



## DOWN SYNDROME HEALTH CARE GUIDELINES

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

### Ages 1 – 5 Years

- Chromosomal karyotype; genetic counseling, if not already done.
- Discuss chances of having another child with Down syndrome, if not already done.
- If constipation present, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, or Hirschsprung disease.
- Hemoglobin count annually. Include (a) ferritin and CRP or (b) reticulocyte hemoglobin if there is a concern for a diet low in iron or if hemoglobin < 11g.
- Thyroid function tests annually (FT4 and TSH).
- Review signs and symptoms of myopathy. If myopathic signs exist, obtain neck X-rays (C-spine). Contact physician if change in gait, change in the use of arms or hands, change in bladder function, neck pain, head tilt, torticollis, or new-onset weakness. (Note: Some athletic organizations might require a C-spine for entry and participation.)
- Trampoline use should be avoided in all children with or without Down syndrome under age 6 and only under professional supervision over age 6.
- Hearing exam every 6 months until normal bilateral ear-specific test. At that point, hearing exams should be done annually. Refer to Ears-Nose-Throat specialist for any abnormal hearing exam.
- Sleep study for everyone by the age of 4 regardless of presence or absence of symptoms. Review signs and symptoms for obstructive sleep apnea.
- Referral to pediatric ophthalmologist or ophthalmologist with expertise in Down syndrome annually.
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure, subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Use typical growth charts from Centers for Disease Control (CDC), available at [www.cdc.gov/growthcharts](http://www.cdc.gov/growthcharts). Use body-mass index (BMI) or weight/height measurements to assess weight proportionality. Consider referral to a dietician, especially for individuals who are “overweight” or “obese.”
- Screen for celiac disease with IgA and TTG-IgA on an annual basis, if symptoms present and your child is on diet that contains gluten.
- Delayed or irregular dental eruption, hypodontia is common.
- Establish optimal dietary and physical exercise patterns.
- Encourage and model use of accurate terms for genitalia and other body parts any times these parts are discussed or examined. Remind person with Down syndrome that the only reason that anyone should be looking at or touching private body parts is for health (doctor office visits) or hygiene (bathing or showering).
- Well child care: immunizations; If chronic cardiac or pulmonary disease, give 23-valent pneumococcal vaccine age > 2 years.

“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)



## DOWN SYNDROME HEALTH CARE GUIDELINES

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

### Ages 1 – 5 (Page 2 of 2)

- Review behavior and social progress, with particular attention to signs and symptoms of ADHD, autism, and other psychiatric/behavioral problems
- Early Intervention: speech therapy, physical therapy, occupational therapy. Discuss complementary and alternative therapies.
- Encourage and model use of accurate terms for genitalia and other private body parts.
- 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)

National Down Syndrome Society • [www.ndss.org](http://www.ndss.org) • [info@ndss.org](mailto:info@ndss.org) • 800-221-4602