1 year to 5 years

down syndrome care hub

Assessments & Health Visits for People Living with Down Syndrome
Guided Checklist

◯ Regular well-care visits
- Continue updating and obtaining family history from past lab requisitions
- Perform physical exam and review past and current health conditions
- List current or past medications
- Assess family and intra-familial relationship status
- Annual visit with family; schedule any necessary follow-ups

◯ Monitor growth
- Obtain BMI, weight and height trends; use standard growth charts of the National Center for Health statistics or WHO
- Encourage exercise and balanced diet
- Discuss supplements (i.e. adequate calcium and vitamin D, iron and others)

◯ Immunizations
23-valent pneumococcal polysaccharide vaccine at >2yrs for cardiac/pulmonary risk patients

◯ Heart
Patients with cardiac lesions; follow-up with pediatric cardiologist and monitor for recurrent/residual lesions and development of pulmonary hypertension

◯ Hearing
- High risk of hearing loss due to otitis media
- Screening: Behavioural audiogram and tympanometry every 6 months until normal hearing levels established bilaterally by ear-specific testing after 4 years of age; otoacoustic emissions or brain stem auditory response if prior testing does not establish normal hearing
- Refer children with hearing loss to otolaryngologist; stenotic ear canal issues

◯ Vision
- Check vision using developmentally appropriate subjective criteria
- Refer annually to ophthalmologist; address any refractive errors and strabismus for amblyopia prevention

◯ Thyroid
Measure TSH annually; assess child for symptoms of thyroid dysfunction

◯ Blood tests
- Obtain hemoglobin concentration annually
- Obtain serum ferritin and CRP

◯ Stomach or bowel problems
- Each visit: review symptoms related to celiac disease, diarrhea/protracted constipation, slow growth, failure to thrive, anemia, abdominal pain or bloating
- Symptoms present; obtain tissue transglutaminase IgA level and quantitative IgA

◯ Cervical spine positioning
- Maintain neutral positions during anesthetic, surgical, or radiographic procedure to minimize risk of spinal cord injury
- Child with significant neck pain, radicular pain, weakness, spasticity or change in tone, gait difficulties, hyperreflexia, change in bowel or bladder function must undergo plain cervical spine radiography in neutral position
- Immediate referral to pediatric neurosurgeon or orthopedic surgeon if abnormalities present; txt of atlantoaxial instability

◯ Myopathy
Perform physical examination for myopathic signs and symptoms; clinical history discussed

◯ Sleep issues
- Each visit: discuss symptoms of obstructive sleep apnea with parents
- Referral for sleep study (polysomnography) by age 4 for all is recommended

◯ Brain and nervous system

Monitor for neurologic dysfunction; seizures

◯ Dental

Reassure parents of delayed and irregular dental eruption; hypodontia occurs frequently with DS

◯ New treatments

Be prepared to discuss and answer questions about alternative txts

◯ Recurrence risk counseling

Genetic counseling referral; discuss future pregnancy planning, availability of prenatal diagnoses, and risk of recurrence of DS

◯ Developmental/Early intervention

Each visit: review early intervention; physical, occupational, and speech therapy

◯ Behavioural issues and management

- Discuss child's behavioural and social progress; risks of autism, ADHD, other psychiatric issues (manifest 2-3 years of age)
- Behavioural management, sibling adjustments, socialization and recreation