



Welcome

As a new parent of a child with Down syndrome, you probably have many questions. One of the best things you can do is to familiarize yourself with Down syndrome. There are a wide range of health conditions that affect individuals with Down syndrome.

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 change in the way your baby uses their arms or legs, muscle weakness or loss of muscle strength, or muscle wasting.

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

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



PRENATAL — Newborn to 1 month



HEALTHCARE GUIDELINES

PRENATAL — Newborn to 1 month

Where to Start

If you did not receive genetic counseling during your prenatal care or in the hospital at the time of your child's birth, it is a great place to start. Genetic counselors talk with you in detail about your child's diagnosis and many of the medical conditions that affect children with Down syndrome. In addition, genetic counselors can address any concerns you may have regarding future pregnancies. Your local Regional Center will also serve as an excellent source of information regarding your child's diagnosis.

Your Child's Growth

Children with Down syndrome are usually smaller than other children the same age. Your child's growth should be plotted on the Centers for Disease Control growth charts for children with

Finding out that your child has
DOWN SYNDROME IS NOT EASY.

Down syndrome. Ask your child's doctor to review the growth charts with you at each visit.

Gastrointestinal Health

Children with Down syndrome are at increased risk for problems with their gastrointestinal tract. Notify your child's doctor if your child has constipation, vomiting, slow feeding, difficulty swallowing, coughing or choking with feeds, or chronic respiratory symptoms. Your doctor may wish to order additional testing to evaluate for feeding problems. Newborns with

Down syndrome can usually nurse, and many can breastfeed successfully. If you wish to breastfeed, consider speaking with a lactation (breastfeeding) specialist

Heart Health

Children with Down syndrome are also at increased risk for heart defects. All children with Down syndrome should have an echocardiogram (ultrasound) of their heart in the newborn period. A referral to a pediatric cardiologist (heart specialist) should be made if any abnormalities are found.

Muscle Tone and Strength

Part of your newborn's first physical exam should be an assessment of muscle tone. If your child has low muscle tone (or has had heart surgery), a car seat evaluation should be done prior to discharge from the hospital.

Blood Tests

A blood test should be obtained to evaluate your child's complete blood count. Your child's thyroid will also be tested as part of the routine state newborn screening.

Your Child's Hearing

Hearing tests are obtained for all newborn infants before hospital discharge. Children with Down syndrome should receive this hearing screen before they go home. If your child failed the hearing test at birth, a referral to an ear, nose and throat (ENT) specialist is recommended.

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 with Down syndrome should undergo an eye exam by a pediatric ophthalmologist (eye doctor) or an ophthalmologist familiar with the health care problems of infants with Down syndrome.



Development

Newborns with Down syndrome generally behave like other babies their age, and need the same care, attention and love. As your child grows, you may begin to notice delays in motor skills, language and intellectual abilities. Ask your child's doctor about a referral to your local Regional Center to help give your baby a good head start.

Parental and Family Support

When you find out that your child has Down syndrome you may experience a wide range of very typical emotions ranging from joy and elation to anger and denial. Finding and joining support groups can help you ease any uncertainties, make you aware of community resources, and give you the opportunity to hear about the emotions and experiences of people who have been down this path before you.