



Down Syndrome Practice Tool Series 2 of 5

Medical Care for the Child with Down Syndrome from 1 Month to 1 Year of Age



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When your child needs a hospital, everything matters.

Brief Overview of Down Syndrome

Down syndrome is the most common chromosomal condition in the United States. About 1 in every 700 babies born will be diagnosed with Down syndrome, totaling to approximately 6,000 babies each year.¹ Down syndrome is caused by the presence of the genetic material from a third copy of chromosome 21 (trisomy 21) or an unbalanced translocation between chromosome 21 and another chromosome. Approximately 95% of cases of Down syndrome are sporadic, with no familial history.²

In addition to common physical features (e.g. hypotonia, small brachycephalic head, epicanthal folds, and flat nasal bridge), a number of life-time associated health conditions may affect babies with Down syndrome. Some are age specific but can occur at a variety of ages.

More Common Conditions	%	Less Common Conditions	%
Hearing problems	75	Gastrointestinal atresias	11
Vision problems	60	Thyroid disease	4-18
Refractive errors	50	Seizures	1-13
Obstructive sleep apnea	50-75	Iron deficiency	10
Otitis media	50-70	Transient myeloproliferative disorder	10
Congenital heart disease	40-50	Celiac disease	5
Hypodontia/ delayed dental eruption	23	Anemia	3
Cataracts	15	Other (atlantoaxial instability, autism, Hirschsprung disease, leukemia)	1-2

Here, we summarize guidelines designed by the American Academy of Pediatrics to assist the pediatrician with medical care for a child with Down syndrome between one month and one year of age.²

If this is your first time meeting the family, prior to providing information on Down syndrome, remember to first congratulate the parents/guardians on the birth of their child.

Periodic Care and Follow Up Specific for Babies from 1 Month to 1 Year

Several aspects of care require ongoing assessment throughout childhood and should be reviewed at every physician visit, while others may be conducted at different time intervals depending on the patient's age and health care needs.

• Provide parent-to-parent contact, support groups, current books and pamphlets (see Additional Resources)	Do once at this age
• Confirm diagnosis with chromosomal analysis	Do if not done previously
• Discuss risk of recurrence of Down syndrome (or defer to Genetics/DS Clinic)	Do if not done previously
• Refer to Genetics/DS Clinic	Do if not done previously
• Conduct radiographic swallowing assessment if needed: marked hypotonia, slow feeding, choking with feeds, recurrent or persistent respiratory symptoms, failure to thrive	Do if not done previously
• Reassure parents/guardians delayed and irregular dental eruption, hypodontia are common	Do if not done previously
• Assess TSH to screen for hypothyroidism	At 6 mo & at 12 mo
• Conduct audiology evaluation	At 6 mo
• Discuss symptoms of obstructive sleep apnea	Do once in the first 6 months
• Refer to pediatric ophthalmologist to assess strabismus, cataracts, and nystagmus	Do once at 6 mo & at 12 mo

Care and Follow Up Needs at All Visits or All Health Maintenance Visits (HMs)

Assess the emotional status of parents/guardians and intrafamilial relationships	All HMs
Review signs and symptoms of hypotonia and myopathy- refer for therapies, including Help-Me-Grow if appropriate	All HMs
Discuss cervical spine positioning, especially for anesthesia or surgical or radiologic procedures	All HMs
Discuss complementary & alternative therapies	All HMs
Evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, If child is experiencing constipation, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, & Hirschsprung disease	All visits
If infant presents myelopathic signs or symptoms, obtain neutral position spine films	All visits
If child has congenital heart disease, monitor for signs & symptoms of congestive heart failure	All visits

References: 1) Centers for Disease Control and Prevention. Data and Statistics on Down Syndrome. Accessed 3/21/2021 at: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>. 2) Bull MJ; Committee on Genetics. Health supervision for children with Down syndrome. Pediatrics. 2011 Aug;128(2):393-406. doi: 10.1542/peds.2011-1605. Epub 2011 Jul 25. Erratum in: Pediatrics. 2011 Dec;128(6):1212. PMID: 21788214 (<https://pubmed.ncbi.nlm.nih.gov/21788214/>).

Specialty Services at Nationwide Children's and When to Refer

Genetics & Down Syndrome Clinic

For initial assessments, please refer to the Genetics to discuss test results and general outcomes. We can also address reoccurrence risk and provide psychological support if needed.

The Down Syndrome Clinic at Nationwide Children's Hospital is a family-centered clinic providing diagnostic and treatment services to children and adolescents with Down syndrome and their families.

Families are linked with medical, educational, social and financial supports in their communities as indicated and resources identified to assist them in meeting the unique needs of their child.

Our team of developmental pediatricians, psychologists, geneticists and advanced practice nurses maintain a close working relationship with the child's primary care physician throughout their care.

Services We Offer

Services are covered by most insurance providers. To expedite insurance coverage we recommend a referral be sent to the clinic by the patient's primary care physician.

- Comprehensive evaluation — Monitoring for feeding difficulty in infants, atlantoaxial instability and signs of celiac disease
- Assessments for Attention Deficit Hyperactivity Disorder or Autism Spectrum Disorders in individuals with Down syndrome
- Lab and radiology assessments, including recommended health supervision screening and focusing on individual concerns
- Behavior management counseling for families whose children are experiencing behavioral difficulties

Reasons to Call

Parents/guardians should notify the patient's pediatrician or the Down Syndrome Clinic for the following symptoms:

- Not necessarily walking and gait may be unstable
- Changes in use of arms or legs
- Changes in bowel or bladder habits
- New onset of snoring
- New onset of apnea when sleeping
- New behavior or developmental concerns

Additional Resources

Nationwide Children's Down Syndrome Clinic: www.NationwideChildrens.org/specialties/down-syndrome-clinic

Down Syndrome Association of Central Ohio: dsaco.net

Down Syndrome Awareness Ohio: www.downsyndromeohio.org

Down Syndrome Association of Greater Toledo: www.dsagt.org

Down Syndrome Association of Greater Cincinnati: www.dsagc.com

The Up Side of Downs of Northeast Ohio: www.theupsideofdowns.org

Miami Valley Down Syndrome Association: www.mvdsa.org

The National Down Syndrome Congress: www.ndsccenter.org

National Down Syndrome Society: www.ndss.org

International Mosaic Down Syndrome Association: www.imdsa.org

Down Syndrome Resource Foundation: www.dsrf.org

Down Syndrome Medical Interest Group – USA: www.dsmig-usa.org

Referrals and Consultations

Online: NationwideChildrens.org/Request-An-Appointment

Phone: (614) 722-6200 or (877) 722-6220 | Fax: (614) 722-4000

Physician Direct Connect Line for 24-hour urgent physician consultations:

(614) 355-0221 or (877) 355-0221.

