



# Welcome

A Parent's Guide to Medical Care was designed to help you learn more about the general medical needs of infants, children and adolescents with Down syndrome. Each brochure in this series will guide you through the age-based medical recommendations for children with Down syndrome, so that you can better work with your child's healthcare provider.

## Always...

- Bring up any concerns you may have about your child with your child's doctor.
- Tell your child's doctor about any medications or home remedies your child is taking.
- Tell your child's doctor right away if you notice any of the following: changes in the way your child walks or uses their arms or hands; a change in urination; any weakness; neck pain or head tilt.
- Tell your child's doctor about any heavy breathing, snoring, uncommon sleep positions, frequent night awakening, daytime sleepiness, pauses in breathing and behavior problems. These could be signs of additional healthcare concerns.

## COMMUNITY RESOURCES

**Break the Barriers**  
www.breakthebarriers.org  
(559) 432-6292

**Central Valley Regional Center (CVRC)**  
www.cvrc.org  
4615 N. Marty Ave.  
Fresno, CA 93722  
Fresno: (559) 276-4300  
Merced: (209) 723-4245

**CITI Kids**  
965 N. Sunnyside Ave., #24  
Clovis, CA 93611  
(559) 327-8450

**Down Syndrome Association of Central California (DSACC)**  
www.dsacc.org  
1491 W. Shaw Ave.  
Fresno, CA 93711  
(559) 228-0411

**Exceptional Parents Unlimited Children's Center**  
www.epuchildren.org  
4440 N. First St.  
Fresno, CA 93726  
(559) 229-2000

**National Down Syndrome Congress**  
www.ndscenter.org  
(800) 232-6372

Healthcare Website:  
www.ds-health.com

**National Down Syndrome Society**  
www.ndss.org  
(800) 221-4602

**Parenting Network – Visalia Family Resource Center**  
1900 N. Dinuba Blvd., Suite C  
Visalia, CA 93291  
(559) 625-0384

**Valley Children's Hospital – Family Resource Center**  
(559) 353-6178

**Based on the Clinical Practice Guidelines of the American Academy of Pediatrics**

"Health Supervision for Children with Down Syndrome." *Pediatrics* (Vol. 128, No. 2, August 1, 2011, pp. 393-406)

"Down Syndrome Health Care Guidelines." National Down Syndrome Society



# DOWN SYNDROME

*A Parent's Guide to Medical Care*



CHILDREN – 5 to 13 years

# HEALTHCARE GUIDELINES

## CHILDREN — 5 to 13 years

### Your Child's Growth

Ask your child's doctor to review the Down syndrome-specific growth charts with you at each visit. Children with Down syndrome are at increased risk of obesity. A good way to help avoid this is to establish a routine of healthy eating and exercise. Ask your child's doctor for a consult with a nutritionist if your child is overweight.

### Gastrointestinal Health

Children with Down syndrome may have additional problems with their digestive tract. Tell your doctor if your child has problems with constipation (hard stools). Additional testing for celiac disease may be indicated if your child is having symptoms such as diarrhea, excessive gas, bloating, poor appetite, abdominal pain or weight loss.

### Heart Health

If your child has been diagnosed with a heart condition, their doctor will continue to monitor for signs of heart failure. Your child's cardiologist (heart doctor) will recommend whether antibiotics are needed before any dental procedure.

### Blood Tests – Iron-Deficiency Anemia

Annual tests for anemia should continue. This may consist of a simple finger stick blood test. If there are signs of anemia, your doctor may explore additional testing.

### Blood Tests – Thyroid Function

Children with Down syndrome are at increased risk of thyroid disease. Thyroid function tests should be obtained once every year in this age group, and sooner if there are additional signs or symptoms.

### Your Child's Hearing

A hearing exam should be performed every six months until both ears test normal. Once both ears test normal, hearing exams can be performed once per year. A referral to an ear, nose and throat (ENT) specialist should be made following any abnormal hearing test.

### Ears, Nose, Throat and Lungs

Respiratory tract infections (infections of the ears, sinuses, nose, throat and lungs), as well as sleep apnea, are more common in children with Down syndrome. Continue to monitor your child for signs of sleep apnea.

### Eyes

All children should have an eye exam by a pediatric ophthalmologist (eye doctor) or ophthalmologist familiar with the healthcare problems of children with Down syndrome every two years, and sooner if concerns arise.

### Development

Children with Down syndrome are typically delayed in motor, language and intellectual development. Referrals to speech therapy, physical therapy and occupational therapy can be made, if indicated. It is important to know that your child is not exempt from other diagnosis such as ADHD (attention deficit hyperactivity disorder) that can affect learning.

### Dental Care

Routine dental care is very important. The risk of tooth decay can be greatly decreased if your child establishes a regular tooth-brushing & flossing routine. Regular dental visits also play a major role in your child's oral health.

### Parental and Family Support

Despite cognitive and developmental delays, children with Down syndrome walk, talk, play and attend school just as other children do. Children with Down syndrome have many wonderful attributes, and can contribute to society in many positive ways. Local and national support groups can continue to be a source of information, as well as a forum in which to discuss your concerns and fears as you step into the school years.

### Vaccines

Children with Down syndrome should receive all routine childhood immunizations, including the seasonal influenza vaccine, unless there are specific contraindications.

### Safety

As with all children, it is important to talk to your child about personal boundaries and appropriate behavior. Additionally, it is not unusual for children with Down syndrome to begin wandering off at this age, and ongoing supervision is important.

Children with Down syndrome are at increased risk of neck injury. If your child wishes to participate in sports, a cervical spine (neck) X-ray should be obtained ahead of time. Trampoline use should be avoided for all children under the age of 6 years, and only under professional (Parental?) supervision over age 6, and only after clearance is obtained from your child's doctor.

### Transition

Continue to work with your child on independence with self-help skills. You may also begin to think about guardianship, conservatorship and financial planning for the future.

