



Down Syndrome Information for New and Expectant Parents

Nebraska Down Syndrome Support Organizations

Omaha

Down Syndrome Alliance of the Midlands

531-375-5791

www.dsamidlands.org

Lincoln

Down Syndrome Association for Families of Nebraska

www.dsafnebraska.org

Down Syndrome Advocates in Action

www.dsaane.org

Northeast Nebraska

Northeast Nebraska Down Syndrome Association

www.nendsa.org

Kearney Area

Down Syndrome Advocates in Action Kearney

www.dsaane.org/kearney

402-413-0199

Nebraska Genetics Clinic UNMC Munroe-Meyer Institute

402-559-6418 or toll-free
800-559-3937 ext 96418

www.unmc.edu/mmi/services/geneticmed/down-clinic.html

This information available with web links at www.dhhs.ne.gov/DownSyndrome

Overview of Down Syndrome

Down syndrome is a genetic condition and developmental disability usually caused by an extra copy of the twenty-first chromosome.

According to current data, about 250,000 people in the United States have Down syndrome. Studies show that about 1 in 800 babies are born with Down syndrome and the chance of having a baby with the genetic condition increases with the age of the expectant mother. Down syndrome does not typically run in families and is not caused by anything either parent did or did not do.

Advances in medical care and research over the years have given people with Down syndrome better overall health. The traits, medical conditions, and abilities of people with Down syndrome vary widely and cannot be predicted before they are born. They generally have mild to moderate cognitive delays, low muscle tone, and higher chances for a variety of other health issues over their lifespan. Because of advances in health care, education, and public attitudes, common perceptions and future opportunities for people with Down syndrome have improved significantly over the past few decades.

Understanding Down Syndrome

- Children with Down syndrome are more similar to other children than they are different.
- Individuals with Down syndrome have a variable range of intellectual abilities.
- Babies with Down syndrome usually have developmental delays and benefit from early intervention, including physical, occupational, and speech therapy, to help them meet their milestones.
- 80% of babies with Down syndrome have hypotonia or low muscle tone at birth. This usually improves with time, and physical therapy can help.
- 50% of babies with Down syndrome have one or more health issues:
 - 40–60% of babies with Down syndrome have a heart condition.
 - 12% have a gastrointestinal condition, which may require surgery. The outcomes of these surgical repairs are very good.
 - Referrals to specialists are appropriate for identified complications.



- Babies with Down syndrome have higher chances for feeding and digestive issues, hearing loss, vision impairments, and respiratory infections. Most of these conditions can be treated with good health care.
- Currently, the average life expectancy for people with Down syndrome is about 60 years.
- Raising a child with Down syndrome is much like raising any other child; however, providing for their needs may involve more time than typical children from time to time.
- Individuals with developmental disabilities can participate in community sports, activities, and leagues provided they have medical clearance.
- Individualized education programs can help children with Down syndrome reach their potential. Special education services at school can range from inclusion in the typical classroom with extra help to small group instruction. There are also over 300 college programs for people with intellectual disabilities.
- Individuals can be employed competitively with or without support.
- Adults with Down syndrome may live independently, with family, or in a group home.
- Individuals with Down syndrome of all ages have friends and adults may choose to develop intimate relationships.

National Down Syndrome Information Sources

Information about Down Syndrome is available in multiple languages at www.understandingdownsyndrome.org

Down Syndrome Diagnosis Network
www.dsdiagnosisnetwork.org

Global Down Syndrome Foundation
www.globaldownsyndrome.org

The National Down Syndrome Society
800-221-4602
www.ndss.org

National Down Syndrome Congress
800-232-6372
www.NDSCcenter.org

The National Down Syndrome Adoption Network
www.ndsan.org

National Center for Prenatal and Postnatal Down Syndrome Resources
www.downsyndromediagnosis.org
www.lettercase.org

National Society of Genetic Counselors
www.nsgc.org/



Many people with Down syndrome are thriving as active and valued members of the community. This includes children involved in social and school programs with peers, and adults employed and living independently or with some support. Research shows that almost all persons living with Down syndrome are happy with their lives and loved by their families.

Reviewed by the National Society of Genetic Counselors Down Syndrome Information Act Working Group, with assistance from the National Center for Prenatal and Postnatal Down Syndrome Resources and by the University of Nebraska Medical Center Munroe-Meyer Institute.