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Pediatric Healthcare Guidelines

Laura Cifra-Bean MD
Medical Outreach Director, DSANEO
American Academy of Pediatrics
Health Supervision for Children and Adolescents with Down Syndrome

Guidelines were first created in 1994. They were revised in 2011, and most recently in 2022.

At birth, the baby will get a thorough evaluation looking for any medical issues, especially:

a heart problem

a gastrointestinal problem

feeding issues

an eye problem, such as cataracts
Heart Problems

https://www.heart.org/en/health-topics/congenital-heart-defects

Typical Heart Structure

AV Canal

Figure A

Atrial septum
Right atrium
Right ventricle

Left atrium
Left ventricle
Ventricular septum

Atrioventricular Canal Defect

Defect
Gastrointestinal Problems

Duodenal atresia

Typical duodenum
Hirschsprung's Disease

https://www.childrenshospital.org/conditions/hirschsprungs-disease
Testing at Birth

Blood work:
- Karyotype to show chromosomes
- Complete blood count with differential
- State metabolic screen will check thyroid function

Other tests
- All babies should get an **echocardiogram**
- Hearing screen
- Car seat challenge to make sure baby’s oxygen stays normal while in car seat
Transient Myeloproliferative Disorder

Increased number of immature white blood cells

Most of the time this goes away

Puts the baby at risk for leukemia in the first 4 years of life

Needs evaluation by a hematologist
Birth to 1 Month

Monitoring of feeding and weight gain

Lactation consultation can be very helpful
http://www.mobimotherhood.org/helping-babies-who-have-down-syndrome-learn-to-breastfeed.html
https://www.llli.org/breastfeeding-info/special-needs/

Referral to early intervention
https://ohioearlyintervention.org/

Safe sleep
1 month to 1 year

Attention to feeding and weight gain

Repeat hearing test at 6 months old if newborn test was normal

Repeat thyroid testing at 6 months and 1 year

Evaluation by an eye doctor by age of 6 months

Blood count and test for iron deficiency at 1 year

Vaccines per usual schedule, some babies might qualify for RSV prevention
Concerns throughout Childhood

- Obstructive Sleep apnea (OSA)
- Overweight or obesity
- Blood abnormalities
- Atlantoaxial instability
From the American Academy of Pediatrics
“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.”

AAI Precautions for All Children with Down syndrome

Avoid excessive flexion or extension of the neck during any, anesthetic, surgical or radiologic procedure to minimize risk of spinal cord injury

Avoid trampoline use unless it is part of a training program with appropriate supervision and safety measures

Participation in contact sports such as football, soccer, and gymnastics, places children at risk for spinal cord injury
Common Concerns

Autism

Attention Deficit Disorder

Behavior concerns

Regression

Risk for abuse
Autoimmune diseases
  Celiac disease
  Thyroid disease
  Type 1 diabetes
  Alopecia
  Juvenile Idiopathic Arthritis

Skin Conditions

Moya Moya

Dental care

Infectious diseases, especially pneumonia
1 Year to 5 Years

Monitor development, and screen for autism at 18 to 24 months

Begin dental care
https://www.ndss.org/resources/dental-issues-syndrome

Sleep study at age 3-4 years, even if no sign of disordered breathing during sleep

Every check up monitor growth and assess for feeding issues

Yearly blood work to monitor blood count, iron deficiency and thyroid function

Yearly vision and hearing screening, review signs of atlantoaxial instability

Vaccines per usual schedule
Procedures can get more difficult at this age so consider social stories to prepare your child for a new experience
https://sites.google.com/view/charlies-clinic/development/behavior#h.tngljx5m65ui

This age is also a good time to talk to kids about body parts, appropriate touch, and privacy

These things will come up as potty training begins

At age 3yrs, responsibility for services and education transitions from early intervention to the school district and the child moves from an IFSP to an IEP
5 through 12 years old

Monitor weight

Starting at 10 years old look at BMI on the chart not specifically for people with Ds to gauge weight status

Many teens and adults with Ds are overweight or obese and that puts them at risk for medical problems such as sleep apnea, type 2 diabetes, and joint problems

A healthy diet and regular exercise are important to prevent weight gain
doi: 10.1542/peds.2016-0541
Monitor development and behavior

Discuss transition to middle school

Encourage increasing ability in the bathroom


https://adscresources.advocatehealth.com/toilet-hygiene/
Transition to middle school

Social media and internet use

Discuss puberty

Timing of puberty is not delayed

Period management

https://adscresources.advocatehealth.com/menstrual-hygiene/

https://www.nytimes.com/wirecutter/reviews/thinx-period-panties/
Story About How to Change My Pad

1. This is how I will change my sanitary pad.
2. I will go to the bathroom for privacy.
3. I can keep clean pads and underwear in a bag so I can bring the supplies to the bathroom with me.
4. When I go to the bathroom, I will pull down my pants and my underwear.
5. I will sit on the toilet.
6. I will take the dirty pad out of my underwear.
7. I will fold it in half so that it can't hurt the blood. Then I will wrap it in toilet paper.
8. I will throw the pad and toilet paper in the garbage can.
9. I will NOT throw it into the toilet.
10. I will make sure there is no blood on my underwear. If there is, I will need to put on clean underwear.
11. I will get a new, clean sanitary pad out of my bag.
12. I will open the wrapper and take the pad out.
13. I will remove the paper so I can see the sticky tape.
14. I will put the clean pad in my underwear with the sticky side touching my underwear.
15. I will make sure the pad sticks to my underwear.
16. I can throw the paper away in the garbage can.
17. The pad will cling to my underwear and pants.
18. I will take my bag of supplies with me when I leave the bathroom.
19. I will wash my hands.
20. If I have questions, I can ask my mom.
Terri Couwenhoven resources

Books:
A Girls’ Guide to Growing Up
Choices & Changes in the Tween Years

The Boys’ Guide to Growing Up
Choices & Changes During Puberty

Podcasts:
Puberty and Sexuality Issues, Part 1

Puberty and Sexuality Issues, Part 2
Assess hearing and vision

Yearly blood count, iron studies and thyroid functions

Vaccines per usual schedule
Thank You

## TABLE 1
Medical Problems Common in Down Syndrome

<table>
<thead>
<tr>
<th>Condition</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing problems</td>
<td>75</td>
</tr>
<tr>
<td>Vision problems 60–80</td>
<td></td>
</tr>
<tr>
<td>Nystagmus</td>
<td>3–33</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>&lt;1–7</td>
</tr>
<tr>
<td>Nasolacrimal duct occlusion</td>
<td>3–36</td>
</tr>
<tr>
<td>Cataracts</td>
<td>3</td>
</tr>
<tr>
<td>Strabismus</td>
<td>36</td>
</tr>
<tr>
<td>Refractive errors</td>
<td>36–80</td>
</tr>
<tr>
<td>Keratoconus</td>
<td></td>
</tr>
</tbody>
</table>
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
Moya Moya disease      Down syndrome 26 times greater in patients with Moyamoya