

DOWN SYNDROME HEALTH CARE GUIDELINES

(Based on “Health Supervision for Children with Down Syndrome” as published in *Pediatrics*)

Neonatal (Birth - 1 Month)

- Review parental concerns. Chromosomal karyotype; genetic counseling, if not done prenatally.
- Check for signs and symptoms of gastrointestinal tract blockage (e.g., duodenal web, duodenal atresia, or Hirschsprung disease).
- Use typical growth charts from Centers for Disease Control (CDC), available at www.cdc.gov/growthcharts. Use weight/height assessment, as well.
- If constipation present, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, or Hirschsprung disease.
- Radiographic swallowing assessment if marked low muscle tone, slow feeding, choking with feeds, recurrent or persistent respiratory symptoms, failure to thrive. Consider feeding referral, if needed.
- Echocardiogram read by a pediatric cardiologist and referral to pediatric cardiology if abnormalities present. Subacute bacterial endocarditis prophylaxis (SBE), in susceptible children with cardiac disease. If a heart condition is identified, monitor for signs and symptoms of congenital heart failure.
- Car seat evaluation to evaluate for apnea, low heart rate, or oxygen desaturation prior to discharge from the hospital at birth if child is hypotonic or has had cardiac surgery.
- Complete blood count (CBC) to rule out transient myeloproliferative disorder (TMD) or polycythemia.
- Review feeding history to ensure adequate caloric intake. Children with Down syndrome can usually nurse, and many can breastfeed successfully. Consider lactation consultation.
- Thyroid function tests – check on results of state-mandated screening at birth. Add TSH is the state-mandated screening only included T4 results.
- Newborn hearing screen – auditory brainstem response (ABR) or otoacoustic emission (OAE) – to assess for hearing loss.
- Discuss risk for respiratory infections.
- Discuss complementary and alternative therapies.
- Discuss cervical spine positions, especially for anesthesia or surgical or radiologic procedures.
- Review signs and symptoms of myopathy. If myopathic signs exists, obtain neck X-rays (C-spine).
- Eye exam for cataracts.
- Discuss value of Early Intervention (infant stimulation) and refer for enrollment in local program.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

“Health Supervision for Children with Down Syndrome” is published in *Pediatrics* (Vol. 128, No. 2, August 1, 2011. pp. 393 -406).

An electronic version can be accessed here: <http://aappolicy.aappublications.org> (Search: Health Supervision for Children with Down Syndrome)