



Down Syndrome Information for New and Expectant Parents

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

Nebraska Down Syndrome Support Organizations

Omaha

Down Syndrome Alliance of the Midlands

A 501(c)3 not-for-profit org serving Omaha and the state for over 20 years.

www.dsamidlands.org

Lincoln

Down Syndrome Association for Families of Nebraska

A 501(c)3 not-for-profit org serving Lincoln and the state for over 20 years.

www.dsafnebraska.org

Down Syndrome Advocates in Action

A 501(c)3 not-for-profit org formed by advocates with over 20 years experience to promote inclusion and acceptance.

www.dsaane.org

Northeast Nebraska

Northeast Nebraska Down Syndrome Association

A local support group based in Norfolk.

<http://www.nendsa.org/>

Kearney Area

A local support group based in Kearney. 308-224-7034

Nebraska Genetics Clinic UNMC Munroe-Meyer Institute

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

<http://www.unmc.edu/mmi/departments/geneticmed/genmedservices/geneticsclinic.html>

Overview of Down Syndrome

Down syndrome is a genetic condition and developmental disability that is 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 disability from mild to moderate (not typically severe).
- 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 this condition have hypotonia or low muscle tone at birth. This usually improves with time, and physical therapy can help.
- 50% of babies with Down syndrome will have one or more health issues: 40–60% of babies with Down syndrome have a heart condition and 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.



National Down Syndrome Information Sources

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

The National Down Syndrome Society

666 Broadway
New York, NY 10012-2317
800-221-4602
www.ndss.org

National Down Syndrome Congress

1370 Center Drive, Suite 102
Atlanta, Georgia 30338
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

<http://nsgc.org/>

- Babies with Down syndrome also 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 250 college programs for people with intellectual disabilities.
- Individuals can be employed competitively or with supports; live independently or in a group home; and have friends and intimate relationships.



As a result of improved public attitudes and acceptance, many people with Down syndrome are thriving as active and valued members of the community. This includes children who are involved in social and school programs with their peers and many adults who are employed and live independently or with some support. Research shows that almost all persons living with Down syndrome are happy with their lives and are 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.