Down Syndrome Checklist

The following are suggested ages for health checks. Check at other times if there are parental or other reasons for concern

Birth to 5 years old	Neonatal – 6 Months	6-12 Mnths	1 yo	2 yo	3 yo	4 yo	5 yo
Completed -	Date:	Date:	Date:	Date:	Date:	Date:	Date:
Confirm diagnosis with chromosomes (if not confirmed, important to identify translocations for recurrence risk counseling)							
Screen for hypothyroidism (newborn screen, if state newborn screen is T4 based, obtain TSH in addition)							
Observe for any signs of gastrointestinal malformations (duodenal atresia, malrotation, hirschsprung's disease)							
Monitor for signs of poor feeding or aspiration, low threshold to order swallow study							
Check for cataracts and nystagmus, refer immediately if vision concerns							
Echocardiogram in all infants (immediately if concerns otherwise by 6-8 wks)							
If stridor or other signs of airway anomaly, refer for evaluation							
CBC in newborn to check for transient myeloproliferative disorder or polycythermia, if present, manage per specialty input.							
Discuss and refer to Early Intervention Services							
Genetic Counseling referral (if not already obtained)							
Refer parents to support groups and literature							
Address questions about alternative therapies							
Consider RSV prevention if premature or other co-morbidity							
Repeat thyroid screening (TSH) at 6 months, 12months, then yearly							
Vigilant attention to middle ear effusion (If canals preclude exam, consult ENT for microscopic examinations [every 3-6 months])							
Review growth (use WHO growth charts under age two, either WHO or CDC after age 2, do not use DS specific growth charts)							
Discuss development with particular focus on feeding, language, social, and gross motor skills and services to optimize							
Refer to Ophthalmologist by 6 months, follow-up at 12 months then yearly.							
Check hearing at birth, 6months, 12months, then yearly							
Review access to support groups and Early Intervention services at all well child visits							
Ensure follow-up for all prior diagnosed health issues (e.g., cardiac, GI etc.)							
Lab: Thyroid Screening (TSH, free T4 if TSH abnormal) at 6 and 12 months, then yearly							
Lab: Hemoglobin at 12 months, then yearly							
Lab: Iron studies (ferritin and CRP) at 12 months and yearly if medical or dietary risk factor for iron deficiency							
Lab: If diet contains gluten, review signs and symptoms of celiac disease, if present, screen for celiac disease (need for repeat testing if symptoms persist unclear at this time but consider rescreen if new symptoms emerge)							
Biannually, educate families on symptoms of myelopath, avoidance of trampoline under age 6 (with supervision only after age 6), potential risk of contact sports/gymnastics, and perform neurologic examination yearly							
Monitor for symptoms of obstructive sleep apnea. Sleep study if any symptoms, otherwise sleep study at age 4. Repeat as clinically indicated							
Discuss transition from early intervention program to developmental preschool that will occur at age three.							
Consider pneumovax if co-morbidities							

adapted for the Medical Home Portal 2013

Note: Children with Down syndrome are at increased risk for leukemia and for obstructive sleep apnea.

Ages 5-12 years old	6 yo	7 yo	8 yo	9 yo	10 yo	11 yo	12 yo
Completed -	Date:	Date:	Date:	Date:	Date:	Date:	Date:
Ensure follow-up for all prior diagnosed health issues (e.g., cardiac, GI etc.)							
Monitor growth (WHO or CDC charts, not DS specific charts)							
Review diet/nutrition/exercise, specific emphasis on lifestyle to prevent obesity							
Annual hearing screening							
Annual vision screening every 2 years							
Lab: Annual Thyroid Screening (TSH))							
Lab: Annual hemoglobin (or hematocrit)							
Lab: If risk factors for iron deficiency, annual screen (ferritin and CRP)							
Lab: Consider repeat screen for celiac disease							
Educate families on symptoms of myelopath, avoidance of trampoline and perform neurologic examination yearly,							
If child has OSA, monitor effectiveness of treatment. If no OSA, monitor for emergence of symptoms indicating need for evaluation.							
Discuss development with particular focus on language and social skills and services to optimize							
Discuss behavior, referral for evaluation and supports if challenging							
Discuss menstrual hygiene management; contraception							

Note: Children with Down syndrome are at increased risk for leukemia and for obstructive sleep apnea.

Ages 13 – Adult	13 yo	14 yo	15 yo	16 yo	17 yo	18 yo	19 yo
Completed -	Date:	Date:	Date:	Date:	Date:	Date:	Date:
Ensure follow-up for all prior diagnosed health issues (e.g., cardiac, GI etc.)							
Monitor growth (WHO or CDC charts, not DS specific charts)							
Ensure follow-up for all prior diagnosed health issues (e.g., cardiac, GI etc.)							
Monitor yearly for symptoms/signs of mitral or aortic valvular dysfunction, ECHO if concerns							
Lab: Continue thyroid screening annually							
Lab: Continue yearly hemoglobin							
Lab: If risk factors for iron deficiency, annual screen (ferritin and CRP)							
Lab: Consider repeat screen for celiac disease							
Continue hearing screening annually							
Continue vision screening every 3 years							
Educate families on symptoms of myelopath, avoidance of trampoline and perform neurologic examination yearly							
Discuss menstrual hygiene, sexuality, risk of victimization, contraception (girls fertile, boys rare fertility but has been reported; 50% recurrence for both)							
If child has OSA, monitor effectiveness of treatment. If no OSA, monitor for emergence of symptoms indicating need for evaluation.							
Discuss parents goals for child (e.g., academic, self help, athletic, social) and child's progress, ensure supports to optimize							
Discuss behavior, referral for evaluation and supports if challenging							
Discuss transition issues, group homes, settings, and other community supported employment							

Bull MJ and the American Academy of Pediatrics Committee on Genetics.
Health Supervision for Children With Down Syndrome.
Pediatrics. 2011;128(2):393-406

adapted for the Medical Home Portal by Lisa Samson-Fang, MD 2013