



DOWN SYNDROME HEALTH CARE GUIDELINES

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

Ages 13 – 21 Years

- Thyroid function test annually (FT4 and TSH).
- Auditory testing (annually).
- 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.)
- Hemoglobin count annually. Include (a) ferritin and CRP or (b) reticulocyte hemoglobin. (ChR if there is a concern for iron deficiency or if hemoglobin < 11g.)
- Review signs and symptoms for obstructive sleep apnea.
- Screen for celiac disease with IgA and TTG-IgA on an annual basis, if symptoms present.
- Review behavior and social progress.
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure. Subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Ophthalmologic exam, looking especially for keratoconus and cataracts (every 3 years).
- Low calorie, high-fiber diet. Regular exercise. Monitor for obesity. Consider referral to a dietician, especially for individuals who are “overweight” or “obese.”
- 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.
- Continue speech and language therapy, as indicated.
- Facilitate transition: guardianship, financial planning, behavioral problems, school placement, vocational training, independence with hygiene and self-care, group homes, work settings.
- Discuss sexual development and behaviors, contraception, sexually transmitted diseases, recurrence risk for offspring.
- Discuss physical and psychosocial changes through puberty, need for gynecologic care in the pubescent female.
- Review signs and symptoms for obstructive sleep apnea.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

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