

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, though 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 all cases, is called trisomy 21.

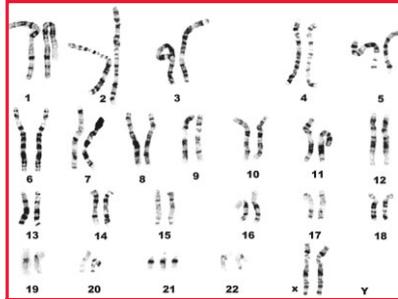
The two other types of Down syndrome are called mosaicism and translocation. Mosaicism (or mosaic Down syndrome) occurs when nondisjunction of chromosome 21 takes place in one (but not all) of the initial cell divisions after fertilization. When this occurs, there is a mixture of two types of cells, 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 additional 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.

While the cause of nondisjunction is currently unknown, research has shown that the likelihood of it occurring increases 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. 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..



Karyotype of a person with Down syndrome, showing three copies of chromosome 21.

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, so a karyotype chromosomal analysis is done to make a diagnosis. To obtain a karyotype, doctors draw blood and photograph the chromosomes within the cells. They 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 mother's blood. Together with the mother's age, the tests 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 prenatal screening shows a high chance of the child being born with Down syndrome, doctors will often advise a mother to undergo diagnostic testing to get 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.

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

National Down Syndrome Society

NDSS Community Support Programs



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 Advocacy & 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 were limited resources and support available to parents of a child with Down syndrome. She started NDSS to address the pressing needs of parents of children with Down syndrome. Since then NDSS has gradually become the largest organization in the United States advocating for those with 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 is committed to providing the Down syndrome community with quality support and informational services.

- NDSS supports 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 10,000 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 the most comprehensive 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 100 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 three million page views each year and includes Spanish translation.



NDSS National Advocacy & Policy Center

The NDSS National Advocacy & Policy Center in Washington, DC strives to protect the rights of and remove barriers for all individuals with Down syndrome by advocating before Congress, the Administration, and federal departments and agencies. NDSS leads a national, cutting-edge advocacy operation that seeks to involve the Down syndrome community, self-advocates, parents, and professionals in all aspects of public policy at the local, state, and national levels of government.

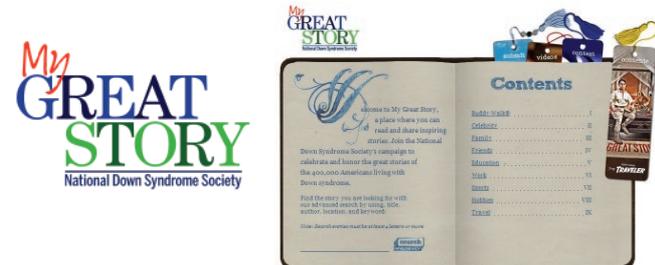


- The work of the National Advocacy & Policy Center is guided by a dynamic legislative agenda that spans the lifespan of people with Down syndrome.
- Through the NDSS DS-Ambassador Program, NDSS maintains the leading Down syndrome grassroots network that trains, educates and inspires self-advocates, parents and others in all 50 states to make a difference in the lives of people with Down syndrome.
- 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 on Capitol Hill. In 2014, NDSS spearheaded the effort to pass the *Stephen Beck Jr. Achieving a Better Life Experience (ABLE) Act*, a bill that gives people with Down syndrome and other disabilities the right to save money for the future in a tax-free savings account.

NDSS Public Awareness Initiatives

The purpose of the public awareness initiatives is to ignite the stories, successes and milestones of individuals with Down syndrome in the general public by turning the NDSS 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 to promote positive and inspirational news stories.
- Igniting the stories, successes and milestones of people with Down syndrome in the national media. NDSS has been featured in the *New York Times*, *Wall Street Journal*, *USA Today*, *Al Jazeera America*, *NBC*, *MSNBC.com*, *ABC* and the *Washington Post*.
- 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 messages 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 My Great Story campaign have been featured in national and local media outlets across the country.



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 in 1995.

- Today, 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, over 300,000 people participate in a Buddy Walk®, raising nearly \$13 million 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 a 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, a registered 501(c)(3) tax-exempt organization. We greatly appreciate support of all kinds from our generous community.

- 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 Your Way is a fundraising program that gives you the opportunity to create fundraising pages under the categories, Compete, Celebrate, Create and College. This program is 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, NDSS New Ideas or NDSS on Campus 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 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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