

National Down Syndrome Society



The national advocate for the value, acceptance and inclusion of people with Down syndrome

national down syndrome society
ndss®

What is Down Syndrome?

Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies in the United States is born with Down syndrome and it is found in people of all races and economic levels.

A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.

People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia and thyroid conditions. However, many of these conditions are now treatable, so most people with Down syndrome lead healthy lives. Life expectancy for people with Down syndrome has increased dramatically in recent decades - from 25 in 1983 to 60 today.

People with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses. Children with Down syndrome learn to sit, walk, talk, play and do most other activities, only somewhat later than their peers without Down syndrome.

Quality educational programs, a stimulating home environment, good health care and positive support from family, friends and communities enable people with Down syndrome to realize their aspirations and lead fulfilling lives. People with Down syndrome attend school, work and contribute to society in many wonderful ways.

People with Down syndrome should always be referred to as people first. Instead of "a Down syndrome child," it should be "a child with Down syndrome." Also avoid "Down's child" and describing the condition as "Down's," as in, "He has Down's." People "have" Down syndrome, they do not "suffer from" it and are not "afflicted by" it.

What Causes Down Syndrome?

In every cell in the human body there is a nucleus where genetic material is stored in genes. Genes carry the codes responsible for all of our inherited traits and are grouped along rod-like structures called chromosomes. Normally, the nucleus of each cell contains 23 pairs of chromosomes, half of which are inherited from each parent.

Down syndrome is usually caused by an error in cell division called nondisjunction. Nondisjunction results in an embryo with three copies of chromosome 21 instead of the usual two. Prior to or at conception, a pair of 21st chromosomes in either the sperm or the egg fails to separate, passing on both copies of the 21st chromosome instead of the typical one. As the embryo develops, the extra chromosome is replicated in every cell of the body. This type of Down syndrome, which accounts for 95% of cases, is called trisomy 21.

The two other types of Down syndrome are called mosaicism and translocation. Mosaicism (or mosaic Down syndrome) occurs when nondisjunction of chromosome 21 takes place in one -but not all- of the initial cell divisions after fertilization. When this occurs, there is a mixture of two types of cells, some containing the usual 46 chromosomes and others containing 47. Those cells with 47 chromosomes contain an extra chromosome 21. Mosaicism accounts for about 1% of all cases of Down syndrome. Research has indicated that individuals with mosaic Down syndrome may have fewer characteristics of Down syndrome than those with trisomy 21 or translocation Down syndrome. However, broad generalizations are not possible due to the wide range of abilities people with Down syndrome possess.

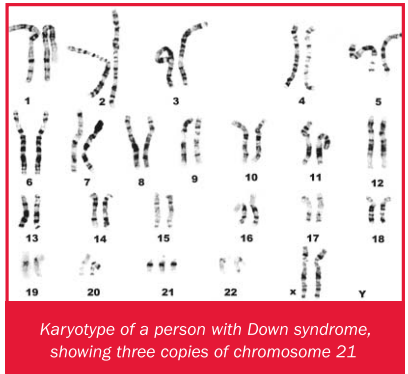
Translocation accounts for about 4% of all cases of Down syndrome. In translocation, an additional full or partial copy of chromosome 21 breaks off during cell division and attaches to another chromosome, typically chromosome 14. While the total number of chromosomes in the cells remains 46, the presence of an extra full or partial chromosome 21 causes the characteristics of Down syndrome.

Regardless of the type of Down syndrome a person may have, all people with Down syndrome have an extra, critical portion of chromosome 21 present in all or some of their cells. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.

The cause of nondisjunction is currently unknown, but research has shown that it increases in frequency as a woman ages. However, due to higher birth rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age. Down syndrome is not caused by environmental factors or the parents' activities before or during pregnancy.

Once a woman has given birth to a baby with trisomy 21, it is estimated that her chance of having another baby with trisomy 21 is 1 in 100 (up to age 40). The probability of having a baby with Down syndrome increases substantially after age

40, regardless of whether a mother has already had a baby with Down syndrome. However, unlike in trisomy 21 or mosaicism, however, the age of the mother does not seem to be linked to the risk of having a child with translocation Down syndrome. Most cases of translocation are chance events, just like trisomy 21 and mosaicism. About a third of cases of translocation (1% of all cases of Down syndrome) have a hereditary component - one unaffected parent is a carrier of a translocated chromosome. Genetic counseling can determine if a parent is a carrier of the translocated chromosome.



Maternal Age	Incidence of Down syndrome	Maternal Age	Incidence of Down syndrome	Maternal Age	Incidence of Down syndrome
20	1 in 2,000	30	1 in 900	40	1 in 100
21	1 in 1,700	31	1 in 800	41	1 in 80
22	1 in 1,500	32	1 in 720	42	1 in 70
23	1 in 1,400	33	1 in 600	43	1 in 50
24	1 in 1,300	34	1 in 450	44	1 in 40
25	1 in 1,200	35	1 in 350	45	1 in 30
26	1 in 1,100	36	1 in 300	46	1 in 25
27	1 in 1,050	37	1 in 250	47	1 in 20
28	1 in 1,000	38	1 in 200	48	1 in 15
29	1 in 950	39	1 in 150	49	1 in 10

How is Down Syndrome Diagnosed?

Down syndrome is usually identified at birth by physical traits. These features may be present in babies who do not have Down syndrome, however so a karyotype chromosomal analysis is done to make a diagnosis. To obtain a karyotype, doctors draw blood to examine the baby's cells. They photograph the chromosomes within the cells and group them by size, number and shape. Down syndrome is diagnosed by examining the karyotype and identifying an additional full or partial copy of chromosome 21. A similar genetic test called fluorescence in situ hybridization (FISH) can also confirm a diagnosis.

There are two types of tests for Down syndrome that can be performed before a baby is born: screening tests and diagnostic tests. Prenatal screens estimate the chance of the fetus having Down syndrome. Diagnostic tests can provide a definitive diagnosis with almost 100% accuracy.

Most screening tests involve a blood test and an ultrasound (sonogram). The blood tests (or serum screening tests) measure quantities of substances in the blood of the mother. Together with the mother's age, these are used to estimate her chance of having a child with Down syndrome. Serum screening tests are often performed in conjunction with a detailed sonogram to check for markers (characteristics that some researchers feel may have a significant association with Down syndrome). Researchers have developed a maternal serum/ultrasound/age combination that yields higher accuracy at an earlier stage in the pregnancy. New noninvasive prenatal screening tests like MaterniT21 and Harmony involve blood being taken from the expectant mother at as early as 10 weeks of gestation and rely on the detection of cell-free DNA that circulates between the fetus and the expectant mother.

Prenatal screening tests are now routinely offered to women of all ages. If the chance of having a child with Down syndrome is determined to be high from a prenatal screening, doctors will often advise a mother to undergo diagnostic testing if she desires a definitive diagnosis. The diagnostic procedures available for prenatal diagnosis of Down syndrome are chorionic villus sampling (CVS) and amniocentesis. CVS is usually performed in the first trimester between 9 and 11 weeks, and amniocentesis is usually performed in the second trimester after 15 weeks of gestation. These procedures, which carry up to a 1% risk of causing a miscarriage, are practically 100% accurate in diagnosing Down syndrome.

National Down Syndrome Society



The National Down Syndrome Society (NDSS) has worked since 1979 to promote the value, acceptance and inclusion of people with Down syndrome. NDSS programming reflects our mission to enhance the quality of life for people with Down syndrome: Community Support Programs; the National Policy Center; Public Awareness Initiatives and the National Buddy Walk® Program.

NDSS was founded by Elizabeth Goodwin following the birth of her daughter, Carson, who has Down syndrome. After Carson was born, Elizabeth and her husband soon discovered that there was limited support and resources available to parents of a child with Down syndrome. She started NDSS to address the pressing needs of parents of children with Down syndrome, and it has gradually become the largest organization in the United States focusing on Down syndrome.

The mission of NDSS is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome. NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.

NDSS Community Support Programs

NDSS is committed to providing the Down syndrome community with quality support and informational services.

- NDSS leads a network of over 375 affiliate groups across the country, consisting of local parent support groups and other organizations that provide services to the Down syndrome community.
- Through our helpline and email service, NDSS responds to more than 8,000 requests for information on Down syndrome each year. The helpline is supported by a translation service that can be accessed in over 150 languages.
- NDSS publishes information for new and expectant parents, a guidebook for aging adults with Down syndrome, and an overview of Down syndrome and NDSS. All are available online and printed in English and Spanish.
- Since 2005, the O'Neill Tabani Enrichment Fund has awarded more than 75 grants for post-secondary and enrichment courses to students with Down syndrome.
- A comprehensive, up-to-date resource for families and professionals, NDSS.org receives over 3 million page views each year and includes Spanish translation.



NDSS National Policy Center

The NDSS National Policy Center in Washington, DC strives to protect the rights of and help remove barriers for all individuals with Down syndrome by working with Congress and federal agencies, and educating parents and self-advocates on how to advocate on the local, state and national levels.

- The work of the National Policy Center is guided by a dynamic legislative agenda that includes a wide range of issues and touches every stage of life.
- The National Policy Center facilitates and mobilizes advocacy efforts for federal, state and local policies that positively impact people with Down syndrome across the country.
- The National Policy Center works with Congress and federal agencies to develop and improve legislation.
- Through the NDSS DS-Ambassador Program, the National Policy Center trains and educates parents, self-advocates and others in all 50 states.
- NDSS Government Affairs Committee (GAC) Program helps Down syndrome support organizations, parents and self-advocates across states to join forces with NDSS to achieve positive systems change at the state and local levels of government.
- The NDSS Buddy Walk® on Washington is an annual two-day conference that brings the Down syndrome community together to advocate at the national level.
- The National Policy Center organizes and participates in coalitions of national disability organizations.



NDSS Public Awareness Initiatives

The purpose of public awareness at NDSS is to turn the mission of “value, acceptance and inclusion” into a comprehensive national public awareness message.

- NDSS proactively reaches out to national media outlets (including television, print, radio, online and social media) to secure editorial content on issues within the Down syndrome community, as well as promote positive and inspirational news stories.
- NDSS monitors all forms of media on a daily basis, 365 days a year, and responds to any inappropriate comments in an ongoing effort to educate and to promote accurate and positive messaging about Down syndrome.
- The My Great Story public awareness campaign seeks to ignite a new way of thinking about people with Down syndrome by sharing stories which are displayed in an online storybook on the NDSS website. The stories are written by people with Down syndrome, their family members, friends, coworkers, teachers and others.
- Public service announcements for the campaign in both print and digital forms have been featured in national and local media outlets across the country.
- The NDSS My Great Story Video Project features 10 short videos based on submitted stories to the My Great Story public awareness campaign.



NDSS National Buddy Walk® Program



NDSS established the Buddy Walk® Program to celebrate Down Syndrome Awareness Month in October and to promote acceptance and inclusion of people with Down syndrome in their own cities.

- The National Buddy Walk® Program is the world's largest and most recognizable Down syndrome awareness program.
 - Supported nationally by NDSS, the National Buddy Walk® Program is organized at the local level by parent support groups, schools, other organizations and individuals.
 - Since 1995, the National Buddy Walk® Program has grown from 17 walks to more than 250 across the country and around the world.
 - Each year, close to 300,000 people participate in a Buddy Walk® and nearly \$12 million is raised to benefit local programs and services and national advocacy initiatives to support all people with Down syndrome.
- The National Buddy Walk® public service announcement features the Emmy-award winning Imagination Movers, who, along with the number of self-advocates, encourage viewers across the country to find and participate in a Buddy Walk®.



Ways to Give

There are several ways to get involved in giving to NDSS, which is a registered 501(c)(3) tax-exempt organization. We greatly appreciate support of all kinds from our generous community.

- NDSS Your Way invites participants to compete, celebrate or create an individual campaign through our online program geared towards independent fundraisers interested in raising money on behalf of NDSS. Each campaign includes a personalized web page in support of an event or individual pursuit. Participants can join Team NDSS, NDSS Celebrations or NDSS New Ideas and set their own goals, with NDSS staff available to provide support along the way.
- Shop NDSS includes a variety of partners that donate a portion of sales to NDSS. From apparel, to awareness products, to jewelry to gift baskets and more we invite shoppers to make a purchase that will benefit NDSS.
- NDSS hosts several flagship events throughout the year in the New York City area, where we are headquartered, and near the NDSS National Policy Center in Washington, DC. We are also affiliated with regional events throughout the country, including events planned by our Young Leadership Committees.
- NDSS welcomes donations online, by phone or mail.



Connect with NDSS to learn more about Down syndrome, find a local Down syndrome organization, locate a Buddy Walk®, participate in NDSS programming, become an NDSS affiliate or volunteer, receive our monthly e-newsletter or make a donation.

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