Primary Care Challenges for Preterm Infants & Children

Harvard-MGH Primary Care Pediatrics
December 4, 2024

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california perinatal
quality care collaborative

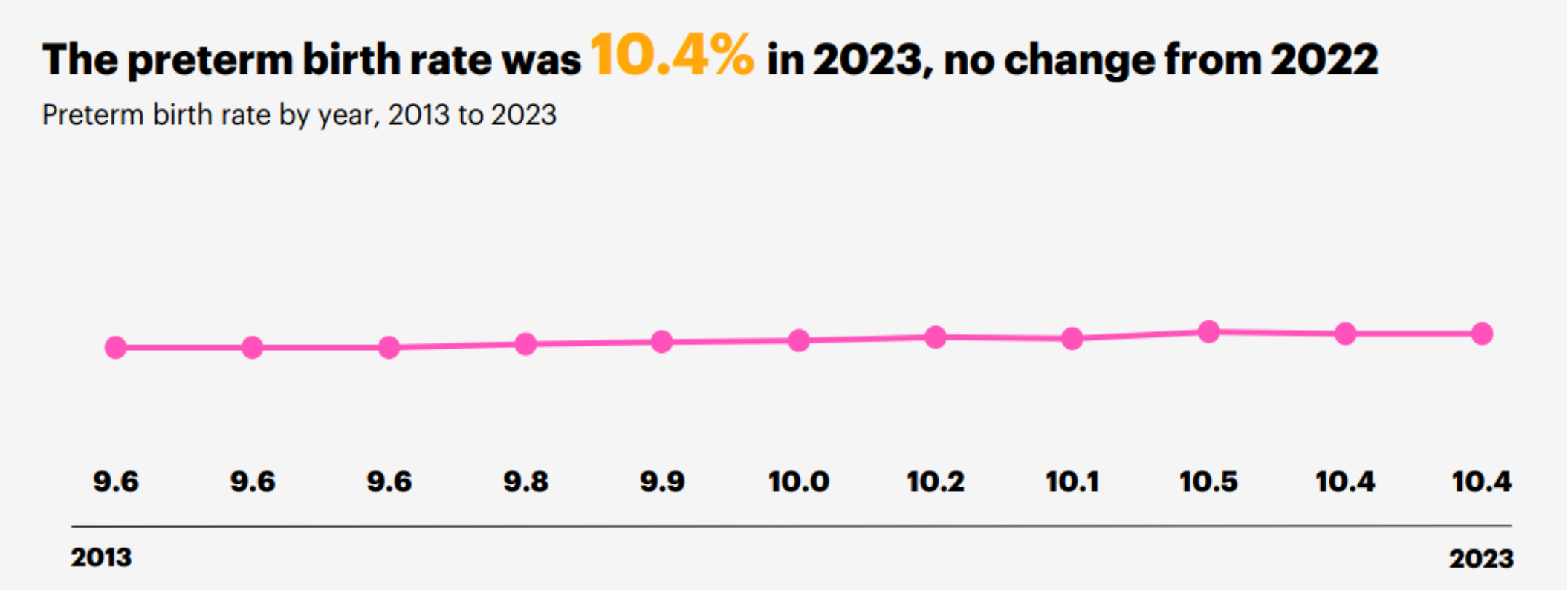
Disclosures

- No financial affiliation or conflicts of interest with the material in this presentation

Learning points

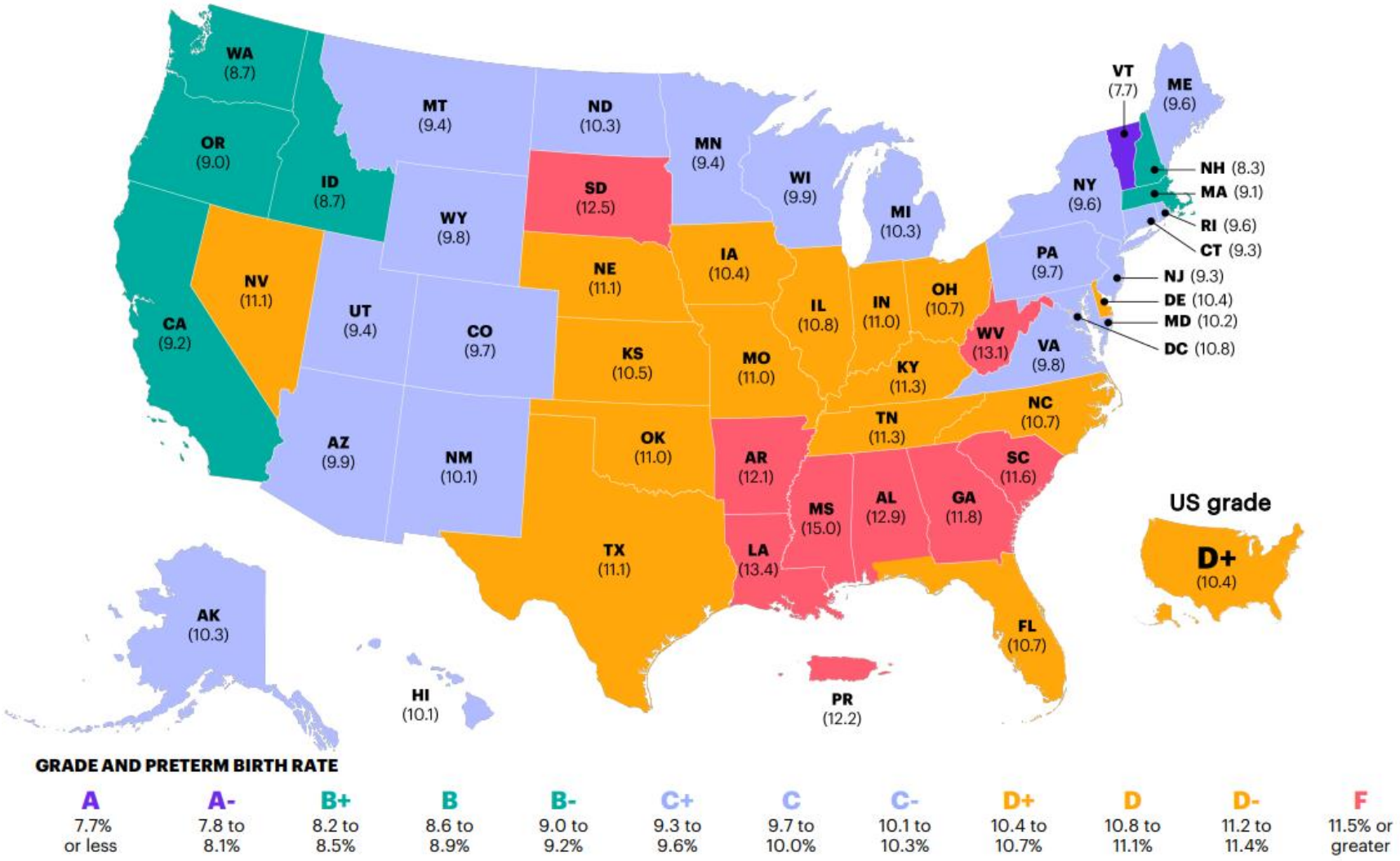
- Preterm infant care involves critical components in the transition from NICU discharge to primary care
- Preterm infants may require nutritional supplements
- Preterm infants and children require careful developmental screening and additional screening by ophthalmology and audiology

US preterm birth rate 10.4% for 2023



Data from National Center for Health Statistics (NCHS)
https://www.marchofdimes.org/sites/default/files/2024-11/US_Report_Card_2024_English.pdf

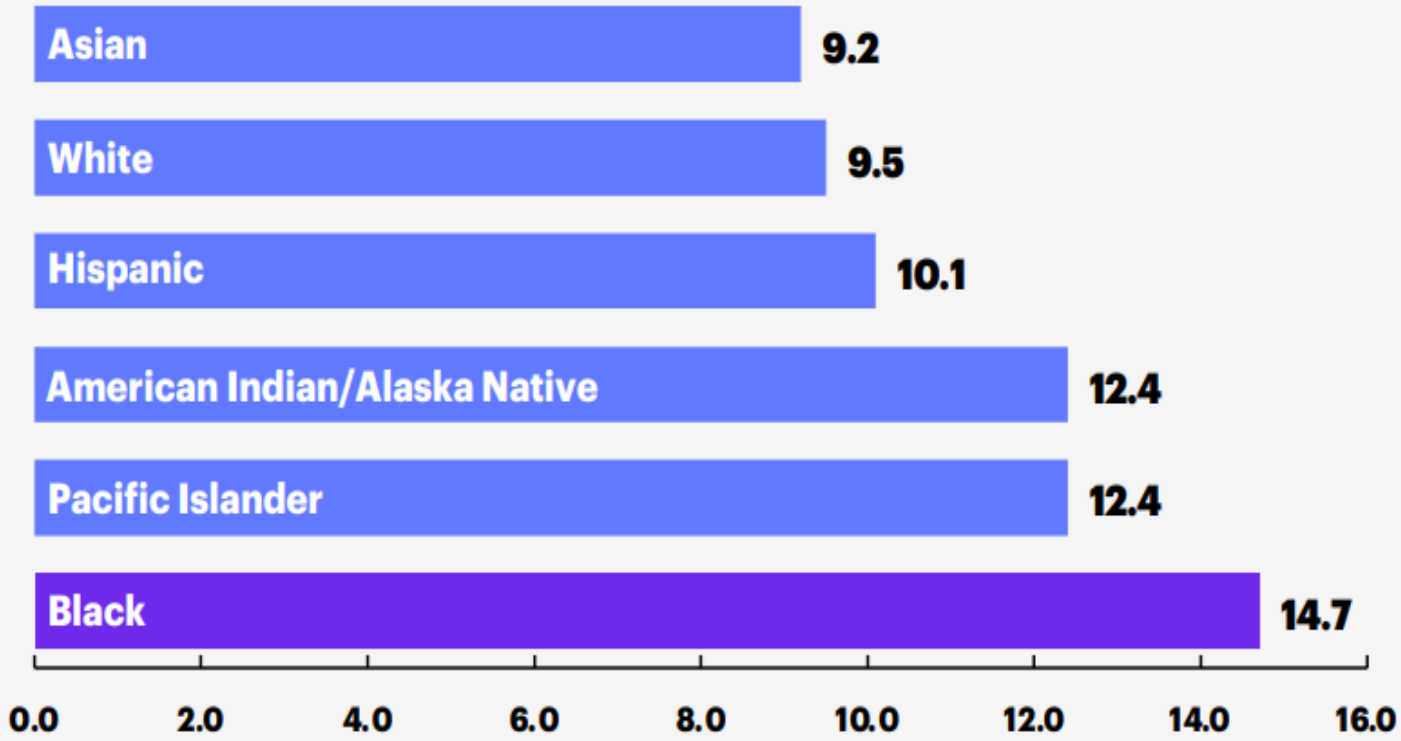
Preterm birth rate and grade by state, 2023



https://www.marchofdimes.org/sites/default/files/2024-11/US_Report_Card_2024_English.pdf

In the US, the preterm birth rate among babies born to Black birthing people is 1.4x higher than the rate among all other babies

Preterm birth rate by race/ethnicity, 2021-2023



DISPARITY RATIO 1.29

This data is intended to highlight disparities in outcomes related to race/ethnicity and should serve as a starting point for discussion about addressing systemic racism and inequality.

Note: The disparity ratio is a summary measure of the gap between the racial/ethnic group with the lowest rate of preterm birth compared to all others. A value closer to 1 is most desirable, with 1 indicating no disparity.

https://www.marchofdimes.org/sites/default/files/2024-11/US_Report_Card_2024_English.pdf

Taking care of preterm infants and children is a moving target

- Recommendations vary by gestational age
- Specific recommendations are continually updated
- Recommendations come from a variety of different organizations

Case 1

Amelia is an ex-28 week female (birth weight 900 g) who had good weight gain in the NICU with breast milk and 3 feeds/day of 24 cal/oz formula. At her 4 month well visit, her PCP notices she is gaining weight rapidly and crossing percentiles on her growth curve for weight. What should the PCP do?

A. Continue the same feeding regimen because preterm infants need nutrition supplementation
B. Switch feeding regimen to exclusive breast milk
C. Decrease the frequency and/or calories of the formula feeds

Growth and Nutrition

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WHO and CDC growth charts

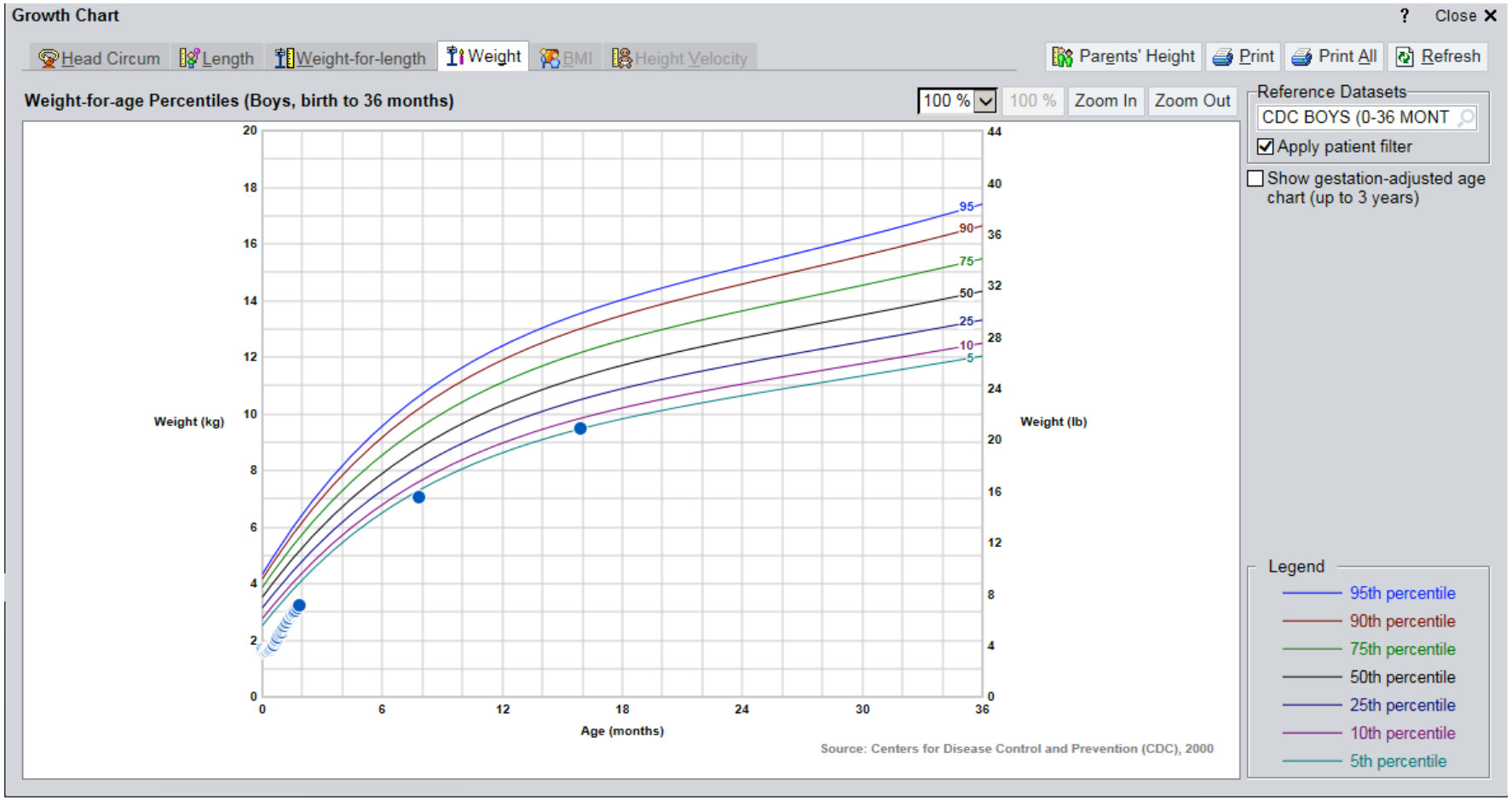
- WHO growth chart
  - Recommended for infants and children 0 to 2 years
  - Based on breastfed infants and children in 6 different countries

- CDC growth chart
  - Recommended for children 2 years and older in the United States
  - Based on National Health and Nutrition Examination Survey (NHANES) data

Plotting growth - example

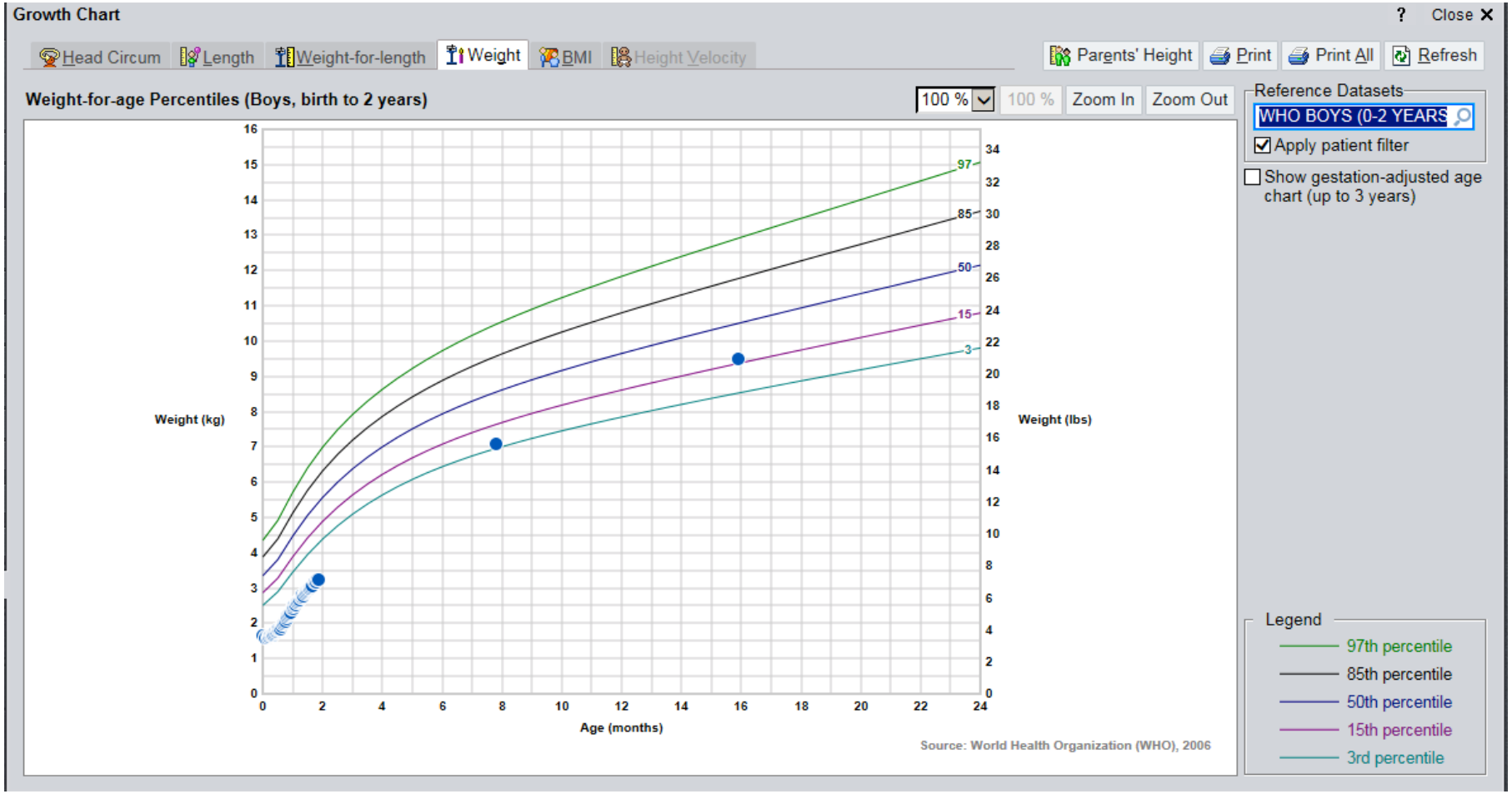
- 16 month old male
- 31+2 weeks gestational age
- Current weight 9.5 kg

CDC growth chart - boys



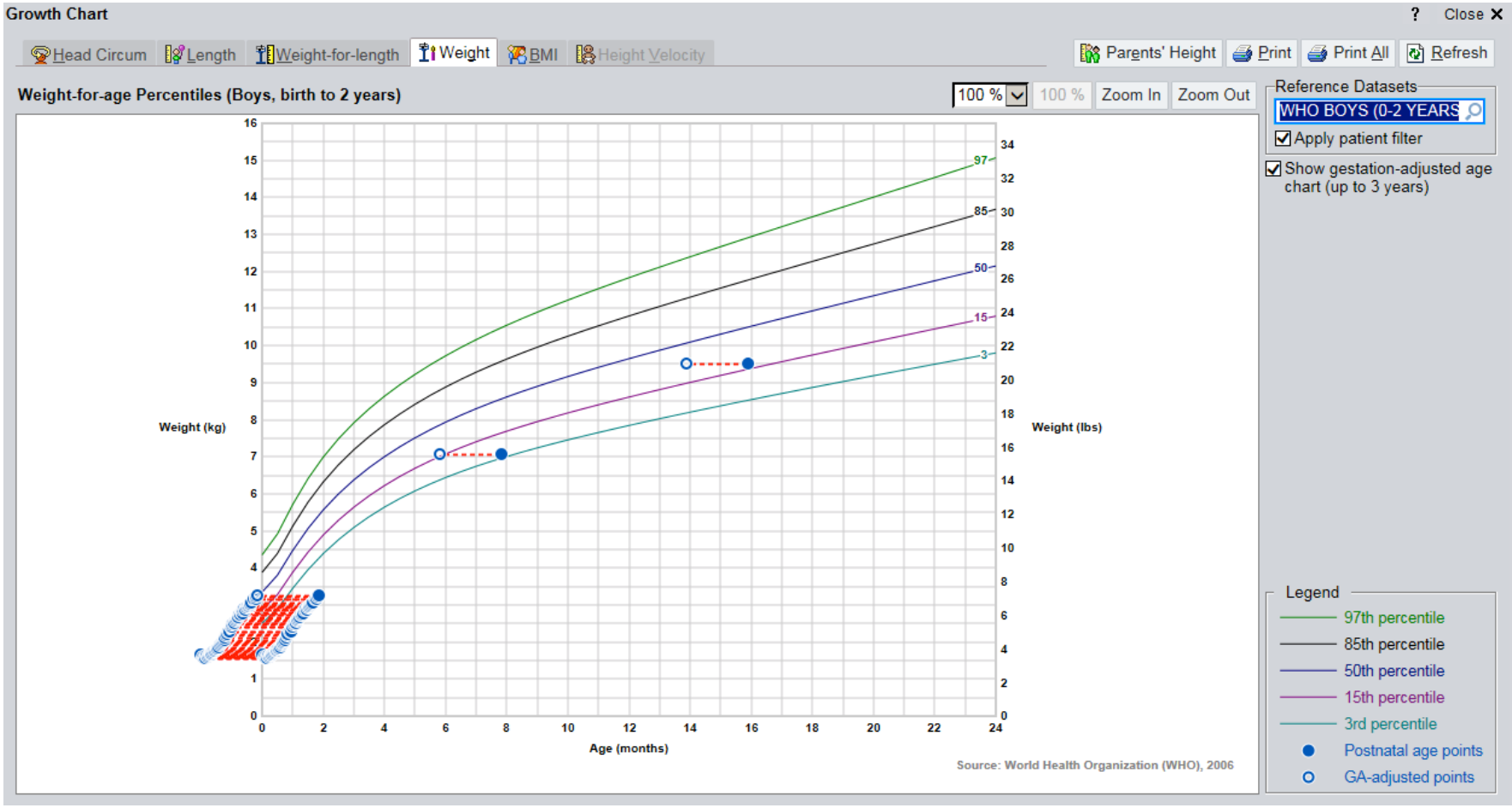
Weight 9.5 kg = 5%

WHO growth chart - boys



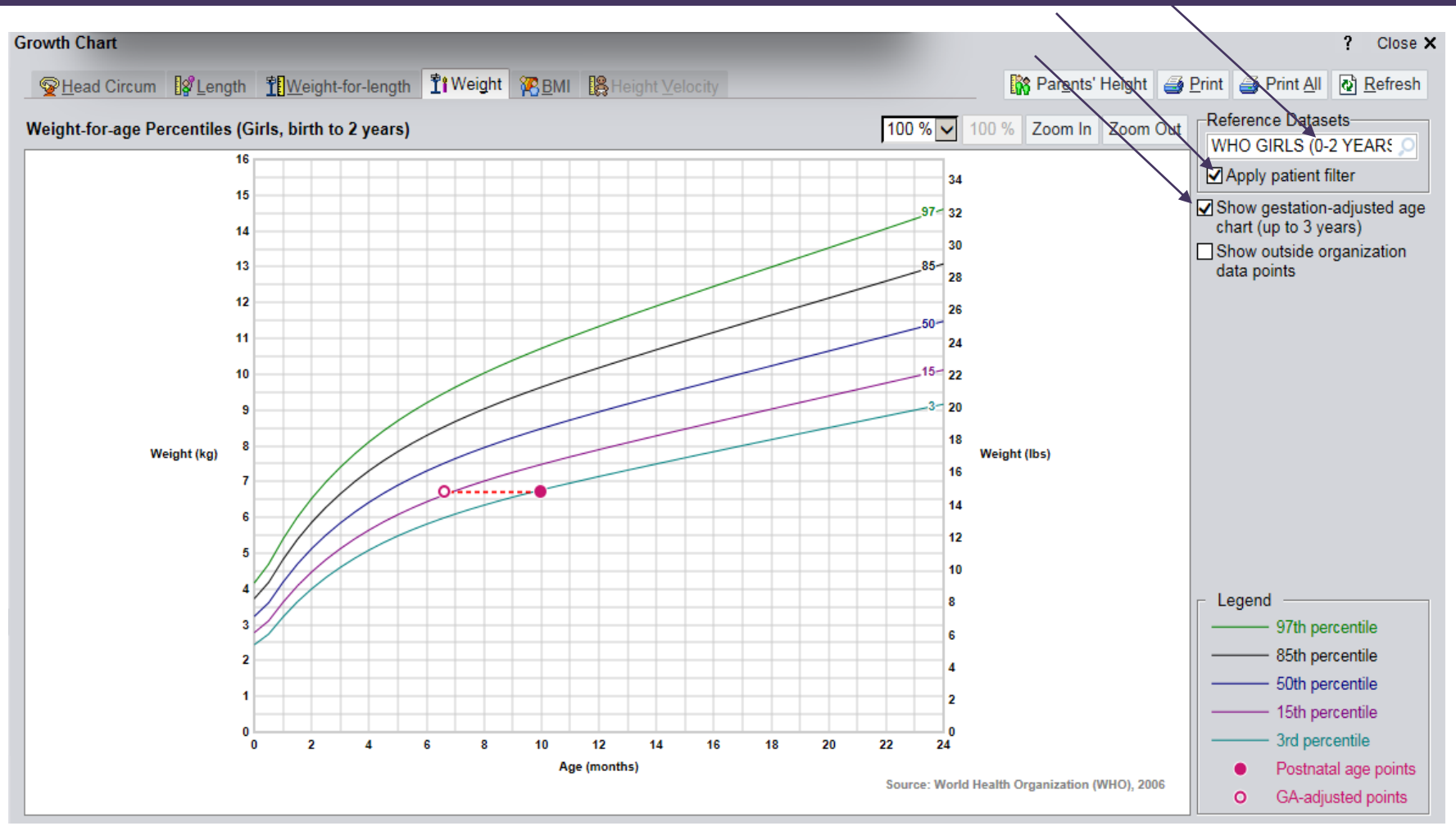
Weight 9.5 kg = 18%

WHO growth chart with corrected age



- 31+2 weeks gestational age
- Weight 9.5 kg = 18% chronological age (15 months 27 days)
- Weight 9.5 kg = 30% corrected age (13 months 27 days)

Weight for corrected age - Epic



- 25+3 week GA girl: 9 mos 29 days chronological age, 6 months 17 days corrected age
- Weight 6.73 kg = 3% chronological age, 18% corrected age

Preterm infants are at risk for growth failure after discharge

Goals post-discharge:

- Prioritize breastfeeding and breast milk
- Normal rate of growth for corrected age
- Proportional gain in weight and length
- Avoid overfeeding

Why should post-discharge formulas be used?

- Post-discharge formula (EnfaCare®, NeoSure®) is intended for preterm infants
- Supplies more calories, protein, vitamins, and minerals (calcium/phosphorus) than standard formula
- Sustain growth pattern achieved in hospital
- Improves brain growth

Safety of post-discharge formulas

AAP News™

FDA, CDC, NIH: Evidence points to lack of human milk, not specialty formulas, as increasing risk of NEC

October 9, 2024

https://publications.aap.org/aapnews/news/30429/FDA-CDC-NIH-Evidence-points-to-lack-of-human-milk

Safety of post-discharge formulas

- FDA, CDC, NIH consensus statement October, 2024
- Preterm infants have complex nutritional needs for growth and development
- No conclusive evidence that preterm infant formulas cause necrotizing enterocolitis (NEC)
- Strong evidence that human milk is protective against NEC

https://www.hhs.gov/about/news/2024/10/03/fda-cdc-nih-consensus-statement-recent-advisory-council-report-premature-infants-necrotizing-enterocolitis.html

Who needs post-discharge formula supplementation to breast milk?

- Infants who need catch-up growth
- VLBW infants at highest risk
- Supplementation recommendations vary
  - Differ by geographic area and institution
  - Continual evolution as NICU nutrition knowledge improves

Approaches to using post-discharge formula (PDF)

- Substitute PDF for breast milk 2 to 3 feedings/day
- Fortification of breast milk with PDF (EnfaCare® or NeoSure® powder) for 2 to 3 feedings per day
- Adjust PDF concentration (22 or 24 cal/oz) and frequency based on growth trajectory

Mixing post-discharge formula examples

PDF formula alone

Concentration	Water volume	Scoops PDF powder (22cal/oz)	Approx final volume
22 cal/oz	2 oz (60 ml)	1	2.2 oz (66 ml)
24 cal/oz	1.8 oz (53 ml)	1	2 oz (60 ml)
26 cal/oz	1.6 oz (48 ml)	1	1.9 oz (56 ml)

Breast milk fortification

Concentration	Breast milk volume	Scoops PDF powder (22cal/oz)	
22 cal/oz	3 oz	0.5 tsp	
24 cal/oz	3 oz	1.25 tsp	
26 cal/oz	2 oz	1.25 tsp	

https://hcp.meadjohnson.com/file-asset/hcpm_res_enfamil_neuropro_enfacare
https://www.childrensmn.org/references/pfs/nutr/breast-milk-fortified-(using-20-cal-oz-standard-formula).pdf

How long to use post-discharge formula?

- Suggested guidelines:
  - BW>1800 grams: Probably not necessary
  - BW 1501-1800 grams: Up to 3 months chronologic age
  - BW 1001-1500 grams: Up to 6 months chronologic age
  - BW 751-1000 grams: Up to 9 months chronologic age
  - BW <750 grams: Up to 12 months chronologic age

Monitor growth closely

- Provide follow up within 72 hours after discharge from the NICU
- Recheck every two weeks initially until stable weight gain is established
- Follow closely while on post-discharge formula to monitor for adequate weight gain as well as too rapid weight gain
- Use clinical judgment

Iron supplementation

- Give maintenance iron supplement (2 mg/kg/day) through at least the first 6 months (some recommend 12 months)
- Reasons for iron supplementation
  - Preterm iron deficit
    - Missed maternal iron transfer in 3rd trimester
    - Iatrogenic lab draws
  - Improves developmental outcome

Rao, Raghavendra, and Michael K. Georgieff. “Iron Therapy for Preterm Infants.” Clinics in Perinatology, vol. 36, no. 1, Mar. 2009, pp. 27–42. Crossref, doi:10.1016/j.clp.2008.09.013.

Iron supplementation

- Consider monitoring labs
  - Refer to NICU discharge summary
  - Can obtain hemoglobin 4-6 weeks after discharge
  - Ferritin <35 can indicate iron deficiency
- Treat with therapeutic dose of iron (4-6 mg/kg/day) for anemia

Rao, Raghavendra, and Michael K. Georgieff. “Iron Therapy for Preterm Infants.” Clinics in Perinatology, vol. 36, no. 1, Mar. 2009, pp. 27–42. Crossref, doi:10.1016/j.clp.2008.09.013.

Case 2

Callie is an ex-32 week female (birth weight 1.5 kg) who is 5 weeks old and was just discharged from the NICU (discharge weight 1.8 kg) in Nov. Her mother reports Callie only received the Hepatitis B vaccine in the NICU and asks if she needs other immunizations? What do you recommend?

A. No vaccines until 2 months age
B. Give RSV protection
C. Give RSV protection and Hepatitis B vaccine
D. Give RSV protection, Hepatitis B vaccine, and Rotavirus vaccine

Immunizations

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Lower immunization rates in preterm infants

- Preterm infants had lower immunization rates than term infants (7-vaccine series)
- Differences persisted through 36 months
- Possible influences:
  - parental decisions
  - provider decisions
  - provider knowledge
  - more frequent illness

Hofstetter, Annika M., et al. “Early Childhood Vaccination Status of Preterm Infants.” Pediatrics, vol. 144, no. 3, Sept. 2019,

Hepatitis B vaccine

- The only vaccine for which data clearly indicate a lower response in preterm infants
- If given at <2000 grams and prior to 1 month age, cannot be counted as part of the primary series

Hepatitis B vaccine

Birthing person is HBsAg-negative:

- ≥2,000 grams: 1 dose within 24 hours of birth
- <2,000 grams: 1 dose at chronological age 1 month or hospital discharge

Birthing person is HBsAg-positive

- Give Hep B vaccine and 0.5 mL of HBIG (at separate anatomic sites) within 12 hours of birth regardless of birth weight

Birthing person's HBsAg status is unknown:

- Give Hep B vaccine within 12 hours of birth, regardless of birth weight
- <2,000 grams, give 0.5 mL of HBIG in addition to Hep B vaccine within 12 hours of birth

Rotavirus vaccine

- Do not start the series on or after age 15 weeks, 0 days
- Not given during most NICU admissions in the United States (a few give on discharge)
- Studies showed missed opportunities to start Rotavirus right after NICU discharge*
- Always think of Rotavirus vaccine at the first visit after NICU discharge

*Sederdahl, Bethany K., et al. “Missed Opportunities for Rotavirus Vaccination.” Pediatrics, vol. 143, no. 5, May 2019

RSV Protection

- Nirsevimab
- Palivizumab
- RSV vaccine for pregnant persons

Nirsevimab introduced August 2023

American Academy of Pediatrics

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News Release

American Academy of Pediatrics Recommends Medication to Prevent RSV Be Given to All Infants and Urges Equitable Access

8/15/2023
https://www.aap.org/en/news-room/news-releases/aap/2023/american-academy-of-pediatrics-recommends-medication-to-prevent-rsv-be-given-to-all-infants-and-urges-equitable-access/?_ga=2.14945589.2088326648.1692571927-312262833.1594132999

Nirsevimab guidelines

- Long-acting monoclonal antibody to protect against RSV in newborns
- AAP recommends use in:
  - All infants age < 8 months born during or entering 1st RSV season
  - Infants/children age 8-19 months at increased risk and entering 2nd RSV season
- Increased risk includes chronic lung disease of prematurity, immunocompromised, cystic fibrosis with severe lung disease or weight/length < 10%ile, and American Indian and Alaska Native children

https://publications.aap.org/redbook/resources/25379?utm_source=MagnetMail

Nirsevimab guidelines

- Administer October through March
- Adjust season using regional guidance based on local RSV activity
- Give Nirsevimab in 1st week of life or just prior to start of RSV season
- If prolonged birth hospitalization, give just before or after discharge
- If Nirsevimab administered, do not give Palivizumab
- If Palivizumab course started, give 1 dose Nirsevimab
- Give Palivizumab if Nirsevimab unavailable

https://publications.aap.org/redbook/resources/25379?utm_source=MagnetMail

Palivizumab guidelines – November 2022

- RSV activity in the US is variable by region
- AAP supports use of Palivizumab for eligible infants in any season if a region experiences typical fall-winter season RSV activity
- Standard administration of 5 consecutive monthly doses provides 6 months protection
- Consider more than 5 consecutive doses depending on duration of RSV surge in a given region

https://www.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/interim-guidance-for-use-of-palivizumab-prophylaxis-to-prevent-hospitalization/

Palivizumab indications

- First year of age
  - Born < 29 weeks GA
  - Born < 32 weeks GA and O2 requirement ≥28 days after birth
  - May give for hemodynamically significant heart disease, pulmonary abnormality, or neuromuscular disease that impairs ability to clear secretions
- Second year of age
  - Required ≥ 28 days O2 after birth and medical intervention within 6 months of start of second RSV season
  - Consider for profoundly immunocompromised

RSV vaccine for pregnant persons

- Recombinant bivalent RSV preF vaccine for pregnant persons 32-36 weeks gestation
- Protects infants up to 6 mos age
- Administration September-January or based on regional seasonality
- Additional doses not recommended in future pregnancies
- Nirsevimab not indicated unless birthing person received vaccine < 14 days before birth, during a prior pregnancy, or has immune or antibody response issues

https://www.cdc.gov/rsv/hcp/vaccine-clinical-guidance/pregnant-people.html

Summary: preterm immunizations

- Remember Hepatitis B vaccine exceptions to the usual immunization schedule
- Do not miss the opportunity to give Rotavirus vaccine at or after NICU discharge
- Keep a year-round list of children who need RSV protection
- Be alert for changes in RSV protection recommendations due to new products, available supply, and atypical seasonal patterns of RSV

Case 3

Mary was born at 30 weeks gestational age and weighed 1400 grams at birth. She is now 9 months old. Her parents have sent you a message that they are concerned because she is not yet sitting. She started rolling over when she was three months old and likes to stand but does not like to sit. How do you respond?

A. Reassure parents that this is normal and she will learn to sit soon
B. Ask parents to bring her in for an appointment
C. Refer her to neurology

Screening

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Cerebral Palsy history concerns

- Early rolling
- Thumb in fist after 7 months
- Inability to sit by 9 months
- Milestones “out of order”
- Asymmetric creeping or crawling
- Inability to walk by 18 months
- Persistent toe walking

Noritz, Garey, et al. “Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy.” Pediatrics, vol. 150, no. 6, Dec. 2022, p. e2022060055. DOI.org (Crossref), https://doi.org/10.1542/peds.2022-060055.

Cerebral Palsy physical exam concerns

- Hypertonia
- Hypotonia
- Scissoring of the legs
- Asymmetric strength or reflexes
- Persistent primitive reflexes
- Ankle clonus associated with other abnormalities
- Abnormal movements, postures

Noritz, Garey, et al. “Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy.” Pediatrics, vol. 150, no. 6, Dec. 2022, p. e2022060055. DOI.org (Crossref), https://doi.org/10.1542/peds.2022-060055.

Altered muscle tone – hypotonic infant

Photo by Janelle Aby, MD
https://med.stanford.edu/newborns

Altered muscle tone – scissoring and muscle spasticity

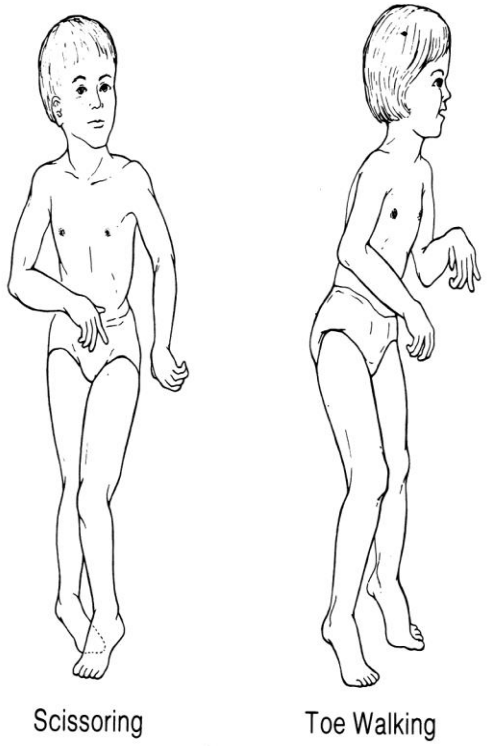


Figure 24.11. Scissoring results from increased tone in the muscles on the inner aspect of the thigh that tend to pull the legs together and turn the legs inward. Toe walking is due to tightness of the calf muscles and Achilles tendon and increased extensor tone in the legs.

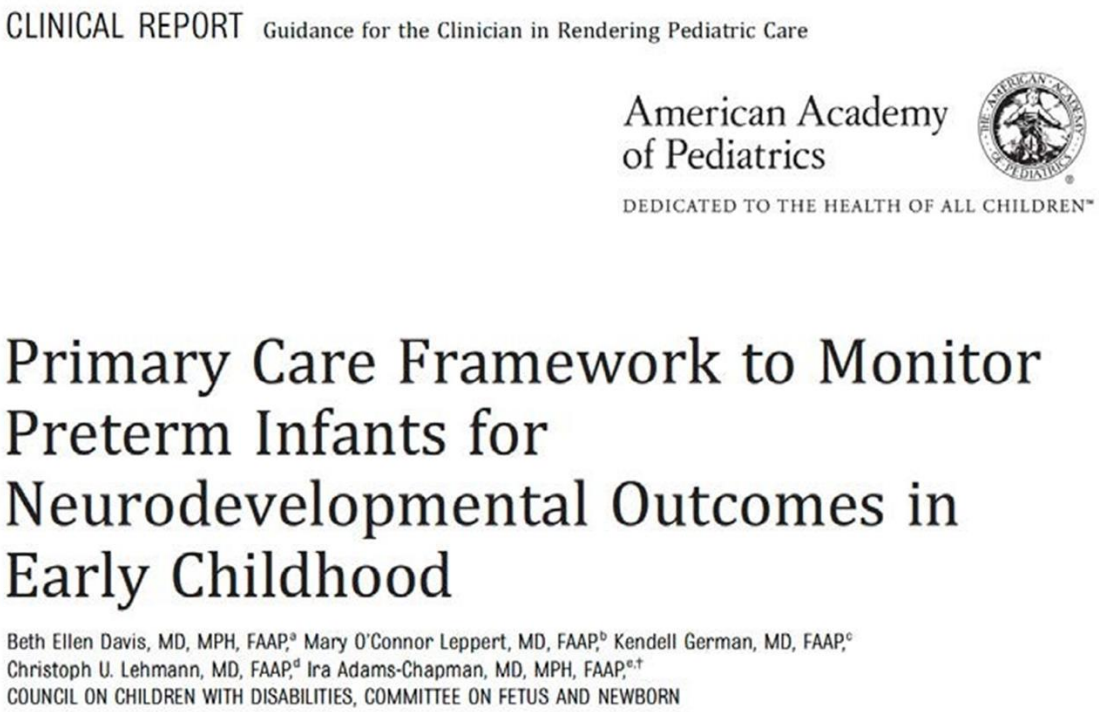
Cerebral Palsy risk factors

- Prevalence of cerebral palsy in the United States is approximately 3.1 per 1000 children
- Multiple studies show increased rates in children born preterm
- One study showed prevalence approximately 50 times greater in children with birth weight <1000 grams

CDC. Data and Statistics for Cerebral Palsy | CDC. Centers for Disease Control and Prevention. Published December 30, 2020. Accessed September 30, 2023. https://www.cdc.gov/ncbddd/cp/data.html

Wang HH, Hwang YS, Ho CH, Lai MC, Chen YC, Tsai WH. Prevalence and Initial Diagnosis of Cerebral Palsy in Preterm and Term-Born Children in Taiwan: A Nationwide, Population-Based Cohort Study. *Int J Environ Res Public Health*. 2021;18(17):8984. doi:10.3390/ijerph18178984

Preterm developmental outcomes



CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

Primary Care Framework to Monitor Preterm Infants for Neurodevelopmental Outcomes in Early Childhood

Beth Ellen Davis, MD, MPH, FAAP,[a] Mary O'Connor Leppert, MD, FAAP,[b] Kendell German, MD, FAAP,[c] Christoph U. Lehmann, MD, FAAP,[d] Ira Adams-Chapman, MD, MPH, FAAP,[e,f]
COUNCIL ON CHILDREN WITH DISABILITIES, COMMITTEE ON FETUS AND NEWBORN

Davis, Beth Ellen, et al. "Primary Care Framework to Monitor Preterm Infants for Neurodevelopmental Outcomes in Early Childhood." Pediatrics, vol. 152, no. 1, July 2023, p. e2023062511. DOI.org (Crossref), https://doi.org/10.1542/peds.2023-062511.

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Developmental impairment risk factors

- Lower gestational age
- Intraventricular hemorrhage
- Periventricular leukomalacia
- Hypoxic ischemic encephalopathy
- Bronchopulmonary dysplasia
- Retinopathy of prematurity
- Necrotizing enterocolitis

Davis, Beth Ellen, et al. “Primary Care Framework to Monitor Preterm Infants for Neurodevelopmental Outcomes in Early Childhood.” Pediatrics, vol. 152, no. 1, July 2023, p. e2023062511. DOI.org (Crossref), https://doi.org/10.1542/peds.2023-062511.

Developmental disability risks

- Preterm infants and children are at increased risk for developmental disabilities that present early in life
  - Neurodevelopmental impairment (NDI) – presents in early infancy or toddler years
  - Cerebral palsy
  - Intellectual disability
  - Autism spectrum disorder

Davis, Beth Ellen, et al. “Primary Care Framework to Monitor Preterm Infants for Neurodevelopmental Outcomes in Early Childhood.” Pediatrics, vol. 152, no. 1, July 2023, p. e2023062511. DOI.org (Crossref), https://doi.org/10.1542/peds.2023-062511.

Increased risk of autism

- National cohort study was conducted of 4,061,795 singleton infants born in Sweden from 1973–2013 using nationwide outpatient and inpatient diagnoses
- ASD prevalence by gestational age at birth
  - 6.1% for extremely preterm (22–27 weeks)
  - 2.6% for very to moderate preterm (28–33 weeks)
  - 1.9% for late preterm (34–36 weeks)
  - 1.6% for early term (37–38 weeks)
  - 1.4% for term (39–41 weeks)

Crump, Casey, et al. “Preterm or Early Term Birth and Risk of Autism.” *Pediatrics*, vol. 148, no. 3, Sept. 2021, p. e2020032300. *DOI.org (Crossref)*, https://doi.org/10.1542/peds.2020-032300.

Later developmental outcomes

- Preterm infants and children are at increased risk for later-presenting, high prevalence, lower-severity developmental disabilities
  - Academic underachievement
  - Speech and language disorders
  - Attention deficit/hyperactivity disorders
  - Learning disabilities
  - Visual motor integration issues
  - Developmental Coordination Disorder

Davis, Beth Ellen, et al. “Primary Care Framework to Monitor Preterm Infants for Neurodevelopmental Outcomes in Early Childhood.” Pediatrics, vol. 152, no. 1, July 2023, p. e2023062511. DOI.org (Crossref), https://doi.org/10.1542/peds.2023-062511.

Increased risk of attention deficit disorder (ADHD)

- Preterm children have an increased rate of attention deficit disorder (ADHD)
- Risk of ADHD increases by declining weeks of gestational age
- ADHD affects late preterm children

Sucksdorff M, Lehtonen L, Chudal R, et al. Preterm Birth and Poor Fetal Growth as Risk Factors of Attention-Deficit/Hyperactivity Disorder. *Pediatrics*. 2015;136(3):e599-e608. doi:10.1542/peds.2015-1043

Long-term health issues

- Studies have shown increased risk for long-term health issues in preterm infants and children
  - Cardiometabolic disease
  - Metabolic Syndrome
  - Hypertension
  - Chronic renal issues
- Infants born SGA also at increased risk

Persistent high blood pressure and renal dysfunction in preterm infants during childhood. Wickland J, Steven Brown L, Blanco V, Heyne R, Turer C, Rosenfeld CR. Pediatr Res. 2023 01;93(1):217-225
Preterm birth and mortality in adulthood: a systematic review. Crump C. J Perinatol. 2020 06;40(6):833-843.

Late preterm infant (34 to 36+6 weeks GA) risks

- Developmental disability
- School failure
- Behavioral problems
- Social disabilities
- Medical disabilities
- Death

Woythaler, Melissa. “Neurodevelopmental Outcomes of the Late Preterm Infant.” *Seminars in Fetal and Neonatal Medicine*, vol. 24, no. 1, Feb. 2019.

Developmental screening

- Recommend general surveillance at each WCC visit and schedule interim visits as indicated
- Follow milestones closely
- Check for abnormalities of tone and movement at each visit
- AAP recommends developmental screening with evidence-based tools at 9, 18, and 30 months
- AAP recommends autism screening at 18 and 24 months

Referrals for developmental concerns

- Early intervention program
- Physical therapy
- Occupational therapy
- Speech and language therapy
- Orthopedics
- Neurology
- Genetics

Case 4

Billy was born at 32 weeks gestation, and he is now 12 months corrected age. At his WCC visit, he had very limited vocal production, and parents reported that he coos but does not yet babble or produce anything that sounds like words. He is smiling and happy, and he is crawling around the exam room. What would you do?

A. Tell the parents that everything looks normal, and you would like to see him back for his 15-month visit
B. Refer him for audiology testing
C. Refer him for developmental assessment
D. Refer him for speech and language evaluation

Hearing screening

- Hearing loss occurs in 1-2% of screened newborn infants (defined as bilateral loss >40dB)
- Infants admitted to NICU have 6.9 times higher rate*

*Butcher, Emma, et al. “Prevalence of Permanent Childhood Hearing Loss Detected at the Universal Newborn Hearing Screen: Systematic Review and Meta-Analysis.” *PLOS ONE*, edited by Tim Mathes, vol. 14, no. 7, July 2019, p. e0219600. *DOI.org (Crossref)*, https://doi.org/10.1371/journal.pone.0219600.

AAP guidelines for Early Hearing Detection and Intervention programs (2007)

- All newborns (ABR or OAE)
  - All infants screened by 1 month of age
  - If hearing screen failed, assessment by 3 months of age
  - If needed, Early Intervention services by 6 months of age
- NICU admissions for > 5 days (ABR)
- Readmissions in first month of life for high-risk conditions
  - Hyperbilirubinemia requiring exchange transfusion
  - Culture positive sepsis

Joint Committee on Infant Hearing. “Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs.” PEDIATRICS, vol. 120, no. 4, Oct. 2007, pp. 898–921. Crossref, doi:10.1542/peds.2007-2333.

Early intervention makes a difference

- Hearing loss detected prior to 9 months of age improved reading and communication skills and long-term reading comprehension skills through teen years (ages 13-19 in one study)
- Amplification with hearing aids by 6 months of age was associated with better early language skills

Pimperton, Hannah, et al. “The Impact of Universal Newborn Hearing Screening on Long-Term Literacy Outcomes: A Prospective Cohort Study.” Archives of Disease in Childhood, vol. 101, no. 1, Jan. 2016, pp. 9–15. Crossref, doi:10.1136/archdischild-2014-307516.

AAP: Early Hearing Detection and Intervention (EHDI) 1-3-6

- Hearing screening by 1 month
- Diagnosis of hearing loss by 3 months
- Enrollment in intervention by 6 months

https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx

Children who met 1, 3, 6

- Increased vocabulary
- Helped all children, regardless of their level of hearing loss or other determining factors

Yoshinaga-Itano C, Sedey AL, Wiggin M, et al. Early Hearing Detection and Vocabulary of Children with Hearing Loss. Pediatrics. 2017;140(2):e20162964

2023 AAP Guidelines for Hearing Assessment Beyond Neonatal Screening

- Referral to audiologist before 9 months for all NICU admissions > 5 days
- Close monitoring of language acquisition skills, auditory skills, middle ear status
- Refer sooner for hearing concerns, delayed language milestones
- Consider risk status for ongoing monitoring

Bower, Charles, et al. “Hearing Assessment in Infants, Children, and Adolescents: Recommendations Beyond Neonatal Screening.” *Pediatrics*, Aug. 2023, p. e2023063288. *DOI.org (Crossref)*, https://doi.org/10.1542/peds.2023-063288.

2019 Joint Commission on Infant Hearing (JCIH) Position Statement

High-risk conditions and recommended audiology follow up*

NICU admissions >5 days	9 months
Hyperbilirubinemia with exchange transfusion	9 months
Hypoxic ischemic encephalopathy	9 months
Meningitis, encephalitis	3 months
In utero infections	9 months
CMV in utero	3 months
ECMO	3 month
Zika	1 month

- Partial and abbreviated list
- Joint Committee on Infant Hearing. Year 2019 position statement: principles and guidelines for early hearing detection and intervention programs. *J Early Hear Detect Interv*. 2019;4(2): 1-44.

Ophthalmologic screening

- Retinopathy of prematurity (ROP)
  - Birth weight <1500 grams
  - GA ≤30 weeks
  - Infants 1500-2000 grams and GA >30 weeks with unstable clinical course

ROP incidence

- Population-based cohort study from New Zealand, Australia:
  - Overall incidence of severe ROP 10% of infants <32 weeks
  - Incidence 3% at 27 weeks, 34% at 24 weeks
  - ≥32 weeks: not at risk
  - ≥28 weeks: most have mild disease that does not require treatment

Tan, Zachary, et al. "Visual Impairment Due to Retinopathy of Prematurity (ROP) in New Zealand: A 22-Year Review." British Journal of Ophthalmology, vol. 99, no. 6, June 2015, pp. 801–06. Crossref, doi:10.1136/bjophthalmol-2014-305913

Timing of ROP screening

- 31 weeks postmenstrual age (PMA) for infants born 22 to 26 weeks gestational age
- 4 weeks chronological age for infants born ≥27 weeks gestational age
- Follow-up visits: every 1 to 3 weeks based on findings
- Additional exam generally 4 to 6 months after NICU or ophthalmological care discharge, then yearly

American Academy of Pediatrics. Screening Examination of Premature Infants for Retinopathy of Prematurity. Volume 31 (1), 2013

Additional ophthalmologic issues

- Overall, refractive errors are four times more common in those born preterm (29.6%) than those born at term (7.8%)
- Very preterm births are more affected (<32 weeks)
- Higher rates of strabismus (5-25% in preterm)
- Presence of high refractive errors (particularly myopia 3-20%)
- Lowered stereoacuity and loss of peripheral vision

Leung, Myra PS, et al. “The Effects of Preterm Birth on Visual Development: Preterm Birth and Visual Development.” Clinical and Experimental Optometry, vol. 101, no. 1, Jan. 2018, pp. 4–12. Crossref, doi:10.1111/cxo.12578

Case 5 – last one!

Marco was born at 30 weeks gestational age and weighed 1400 grams at birth. Assuming appropriate screening in the newborn period, what additional evaluations are recommended by 30 months of age?

A. Developmental screening
B. Developmental, audiology, and ophthalmology
C. Audiology and ophthalmology

Take home screening points for preterm infants and children

- They have increased risks for developmental delays and differences.
- They have increased risks for hearing issues and ophthalmologic and vision abnormalities.
- They should receive developmental surveillance and screening as recommended by Bright Futures at routine WCC visits and more frequently if there are concerns.
- There are recommendations for more frequent audiology and ophthalmologic exams.

Care Coordination and Transition

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California Perinatal Quality Care Collaborative (CPQCC)

- Statewide network of California's NICUs and High Risk Infant Follow-up (HRIF) clinics housed at the Stanford University School of Medicine
- Founded in 1997 to improve the quality of care for California's mothers and most vulnerable infants
- Help NICU teams to use collaborative quality improvement methods and evidence-based toolkits to improve outcomes for their most vulnerable patients
- Use QI data to generate insights that inform improvements in care in NICUs around the world

Coordinate NICU discharge plan

When possible, NICU should provide and arrange all possible care before discharge

- Update immunizations
- Make referrals and appointments for indicated follow up
  - Primary Care
  - Early Intervention
  - Ophthalmology
  - Audiology
  - Other subspecialties
  - Other therapeutic interventions (physical therapy, feeding therapy, occupational therapy)
- Include primary care guidance and relevant information in the discharge summary

NICU Discharge Provider Template

NICU DISCHARGE PROVIDER TEMPLATE

Primary Care Guidance for Preterm Infants

The following information provides general guidance, and not all recommendations are applicable to all infants. This does not indicate an exclusive course of treatment or serve as a standard of medical care. The information provided in this discharge summary is derived from the CPQCC Primary Care for Preterm Infants and Children Toolkit.

Nutrition: Use corrected age (adjusted for prematurity) on WHO growth chart until 2 years of age. Always promote breastfeeding, aim to maintain the growth trajectory achieved in the hospital, and do not overfeed. Length of use of post-discharge formula (usually EnfaCare® or NeoSure®) is controversial and without standard recommendations and should not replace breastfeeding in an adequately growing infant. These are some informal suggestions for using post-discharge formula in formula-fed infants:

- ***BW >1800 grams:*** probably not 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 and frequency of post-discharge formula will depend on growth history in the NICU and other medical issues.

Vitamin D: 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.

Iron Supplementation: 2-3 mg/kg/day for 6 to 12 months; 4-6 mg/kg/day if anemic.

Hepatitis B Vaccine: A dose received by an infant < 2000 grams AND < 1 month of age does not count towards the primary series.

Rotavirus Vaccine: Infants usually do not receive rotavirus vaccine in the NICU. The first dose of rotavirus vaccine must be administered by age 14 weeks 6 days. Consider administering at the first outpatient visit for infants 6 weeks to 14 weeks 6 days.

RSV Immunization: During RSV season (typically October - March), infants < 8 months age should receive nirsevimab at birth hospitalization or soon after discharge. If birthing person received RSV vaccine during 32-36 weeks gestation and at least 2 weeks before birth, nirsevimab is not indicated. Infants 8-19 months age entering their second RSV season and at high risk should also receive nirsevimab. Refer to cdc.gov/rsv and aap.org/en/patient-care/respiratory-syncytial-virus-rsv-prevention/ for detailed information.

If nirsevimab is unavailable, palivizumab may be given to high risk infants and children. Consider for infants < 12 months at start of RSV season if < 29 weeks GA at birth or < 32 weeks GA at birth and O2 requirement for at least 28 days. Consider for infants < 24 months at the start of RSV season with chronic lung disease on medical therapy within 6 months of start of RSV season. For complete palivizumab recommendations, including infants with CHD and neuromuscular disease, see https://pediatrics.aappublications.org/content/134/2/415.full

Developmental Screening: Perform at every WCC visit. Use evidence-based tools at 9, 18, and 30 months. Infants at high risk for developmental delays or with documented developmental delays should be referred to an Early Intervention Program. Contact information ***. Consider referrals for additional evaluations and services such as high risk infant follow-up programs and neurology.

Hearing Screening: ABR screening (such as ALGO) prior to discharge. If initial screen was not passed, repeat outpatient screening as quickly as possible and by one month of age. If initial screen was normal, repeat hearing screening by 9 months. Audiology referral advised at any time for concerns or language delays. To schedule an audiology appointment at ***, please call ***.

Ophthalmologic Screening: Monitor for ROP until mature retinae for GA<30 weeks or <1500 g or selected infants 1500-2000 g or GA >30weeks. For all, follow up at 4-6 months after NICU discharge and yearly. To schedule an ophthalmology appointment at ***, please call ***.

Psychosocial Screening: Perform at every WCC and other visits as feasible. Resources for families include ***.

For Additional Guidance

Please refer to the CPQCC Primary Care for Premature Infants & Children Toolkit available at: https://www.cpqcc.org/preterm-primary-care-toolkit.

Additional Information

[Use the space below to enter your organizational contact info, additional instructions, and information or references specific to your institution.]

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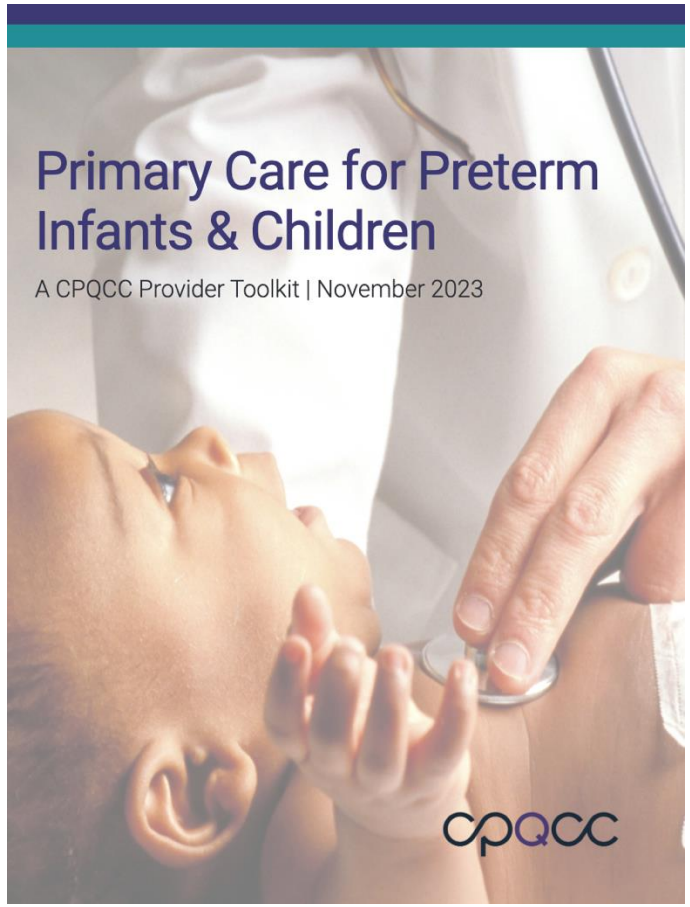
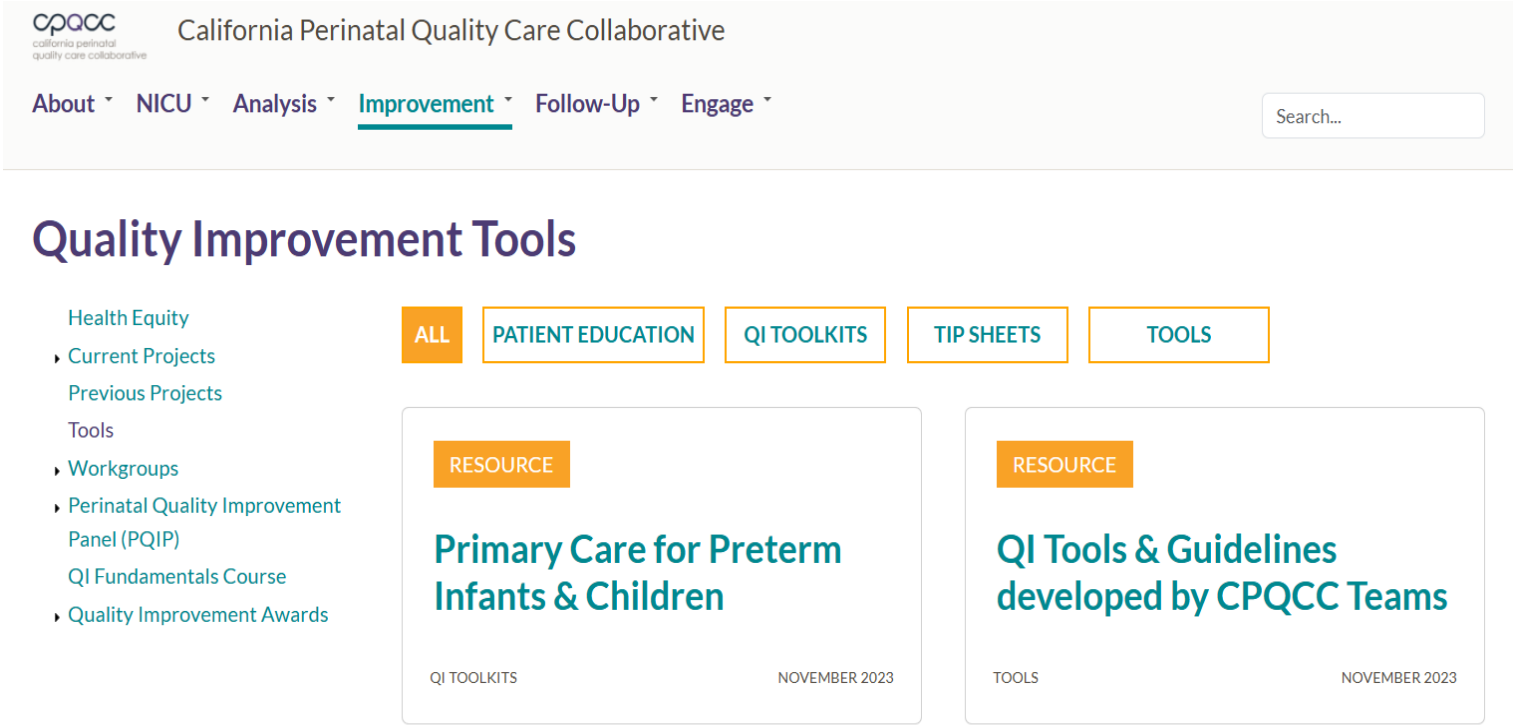
Primary Care for Preterm Infants & Children Provider Toolkit



Available as a "Quality Improvement Tool" on the CPQCC website (https://cpqcc.org/improvement/qi-tools)



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Primary Care for Preterm Infants & Children Provider Toolkit

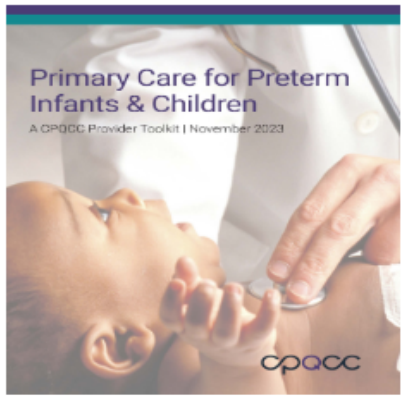
Primary Care for Preterm Infants & Children

- Stay Informed
- Annual Improvement Palooza
- Annual Data Training
- Annual Reports
- FAQs
- Connect With Us
- Glossary
- Media Inquiries

The Primary Care for Infants & Children Toolkit:

- Highlights nutritional, immunization, and special screening requirements for preterm infants and children
- Consolidates recommendations from national organizations such as the AAP, CDC, and ACIP
- Provides updated information in an easily-accessible reference for busy primary care pediatric providers
- Includes a supplemental NICU Discharge Provider Template modifiable word document that NICUs can edit for their specific needs and include in their discharge summaries

Was this tool helpful? Take this 4-question survey.



Download Toolkit (6.76 MB)

Resource Category:
QI Toolkits
Date:
November 2023
Additional Resources:

Tip Sheet: Primary Care for Preterm Infants & Children

Periodicity Chart: Primary Care for Preterm Infants and Children

Related Links:
NICU Discharge Provider Template

https://cpqcc.org/resources/primary-care-preterm-infants-children

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Tip Sheet

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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 to maintain growth trajectory. Do not overfeed.	
Monitoring growth	Use corrected age (adjusted for prematurity) until at least 2 years of age. Use corrected age (adjusted for prematurity) until at least 2 years of age. • WHO growth chart until 2 years • CDC growth chart for children 2-20 years
Breastfeeding	Always promote breastfeeding.
Post-discharge formulas	Length of use of post-discharge formula (usually EnfaCare® or NeoSure®) is controversial without standard recommendations and should not replace breast milk in an adequately growing infant. • 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 and frequency of post-discharge formula will depend on growth history 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.
Vitamin supplementation	**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 taking less than 1 liter of formula per day **IRON:** Almost all preterm infants should receive iron supplementation. They are iron deficient unless they received blood transfusions. • Maintenance dose 2-3 mg/kg/day for 6 to 12 months (until dietary intake is sufficient) • Treatment dose 4-6 mg/kg/day if anemic

IMMUNIZATIONS: Follow standard recommendations by chronological age except for special recommendations for Hepatitis B Vaccine and Rotavirus Vaccine.	
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 babies. A dose received by an infant <2000 grams AND <1 month of age does not count towards the primary series.
Rotavirus vaccine	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.
RSV Immunization	***Do not miss the opportunity to protect vulnerable children from Respiratory Syncytial Virus infections.*** Give nirsevimab for the following patients: • Infants < 8 months during RSV season if not given at birth hospitalization or if birthing person received RSV vaccine at least 14 days before birth • Infants 8-19 months at start of RSV season with chronic lung disease of prematurity, immunocompromised, cystic fibrosis with severe lung disease or weight-for-length < 10%ile, and American Indian and Alaska Native children • Complete recommendations: cdc.gov/rsv and aap.org/en/patient-care/respiratory-syncytial-virus-rsv-prevention/ If nirsevimab is unavailable, consider palizivumab for the following patients: • Infants < 12 months at start of RSV season if < 29 weeks GA at birth or < 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.	
Developmental 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 9 months. Screen earlier for high-risk conditions, such as history of CMV infection, meningitis, and ECMO • Audiology referral advised at any time for concerns or language delays
Ophthalmologic screening	• Monitor for retinopathy of prematurity (ROP) until mature retinae for birthweight ≤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 and indicated by risk status

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

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Periodicity Chart

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PERIODICITY CHART

Primary Care for Preterm Infants & Children

	Post-discharge visit	1 mo	2 mo	4 mo	6 mo	9 mo	12 mo	15 mo	18 mo	2 yr	2½ yr	3 yr	4 yr	5 yr
Nutrition: Monitor growth carefully using corrected age on appropriate growth charts. Always support breastfeeding. Supplement with post-discharge formula when indicated to achieve a normal rate of growth. Do not overfeed.														
Growth Charts	GC	GC	GC	GC	GC	GC	GC	GC	GC	GC	GC	GC	GC	GC
Post-discharge formulas	PF	PF	PF	PF	PF	PF	PF							
Iron supplement	IS	IS	IS	IS	IS	IS	IS							
Vitamin D	D	D	D	D	D	D	D							
Immunizations: Follow standard recommendations by chronological age except for special recommendations for Hepatitis B Vaccine and Rotavirus Vaccine. Do not miss the opportunity to protect vulnerable children from Respiratory Syncytial Virus infections.														
Rotavirus vaccine			R	R	R									
Hepatitis B vaccine	H	H	H	H	H	H								
RSV vaccine	RSV	RSV	RSV	RSV	RSV	RSV	RSV	RSV	RSV					
Screening: Preterm infants and children need more frequent hearing and ophthalmologic screenings and careful monitoring of neurodevelopmental and psychosocial issues.														
Developmental surveillance		DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS
Developmental screening						DSc			DSc		DSc			
Autism screening									ASD	ASD				
Hearing screening	HS	HS	HS	HS	HS2	HS2	HS2	HS2	HS2	HS2	HS2	HS2	HS2	HS2
Ophthalmologic screening	OS	OS	OS	OS	OS	OS	OS	OS	OS	OS	OS	OS	OS	OS
Psychosocial screening	PS	PS	PS	PS	PS	PS	PS	PS	PS	PS	PS	PS	PS	PS

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 formula (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 and frequency of formula will depend on growth history in the NICU and other medical issues. Always support breastfeeding. Maintain growth trajectory. 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.
  - **Birthing person is HBsAg-negative:** 1 dose within 24 hours of birth for all medically stable infants ≥2,000 grams. Infants <2,000 grams: administer 1 dose at chronological age 1 month or hospital discharge. A dose received by an infant <2,000 grams AND <1 month of age does not count towards the primary series.
  - **Birthing person 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 <2,000 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.
  - **Birthing person's HBsAg status is unknown:**
    - Administer Hepatitis B vaccine within 12 hours of birth, regardless of birth weight.
    - For infants <2,000 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 HBsAg status as soon as possible. If HBsAg is positive, administer HBIG to infants ≥2,000 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**

- **RSV: *RSV immunization***
  - **Give nirsevimab for the following patients:**
    - Infants < 8 months during RSV season if not given at birth hospitalization or if birthing person received RSV vaccine at least 14 days before birth
    - Infants 8-19 months at start of RSV season with chronic lung disease of prematurity, immunocompromised, cystic fibrosis with severe lung disease or weight-for-length < 10%ile, and American Indian and Alaska Native children

    For complete recommendations: cdc.gov/rsv and aap.org/en/patient-care/respiratory-syncytial-virus-rsv-prevention/
  - **If nirsevimab is unavailable, consider palizivumab for the following patients:**
    - Infants < 12 months at start of RSV season if < 29 weeks GA at birth or < 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
    - 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

    For complete recommendations: 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 indicated by risk status and concerns.
- **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 9 months of age. Screen earlier for high-risk conditions such as history of CMV infection, meningitis, and ECMO. 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 >30weeks. 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 and indicated by risk status.

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

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For more information

Additional information is available on the CPQCC website:

https://cpqcc.org/resources/primary-care-preterm-infants-children

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