



Boston Children's Hospital
Down Syndrome Program

Important Updates to the NEW
2022 AAP Health Guidelines for
Children and Adolescents with
Down Syndrome



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5.16.23



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I have no financial disclosures or conflicts to disclose

Relevant information:

- Board of Directors for the Down Syndrome Medical Interest Group
- Board of Directors for the National Down Syndrome Congress, Executive committee
- Massachusetts Down Syndrome Congress Scientific Advisory Council
- Board of Directors for the Federation for Children with Special Needs
- **My sister, Heather, has Down syndrome**

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2022 AAP Updated Health Care Guidelines for Children and Adolescents

CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care


American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

Health Supervision for Children and Adolescents With Down Syndrome

Martin J. Bull, MD, FAAP; Tracy Tostler, MD, FAAP; Stephanie L. Semenski, MD, FAAP; Catherine Christensen, MD, MS, FAAP; Ronald W. Gruch, MD, MS, FAAP; THE COLLEGE ON GENETICS



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A Tour of the New AAP Guidelines

- Associated medical, developmental, behavioral and mental health conditions in Down syndrome
- New updates and additions
- Review of previous, reaffirmed recommendations
- Resources



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Associated Medical Conditions

- More research between 2011-2022 allowed for expanded list of associated medical conditions
 - 11 associated medical conditions in 2011
 - 36 associated medical conditions in 2022
- General prevalence estimates for most conditions remained the same, however, some notable differences



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AAP Guidelines

- The Prenatal Visit
- Age-Based Visit Recommendations:
 - Newborn Infants: Birth to 1 month
 - Infancy: 1 month – 1 year
 - Early Childhood: 1 to 5 years
 - Late Childhood: 5 to 12 years
 - Adolescence to Early Adulthood: 12 to 21 years
- Health Supervision
 - Physical Examination / Laboratory Studies / Diagnostic Tests
 - Issues to Discuss and Review
 - What to Evaluate For
- Anticipatory Guidance
- Resources for Families




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What is New?




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The Prenatal Visit

- Newest non-invasive prenatal **screening test** is the **cell free DNA test (cfDNA)**
- Now widely available, more sensitive and specific than other screening tests
- High Down syndrome detection rate: 99.7%
- Low false positive rate: 0.04% (singleton pregnancies)
- NOT a diagnostic test
- Diagnostic testing options are the same: chorionic villus sampling (T1) and amniocentesis (T2)
- Any additional testing that may be needed: fetal echocardiogram, specialist consultations
- Balanced Counseling, Family support




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Communication

- Increased guidance and information on Communication with families
- This has been a clear area of need, as families often report a less than ideal experience when health care providers communicate that their newborn has Down syndrome.

→ Provide accurate and updated information (e.g. life expectancy)
 → Discuss health problems to anticipate, screen, and monitor for
 → Use a balanced approach
 → Include the perspectives of individuals with Down syndrome, their parents, and their siblings

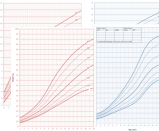


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Growth Charts

- **Down Syndrome Growth Charts (2015)**
- For girls / boys
- 0-36 months: Weight, length/height, head circumference, weight/length 2-20 years: Weight, height, head circumference
- BMI 2-10 years: available for Down syndrome, but not on CDC website
- BMI for > 10 years: use general CDC charts



Zemel BS, Papan-M, Stallings VA, Hall W, Schadt K, Freedman DC, Thorpe P. Growth charts for children with Down syndrome in the United States. Pediatrics. 2015 Nov; 113(6):e1204-11.
<https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>



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Anemia and Iron Deficiency / Insufficiency

- New recommendations to check specifically for iron deficiency / insufficiency, which is not more likely in DS, but harder to detect

→ Recommended annual testing with:


- 1) Annual CBC with differential AND
- 2) Ferritin and C-reactive Protein (CRP) (markers of inflammation)

OR

Ferritin, serum iron and total iron binding capacity (TIBC)

- MCV is not reliable because macrocytosis (large RBC) is common; Red cell distribution width (RDW) may be helpful

→ Ferritin less than 50 can also contribute to restless sleep / sleep problems, and may be treated with iron supplementation



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Vision Screening

- Vision Problems – prevalence increased from 60 to 60-80%

→ **Photoscreening: an additional / alternative way to conduct vision screening, which is recommended annually at every well visit**

- Can detect risk factors for vision loss: refractive errors, ocular misalignment, focusing problems, differences between eyes
- Especially useful in children who cannot reliably use an eye chart
- Camera images can be interpreted by a trained test administrator or by software incorporated into the equipment
- Refer when any abnormalities (may minimize need for pediatric ophthalmology)

- Risk for **keratoconus** (1-13%); typically diagnosed after puberty: can cause blurred vision, corneal thinning, corneal haze

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Down Syndrome and Autism

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- Prevalence dramatically increased from 1% (2011) → 7-19% (2022)

→ Recognize overlapping features and symptoms, and consider wide range of abilities seen in Down syndrome
→ Know about diagnostic overshadowing

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Down Syndrome and Autism

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- Symptoms may be present between 2-3 years of age, but diagnosis often delayed and may be subtly different
- Clinical Presentation:
 - Compared to those with ASD (without DS):
 - Better imitation, relating and receptive skills
 - Compared to those with DS:
 - Lower cognitive abilities
 - More difficulty with language and communication (verbal and nonverbal)
 - Social difficulty
 - More frequent repetitive behaviors and sensory symptoms
 - More mood and behavior challenges

→ Screen 18-24 months of age with standard screening tools
→ Refer to specialized evaluation and intervention as soon as suspected

Specialists must be aware of dual diagnosis, know how to evaluate for distinguishing features, must rule out other medical / mental health conditions, consider overall developmental abilities

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Down Syndrome & Behavioral and Mental Health Needs

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- Consider medical problems that can be associated with behavior changes (thyroid, celiac, sleep, gastroesophageal reflux, constipation)
- Consider co-occurring diagnoses: Attention Deficit Hyperactivity Disorder (ADHD), psychiatric, behavioral disorders
- Developmental and behavioral intervention strategies depending on child's age, severity of problem, setting in which problem occurs
- Referral for community treatment programs, psychosocial services, behavioral specialists
- Special considerations for use of psychoactive medications
 - Children with Down syndrome may be more sensitive (side effects)
 - There is limited scientific evidence available
 - Start Low, Go Slow

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Regression

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- An increasingly recognized phenomenon also known as:
 - Down Syndrome Disintegrative Disorder
 - Unexplained Regression
 - Catatonia (decreased movement or increased movement)
- Characterized by loss of skills, marked mood / behavior changes, adaptive skills, mental health symptoms
- Occurs in late childhood, adolescents, young adults

→ Refer to specialist familiar with the diagnosis and evaluation / treatment

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What remains the same?

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Previous recommendations included in the 2011 update were reaffirmed in the 2022 guidelines

There is an increased emphasis on certain conditions as a result of new research and information since 2011

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Hearing / Ears

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- Hearing issues are among the most common associated conditions
- Optimal hearing is essential for speech development and learning
- High risk for middle ear disease (otitis media, effusion)

→ Newborn hearing screen AND re-screen at 6 months for confirmation and refer immediately if abnormal

→ Check every 3-6 months until tympanic membranes can be visualized and tympanometry can be performed reliably – if canals are too narrow, referral to otolaryngologist to visualize

→ Behavioral audiogram and tympanometry should be performed every 6 months until normal hearing levels are established bilaterally by ear-specific testing (usually after 4 years of age), then annually

→ If normal hearing is not established by behavioral testing, additional screening by otoacoustic emissions or diagnostic BAER should be performed, with sedation if necessary

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Cardiovascular


→ **Echocardiogram for all at birth, regardless of whether fetal echocardiogram was performed**

- Monitor for fast breathing, difficulty breathing, and poor weight gain which may be signs of congestive heart failure
- Pulmonary hypertension is associated with Down syndrome even in those without structural heart defects

→ Examine annually for acquired mitral and aortic valvular disease in older patients with Down syndrome.

→ Obtain an echocardiogram if increasing fatigue, shortness of breath, trouble with exertion, or new examination findings of a murmur

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Feeding / Respiratory

- Stridor, wheezing, noisy breathing, respiratory infections common
- Feeding challenges very common, due to both oromotor problems and oropharyngeal dysfunction
- If symptoms such as marked hypotonia, underweight, slow feeds, choking with feeds, recurrent or persistent respiratory symptoms, desaturations with feeds:
 - refer for skilled feeding assessment or video feeding study
- Aspiration may be an overlooked cause of recurrent respiratory symptoms

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Hematological / Cancer

- Increased risk of hematologic abnormalities and leukemia
 - Transient abnormal myelopoiesis (TAM), polycythemia common in newborn
 - TAM usually regresses spontaneously but may require chemotherapy
 - Close monitoring needed due to increased risk for leukemia in first 4 years
- Overall leukemia risk is higher than in general population but still rare (1%)
- Overall risk for solid tumors is not increased in Down syndrome, and there is lower risk for some
 - **Testicular cancer is the only solid tumor that is more common in Down syndrome**
 - Clinicians should palpate testes during routine health supervision examinations to look for changes like lumps or swelling
 - Physician may recommend routine screening by a trusted adult

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Infantile Spasms / Epilepsy

- Infantile spasms: sudden, brief jerks of the neck, trunk, extremities lasting 1-2 seconds, developmental regression may occur
 - EEG shows hypsarrhythmia, treatment with ACTH (1st choice), Vigabatrin, others
 - Not all funny movements are seizures: reflux, startle, stereotypic movements, shuddering, sleep myoclonus, paroxysmal tonic upgaze
- Complex partial and generalized seizures / epilepsy may occur, typically in late childhood/adolescence
- Moyamoya disease: narrowing of carotid artery, abnormal vessels in brain

→ **Regular monitoring for signs of neurologic dysfunction**

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Thyroid Function


- Risk of congenital hypothyroidism 2-7%

→ **Verify results of newborn thyroid function screening which should include TSH (some only do free T4), recheck at 6 months**

- Risk of thyroid abnormalities is 50% by late childhood
- Many children have mildly elevated TSH and normal free T4 (Subclinical hypothyroidism)
- Hyperthyroidism is less common but there is higher risk in Down syndrome

→ **Measure TSH annually or sooner if symptoms, and every 6 months if antithyroid antibodies were detected**

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Cervical Spine / Atlantoaxial Instability

- **Symptom screening:** change in walking or use of arms or hands, changes in bowel or bladder function, neck pain, head tilt, change in head posture, weakness
- **Precautions for protecting spine during anesthetic, surgical, radiographic procedures, treatment**
- **No routine radiographic screening as it is not reliable**
- Trampoline use should be avoided, unless part of structured program with appropriate supervision and safety measures (all children)
- Increased risk with contact sports

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Gastrointestinal

- Increased risk for congenital anatomical problems (Hirschsprung, duodenal atresia)
- Constipation, gastroesophageal reflux common
- Celiac disease common, but no routine lab screening for asymptomatic children
 - Review symptoms potentially related at health supervision visits: diarrhea, constipation, slow growth or weight gain, anemia, abdominal pain, behavioral problems
 - If symptomatic, check Tissue transglutaminase IgA, and total IgA, refer if abnormal, confirmation through diagnostic biopsy (while on gluten-containing diet)

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Obstructive Sleep Apnea

- Markedly increased risk
- Discuss symptoms at all visits: heavy breathing, snoring, restless sleep, uncommon sleep positions, frequent night awakening, daytime sleepiness, pauses in breathing, behavior problems
- Obesity is a risk factor
- There is poor correlation between parent report of symptoms and sleep study results
 - Polysomnogram at pediatric sleep laboratory for all children with Down syndrome between ages 3-4 years
- Adenotonsillectomy typically recommended for treatment, requires post-surgical repeat sleep study

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Immune System

<ul style="list-style-type: none"> • Autoimmune Conditions • Hashimoto thyroiditis, Graves disease • Celiac disease • Type 1 diabetes • Juvenile idiopathic arthritis • Autoimmune skin conditions: vitiligo, alopecia areata, hidradenitis suppurativa (inflammatory) 	<ul style="list-style-type: none"> • Infection Risk • Skin infections • Respiratory infections <p>→ Regular immunizations recommended</p> <ul style="list-style-type: none"> • RSV prophylaxis (< 2y w/ qualifying conditions) • 23-valent pneumococcal polysaccharide (≥ 2y if chronic cardiac or pulmonary disease)
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Puberty / Adolescents / Early Adults

- Development of self-help and hygiene skills
- Counsel and prepare for transition times: elementary to middle school and change to several teachers and changing classes, academic inclusion may become more difficult
- Teach, model, respect privacy and discuss appropriate management of sexual behaviors
- Discuss need for gynecologic care

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Key Take Home Updates

- New resources stressing best practices for communication with families to improve the ways families receive information
 - Includes updates on prenatal testing, sharing balanced and accurate information, offering guidance and emotional support
- Increased emphasis on co-occurring neurodevelopmental, behavioral, mental health conditions, and recommendations for screening, diagnosis, and management
 - Children and adolescents with Down syndrome should receive the same specialized intervention and care as children with these conditions who do not have Down syndrome
- Most health care supervision guidelines remain the same with a few important additions:
 - Photoscreening for eye abnormalities when available
 - Down syndrome specific growth charts
 - Laboratory assessment specifically for iron deficiency / insufficiency annually
 - Testicular examinations

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Resources and References

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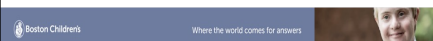


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Resources for families and age-based checklists

<https://www.healthychildren.org/english/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx>




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Boston Children's Hospital Clinical Report Summary
Down Syndrome Program

The recommendations below are based on the article "Health Supervision for Children and Adolescents With Down Syndrome" by Marilyn J. Bull, MD, FAAP; Tracy Trotter, MD, FAAP; Stephanie L. Santoro, MD, FAAP; Colaine Christensen, MD, MS, FAAP; Randall W. Grout, MD, MS, FAAP THE COUNCIL ON GENETICS published in Pediatrics on April 18, 2022. The entire article is available for free download: <https://publications.aap.org/pediatrics/article/doi/10.1542/peds.2022-057010/186778/Health-Supervision-for-Children-and-Adolescents>. The AAP has also developed age-based parent handouts based on this article which are available online: https://www.healthychildren.org/english/health-issues/conditions/developmental-disabilities/Documents/Health_Care_Information_for_Families_of_Children_with_Down_Syndrome.pdf.




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- 1. Audiology:** Because of the risk of both conductive and sensorineural hearing loss (which can develop as children get older even if not initially present), the AAP recommends testing hearing every six months until ear-specific hearing is established and then annually through age 21. If the ear canals are too narrow and the tympanic membrane cannot be seen, internal ear examinations should be performed by an otolaryngologist.
- 2. Vision:** Children with Down syndrome have an increased risk for congenital cataracts, strabismus, refractive errors, and amblyopia. The AAP guidelines recommend evaluation by a pediatric ophthalmologist within the first 8 months of life. Also assess for lamellar slit obstruction. Vision screening is recommended at every well-child check and photoscreening can be used if pediatric or specialized ophthalmology visits are not available. Some eye conditions can also begin after puberty. Ongoing assessment for cataracts, refractive errors, and keratoconus is recommended.
- 3. Growth and Nutrition:** Children with Down syndrome are at risk for developing obesity or being overweight. For all children with Down syndrome we recommend a healthy diet emphasizing fresh fruit and vegetables and whole grains. Total caloric intake should be below the recommended daily allowance for children of similar height and age. We recommend eliminating sugar-sweetened beverages and limiting juice to no more than 4 ounces daily. Routine exercise is also very important as many individuals with Down syndrome are less active than their same-age peers. Growth parameters should be plotted on Down syndrome specific growth charts in infancy and early childhood. Down syndrome specific BMI charts should be used for children up to age 10 years, and CDC BMI charts should be used for children with Down syndrome over age 10 years. The most recent growth charts published by Zemel et al in 2015 can be found on the CDC website (<https://www.cdc.gov/nchs/data/tables/DownSyndromeGrowthCharts.html>). Peditools offers a percentile calculator at their website (www.peditools.org). Note that body mass index should be plotted on the general CDC growth chart for children over 10.




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- 4. Celiac:** There is an increased incidence of celiac disease in children with Down syndrome. The AAP does not recommend celiac screening for children with Down syndrome with no symptoms. If abdominal complaints develop (diarrhea, constipation, poor weight gain, bloating, abdominal pain), in a child whose diet contains gluten, screening should be performed including tissue transglutaminase IgA and a total IgA.
- 5. Cervical Spine:** Children with Down syndrome are at increased risk for atlantoaxial instability. The current health supervision guidelines from the American Academy of Pediatrics (AAP) do not recommend routine cervical spine films but recommend discussion of signs of spinal cord involvement with families. We routinely review that changes in gait, legging, hands and feet, unusual positioning of the head, neck pain, new onset of weakness or change in behavior or bowel function could be symptoms of spinal cord involvement and, if present, require prompt medical attention. Additionally, it is important to maintain the cervical spine in a neutral position during any anesthetic, surgical, or radiographic procedure to minimize risk of spinal cord injury.
Note: If a child with Down syndrome presents with symptoms suggestive of AAI, a lateral neck x-ray should be performed. If abnormal, urgent referral to orthopedics or neurosurgery is indicated. If the lateral film is within acceptable limits, then extension and flexion films should be performed with a request for the radiologist to report atlantoaxial interval in all 3 views along with neural canal width and then referral to orthopedics or neurosurgery (note: this referral should be expedited if the films are concerning).
- 6. Thyroid Screening:** Children with Down syndrome are at increased risk for thyroid disorders (more commonly hypothyroidism but hyperthyroidism also occurs). The AAP recommends checking thyroid function with a TSH at birth, six months, and one year and then an annual TSH. We generally check a free T4 as well. If thyroid autoantibodies are present, TSH should be measured every 6 months.

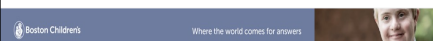


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Down Syndrome Program

- 7. Obstructive Sleep Apnea (OSA):** The American Academy of Pediatrics recommends that all children with Down syndrome have at least one sleep study between age 3 and 4, as research has shown that a substantial number of children with Down syndrome have some degree of OSA. For patients planning a sleep study at Boston Children's Hospital, we have created a "Social Story" to prepare available on our Patient Resource page: www.childrenshospital.org/downsyndrome (click Patient Resources in sidebar).
- 8. Dental:** Children with Down syndrome often have delayed eruption and even missing teeth. Gingivitis is also common. We recommend routine dental care at least every 6 months.
- 9. Anemia and Iron Deficiency:** The American Academy of Pediatrics recommends that children with Down syndrome be tested annually starting at 1 year of age for iron-deficiency or anemia with a screening hemoglobin as well as either iron studies or serum ferritin along with a CFP as ferritin is an acute phase reactant so a normal or high ferritin level could be falsely reassuring. Note: the MCV is generally not a helpful screen in children with Down syndrome as the MCV is generally elevated in children with Down syndrome and a normal MCV does not exclude iron deficiency. Additionally, low ferritin (<50) may be associated with sleep problems, and assessment of iron deficiency may be considered for children with sleep difficulty. Treatment with iron supplementation may be considered if there are sleep problems as well.
- 10. Neurological:** A complete neurological history and examination is recommended. Children with Down syndrome have increased risk of seizures including infantile spasms and other conditions including moyamoya, as well as other benign movement disorders.

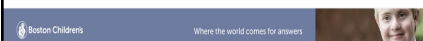


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- 11. Dermatology:** dry skin, eczema, molluscum, keratosis pilaris, and autoimmune skin conditions, and inflammatory skin conditions are common in Down syndrome, and referral to a dermatologist may be needed.
- 12. Oncologic:** Children with Down syndrome are at increased risk of acute lymphoblastic leukemia and acute myeloid leukemia, especially if there is a history of transient abnormal myelopoiesis (formerly called transient myelodysplastic disorder). Monitoring for symptoms is recommended. The overall risk for solid tumors is not increased in Down syndrome. However, there is an increased risk of testicular cancer in Down syndrome, and clinicians should palpate testes during routine health supervision examinations.
- 13. Vaccinations:** routine vaccinations are recommended. Influenza vaccination should be provided annually. Respiratory syncytial virus may be considered for children < 2 years who have conditions, children with chronic cardiac or pulmonary disease should receive the 23-valent pneumococcal polysaccharide vaccine at 2 years or older.



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Resources for Families from the AAP Guidelines


- Prenatal and Infancy
 - Brighter Tomorrows Supporting Families: <https://hdl.umk.edu/projects/brighter-tomorrows>
 - Supporting Families with Down Syndrome: <https://www.supportingfamilieswithdownsyndrome.org/> Supporting families with accurate information about Down syndrome (includes Lettercase resources), Interdisciplinary Human Development Institute, University of Kentucky.
 - Lettercase resources: www.lettercase.org. Provides prenatal and postnatal counseling for families. One copy provided free to professionals and family.
 - Down Syndrome Diagnosis Network: www.dsdiagnosisonline.org. Cohorts of families with similar due dates or birthdates connected in moderated Facebook groups.
 - Skallerup SJ. *Babies With Down Syndrome: A New Parents Guide*, 3rd ed. Bethesda, MD: Woodbine House; 2009. (English and Spanish editions available at www.woodbinehouse.com) Provides guidance for raising and caring for a child with Down syndrome through age 5.



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Resources for Families from the AAP Guidelines


- Childhood
 - Pusechel SM, ed. *A Parent's Guide to Down Syndrome: Toward a Brighter Future*. Bethesda, MD: Brookes Publishing; 2001.
 - Stein DS. *Supporting Positive Behavior in Children and Teens with Down Syndrome: The Respond but Don't React Method*. Bethesda, MD: Woodbine House; 2016.
 - www.woodbinehouse.com. Variety of books for families, therapists, and teachers of children with Down syndrome.
- Adolescence
 - Got Transition: <http://www.gottransition.org/>. Provides resources and guidance for transition.
 - Couwenhoven T. *Boys Guide to Growing Up—Choices & Changes During Puberty Written for Persons with Intellectual Disability*. Bethesda, MD: Woodbine House; 2012.
 - Couwenhoven T. *Girls Guide to Growing Up—Choices & Changes During Puberty Written for Persons with Intellectual Disability*. Bethesda, MD: Woodbine House; 2012.
 - Simmons J. *The Down Syndrome Transition Handbook: Charting Your Child's Course to Adulthood*. Bethesda, MD: Woodbine House; 2010. Available at: www.woodbinehouse.com.



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Resources for Families from the AAP Guidelines



- Across the Lifespan
 - DS Connect: The Down Syndrome Registry: <https://dsconnect.nih.gov>. Families and patients connect with researchers and health care providers and may participate in clinical studies and take confidential health-related surveys that help achieve better understanding of people with Down syndrome across the lifespan.
 - National Down Syndrome Congress: www.ndsccenter.org. Information, advocacy, education, and support for persons with Down syndrome, siblings, and families in English and Spanish.
 - National Down Syndrome Society: www.ndss.org. Advocacy and information regarding Down syndrome across the lifespan.
 - Family Voices: <https://familyvoices.org/affiliates/>. Family-to-family health information centers that help families navigate systems needed for children with special health care needs.
 - Parent to Parent USA: <http://www.p2usa.org/nrc2014>. Provides support to deal with challenges of raising children with special health care needs.
 - Parent Training and Information Centers: <https://www.parentcenterhub.org>. Resources in each state that inform, prepare, and assist families with navigation of the education system.
 - March of Dimes: www.marchofdimes.com. Information for parents on health issues related to pregnancy and birth defects.
 - Down Syndrome Education International: www.downed.org. Resources for educators and parents relevant to communication, numeracy, speech, and supporting inclusion.
 - Canadian Down Syndrome Society: www.cdss.ca. Resources for families on a variety of issues related to Down syndrome.
 - ABLE ACT 2014: <http://www.irs.gov/government-entities/State-local-government/able-act-complex-2014>. <https://www.irs.gov/government-entities/State-local-government/able-act-complex-2014>. The benefit for people with disabilities allows states to create tax-advantaged savings programs for eligible people with disabilities (designated beneficiaries) and can help pay for qualified disability expenses.
 - DISCU Down syndrome clinic to you: www.dsctu.org. Provides personalized health and wellness information about Down syndrome to caregivers and primary care physicians.




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Additional resources available at Global Down Syndrome Foundation

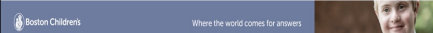
IMPORTANT NEW RESOURCE FROM THE AMERICAN ACADEMY OF PEDIATRICS
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Thank you to my team and the patients and families who inspire me and the work I do every day



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