What is New and What is Important in Guidance for Down Syndrome Health Care

National Down Syndrome Congress'
51st Annual Convention
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Faculty Disclosure Information

- In the past 12 months, I have had no relevant financial relationships with the manufacturer of any commercial product or any provider of commercial services discussed in this CME activity

- I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation

Learning Objectives

- Understand genetic screening and testing for Down Syndrome
- Learn about counseling families with a new diagnosis of Down syndrome - genetics management, future prognosis, and resources
- Provide effective medical care for a child or adolescent with Down syndrome
- Know how to find a summary of Down syndrome specific care and resources that are helpful to families

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FROM THE AMERICAN ACADEMY OF PEDIATRICS

Guidance for the Clinician in Rendering Pediatric Care

Clinical Report—Health Supervision for Children With Down Syndrome

Marilyn J. Bull, MD, and the COMMITTEE ON GENETICS

CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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Health Supervision for Children and Adolescents With Down Syndrome

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Expanded Associated Medical Conditions

TABLE 1 Medical Problems Common in Down Syndrome

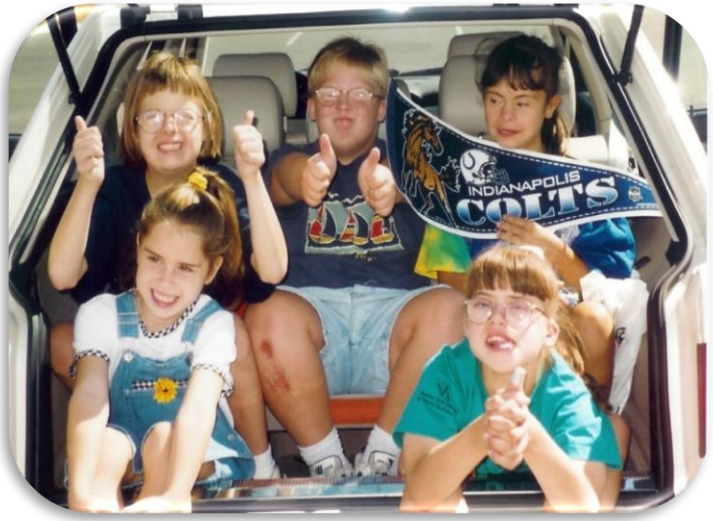
Condition	%
Hearing problems	75
Vision problems	60
Cataracts	15
Refractive errors	50
Obstructive sleep apnea	50–75
Otitis media	50–70
Congenital heart disease	40–50
Hypodontia and delayed dental eruption	23
Gastrointestinal atresias	12
Thyroid disease	4–18
Seizures	1–13
Hematologic problems	
Anemia	3
Iron deficiency	10
Transient myeloproliferative disorder	10
Leukemia	1
Celiac disease	5
Atlantoaxial instability	1–2
Autism	1
Hirschsprung disease	<1

TABLE 1 Medical Problems Common in Down Syndrome

Condition	%
Hearing problems	75
Vision problems	60–80
Nystagmus	3–33
Glaucoma	<1–7
Nasolacrimal duct occlusion	3–36
Cataracts	3
Strabismus	36
Refractive errors	36–80
Keratoconus	1–13
Obstructive sleep apnea	50–79
Otitis media with effusion	50–70
Congenital heart disease	40–50
Feeding difficulty	31–80
Respiratory infection	20–36
Dermatologic problems	56
Hypodontia and delayed dental eruption	23
Congenital hypothyroidism	2–7
Antithyroid antibody positive (Hashimoto thyroiditis; incidence dependent on age)	13–39
Hyperthyroidism	0.65–3
Thyroid disease by adulthood	50
Gastrointestinal atresias	12
Seizures	1–13
Hematologic problems	
Anemia	1.2
Iron deficiency	6.7
Transient abnormal myelopoiesis	10
Leukemia	1
Autoimmune conditions	
Hashimoto thyroiditis	13–39
Graves' disease	1
Celiac disease	1–5
Type 1 diabetes	1
Juvenile idiopathic arthritis	<1
Alopecia	5
Symptomatic atlantoaxial instability	1–2
Autism	7–19
Hirschsprung disease	<1
Moyamoya disease	Down syndrome 26 times greater in patients with Moyamoya than Down syndrome in live births

Down Syndrome

- Most common chromosomal cause of intellectual disability
- 1/700 births = ~6,000 babies are born with DS yearly
- Over 250,000 individuals with Down syndrome live in the US



Mai CT, et al. National population-based estimates for major birth defects, 2010–2014. *Birth Defects Research.* 2019; 111(18): 1420-1435.
Presson AP,et al. Current estimate of Down Syndrome population prevalence in the United States. J Pediatr. 2013 Oct;163(4):1163-8

Prenatal Screening and Diagnosis of Down Syndrome

Newest non-invasive prenatal screening test = cell-free DNA (cfDNA) (10+ weeks)

- Widely available
- Most sensitive and specific
  - Down syndrome detection rate 99.7% and false positive rate 0.04% in singleton pregnancies

NOT a diagnostic test

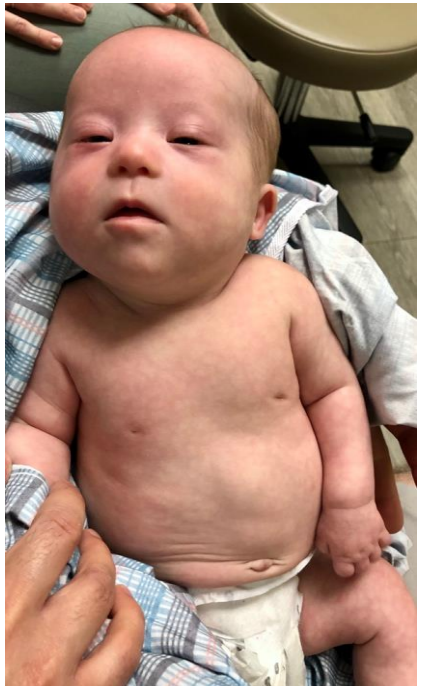
Diagnostic testing remains the same - KARYOTYPE

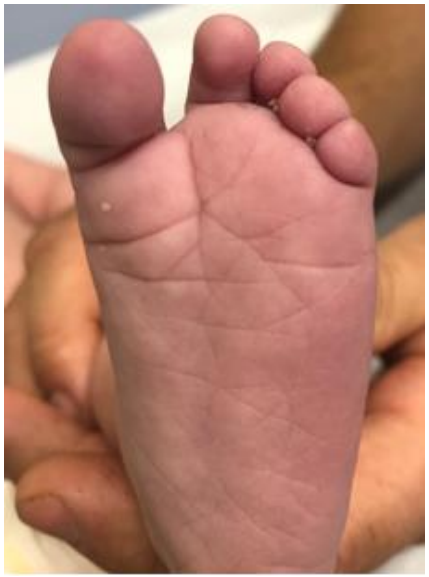
- Chorionic villus sampling
- Amniocentesis

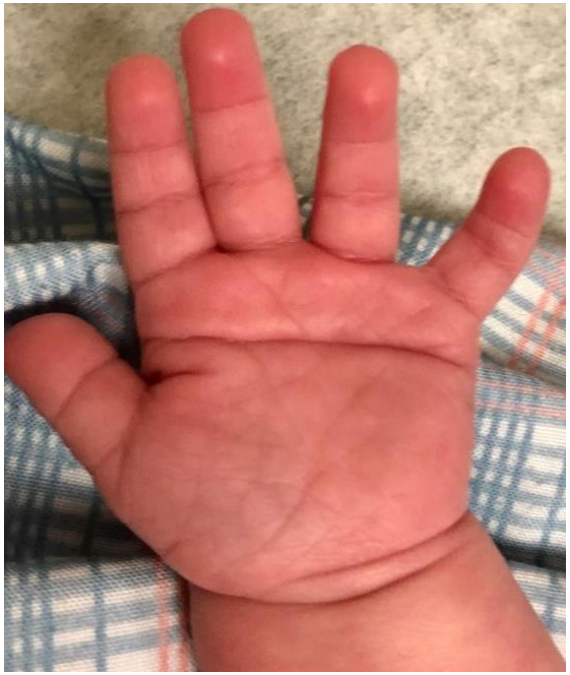
Benefits of Prenatal Detection

- Allows for optimal delivery arrangements
- Prenatal diagnosis of other conditions
  - Congenital heart disease
  - Duodenal atresia
- Opportunity for parent/family support and resources

Newborn Diagnosis







Following Recommendation is Based on Family Feedback

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Delivering the News: Best Practices

- Congratulations!!!
- Refer to the baby by name and have baby present if possible
- Meet with family as soon as diagnosis is suspected
- Have a support person present for mother/family
- Give up to date/accurate information
- Offer connection to family supports and resources

TABLE 3 Communicating With Families[31]

At diagnosis, immediate advice remains pertinent regarding the need to:

- first, congratulate the family
- have infant present; refer to infant by name
- use a respectful bedside manner
- time discussion after labor is complete and as soon as diagnosis is suspected (not necessarily confirmed)
- have a support person present for mother, father, and family members as appropriate
- use a cohesive, physician-led team approach

Helpful discussion will include:

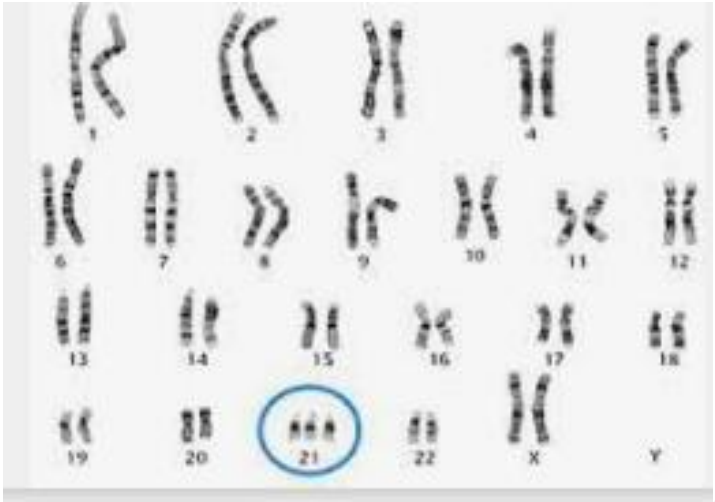
- up-to-date, accurate information
- a balanced approach rather than relying on personal opinions and experience
- person-first language (ie, child *with* Down syndrome)[32];
- connection to other parents and resource groups
- discussion of life potentials for people with Down syndrome

Share with families the interplay within families and individual perspectives:

- individuals with Down syndrome: nearly 99% indicated that they were happy with their lives, and 97% liked who they are and encouraged health care professionals to value them, emphasizing that they share similar hopes and dreams as people without Down syndrome[33];
- parents: 79% felt their outlook on life was more positive because of people with Down syndrome[31];
- siblings: 88% felt that they were better people because of their siblings with Down syndrome[33];
- a majority of families report unanimous feelings of love and pride
- positive themes dominate modern families[34]

Appropriate Genetic Testing for Down Syndrome

- Karyotype
- Do NOT order a Chromosome Microarray (CMA)



Chromosomal Causes of Down Syndrome

- **96% Meiotic nondisjunction** (95% occur in egg, with recurrence risk of 1% until mother's age risk exceeds 1% at age 40, and it then increases according to maternal age)
- **3–4% Translocation** (usually occurs with 1 chromosome 21 attached to chromosome 14, 21, or 22)
  - 14/21 translocation (1/3 of patients have a parent carrier with balanced karyotype)
  - 90% have mother as the carrier parent, with a recurrence chance of 10%–15%
  - 10% have father as the carrier, with a recurrence chance of 2%–5%
  - 21/21 translocation (1/14 of patients have parent carrier with a balanced karyotype), Carrier parent equally likely mother or father, with recurrence chance of 100%
- **1–2% Mosaicism**: number of affected cells vary between individuals; clinical findings
  - vary widely, Medical complications fewer and intellectual disability often less severe
- **Partial trisomy:** duplication of delimited segment of chromosome 21 present,
  - Extremely rare

Pediatrics 2022
Adapted NEJM 6/2020

Early Discussions with Families

- Confirm laboratory diagnosis
- Review karyotype with family when available
- Discuss child's specific findings and symptoms
- Refer for genetic counseling (if not already done)
- Work for smooth transition from newborn care to primary care

The Basics

- Regular well visits with primary care

- Standard immunization schedule recommended, including yearly flu shots

Congenital Heart Disease (CHD)

- Newborn echocardiogram recommended
  - Even if fetal echo was normal
- 40-50% incidence of cardiac anomalies
- Increased risk of pulmonary hypertension - with and without CHD
- For those with CHD, follow-up as recommended by Cardiology
- Retest if concerning symptoms develop

Hematology/Oncology Concerns in Down Syndrome

- **Obtain a CBC with differential by 3 days and then annually**
  - Transient Abnormal Myelopoiesis (TAM) (up to 9%)
    - Usually regresses in first 3 months though can require treatment
    - Increased risk of AML in the 1st 4 years of life (up to 30%)
    - Manage TAM and other persistent hematologic problems with subspecialist guidance
  - Macrocytosis present in ~1/3 children with DS
  - Leukemia (ALL and AML) = lifetime risk (~1%)
  - Solid tumor risk not increased except testicular cancer
    - **Examine testicles at every well child visit and by a trusted adult at home**

Other Hematology Abnormalities

- Anemia – incidence same as general population
- Iron insufficiency – increased incidence (6.7%)
  - MCV not useful due to frequent macrocytosis
- Iron insufficiency can cause restless sleep
  - Consider treating with iron if ferritin is less than 50 micrograms

Anemia and Iron Deficiency Screening

CBC with differential in first 3 days

CBC with differential

And either

Ferritin and C-Reactive Protein

Or

Serum iron and Total iron-binding capacity

Annually thereafter

Thyroid Problems

- Incidence
  - Congenital hypothyroidism (2-7%)
  - Thyroid disease by adulthood (50%)
    - Autoimmune hypothyroidism
    - Subclinical thyroid disease
    - Hyperthyroidism

Thyroid Problems

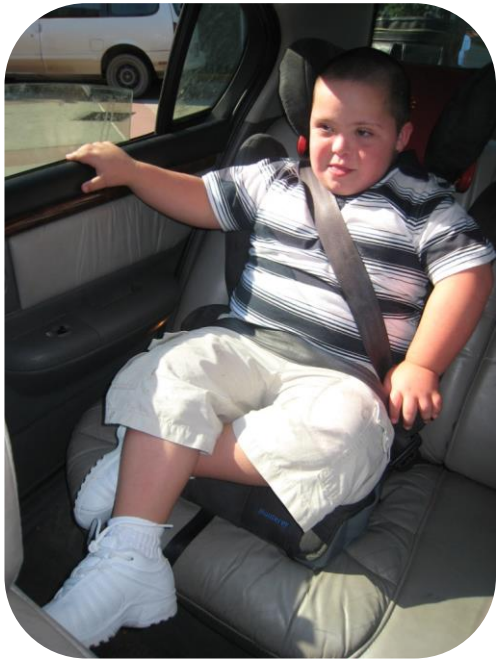
- Newborn TSH - Newborn screen or TSH
  - Newborn screen is adequate in Indiana
- Obtain TSH at age 6 months, 12 months, and then yearly
- **If TSH is elevated, obtain anti-thyroid antibodies**
- **If anti-thyroid antibodies are elevated, repeat TSH every 6 months**

Feeding Difficulties

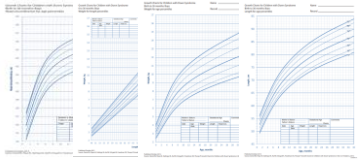
- Swallowing dysfunction is common
- Higher risk with any of the following:
  - Prematurity
  - Marked hypotonia
  - Slow feeding
  - Choking/desaturations with feeding
  - Slow weight gain
  - Unexplained respiratory symptoms
- If concerns, refer for skilled feeding evaluation or video feeding study

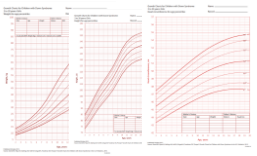
Nutrition in Down Syndrome

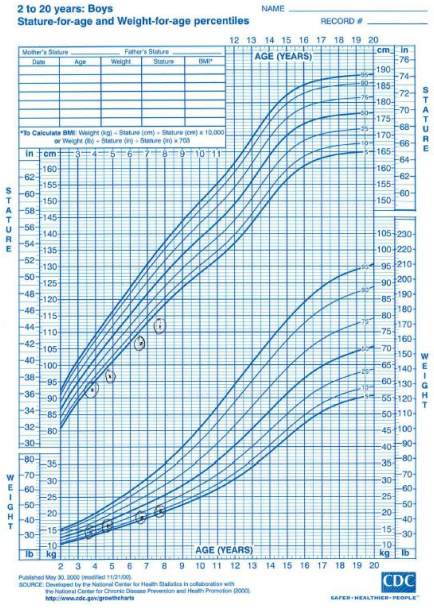
- Early poor weight gain associated with feeding difficulties or heart disease
- Excessive weight gain and obesity in childhood/adolescence
- Diets are often low in calcium and iron
- Goal – Establish healthy pattern for activity and diet
- Recommend **Down syndrome specific growth charts**!

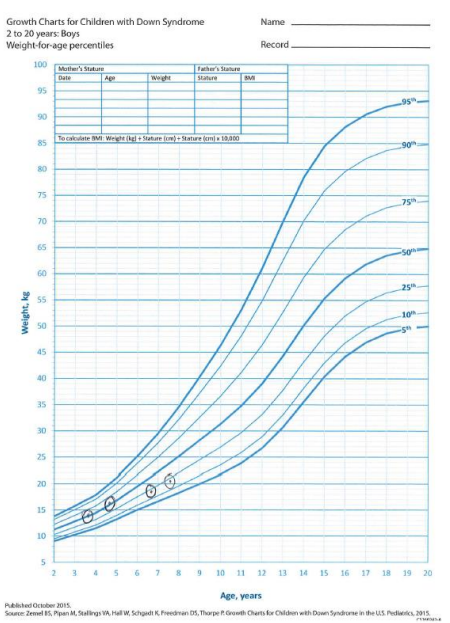


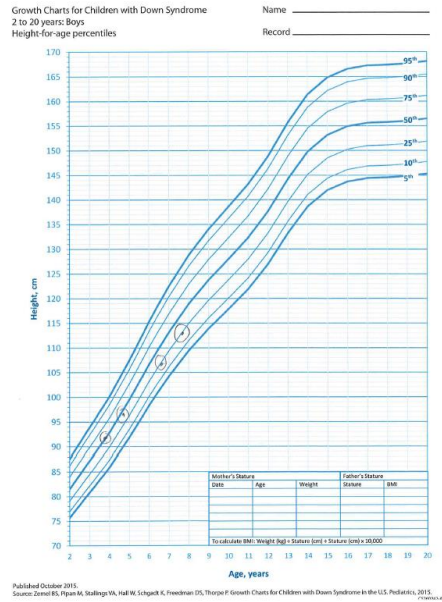
Down Syndrome Growth Charts











Available at www.CDC.gov

Monitoring Growth in Children with Down Syndrome

- Use Down Syndrome weight/length ratio from 0-3 years
- Use CDC BMI after 10 years
- Compare and contrast WHO/CDC charts with Down syndrome specific charts
  - Growth trends are similar and can be reassuring for families

Airway Assessments

- Birth-1 month
  - Monitor for stridor, wheezing, noisy breathing and associated feeding issues and/or cardiorespiratory problems, refer as needed
  - If hypotonia or history of cardiac surgery, obtain car seat study prior to discharge
- 1-6 months
  - Discuss risk and symptoms of OSA with family and refer for evaluation as needed

Obstructive Sleep Apnea

- Throughout childhood as risk very increased
- Review symptoms of OSA
  - Heavy breathing, snoring, uncommon sleep positions, daytime sleepiness, apneas, behavior problems, night awakenings
- Obesity is a risk factor
- **Recommend polysomnogram in pediatric sleep lab between ages 3-4 years for all**
- Repeat PSG 3-6 months after adenotonsillectomy

Gastrointestinal Conditions

- Neonatal – duodenal atresia, anorectal atresia/stenosis
- Neonatal/infancy – Hirschsprung disease less than 1%
- Constipation – very common!
  - Dietary, limited fluids
  - Hypotonia
  - Hypothyroidism

GI – Celiac Disease

- Age over 1 year and on gluten containing diet
  - Review possible symptoms: diarrhea, atypical constipation, slow growth, anemia, abdominal pain or bleeding, refractory behavior problems
- If symptoms suggestive, obtain:
  - Tissue transglutaminase IgA AND Quantitative IgA
- If labs are abnormal, refer for further assessment

Hearing Assessments

- Review newborn hearing screen, if failed:
  - Obtain ABR or otoacoustic emission, refer to otolaryngologist
  - Refer to Early intervention within 48 hours if hearing loss present
- Repeat hearing testing
  - Age 6 months, 1 year, and **every 6 months** until able to complete ear specific testing
  - Once able to participate in ear specific testing, test **yearly**
- Hearing is critical for communication development

Ophthalmology Evaluation

- Assess for cataracts at birth
- By age 6 months, ophthalmology referral
  - Strabismus, cataracts, nasolacrimal duct obstruction, refractive errors, glaucoma, nystagmus are all more common
- **Photo screening** (if available at every well visit)
  - Ophthalmology referral if abnormal or annual ophthalmology if photo screening not available
  - Ages 1-5 years – yearly ophthalmology
  - Ages 5-12 years – every other year ophthalmology

Atlantoaxial Instability (AAI)

- AAI risk = 1-2% symptomatic
- Screen by history and physical exam NOT routine X-rays
  - Plain radiographs are not predictive of increased risk
  - MRI or CT may be more predictive but too invasive for screening
- If symptoms are present, obtain a plain lateral neck radiograph in neutral position and refer to specialist
- Need to discuss proper positioning during procedures to avoid excessive neck extension

ATLANTOAXIAL INSTABILITY

Children with Down syndrome are at increased risk of developing compression of the spinal cord called atlantoaxial instability. This problem is caused by a combination of low tone, loose ligaments and bony changes. The spinal cord can be pressed by the bones and cause nerve damage. Symptoms of nerve damage can occur at any time and there is no test or x-ray that can tell who is at risk.

Parents should watch their child for any changes in how they walk, use their arms or hands, a head tilt, complaints of pain in the neck, or change in bowel or bladder function, change in general function or new onset weakness.

Contact physician immediately for an x-ray of the neck in neutral position if your child has:

Change in how he or she walks
Change in how he or she uses arms/hands
Change in bowel or bladder control
Head stays tilted
Neck Pain
New onset weakness
Decreased activity level or function

If the x-ray is abnormal or symptoms persist, the child should be referred as soon as possible to a pediatric neurosurgeon or pediatric orthopedic surgeon experienced in managing atlantoaxial instability.

Down Syndrome Program
Riley Hospital for Children at IU Health

Atlantoaxial Instability and Activities

- Sports participation
  - Contact sports may have increased risk of spinal cord injury
- Trampolines should be avoided without a structured training program with supervision
- Special Olympics requires documented physical exam

Behavior Concerns

- Review behavior and social communication at each visit
- Common conditions in children with Down syndrome
  - ADHD, anxiety, obsessive-compulsive behaviors, non-compliance, wandering, autism, Down syndrome regression disorder
- Behavior is communication – there is always a reason
- Use developmentally appropriate interventions
- When behavior medications are used, need to start low doses and make changes slowly

Down Syndrome and Autism Dual Diagnosis

- Increased chance over general population (7-19%)
- Symptoms may be present as early as 2-3 years
- May use standard screening tools for autism and should screen between 18-24 months
  - None have been well studied in Down syndrome
- Diagnosis is often delayed
  - Children with autism and Down syndrome have better imitation, relating, and receptive skills compared to children with idiopathic autism
- Refer for appropriate evaluation and intervention as soon as suspected

Acute Regression in Down Syndrome

- Other names: catatonia, disintegrative disorder
- Can occur in late childhood, adolescence, early adulthood
- Symptoms
  - Loss of skills
  - Marked mood changes
  - Develop repetitive thoughts or behaviors that interfere with usual life

Acute Regression in Down Syndrome

- Important to assess for contributing medical problems
  - Thyroid abnormalities
  - Celiac disease
  - Obstructive sleep apnea
  - GERD, constipation

- Refer to specialists familiar with diagnosis and treatment

Other Areas

- Neurology disorders
  - Seizures including infantile spasms, Moya-Moya disease
- Dermatology
  - Xerosis, alopecia areata, vitiligo, folliculitis
- Dental
  - Delayed tooth eruption and missing teeth are common

Therapies and Education

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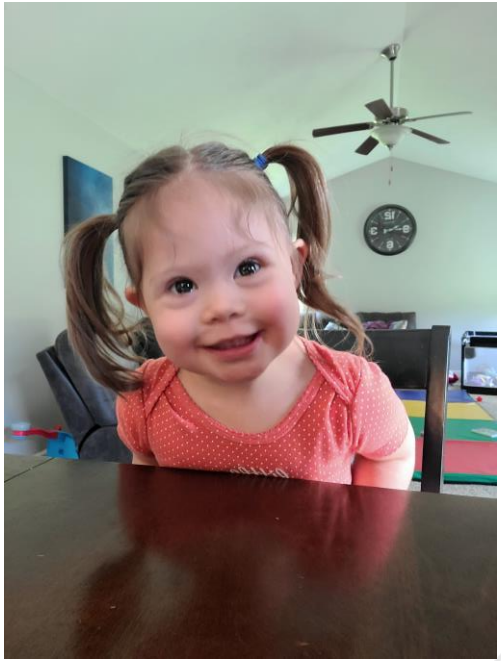
Early Intervention

- Part C of IDEA covering birth to 3 years
- Individual family service plan (IFSP)
  - Therapists are consultants
  - Parents are the primary therapists
- Optimized intervention is the goal
  - Is the child receiving appropriate types and amounts of therapy?
  - What are the current goals? Homework?



Individual Education Plan (IEP)

- Part B of IDEA covering age 3 years through 22 years
  - Appropriate classroom placement – least restrictive environment (LRE)
    - **Ideally has role models with typically developing peers**
  - Appropriate education goals
  - School based therapies
  - Transportation guidelines
  - Nutrition requirements
  - Optimize program to meet each person's needs and goals

Transitions – A Strength of Pediatricians!

- Begin early – encourage families to think about and prepare for what's coming next
- Self-help skills, social boundaries, sexuality, puberty, sexual health
- School transitions to ensure appropriate goals and services
- Increase awareness of community resources

Transitions – A Strength of Pediatricians!

- Enable family planning for future social activities, employment, adult care

- Shared decision making for education, guardianship, long term financial planning

New Recommendations Summary

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New for Down Syndrome Health Supervision

- Updated prenatal screening and maternal/fetal counseling
- Enhanced information presentation for new parents
- CBC with differential as a newborn and annually
- Follow TAM closely with specialist consultation
- Obtain ferritin and CRP OR serum iron and TIBC annually
- Increase awareness of solid tumor incidence and monitor for testicular cancer

New for Down Syndrome Health Supervision

- Obtain antithyroid antibodies if recurrent TSH elevation
  - Obtain TSH every 6 months if elevated
- Down syndrome specific growth charts (except CBC BMI after age 10 years)
- Obtain a baseline polysomnogram between ages 3-4 years
- Use photo screening for ophthalmologic assessment if available
- Screen early for autism and refer for intervention
- Start transition early, focus on puberty and sexual health, emphasize shared decision making

Supplemental Information

SUPPLEMENTAL FIGURE 1. Summary of Down syndrome-specific care.

Action	Pre-natal	Birth up to 1 mo	1 mo up to 1 yr	1 yr up to 5 yr	5 yr up to 12 yr	12 yr up to 21 yr
1. Confirm DS diagnosis with either CVS or amniocentesis prenatally or karyotype postnatally	■					
2. Review recurrence risk and offer the family referral to a clinical geneticist or genetic counselor.						
3. Offer parent-to-parent and support group information to the family.						
4. Use CDC DS-specific growth charts to monitor weight, length, weight-for-length, head circumference, or BMI. Use standard charts for BMI after age 10 years.		All healthcare visits				
5. Order an echo, to be read by a pediatric cardiologist.		■				
6. Feeding assessment or video study if any: marked hypotonia, underweight (<5th %ile weight-for-length or BMI), slow feeding or choking with feeds, recurrent or persistent abnormal respiratory symptoms, desaturations with feeds		Any visit				
7. Obtain objective hearing assessment (may be in NBS protocols) and follow EHDI protocols.		■	Up to 6 mo			
8. If TM can't be visualized, refer to otolaryngologist for exam with microscope until reliable TM and tympanometry exams are possible		Every 3-6 mo				
9. Car safety seat evaluation before hospital discharge.						
10. CBC with differential		By day 3				
11. If TAM, make caregivers aware of risk/signs of leukemia (e.g., easy bruising/bleeding, recurrent fevers, bone pain)		■				
12. TSH		At birth (if not in NBS)	Every 5-7 mo	Annually, and every 6 mo if antithyroid antibodies ever detected		
13. RSV prophylaxis based on AAP guidelines.		Annually		Through 2 yr		
14. Discuss cervical spine-positioning for procedures and atlantoaxial stability precautions.		All HMV		Biennially		
15. Assess for CAM use, discourage any unsafe CAM practices.		All HMV				
16. Refer children to early intervention for speech, fine motor or gross motor therapy.		Any visit	Up to 3 yr			
17. If middle ear disease occurs, obtain developmentally-appropriate hearing evaluation.			When ear clear	After treatment		
18. Rescreen hearing with developmentally-appropriate methodology (BAER, behavioral, ear-specific).			Start at 6mo, every 6 mo until established normal bilaterally by ear-specific testing, then annually			
19. Refer to ophthalmologist with experience and expertise in children with disabilities.			By 6 mo			
20. CBC with differential if easy bruising or bleeding, recurrent fevers, or bone pain			Any visit			
21. Assess for sleep-disordered breathing; if present, refer to physician with expertise in pediatric sleep disorders.			At least once by 6 mo, then all subsequent HMV thereafter			
22. Ensure child is receiving developmental therapies, and family understands and is following therapy plan at home.		All HMV				
23. CBC with differential and either (1) a combination of ferritin and CRP, or (2) a combination of serum iron and Total Iron Binding Capacity				Annually		
24. If a child has sleep problems and a ferritin less than 50 mcg/L, the pediatrician may prescribe iron supplement.				Any visit		
25. Vision screening			All HMV, use developmentally-appropriate criteria	Photoscreen (all HMV); if unable, refer to ophthalmologist annually	Photoscreen (all HMV); if unable, refer to ophthalmologist biennially	Visual acuity or photoscreening at all HMV, or ophthalmology-determined schedule
26. If a child has myelopathic symptoms, obtain neutral C-spine plain films (see text for details).				Any visit		
27. Obtain polysomnogram.				Between 3-5 yr		
28. Prepare family for transition from early intervention to preschool.				At 30 mo		
29. Discuss sexual exploitation risks.				At least once	At least once	At least once
30. Make developmentally-appropriate plans for menarche, contraception (advocate/offer LARC), and STI prevention.					As developmentally-appropriate, then all subsequent HMV	
31. Discuss risk of DS if patient were to become pregnant.					At least once	At least once
32. Assess for any developmental regression.			All HMV			
33. Discuss and facilitate transitions: education, work, finance, guardianship, medical care, independent living					All HMV starting at 10 yr	

■	Do once at this age
	Do if not done previously
	Repeat at indicated intervals
(border)	See report for end point

Abbreviations: DS, Down syndrome; CVS, Chorionic villus sampling; HMV, Health Maintenance Visit; BMI, Body mass index; CDC, Centers for Disease Control; EHDI, Early Hearing Detection and Intervention; NBS, Newborn screen; CAM, Complementary and alternative medicine; BAER, Brainstem auditory evoked response; TM, Tympanic membrane; TAM: transient abnormal myelopoiesis

Health Guidance Summary by Age

AAP 2022

Health Issues

Conditions

- Abdominal
- ADHD
- Allergies & Asthma
- Autism
- Cancer
- Chest & Lungs
- Chronic Conditions
- Cleft & Craniofacial
- Common Surgical Procedures
- COVID-19
- Developmental Disabilities

HEALTH ISSUES

LISTEN ▶ Español

Text Size - +

Children with Down Syndrome: Health Care Information for Families

Down syndrome is a common condition caused by having "extra" copies of genes on the 21st chromosome. Those extra genes change development during

https://www.healthychildren.org/

Thank You

- Our patients and their families

- Co-authors:
  - Dr. Tracy Trotter
  - Dr. Stephanie Santoro
  - Dr. Celanie Christensen
  - Dr. Randall Grout


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What is New and What is Important in Guidance for Down Syndrome Health Care

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51st Annual Convention

Panel Discussion

Marilyn J. Bull, MD, FAAP
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Indianapolis, IN

Brian Skotko, MD, MPP
Mass General Hospital
Boston, MA

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DSMIG-USA®
Down Syndrome Medical Interest Group-USA

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WHO ARE THE MEMBERS OF DSMIG-USA?

DSMIG-USA® is a group of health professionals committed to promoting the optimal health care and wellness of individuals with DS across the lifespan. Members of this DSMIG-USA® are professionals from a variety of disciplines who provide care to individuals with Down syndrome and/or their families. This may include physicians, scientists, psychologists, nurses, genetic counselors, educators, therapists, clinic coordinators, and related health professionals. Members may also include individuals who engage in research or health policy relevant to Down syndrome. Most members work in specialized Down syndrome clinics, at academic institutions, university- and community-based medical centers, or private practice. Students, Residents, Fellows and other Trainees are welcome to join.

NEW! THE AMERICAN ACADEMY OF PEDIATRICS| CLINICAL REPORT| APRIL 18 2022 - Health Supervision for Children and Adolescents With Down Syndrome, read more here.

GLOBAL Medical Care Guidelines for Adults with Down Syndrome can be accessed here.

The Family-Friendly version of the *GLOBAL Medical Care Guidelines for Adults with Down Syndrome* is now available! Important topics include behavior, dementia, cardiovascular disease, obesity, thyroid disease, and more. *Download your FREE copy!*

https://www.dsmig-usa.org/