



DOWN SYNDROME HEALTH CARE GUIDELINES

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

Ages 5 – 13 Years

- Thyroid function test annually (FT4 and TSH). 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).
- 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: 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 occur under professional supervision over age 6.
- Use typical growth charts from Centers for Disease Controls (CDC), available at www.cdc.gov/growthcharts. Use body-mass index (BMI) to assess weight proportionality.
- Low calorie, high fiber diet; regular exercise. Consider referral to a dietician, especially for individuals who are “overweight” or “obese.”
- Auditory testing (annually).
- Monitor for obstructive airway; sleep apnea. Review signs and symptoms for obstructive sleep apnea.
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure. Subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Eye examination (every 2 years).
- Screen for celiac disease with IgA and TTG-IgA on an annual basis, if symptoms present.
- Review behavior and social progress.
- Discuss self-help skills, attention-deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), wandering off, transition to middle school.
- Discuss physical and psychosocial changes through puberty, need for gynecologic care in the pubescent female. Talk to adolescents and their families about the recurrence risk of Down syndrome if they were to become pregnant. Birth control and prevention of sexually transmitted diseases should be discussed with patients and their families. Sexuality education should be emphasized.
- Review dermatologic issues.
- Discuss complementary and alternative therapies.
- Continue speech therapy, physical therapy, occupational therapy, as needed.
- 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)