



NATIONAL
DOWN SYNDROME
CONGRESS



DOWN
SYNDROME



*This brochure is published by
the National Down Syndrome
Congress (NDSC).*

*The NDSC provides information,
advocacy and support concerning
all aspects of life for individuals
with Down syndrome.*

*The NDSC's vision is a world
with equal rights and opportunities
for people with Down syndrome.*



Today, with early intervention programs and medical advances, the possibilities for individuals with Down syndrome are almost limitless.

Like all people, those with Down syndrome have a variety of talents and abilities.

And, like their siblings, 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 television shows, many Americans now are familiar with this fairly common chromosome variation. However, while many people know of Down syndrome, fewer know much about it. This brochure provides an introductory overview about Down syndrome.

More detailed information is available at www.ndsccenter.org or the information line at 1-800-232-6372 (NDSC).



FACTS ABOUT DOWN SYNDROME

Down syndrome is a chromosome variation with no known cause.

- It is not related to race, nationality, religion or socio-economic status.
- In the United States, approximately one in every 800 – 1,000 children is born with Down syndrome.
- Between 250,000 and 350,000 families in the United States are affected by Down syndrome.
- About 80 percent of babies with Down syndrome are born to women under age 35.
- People with Down syndrome widely vary in mental abilities, physical development and behavior.
- 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, just like everyone else.

I have worked with many families with newborns who have Down syndrome. Initially, there is sadness and grief. Inevitably this passes, and is replaced by strength, joy, and love.

Dr. Laura Cifra-Bean, pediatrician and parent of a son with Down syndrome, Ohio

HEALTH

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, heart anomalies, affects approximately 40 to 45 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.

To assist your healthcare provider, you can find lifespan healthcare guidelines for people with Down syndrome on the NDSC Web site at www.ndscenter.org.



GENETIC COUNSELING

Genetic counseling may be helpful once your child is born or if you have a prenatal diagnosis.

- 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 carrier, the chance increases 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.
- The NDSC offers a free publication entitled *Light at the End of the Tunnel* for those who have received a prenatal diagnosis.
- To locate a genetic counselor near you, visit the National Society of Genetic Counselors Web site at www.nsgc.org.

Genetic counselors provide support and guidance and serve as advocates for people with Down syndrome and their parents by helping make connections with other parents, locating educational opportunities and answering medical and inheritance questions.

Cam Brasington, MS, CGC, genetic counselor, North Carolina

CHROMOSOME VARIATION

- Ninety-five percent of people with Down syndrome have an extra #21 chromosome in every cell of their body. This is known as trisomy 21.
- Three to four percent have an additional #21 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 #21 chromosome in some cells, but not in others. This is called mosaic Down syndrome.



DEVELOPMENTAL ASPECTS

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 mental abilities, developmental progress and behavior in children with Down syndrome.

I have dreams and if I work hard my dreams can come true.

Elaine Fickenscher, self-advocate, Maryland

Please do not ever prejudice the limits of my abilities, just because I happen to have a disability.

Ann Forts, self-advocate, New Hampshire

...all of us have abilities and disabilities. Some of us have disabilities that you can see like Down syndrome. People with disabilities are proud of themselves; they can speak for themselves.

Katie Maly, self-advocate, Ohio

A self-advocate is an individual 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 development. These services should begin soon after birth.

Just as early intervention programs foster the development of a child with Down syndrome, preschools, both private and public, 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 a fundamental education, continued school experiences assist the child in feeling a personal identity, self-respect and self-confidence. 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 with Down syndrome, as any other child with differences, 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.

WORK

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.

I'm proud to be working at the same job for seven years. I love my customers and co-workers.

Jeremy Williams, self-advocate, South Carolina

Work is nice to keep me busy. Since I live on my own, it helps me pay my bills and live independently.

Julie Hutchinson, self-advocate, California

I like to work, I like to be paid, and I have fun being there.


Nayef Albinali, self-advocate, Minnesota

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.



*Love always protects, always trusts,
and always hopes.*

Jeff Mattson, self-advocate and best man, California

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.





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Leading the nation in empowering persons with
Down syndrome and their families since 1972