DOWN SYNDROME HEALTH CARE GUIDELINES
(Based on 1999 Down Syndrome Health Care Guidelines)*

Neonatal (Birth-1 Month)

< Review parental concerns. Chromosomal karyotype; genetic counseling, if necessary.

< If vomiting or absence of stools, check for gastrointestinal tract blockage (duodenal web or atresia or Hirschsprung disease).

< Evaluation by a pediatric cardiologist including echocardiogram. Subacute bacterial endocarditis prophylaxis – (SBF), in susceptible children with cardiac disease.

< Exam for plethora, thrombocytopenia.

< Review feeding history to ensure adequate caloric intake.

< Thyroid function test - check on results of state-mandated screening at birth.

< Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (at birth or 3 months).

< Pediatric ophthalmological evaluation (by 6 months) for screening purposes.

< 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.

666 Broadway, NY, NY 10012
(800) 221-4602 / www.ndss.org

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Infant (1-12 Months)

< General neurological, neuromotor and musculoskeletal examination.

< TSH and T4-Thyroid Function Test (6 & 12 months).

< Evaluation by pediatric cardiologist including echocardiogram (if not done at birth). Consider progressive pulmonary hypertension if VSD or atrioventricular septal defect and little or no symptoms of heart failure.

< Subacute bacterial endocarditis prophylaxis (SBE) (as indicated).

< Well child care - immunizations.

< Feeding consult, especially if constipated. Consider Hirschsprung disease.

< Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (by 3 months if not already, or if suspicious).

< Ear, nose and throat exam (as needed), especially if suspicious of otitis media.

< Well-balanced, high-fiber diet.

< Vision exam (by 6 months and annually; earlier if nystagmus, strabismus or indications of poor vision).

< Discuss Early Intervention and refer for enrollment in local program.

< Application for Supplemental Security Income (SSI), depending on family income.

< Consider estate planning and custody arrangements; continue family support.

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Childhood (1-12 Years)

< TSH and T4-Thyroid Function Test (annual).

< Echocardiogram by a pediatric cardiologist if not done previously.

< Behavioral Auditory Testing (every 6 months to age 3, then annually).

< Lateral cervical spine x-rays (neutral view, flexion, extension) to rule out atlanto-axial instability. Radiologist to measure atlanto-dens distance and neural canal width (at 3-5 years, then as needed).

< Pediatric and neurological exam with evaluation for spinal cord compression: deep tendon reflexes, gait, Babinski sign.

< Use Down syndrome growth charts and head circumference charts with others.

< Eye examination (annually, or as indicated).

< Screen for celiac disease IgA antiendomysium antibodies and total IgA (btwn 2 & 3 yrs)

< Question about obstructive sleep apnea; ENT exam (as needed).

< Dental Exam (2 years; follow up exams every 6 months after). Twice daily brushing

< Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) for cardiac problems (as indicated).

< Brief vulvar exam for girls.

< Well child care: immunizations; pneumococcal vaccine (2 years).

< Evaluation by speech/language pathologist.

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**Adolescence (12-18 Years)**

- TSH and T4-Thyroid Function Test (annual).
- Auditory Testing (annually).
- Monitor for obstructive airway; sleep apnea.
- General physical and neurological exam; check for atlanto-axial dislocation. Cervical spine x-ray (as needed for sports).
- Eye examination (annually).
- Monitor for obesity by plotting height for weight on growth charts for typical children.
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. ECHO - Echocardiogram (as indicated by findings).
- Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adolescents.
- Adolescent medicine consult for puberty/sexuality issues; health, abuse prevention and sexuality education. Pelvic exam (only if sexually active).
- Low calorie, high fiber diet; regular exercise.
- Smoking, drug and alcohol education.

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Adulthood (More than 18 Years)

< TSH and T4-Thyroid Function Test (annual).
< Auditory testing (every 2 years).
< Cervical spine x-rays (as needed for sports); check for atlanto-axial dislocation.
< Ophthalmologic exam, looking especially for keratoconus & cataracts (every 2 yrs)
< Clinical evaluation of the heart to rule out mitral/aortic valve problems. Echocardiogram-ECHO (as indicated).
< Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adults with cardiac disease.
< Baseline Mammography (40 yrs; follow up every other yr until 50, then annual).
< Pap smear and pelvic exam (every 1-3 yrs. after first intercourse). If not sexually active, single-finger bimanual exam with finger-directed cytology exam. If unable to perform, screen pelvic ultrasound (every 2-3 years). Breast exam (annually).
< General physical/neurological exam. Routine adult care.
< Clinical evaluation for sleep apnea.
< Low calorie, high-fiber diet. Regular exercise. Monitor for obesity.
< Clinical evaluation of functional abilities (consider accelerated aging); monitor loss of independent living skills.
< Neurological referral for early symptoms of dementia: decline in function, memory loss, ataxia, seizures and incontinence of urine and/or stool.
< Monitor for behavior/emotional/mental health. Psych referral (as needed).
< Continue speech and language therapy (as indicated).

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