



NATIONAL DOWN SYNDROME CONGRESS



We are the **National Down Syndrome Congress**, known around the world as NDSC. We are the leading national resource for support and information about Down syndrome, from the moment of a prenatal diagnosis through adulthood.

We believe in the potential of all people with Down syndrome, demand their rights, and get them affirmed. We **support** them in all they do from infancy to adulthood. We **advocate** for opportunities and respect, so individuals with Down syndrome can live the life of their choosing. We **believe** that by empowering individuals and families from all demographic backgrounds, we **reshape** the way people understand and experience Down syndrome.

Facts About Down Syndrome

- Down syndrome occurs when a baby inherits one extra chromosome at the time of conception. There is **no known cause**. Down syndrome is not related to race, nationality, religion or socio-economic status.
- In the United States, approximately **one in every 700 children** is born with Down syndrome.
- While exact numbers are not known, it is believed that between **250,000 and 350,000 people** in the United States are living with Down syndrome.
- Down syndrome is **not a disease or illness**. It is the presence of an extra 21st chromosome.
- There is a **wide range** in the cognitive abilities and physical development of people with Down syndrome.
- Up to **50% of babies** with Down syndrome are born with a heart defect, and some will require surgery. The vast majority of these heart defects are correctable.
- Developmental milestones vary widely in children with Down syndrome and are impossible to predict. Early intervention services, including physical, occupational, and speech therapies should be **started early** in life to optimize a child's development.
- Individuals with Down syndrome **benefit** from loving homes, early intervention, education, appropriate medical care and positive public attitudes.
- In adulthood, many people with Down syndrome hold jobs, **live independently** and enjoy community life.



Types of Down Syndrome

Ninety-five percent of people with Down syndrome have an extra chromosome in every cell of their body. This is known as **trisomy 21**.

Three to four percent have an additional chromosome attached to another chromosome. This is called **translocation** Down syndrome. In this case, a parent may be a carrier of a balanced translocation.

About one percent of people with Down syndrome have an extra chromosome in some cells, but not in others. This is called **mosaic** Down syndrome.

Genetic Counseling

Genetic counseling may be helpful if you have a prenatal diagnosis or once your child is born. The chance of having a child with Down syndrome increases with the mother's age. Some investigators also report a higher chance of fathering a child with Down syndrome after age 50.

For those who have a baby with trisomy 21, the chance of recurrence in future pregnancies is approximately one percent. However, for those who have a child with translocation Down syndrome and a parent who is a carrier, the chance of a future child with Down syndrome can increase significantly.

After the birth of a child with Down syndrome, many genetic counselors, physicians and parents suggest amniocentesis or chorionic villus sampling (CVS) in future pregnancies so that parents can prepare for their new baby's arrival. Though generally reliable, amniocentesis and CVS results are not 100 percent accurate and these tests slightly increase the chance of miscarriage.

To locate a genetic counselor near you, visit the National Society of Genetic Counselors website at **www.nsgc.org**.



Health and Development

Newborns with Down syndrome should have a careful medical evaluation to rule out or identify conditions that may accompany the syndrome. There is a wide range of health conditions associated with Down syndrome.

Some people with Down syndrome have many serious medical needs and some have few. The most common are heart anomalies, which affect as many as 50 percent of children with Down syndrome. Other medical concerns include gastrointestinal abnormalities, thyroid disorders and difficulties with hearing or vision. With good preventative medical care including immunizations and the recommended screening procedures, people with Down syndrome are **living longer, healthier lives** than ever before.

For more information for you and your healthcare provider, healthcare guidelines for people with Down syndrome can be found on the NDSC Website at www.ndscenter.org.



Children with Down syndrome are **more like other children than they are different**. During the first few months of life, a child with Down syndrome behaves like most other infants and generally needs the same care, attention and love.

Children with Down syndrome usually are smaller than other children. Language, motor and intellectual development are generally delayed in children with Down syndrome.

Most people with Down syndrome experience some degree of cognitive delay, though there is a **wide spectrum** of intellectual abilities, developmental progress and behavior in children with Down syndrome.

Research shows that the development of a child with Down syndrome is **positively influenced** by a caring and enriching home environment, early intervention and improved educational efforts. In most cases, full inclusion in an educational and social community serves the needs of a child with Down syndrome in the most positive way.



Early Intervention and Preschool

Early intervention is provided to children with disabilities and their parents to facilitate learning and development.

Federal law requires each state to offer early intervention services for infants with disabilities or those at risk for developmental delays. An evaluation or assessment is offered at no charge, but the cost for early intervention services will depend on the policies of each state. In some states, there is no charge; in others, services are provided on a sliding scale.

These services should begin soon after birth. Just as early intervention programs foster the development of a child with Down syndrome, preschools play an important role in a young child's life. Exploring the environment beyond the home enables the child to successfully participate in a broader world and continue to grow in self-awareness.

Elementary and Middle School Years

In addition to providing a fundamental education, schools also promote development of a personal identity, self-confidence, and self-respect.

Inclusion in regular classrooms provides an opportunity for children to engage in sharing relationships with others and develop academic skills.

Because of the federal Individuals with Disabilities Education Act (IDEA), every child, including children with Down syndrome, is guaranteed the right to a free, appropriate education in the **least restrictive environment**. All public school systems must comply with the law. Least restrictive environment is most often your neighborhood school's general education classroom.

High School

As is true for all high school students, teens with Down syndrome enjoy many aspects of the high school experience. These often include assisting in student government and athletics, participating in theater productions and attending campus clubs, sporting events, dances and special events—like prom. Many high school students with Down syndrome **graduate with full diplomas**.

Post-Secondary Education

A variety of college experiences ranging from junior colleges to settings where students live on campus are now **available** to people with Down syndrome. The length of time educational services are provided for students with special needs varies by state. These services occur within schools or as part of a transition program independent of the school environment.





Employment

Work opportunities for individuals with Down syndrome range from supported employment to independent employment. In many states, services help support people with Down syndrome as they enter the work world. A **supported employment service provider** assists people with Down syndrome as they get to know their job. People with Down syndrome have proven to be **excellent employees** and assets in their places of work. Increasingly, employers find that directly hiring people with Down syndrome, without additional support, also is beneficial.

Adult Life

People with Down syndrome enjoy living settings as **varied** as the rest of the world. People with Down syndrome live alone or with a spouse, with a roommate or family members, in creatively supported settings or in more traditional supported settings. People with Down syndrome **enjoy living** in communities with transportation, entertainment, shopping and dining options and places of worship.

People with Down syndrome vote, pay taxes and volunteer in places such as fire departments, offices, hospitals, schools and churches. People with Down syndrome are **accomplished** writers, musicians, photographers and poets. When people with Down syndrome are given greater opportunities, their achievements grow correspondingly. With proper support, people with Down syndrome **thrive** from birth through adulthood and give back far more than they receive. Undoubtedly, people with Down syndrome enhance our world.





Often, a family's first interaction with the NDSC comes from a phone call as a new or expectant parent. This can begin a **lifelong relationship** with the NDSC, as our programs and resources are available to individuals with Down syndrome and their families at every step of the way. Our services are available in both English and Spanish.

The future is quite different today than it was a generation ago. Today, with early intervention programs, medical advances and community inclusion, the possibilities for individuals with Down syndrome are almost limitless.

Like all people, those with Down syndrome have a **variety of talents and abilities, strengths and weaknesses**. Like their other family members, many people with Down syndrome graduate from high school, attend college, hold meaningful jobs, and may learn to drive or get married. All bring unique qualities into the world.

With more and more people with Down syndrome included in schools, places of worship, workplaces and even on television shows, many Americans are more likely to interact with someone with Down syndrome. However, while many people know of Down syndrome, fewer know a lot about it. This brochure provides an introductory overview about Down syndrome. More detailed information is available at **www.ndscenter.org** or the information line at **1-800-232-6372 (NDSC)**.



Join the NDSC!

We are a member-sustained non-profit organization, composed of parents, self-advocates, siblings, grandparents, educators, physicians, therapists, other professionals, friends and supporters.



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When you become a member of the NDSC:

- You'll gain **access** to the NDSC Center, a multi-faceted clearinghouse for information on Down syndrome.
- You become **part of an extensive community** of families, self-advocates, and caregivers who face similar daily challenges, with the opportunity to learn from and support each other.
- You'll **make your voice heard** on important legislative issues and support an organization that has been making a positive impact on people with Down syndrome locally, nationally, and globally since 1973.
- You'll have access to the most accurate and up-to-date **information** on Down syndrome from the professional and medical community.
- You'll receive our print publication, **Down Syndrome News**, the journal of the NDSC, four times per year, the best publication available on Down syndrome.
- You can register to attend our highly acclaimed **Annual Convention**, where we present "best practice" information on a wide variety of subjects, and you will connect with professionals, families and friends. Our Annual Convention changes lives – fostering positive attitudes, creating fond memories and empowering families through increased knowledge.

For information on NDSC membership, visit our website www.ndsccenter.org or call us at 800-232-6372.

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