monthly doses during the RSV season. Infants born during the RSV season may require fewer doses. In addition, there may be special considerations for Alaska Native infants and American Indian populations. A complete list of recommendations is available at https://pediatrics.aappublications.org/content/pediatrics/134/2/415.full.pdf

All primary care practices should develop a system by which they keep a record of children who might qualify for palivizumab throughout the year. Designating an office champion may facilitate appropriate systems in an individual practice.
Preterm infants and children need more frequent hearing and ophthalmologic screenings and careful monitoring for neurodevelopmental and psychosocial issues.

One of the most important roles of the primary care provider in the care of preterm children is their continual monitoring and screening. It is well known that preterm children have increased risks in many domains, and it is important to establish and maintain an office structure that assures that routine and indicated screens are performed at appropriate intervals with timely referrals when needed.

**Neurodevelopmental Screening**

Follow Bright Futures guidelines for surveillance and screening. Provide early referrals as indicated.

Numerous studies have shown increased neurodevelopmental risks to preterm and low birth weight children. A meta-analysis of 30 studies that included 10,293 very preterm and very low birth weight children showed decreasing gestational age and birth weight resulted in higher prevalence of cognitive delays (16.9%), motor delays (20.6%), and cerebral palsy (6.8%). Another meta-analysis of 6,163 very preterm and 5,471 term children who were evaluated at ages 4 to 17 years showed that the preterm children scored lower in intelligence measures, executive functioning, and processing speed.

A recent meta-analysis confirmed an increased prevalence of autism spectrum disorder (7% in this study) in preterm children including late preterm children that was well above the prevalence in the general population (0.76%). It has also been shown that preterm children have an increased risk of having attention deficit hyperactivity disorder (ADHD), with the risk of ADHD increased by each declining week of gestational age, including affecting late preterm children.

The AAP recommends developmental surveillance at each preventive care visit in the areas of social language and self-help, verbal language, gross motor skills, and fine motor skills. Developmental screening with evidence-based tools is recommended at 9, 18, and 30 months of age. Autism screening with an autism-
specific tool is recommended at 18 months and 2 years. It is important to follow developmental milestones carefully in all preterm children and examine for abnormalities of tone and movement at each visit. Schedule interim visits as indicated and have a low threshold for referrals for any concerns. It is always important to involve parents and other family members in shared decisions regarding appropriate referrals. Common referrals for additional diagnostic evaluation for preterm children may include orthopedics, neurology, developmental and behavioral pediatrics, and high risk infant follow-up programs (available in some states). Developmental intervention and support often come from physical therapy, occupational therapy, speech and language therapy, and early intervention programs.

Early intervention programs are federally mandated programs that are available in all states and territories to provide services and supports for infants and toddlers with disabilities. These programs were enacted in 1986 under the Individuals with Disabilities Education Act and funded through grants to state governments from the federal government and other state funding sources. Services may be supported by private health insurance, are available free or at reduced cost for any eligible children, and may include speech therapy, physical therapy, and other types of services based on needs.

**Hearing Screening**

Provide screening by 1 month of age, diagnostic evaluation for failed screens by 3 months of age, and intervention for hearing loss by 6 months of age.

All infants admitted to the NICU for >5 days should have ABR screening prior to discharge and, if normal, audiology assessment by 30 months of age.

Infants with high-risk conditions such as meningitis, culture positive sepsis, CMV infection, ECMO requirement, and hyperbilirubinemia requiring exchange transfusion need more frequent screens. Always screen if there are concerns regarding hearing.

Children who were admitted to the NICU have a 2 to 4 percent risk for hearing loss, primarily due to sensorineural hearing loss (SNHL) and auditory neuropathy (AN). This is ten times the rate in the general newborn population (1-2/1000). Some of the risk factors associated with hearing loss are low birth weight, hyperbilirubinemia, hypoxia, ototoxic drugs (especially aminoglycosides), and infection (especially meningitis and CMV).

The AAP’s Early Hearing Detection and Intervention program (EHDI) 1-3-6 recommends hearing screening by 1 month, diagnosis of hearing loss by 3 months, and enrollment in intervention by 6 months. Early detection and intervention have been shown to be highly effective, and they increase vocabulary and help all children regardless of their level of hearing loss or other determining factors. Other studies have shown that amplification with hearing aids by 6 months of age was associated with better early language skills and that hearing loss detected prior to 9 months of age improved reading and communication skills and long-term reading comprehension skills through the teen years.

The 2007 AAP guidelines recommend the following screening:
1. All newborns (ABR or OAE)
2. NICU admissions for >5 days (ABR)
3. Readmissions in the first month of life for high-risk conditions including hyperbilirubinemia with exchange transfusion and culture positive sepsis
4. Referral to audiologist before 30 months for all NICU admissions >5 days. More frequent assessment may be indicated for high-risk conditions such as history of Cytomegalovirus (CMV) infection, meningitis, and history of using ECMO.
5. Close monitoring of language acquisition skills, auditory skills, and middle ear status
6. Refer sooner for hearing concerns or delayed language milestones

It is crucial for providers to understand the types of hearing examinations and the limits of the various exams in order to appropriately order hearing tests. Table 1 illustrates the types of tests that are used in children. Early referral to audiology is recommended for any child with concerns regarding hearing issues or speech and language delay.

**TABLE 1.** Types of Hearing Tests Used on Children

<table>
<thead>
<tr>
<th>TYPE OF TEST</th>
<th>WHAT IT TESTS</th>
<th>APPROXIMATE TYPICAL AGES</th>
<th>LIMITATIONS</th>
<th>USED FOR NEWBORN SCREENING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Auditory Brainstem Response</td>
<td>Measures brainstem activity in response to sounds</td>
<td>All ages</td>
<td>Requires sleeping or quiet baby or calm older child. May require sedation in children older than 3 to 6 months who cannot cooperate.</td>
<td>Yes</td>
</tr>
<tr>
<td>Otoacoustic Emissions</td>
<td>Measures response of inner ear hair cells to sound. Measures middle and inner ear function.</td>
<td>All ages</td>
<td>Does not test neural pathways and can miss hearing loss due to neural conduction disorders.</td>
<td>Yes</td>
</tr>
<tr>
<td>Visual reinforcement audiometry</td>
<td>Child’s behavioral responses to sounds</td>
<td>6 months to 2 years</td>
<td>Requires child’s cooperation. Requires ability to respond motorically.</td>
<td>No</td>
</tr>
<tr>
<td>Conditioned play audiometry</td>
<td>Ability to voluntarily respond to sounds</td>
<td>2 to 5 years</td>
<td>Requires cooperation. Requires ability to respond motorically.</td>
<td>No</td>
</tr>
<tr>
<td>Pure-tone audiometry</td>
<td>Ability to hear sounds and respond</td>
<td>5 and up</td>
<td>Requires cooperation. Requires ability to respond motorically.</td>
<td>No</td>
</tr>
</tbody>
</table>

**Ophthalmologic Screening**

Infants ≤ 1500 grams or gestational age ≤ 30 weeks and other high-risk infants should be screened at 31 weeks postmenstrual age and followed for retinopathy of prematurity (ROP) until the retinæ are mature. Repeat ophthalmologic exam is recommended 4 to 6 months after discharge from the NICU. Continue to screen all preterm children, including those who never had ROP, yearly because of the high risk of other ocular abnormalities.
Children born preterm are at high risk for retinopathy of prematurity (ROP) and other ocular abnormalities. Very preterm children are more affected (<32 weeks gestational age). There are higher rates of strabismus (5-25% in preterm children), higher rates of refractive errors, particularly myopia (3-20%), lower stereoacuity, and loss of peripheral vision. Therefore, while screening for retinopathy of prematurity is important in the newborn period, continued screening for ocular issues is also recommended for preterm children.

The American Academy of Pediatrics and the American Academy of Ophthalmology both recommend screening for ROP for all infants with a birth weight of ≤ 1500 grams or a gestational age of ≤ 30 weeks. Screening is also recommended for infants with birth weight between 1500-2000 grams or gestational age >30 weeks at high risk for ROP. Some high risk factors include hypotension requiring inotropic support, oxygen supplementation for more than a few days, and infants who received oxygen without saturation monitoring. An experienced ophthalmologist should perform the screening, and the initial screen is usually scheduled with regard to postmenstrual age. Exams are recommended at 31 weeks postmenstrual age for infants who were born at or less than 27 weeks gestational age. They are recommended at 4 weeks chronological age for infants who were 27 weeks gestational age or more at birth. Follow-up ophthalmologic visits are recommended every 1 to 3 weeks, depending on findings, until the retinae are mature. In addition, a repeat ophthalmologic examination is recommended 4 to 6 months after discharge from the NICU.

**Psychosocial Screening**

Screen at all preventive care visits and other visits as indicated. Provide early referrals.

Mothers of all infants are at risk for postpartum depression, and parents of preterm infants often experience additional stressors from traumatic experiences in the hospital as well as the additional stressors from care required for preterm infants. In addition, quality and quantity of parental sleep has been shown to be inadequate and may adversely affect psychosocial functioning. One study showed increased post-traumatic stress symptoms in mothers of preterm infants compared to mothers of term infants. While symptoms diminished over time, they remained higher in mothers of preterm infants and children. Providers should consistently monitor families for stressors and make early referrals to provide support for families in their practices.
Summary

The care of preterm infants and children can be complex and challenging. However, they are present in virtually all pediatric practices, and continued vigilance and organized systems of care are required to ensure that these infants and children receive the appropriate screening and special care necessary to optimize their health, development, and well-being.
# TIP SHEET

## Primary Care for Preterm Infants & Children

Recommendations and guidelines for providing care for preterm infants and children come from a variety of national organizations including the American Academy of Pediatrics (AAP), the Centers for Disease Control (CDC), and the Advisory Committee on Immunization Practices (ACIP). The Primary Care for Preterm Infants and Children Tip Sheet summarizes key recommendations from the associated toolkit to support primary care pediatric providers as they care for preterm infants and children.

### NUTRITION:

Monitor growth carefully using adjusted age on appropriate growth charts. Always support breastfeeding. Supplement with post-discharge formulas when indicated. Do not overfeed.

<table>
<thead>
<tr>
<th>Monitoring growth</th>
<th>Use corrected age (adjusted for prematurity) until at least 2 years of age.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• WHO growth chart until 2 years</td>
</tr>
<tr>
<td></td>
<td>• CDC growth chart for children 2-20 years</td>
</tr>
</tbody>
</table>

| Breastfeeding     | Always promote breastfeeding.                                            |

<table>
<thead>
<tr>
<th>Post-discharge formulas</th>
<th>Length of use of post-discharge formulas (usually EnfaCare® or NeoSure®) is controversial without standard recommendations but should not replace breast milk in an adequately growing infant. Informal suggestions for formula-fed infants:</th>
</tr>
</thead>
<tbody>
<tr>
<td>BW &gt;1800 grams</td>
<td>• may not be necessary</td>
</tr>
<tr>
<td>BW 1501-1800 grams</td>
<td>• up to 3 months</td>
</tr>
<tr>
<td>BW 1001-1500 grams</td>
<td>• up to 6 months</td>
</tr>
<tr>
<td>BW 751-1000 grams</td>
<td>• up to 9 months</td>
</tr>
<tr>
<td>BW &lt;750 grams</td>
<td>• up to 12 months</td>
</tr>
</tbody>
</table>

Caloric density of formulas will depend on weight gain in the NICU and other medical issues. Monitor growth carefully and do not overfeed infants who are gaining weight very rapidly.

| Reflux | Reflux is almost universal in preterm infants and in most cases treatment with positioning or pharmacological agents is not indicated and may cause harm. |

<table>
<thead>
<tr>
<th>Vitamin supplementation</th>
<th>VITAMIN D: Almost all infants need Vitamin D supplementation.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• 400 IU per day recommended &lt;1 year old</td>
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<tr>
<td></td>
<td>• Formulas in US contain at least 400 IU per liter</td>
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<td></td>
<td>• Supplement breastfeeding infants and all infants taking less than 1 liter of formula per day</td>
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</tbody>
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<tr>
<th>Iron: Almost all preterm infants should receive iron supplementation. They are iron deficient unless they received blood transfusions.</th>
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<tbody>
<tr>
<td>• Maintenance dose 2-3 mg/kg/day for 6 to 12 months (until dietary intake is sufficient)</td>
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<tr>
<td>• Treatment dose 4-6 mg/kg/day if anemic</td>
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</tbody>
</table>
## IMMUNIZATIONS:
Follow standard recommendations by chronological age except for special recommendations for Hepatitis B Vaccine and Rotavirus Vaccine.

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Details</th>
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<tbody>
<tr>
<td><strong>Hepatitis B vaccine</strong></td>
<td>Hepatitis B vaccine is the only routine childhood vaccine that has been shown to produce insufficient immunogenicity in preterm and low birth weight babies. A dose received by an infant &lt;2000 grams AND &lt;1 month of age does not count towards the primary series.</td>
</tr>
<tr>
<td><strong>Rotavirus vaccine</strong></td>
<td>Infants generally do not receive rotavirus vaccine in the NICU (though a few NICUs administer it at discharge). The first dose of Rotavirus Vaccine must be administered by age 14 weeks 6 days. If not previously given, consider administering at the first outpatient visit for infants 6 weeks to 14 weeks 6 days.</td>
</tr>
</tbody>
</table>
| **Palivizumab (Synagis®)** | *Do not miss the opportunity to protect vulnerable children from Respiratory Syncytial Virus infections.*  
Consider for patients in the following categories:  
- Infants < 12 months at start of RSV season if less than 29 weeks GA at birth or less than 32 week GA and O2 requirement for at least 28 days  
- Infants < 12 months with hemodynamically significant heart disease (may consult with cardiologist) or with pulmonary abnormality or neuromuscular disease that impairs the ability to clear secretions  
- Children < 24 months at the start of RSV season with chronic lung disease on medical therapy (oxygen, chronic corticosteroid, or diuretic therapy) within 6 months of start of RSV season  
- Complete recommendations: https://pediatrics.aappublications.org/content/134/2/415.full |

## SCREENING:
Preterm infants and children need more frequent hearing and ophthalmologic screenings and careful monitoring for neurodevelopmental and psychosocial issues.

<table>
<thead>
<tr>
<th>Screening</th>
<th>Details</th>
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</table>
| **Neurodevelopmental screening** | *Surveillance at every WCC visit*  
*Evidence based tools at 9, 18, 30 months*  
*Autism spectrum disorder screening tool at 18 months and 2 years* |
| **Hearing screening**      | *ABR screening (such as ALGO) prior to discharge*  
*If inpatient screen was not passed, repeat outpatient screening as quickly as possible and by one month of age. Identify any hearing deficit using ABR by 3 months of age. Begin intervention by 6 months of age.*  
*If inpatient screen was normal, repeat hearing screening by 30 months. Screen earlier for high-risk conditions, such as history of CMV infection, meningitis, ECMO, and hyperbilirubinemia requiring exchange transfusion.*  
*Audiology referral advised at any time for concerns or language delays* |
| **Ophthalmologic screening** | *Monitor for retinopathy of prematurity (ROP) until mature retinae for birth weight ≤1500 g or GA ≤30 weeks or selected infants either 1500-2000 g or GA >30 weeks*  
*For all, follow-up ophthalmologic exam 4-6 months after NICU discharge and yearly* |
| **Psychosocial screening** | *At every WCC and other visits as feasible* |
PERIODICITY CHART

Primary Care for Preterm Infants & Children

<table>
<thead>
<tr>
<th>Post-discharge visit</th>
<th>1 mo</th>
<th>2 mo</th>
<th>4 mo</th>
<th>6 mo</th>
<th>9 mo</th>
<th>12 mo</th>
<th>15 mo</th>
<th>18 mo</th>
<th>2 yr</th>
<th>2½ yr</th>
<th>3 yr</th>
<th>4 yr</th>
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<tr>
<td>Monitoring growth/growth charts</td>
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Immunizations: Follow standard recommendations by chronological age except for special recommendations for Hepatitis B Vaccine and Rotavirus Vaccine.

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Screening: Preterm infants and children need more frequent hearing and ophthalmologic screenings and careful monitoring for neurodevelopmental and psychosocial issues.

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Nutrition

- **GC: Monitoring growth/Growth charts** - Use WHO growth chart until 2 years. Use corrected age until at least 2 years. Use CDC growth chart for children 2-20 years.

- **PF: Post-discharge formula** - Length of use of post-discharge formulas (usually EnfaCare® or NeoSure®) is controversial without standard recommendations but should not replace breastfeeding in an adequately growing infant. These are some informal suggestions if using a post-discharge formula: BW >1800 grams – may not be necessary; BW 1501-1800 grams – up to 3 months; BW 1001-1500 grams - up to 6 months; BW 751-1000 grams - up to 9 months; BW <750 grams - up to 12 months. Caloric density of formula will depend on weight gain in the NICU and other medical issues. Always support breastfeeding. Do not overfeed.

- **D: Vitamin D** - Almost all infants need Vitamin D supplementation. 400 IU per day recommended < 1 year old. Formulas in US contain at least 400 IU per liter. Supplement all breastfeeding infants and all infants taking less than 1 liter of formula per day.

- **IS: Iron supplementation** - Almost all preterm infants should receive iron supplementation. Supplement with 2-3 mg/kg/day for 6 to 12 months (until dietary intake is sufficient); 4-6 mg/kg/day if anemic. Almost all preterm infants are iron deficient unless they received blood transfusions.
Immunizations

- **H: Hepatitis B vaccine** - Hepatitis B vaccine is the only routine childhood vaccine that has been shown to produce insufficient immunogenicity in preterm and low birth weight infants. A dose received by an infant <2000 grams AND <1 month of age does not count towards the primary series. There are special considerations for infants <2000 grams.

  - **Mother is HBsAg-negative:** 1 dose within 24 hours of birth for all medically stable infants ≥2000 grams. Infants <2000 grams: administer 1 dose at chronological age 1 month or hospital discharge. A dose received by an infant <2000 grams AND <1 month of age does not count towards the primary series.
  
  - **Mother is HBsAg-positive:**
    - Administer Hepatitis B vaccine and 0.5 mL of Hepatitis B immune globulin (HBIG) within 12 hours of birth, regardless of birth weight. For infants <2000 grams, administer 3 additional doses of vaccine (total of 4 doses) beginning at age 1 month.
    - Test for HBsAg and anti-HBs at age 9-12 months. If Hepatitis B vaccine series is delayed, test 1~2 months after final dose.
  
  - **Mother’s HBsAg status is unknown:**
    - Administer Hepatitis B vaccine within 12 hours of birth, regardless of birth weight.
    - For infants <2000 grams, administer 0.5 mL of HBIG in addition to Hepatitis B vaccine within 12 hours of birth. Administer 3 additional doses of vaccine (total of 4 doses) beginning at age 1 month.
    - Determine mother’s HBsAg status as soon as possible. If mother is HBsAg-positive, administer 0.5 mL of HBIG to infants ≥2000 grams as soon as possible, but no later than 7 days of age.

- **R: Rotavirus vaccine** - Infants usually do not receive rotavirus vaccine in the NICU. The first dose of rotavirus must be administered by age 14 weeks 6 days. Consider administering at the first outpatient visit for infants age 6 weeks to 14 weeks 6 days. All doses must be completed before the age of 8 months.

  **For complete recommendations:** [https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html](https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html)

- **P: Palivizumab (Synagis®)** - Do not miss the opportunity to protect vulnerable children from Respiratory Syncytial Virus infections. Consider for infants < 12 months at start of RSV season if less than 29 weeks GA at birth or less than 32 weeks GA and O2 requirement for at least 28 days. Also consider for children with hemodynamically significant heart disease or with pulmonary abnormality or neuromuscular disease that impairs the ability to clear secretions. Consider for children < 24 months at the start of RSV season with chronic lung disease on medical therapy (oxygen, chronic corticosteroid, or diuretic therapy) within 6 months of the start of RSV season. **For complete recommendations:** [https://pediatrics.aappublications.org/content/134/2/415.full](https://pediatrics.aappublications.org/content/134/2/415.full)

Screening

- **DS: Developmental surveillance** - Perform at every well child check (WCC) health maintenance visit and at other visits as feasible.

- **DSc: Developmental screening** - Perform with an evidence-based tool at 9, 18, and 30 month WCC visits.

- **ASD: Autism Screening**: Use autism spectrum disorder screening tool at 18 months and 2 years.

- **HS: Hearing screening** - ABR screening (such as ALGO) is performed prior to discharge. If initial screen was not passed, repeat outpatient screening is indicated as quickly as possible and by one month of age. Identify any hearing deficit using ABR by 3 months of age. Begin intervention by 6 months of age.

- **HS2: Hearing screening after newborn period** - If newborn hearing screen normal, repeat hearing screen for children hospitalized in NICU > 5 days by 30 months of age. Screen earlier for high-risk conditions such as history of CMV infection, meningitis, ECMO, and hyperbilirubinemia requiring exchange transfusion. Refer at any time for concerns or language delays. In addition, follow Bright Futures guidelines.

- **OS: Ophthalmologic screening** - Monitor for ROP until mature retinae for GA<30 weeks or <1500 g or selected infants 1500-2000 g or GA >30 weeks. For all, follow up at 4-6 months after ophthalmological care discharge and yearly.

- **PS: Psychosocial screening** - Perform at every WCC and at other visits as feasible.
References


40. Lipkin PH, Okamoto J, the COUNCIL ON CHILDREN WITH DISABILITIES and COUNCIL ON SCHOOL HEALTH. The Individuals With Disabilities Education Act (IDEA) for Children With Special Educational Needs. PEDIATRICS. 2015;136(6):e1650-e1662. doi:10.1542/peds.2015-3409


