DSA Down Syndrome Association of San Diego

all Children, are Special

Family Resource Guide

Mission Statement

Our mission is to enhance the quality of life for people with Down syndrome and their families through support, education, and advocacy.

Vision

The Down Syndrome Association of San Diego envisions all people with Down syndrome will be afforded the same life opportunities and valued and respected as contributing members of society.

Dedication: With admiration to people with Down syndrome and their families

Congratulations and Welcome

Congratulations on the birth or anticipated birth of your baby! We understand that you have recently been informed that your baby has Down syndrome. Initially, you may feel overwhelmed by this information and inadequately prepared for the future of your child. The Down Syndrome Association of San Diego would like to offer [you] emotional support, information and resources.

First and foremost, you are not alone. We have all shared this emotional roller coaster of confusion and uncertainly.   ***All Children Are Special*** was designed to assist parents in gaining insight and knowledge about Down syndrome.   You will soon discover that your baby… like all babies… is unique. Down syndrome is just one aspect of your child's whole being. This ***Family Resource Guide*** provides current information about Down syndrome and resources, both local and national. Additionally, at your request, we can arrange for a "support parent" to contact you. Almost without exception, parents will agree that their primary source of information and support has come from sharing their experience with one another. No one else will understand your emotions better.

When informing family members and friends of the birth of your baby, explain the diagnosis simply and candidly. Like all children, your newborn needs love and nurturing. The way you are handling this new challenge will be communicated to others. Most people will take a constructive and straightforward interest. The involvement of family and friends can be a tremendous help to you and an enlightening experience for them.

Parenting a child with Down syndrome is a rewarding and challenging experience. It has added new character and depth of understanding to our other children, family members and friends. We hope this ***Family Resource Guide*** will provide you with a more complete understanding of Down syndrome and dispel myths commonly associated with the diagnosis. Review this information at your own pace, enjoy your baby and keep in mind…***All children are Special.***

What Is Down Syndrome?

Down syndrome is genetic condition, which affects physical, cognitive and language development due to the presence of an extra chromosome on the 21st pair. People with Down syndrome have 47 chromosomes instead of the usual 46. The degree of development delay affecting the individual is variable.

Down syndrome occurs in approximately one in every 800 to 1,000 live births and affects people of all ages, races and socioeconomic levels. Each year approximately 5,000 to 6,000 babies are born with Down syndrome [in the United States or worldwide]. It is estimated that there are 350,000 people with Down syndrome in the United States.

At present, it is not known what causes Down syndrome. The risk of having a child with Down syndrome increases with advancing age of the mother. However, most babies with Down syndrome are born to mothers under the age of 35 years. It has been reported that older fathers may also be at increased risk of having a child with Down syndrome. The extra chromosome can originate in either the mother or father, but more often in the mother. It is essential for both parents to understand that they are not personally responsible for the extra chromosome, or that their baby has Down syndrome. Down syndrome usually occurs during the development of the sperm or the egg before conception, or immediately following conception. Nothing in the parent's diet, activity, emotional state or past experiences caused this genetic anomaly.

Chromosome Subtypes

There are three main types of chromosome variations in Down syndrome:

Trisomy 21: The majority of people with Down syndrome, approximately 95%, have an extra 21 chromosome. Instead of the normal number of 46 chromosomes in each cell, individuals with Down syndrome have 47.

Translocation: The extra 21 chromosome is attached or translocated on to another chromosome, usually on chromosome 14, 21, or 22. When translocation is determined, a chromosomal analysis of the parents is recommended. Translocation occurs in approximately 3-4% of people with Down syndrome.

Mosaicism: Mosaicism occurs in approximately 1% of the people with Down syndrome. Some cells have 47 chromosomes and other have 46. As a result, the individual may have fewer of the usual physical characteristics. How the baby is affected depends on where these cells are in the body.

How Is the Diagnosis Made?

A baby with Down syndrome is typically identified at birth by the presence of certain physical traits. The most common characteristics include low muscle tone, a slightly flattened facial profile and upward slant to the eyes. Other characteristics include low birth size and weight and possibly heart murmurs. Because these characteristics may be present in babies without Down syndrome, a chromosomal analysis is necessary in order to confirm the clinical diagnosis. A blood sample is taken from the baby to perform this test.

Common Characteristics:

- Small nose with low bridge between eyes
- Small mouth, low muscle tone in tongue
- Ears slightly smaller
- Palms may have only one crease across it (a transverse palmar crease)
- Increased space and crease between 1st and 2nd toes

Although people with Down syndrome may have unique characteristics, generally they are more similar to the average person than they are different. Like all people, individuals with Down syndrome need to experience the full spectrum of life opportunities in order to reach their full potential.

A Healthy Beginning

Your newborn may experience certain health issues which require evaluation and screening. We recommend that every family obtain a copy of the ***Health Care Guidelines for Individuals with Down Syndrome.*** The guidelines are designed to assist the physician in detecting or eliminating certain health issues that can affect people with Down syndrome. You can obtain a copy of the Health Care Guidelines by contacting the Down Syndrome Association of San Diego.

In the newborn period, the DSMIG recommends babies be screened for cardiac problems, cataracts, and hearing loss. Approximately 40 to 45 percent of babies with Down syndrome are born with heart defects. Every newborn with Down syndrome should be evaluated by a pediatric cardiologist, and an echocardiogram (even in the absence of a heart murmur) should be performed. A cardiac condition does not necessarily mean the baby is, or will become, seriously ill. Medical and surgical advances have improved the overall success of treatment and the quality of life for babies with cardiac concerns.

A high percentage of children with Down syndrome experience some degree of hearing loss. The most common cause of hearing loss is due to frequent ear infections or fluid accumulation in the middle ear. The Health Care Guidelines recommend an Auditory Brain Stem Response (ABR), or other objective means of assessment to evaluate hearing by 6 months of age, if not performed at birth. Adequate hearing is essential to the development of good language skills. Periodic medical check ups should include visualization of the eardrum to ensure that no infection is present. Additionally, a vision/ophthalmological exam is advised during the first year or immediately if there are any indications of nystagmus, strabismus, or poor vision.

As you learn about Down syndrome, you will probably read information about alternative therapies past and present. Many of these therapies have not been documented to be safe or effective, and none have been scientifically proven to be of benefit. It is understandable that parents feel a need to explore all modalities that they feel will be beneficial to their child's development. It is equally important to research all aspects of any treatment or intervention with your physician.

Feeding My Baby

All babies vary in their enthusiasm to feed. Some are eager and hungry and seem to know immediately how to suck effectively either from breast or bottle. Others are sleepy, less enthusiastic, or tire quickly when feeding. Mothers learn their baby's feeding habits and adjust the times and amounts of feeds so that their babies thrive appropriately.

Babies with Down syndrome are not different than other infants. Some feed enthusiastically where other take longer to feed and may require more encouragement. It can be worrisome and tiring to spent long periods of time feeding your baby… especially if you have other young children at home. But perseverance pays off as one learns the trick of tickling cheeks, chin and feet or of changing a diaper in the middle of a feed, to remind a baby to wake up. Here are some points to help you in the area of feeding:

- When bottle feeding, mother can tell how much her baby has taken at a feed.

- When breast-feeding, mother may need to express milk in order to maintain sufficient supply if her baby has a weak suck and provides little stimulation to the breast.

- Tongue position is crucial for proper feeding of any baby. The tongue must be under the nipple and not stuck to the roof of the mouth. It is important to check at the beginning of a feed that the nipple and tongue are properly positioned. Otherwise your baby may start to suck, get no milk, and give up feeding.

- Holding your baby upright during feeding may also be helpful in preventing regurgitation of milk.

- If possible, allow your baby to feed as long as he or she wants to. This way the baby will pace him or herself and take the amount that he or she needs.

- Some babies may not gain weight at a steady rate. Do not be alarmed. This slower weight gain is to be expected in some babies with Down syndrome. Particularly, if a congenital heart condition is present.

- The nurses in post-partum units and in the nurseries will help you if your baby has difficulties feeding. Please share any concerns you may have with the nursing staff prior to discharge from the hospital, so that follow up care and support can be arranged in your home for you and your baby.

This section excerpted with permission from A Practical Guide for Parents of Babies with Down Syndrome, The Canadian Down Syndrome Society, 1993 (publication is no longer available).

Note: If feeding problems persist, a consultation with a feeding specialist, occupational therapist or lactation nurse may be necessary. It is important to discuss all concerns with your baby's physician.

Family Life and Your New Baby

For most families, a new is a life altering experience under any circumstances. As you get to know your baby and learn about Down syndrome, you will soon discover that your baby is more similar to other babies than different. As with any new baby, it is important for parents to remain attentive to the needs of the entire family in order to maintain unity and a sense of balance. Your family will experience all of the usual joys and pleasures of family life and more!!!

Your child with Down syndrome deserves the love, respect and dignity that is afforded to all people. He or she will acquire their own individual strengths and uniqueness. Overall development for each child with Down syndrome is varied and levels of support will differ. All children will experience success and should be encouraged to pursue their personal goals and dreams.

Today, there is a vast array of opportunity and options for people with Down syndrome in the school system, workplace and in the community. Many people with Down syndrome are being successfully included into the general education classroom along with their peers. Some people with Down syndrome have their driver's license, some graduate from high school or junior college, and many hold jobs in the private sector.

Yes – Family life takes on a whole new dimension. Our family members with Down syndrome are an integral part of family life as we live, learn and grow together.

Talking About Down Syndrome

Words are powerful and can shape one's perception of people. A diagnosis can label a person reinforcing stereotypes as well as negating individual qualities. It is important to use positive language and accurate terminology when we talk about our children, friends and family members with Down syndrome … Language that reflects dignity, ability and individuality.

When talking about your baby, it is important to place emphasis on the child not the disability. You may hear some people refer to your baby as a "Down's or Down syndrome baby." The appropriate verbiage is a "baby with Down syndrome." As parents and advocates for our children, it is essential to set high standards that will transcend into our communities. Your baby will have a unique personality with his or her own strengths and qualities. Proudly acknowledge your child's individuality and accomplishments while emphasizing the person first.

Looking Towards the Future

The more you know about Down syndrome and how it may affect your child, the easier it will be to nurture his or her growth and development. As with any child, it is virtually impossible to predict the future. Enjoy your baby and celebrate each accomplishment. There are many resources available to you and your family.

In the state of California, Early Intervention Services for babies with Down syndrome are primarily administered through the local Regional Centers; non-profit agencies contracted by the Department of Developmental Services (DDS). Please refer to the Resources Guide for local information.

The California Early Intervention Services Act (SB 1085) states:
Children are our most valuable resource. The investment we make in them today benefits all California tomorrow. The implementation of Part H through California's Early Start Program ensures that infants and toddlers with disabilities and their families receive coordinated services early enough to make a difference.

Please contact the Exceptional Family Resource Center to complete intake for CA Early Start services at 619-594-7416.

Children with Down syndrome benefit from many of the same community programs and services other children do, such as play groups, neighborhood preschools, swimming and music lessons, story times at the library, and other social activities.

Aside from the expertise of professionals, parents can find information and support from the Down Syndrome Association of San Diego. An extensive resource library is available to provide parents with guidance as well as current information. Many of the topics addressed in this guide are explained in further detail in various publications. The DSA of San Diego can provide this information.

Resources:

- AAP Guide for Families of Children with Down Syndrome
- Health Care Information for Families of Children with Down Syndrome
- Rady Children's Down Syndrome Center
- UC San Diego Health Adult Down Syndrome Care
- DS Action
- EFRC CA Early Start Intake Services
- Gigi's Playhouse San Diego
- National Down Syndrome Society
- National Down Syndrome Congress

9245 Sky Park Court, Suite 125, San Diego, CA 92123

619.594.7389 *www.dsasdonline.org*

All Children are Special, Family Resource Guide Fourth Edition © 2020

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