



Connecting
Families
for More
Than 20
Years



**Down Syndrome Connection
of the Bay Area**

Empower • Inspire • Support

dscba@dsconnection.org • www.dsconnection.org

Down Syndrome Connection of the Bay Area

The DSCBA office in Danville is staffed and open Monday through Friday, during normal business hours. We offer classes, programs, and events at our office in the East Bay and at satellite locations.

Our mission is to empower, inspire and support people with Down syndrome, their families and the community that serves them, while fostering awareness and acceptance in all areas of life.



Congratulations on the birth of your baby!

Though a baby born with special needs brings a range of emotions and challenges with it, we are here to answer questions, lend support, and invite you to a variety of resources and programs the Down Syndrome Connection of the Bay Area (DSCBA) offers for families like ours.

This brochure will provide you with a brief introduction to Down syndrome and what that might mean for your baby and your family. There is an overwhelming amount of information available to you via the internet, books, other parents, and numerous other sources. We suggest that you take your time and only seek out and digest the information that is helpful for you right now. There will be plenty of time to continue your learning about Down syndrome in the days that come. Please let us know when you're ready for more, and we can guide you.



Most importantly, we want to share with you the DSCBA's philosophy about your baby: Your baby is a baby first, with Down syndrome second. We assure you, the day will come when your child will just be your child, and the diagnosis will not consume every moment, as it might now.

Warmly,

Your friends at the Down Syndrome Connection of the Bay Area

What Is Down Syndrome?

Down syndrome, sometimes known as Trisomy 21, is a condition in which a person is born with three copies of chromosome 21 instead of two. It is the most frequently occurring chromosomal condition, occurring in one of every 691 babies. There are estimated to be about 200,000 people living with Down syndrome in the United States.

An anomaly in cell division is the cause of the extra twenty-first chromosome. Ninety-eight percent of the time, Down syndrome is random and not hereditary. The chance of having a baby with Down syndrome increases with the mother's age; however, 80 percent of babies born with the condition are born to mothers under thirty-five years of age because younger women have more babies than older women do.

Down syndrome has nothing to do with race, nationality, socioeconomic status, religion, or anything the mother or father did before or during the pregnancy.

How Is Down Syndrome Diagnosed?

There are prenatal screenings to predict the likelihood of Down syndrome before a baby is born, as well as diagnostic tests that can confirm the diagnosis before birth. However, many parents who have a baby with Down syndrome are surprised at birth by the diagnosis. In a newborn,



Down syndrome is usually identified by certain physical traits, including low muscle tone, a single deep crease across the palm of the hand, a slightly flattened facial profile, and/or an upward slant to the eyes. The suspicion of Down syndrome may be confirmed with a karyotype chromosomal analysis. A small blood sample is taken from the baby in order to perform the karyotype. The results can take up to two weeks to come back.

How Will Down Syndrome Affect My Baby?

There is no way to know what the future holds for any baby, including babies with Down syndrome. Mostly, babies with Down syndrome are like other babies — they all need to be nurtured, cared for, and loved. However, the healthcare and educational needs of a person with Down syndrome can be different and sometimes more challenging than those of a typical person.



General Facts About People with Down Syndrome in the United States

- ◆ People with Down syndrome have intellectual delays, usually in the mild to moderate range. People with Down syndrome have a wide range of abilities that are impossible to predict. Despite these delays, every individual possesses many strengths and talents.
- ◆ Children with Down syndrome learn to sit, walk, play, communicate, and do most other activities, only somewhat later than their peers without Down syndrome.
- ◆ By federal law, people with Down syndrome must be provided with a free and appropriate public education in the least restrictive environment through their public school system. This applies to individuals three to twenty-two years of age. Since the human and civil rights movements began in the 1960s, people with Down syndrome have been increasingly recognized as valued and contributing members of society.
- ◆ People with Down syndrome participate in school, religious groups, sports teams, and performing and visual arts programs. They have meaningful jobs and relationships and live full lives. A growing number of people with Down syndrome go to specialized college programs and live independently or semi-independently.



Medical Facts About People with Down Syndrome in the United States

- ◆ Approximately 50 percent of babies with Down syndrome are born with a congenital heart defect, and some require surgery. The vast majority of these heart defects are correctable.
- ◆ While there is no “cure” for Down syndrome, quality early intervention services, such as speech therapy and physical therapy, along with a stimulating and supportive home life, can make a significant difference in a child’s physical and intellectual development.
- ◆ Appropriate medical care for children and adults with Down syndrome is important and can strengthen their physical and intellectual capabilities. The American Academy of Pediatrics has published healthcare guidelines for physicians to follow in caring for individuals with Down syndrome. We can provide you with a copy of these guidelines.
- ◆ People with Down syndrome have an increased risk for some medical conditions, such as respiratory issues, hearing problems, sleep apnea, thyroid conditions, and heart issues. It’s important to note that an increased risk does not mean that your baby will have these issues. Also, most of these are now treatable, and the majority of individuals with Down syndrome lead healthy lives. In fact, people with Down syndrome rarely develop certain cancers or suffer from heart attacks or strokes.





How Will a Baby with Down Syndrome Affect My Family?

Many parents are concerned about how a child with Down syndrome will affect their family, their relationships, and any siblings.

It is natural to feel worried or even sad when you have a baby with Down syndrome. A baby with special needs is not usually something people plan for. In addition to grieving the baby you did not have (the one without Down syndrome that you were expecting), you now have to understand and learn about your baby's unique needs. There may be additional medical, educational, and financial challenges to address.

The paperwork alone involved in parenting a child with a disability can feel overwhelming.

Every family is unique and may deal with the birth of a baby with Down syndrome differently.



There is no one right way to react to your baby's birth and diagnosis. Despite potential challenges, personal stories and studies show that most families that have a child with Down syndrome are stable, successful, and happy. Siblings of children with Down syndrome often report having increased compassion and empathy. A major study on marriages and Down syndrome shows that the divorce rate among parents of children with Down syndrome is actually lower than the national average.





Announcing your baby's Birth

Most importantly, your baby is a baby first, and a baby who happens to have Down syndrome second. Although your baby's birth may inspire a range of emotions, it is a milestone to celebrate and share.

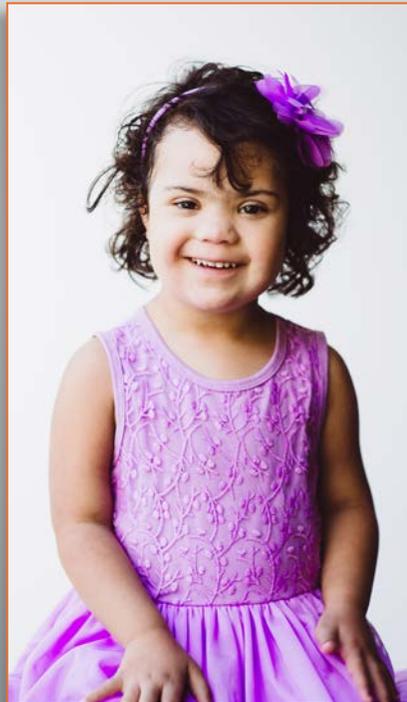
It is suggested that parents not wait to tell friends and family members about their baby having Down syndrome. Some parents may feel afraid to tell others or may be afraid of their responses. But generally, the longer an announcement is put off, the harder it can be.

Most people know very little about Down syndrome, so education is important. Some people might think back to people with Down syndrome that they knew as children. Their thoughts tend to be outdated because today society is more accessible to and accepting of people with Down syndrome, and therefore people with Down syndrome are accomplishing more than they did in past generations. Children born with Down syndrome today have more inclusive educational and community opportunities available to them than those born even a decade ago.

Generally, friends and family will follow your lead. If you announce the news with celebration, they will be more inclined to do the same. Some families have found it helpful to be very upfront about their baby and how they want others to respond to the news. Here is one example of such an announcement:

Dear Friends and Family,

Our beautiful baby boy, Elias, was born January 13th. In addition to sending out this adorable photograph of him, we wanted to add this personal note to let you know that Elias was born with Down syndrome. In the past few days, we've been learning a lot about Elias's needs as well as a great deal about the positive ways he will affect our family. Elias is a beautiful and responsive baby who happens to have an extra chromosome. We want you to share in the joy of his birth and his progress along the way. Though his progress might be slower than some, we know that our lives will be enriched by having Elias—as they already have. Please celebrate his birth with us.





*Teach me to soar,
and I will.*



*Every child is
gifted. They just
unwrap their
packages at
different times.*



*From all of us at the
DSCBA, we congratulate
you on the birth of your
baby and look forward
to supporting
your family.*



DSCBA

Connecting Families for 20 Years

Down Syndrome Connection of the Bay Area

Empower • Inspire • Support

101-J Town and Country Drive • Danville, CA 94526

925-362-8660

dscba@dsconnection.org

www.dsconnection.org