



Welcome

As a new parent of a child with Down Syndrome, you may have many questions. Becoming familiar with Down syndrome is one of the best things you can do. Your child is like every other child in many ways. However, people with Down syndrome can be affected by several additional health conditions.

“Down Syndrome: A Parent’s Guide to Medical Care” is a series of booklets 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.



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

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

Down Syndrome Association of Central California (DSACC)
www.dsacc.org
4277 W. Richert Ave., #102
Fresno, CA 93722
559-228-0411

Exceptional Parents Unlimited (EPU) - Parent and Family Resource Center
www.epuchildren.org
4440 North First St.
Fresno, CA 93726
559-229-2000

National Down Syndrome Congress
www.ndsccenter.org
800-233-6372
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 Healthcare – Family Resource Center
downsyndrome@valleychildrens.org
(559) 353-8880

These guidelines are based on the Clinical Practice Guidelines of the American Academy of Pediatrics and the National Down Syndrome Society.

“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



HEALTHCARE GUIDELINES

INFANT – 1 to 12 months

Your Child's Growth

Children with Down syndrome are usually smaller than other children the same age. There are growth charts designed specifically to track the height and weight of children with Down syndrome. Ask your child's doctor to review the Down syndrome-specific growth charts with you, if available, at each visit.

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 infrequent stools).

Heart Health

Children with Down syndrome are also at increased risk for heart defects. All newborns with Down syndrome should have an echocardiogram (ultrasound) of their heart. If your child has not had a heart ultrasound, speak with your child's doctor.

Blood Tests – Iron-Deficiency Anemia

At 1 year of age, your child's doctor will test for signs of iron deficiency anemia. This may consist of a simple finger-stick blood test. If there are signs of anemia, your doctor may obtain additional blood testing.

Blood Tests – Thyroid Function

As part of routine screening for all children, your child's doctor will test for signs of iron deficiency anemia around 1 year of age. This may consist of a simple finger-stick blood test. If there are signs of anemia, your doctor may obtain additional blood testing.

Your Child's Hearing

Hearing tests are obtained for all newborn infants before hospital discharge. If your child passed the hearing screen at birth, a repeat hearing test should be performed at 6 months of age. If your child failed the newborn hearing test, ask for a referral to a pediatric ear, nose and throat (ENT) specialist.

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. Talk to your child's doctor about symptoms to watch for.

Eyes

All infants should undergo an eye exam by a pediatric ophthalmologist (eye doctor) or ophthalmologist familiar with the healthcare problems of infants with Down syndrome within the first six months of life.

Dental Care

Tooth eruption is often irregular or delayed for children with Down syndrome. Your child's first tooth may not appear until 12-14 months but may be as late as 24 months. Twice daily cleaning and a visit to a dentist is recommended within six months of the first tooth erupting or by 1 year of age.

Development

Children with Down syndrome are typically delayed in motor skills, language and intellectual development. As your child grows, you may begin to notice these delays in motor, language and intellectual abilities. If you have not, ask your child's doctor about a referral to your local Regional Resource Center.

Parental and Family Support

As you adjust to your child's diagnosis, you may continue to experience a wide range of common emotions. If you have not already connected with other parents of children with Down syndrome, you are encouraged to do so. These connections can help you ease any uncertainties, make you aware of community resources, and give you the opportunity to hear about, and share your emotions and experiences.

Vaccines

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

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 change in the way your baby uses her arms or legs, muscle weakness or loss of muscle strength, muscle wasting, spasms or activity that might indicate seizures.

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.