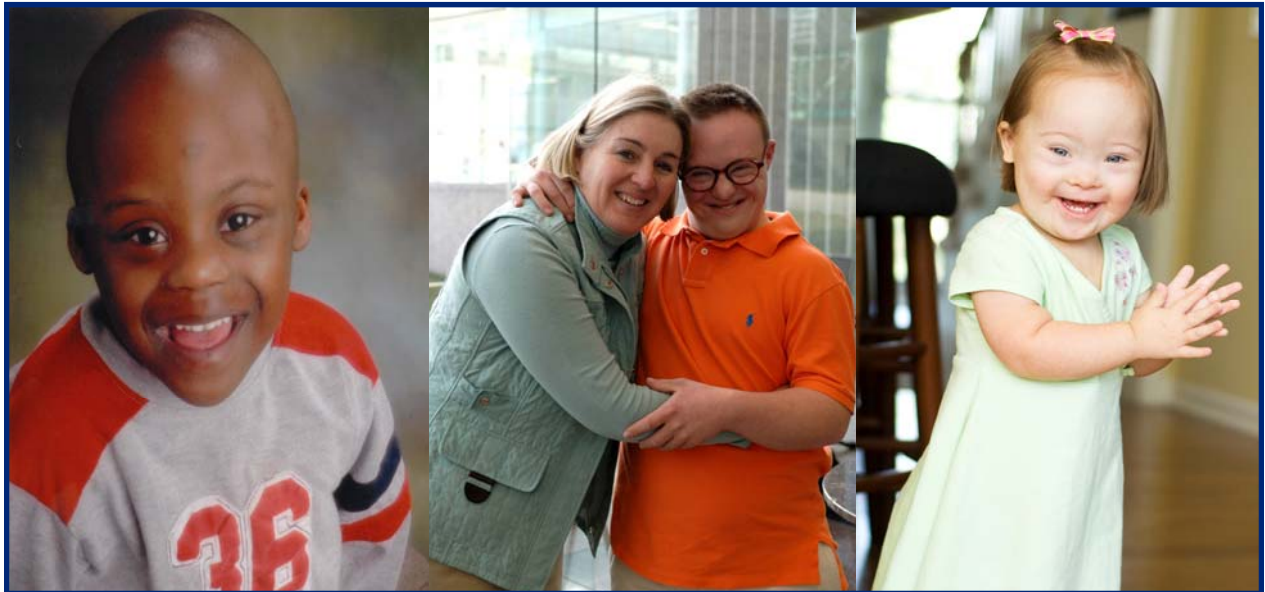




# Facts About Down Syndrome



Named after John Langdon Down, the first physician to identify the syndrome, Down syndrome is the most frequently occurring genetic condition. Down syndrome occurs in one in 733 births, and is present in all races and socio-economic groups. Down syndrome is a chromosomal disorder caused by an error in cell division that results in the presence of a third chromosome 21 or "Trisomy 21." This additional genetic material causes the identifying features as well as the cognitive and developmental delays which are common for individuals who have Down syndrome.

# Myths and Truths

## ***Myth: Down syndrome is a rare genetic disorder***

Truth: Down syndrome is the most commonly occurring genetic condition. One in every 733 births is a child with Down Syndrome. Approximately 5,000 babies are born with Down syndrome each year and there are 400,000 people in the United States living with Down syndrome.

## ***Myth: Down syndrome is hereditary and runs in families***

Truth: Most cases of Down syndrome are sporadic, chance events. However, in the instance of translocation, one parent may be identified as a carrier of the translocated chromosome. Down syndrome does not otherwise run in families and a sibling or aunt has no greater chance of conceiving a child with Down syndrome.



## ***Myth: Adults with Down syndrome cannot form interpersonal relationships, or marry***

Truth: People with Down syndrome are quite capable of forming long term loving relationships at all stages of their development. Many people with Down syndrome will date and some will get married and live with support from their families or provider organizations.

## ***Myth: Adults with Down syndrome may be unable to work or attend college***

Truth: Business owners seek adults with Down syndrome for a variety of positions. They work in offices, banks, corporations, nursing homes, hotels and restaurants. People with Down syndrome bring to their jobs enthusiasm, reliability and unparalleled dedication. There are over 200 colleges currently offering post secondary opportunities for people with disabilities.

## ***Myth: There is little community support available to help parents raise a child with Down syndrome***

Truth: There are over 300 Down syndrome support organizations in the United States which provide a variety of programs and services to individuals with Down syndrome and their families.



## ***Myth: People with down syndrome have severe cognitive delays***

Truth: Most people with Down syndrome have cognitive delays that are mild to moderate. IQ is not an adequate predictor or measure of the functional abilities of people with Down syndrome. People with Down syndrome have great potential if given opportunities.



## ***Myth: Students with Down syndrome are placed in and benefit from segregated special education programs***

Truth: Children with Down syndrome are included in regular academic classrooms across the country. Students may be integrated into specific courses or fully included in the regular classroom for all subjects. The degree of inclusion is based on the ability of the individual, but the goal is full inclusion.

## ***Myth: Most children with Down syndrome are born to older parents***

Truth: Eighty percent of children born with Down syndrome are born to women younger than 35 due to higher fertility rates. However, research has shown a link between the incidence of having a child with Down syndrome and maternal age.

## ***Myth: The life expectancy of people with Down syndrome is 30***

Truth: Thanks to advances in medical and clinical treatment and opportunities to thrive, as many as 80 percent of adults with Down syndrome reach age 55, and many live longer.



## ***Myth: Parents who receive a pre-natal diagnosis of Down syndrome will often choose to terminate their pregnancies***

Truth: While some parents choose to terminate a pregnancy upon receiving a diagnosis of Down syndrome, many keep their babies. Many parents also consider adoption as an option. There are 200 families registered who have indicated they would like to adopt a child with Down syndrome. For more information on adoption, visit [www.dsagc.com/programs\\_adoption.asp](http://www.dsagc.com/programs_adoption.asp)

## ***Myth: All people with Down syndrome will develop Alzheimer's disease***

Truth: Approximately twenty-five percent of adults with Down syndrome over the age of 35 show clinical signs and symptoms of Alzheimer's-type dementia; the percentage increases with age. The incidence of Alzheimer's disease in the Down syndrome population is three to five times greater than in the general population, which is 5-10 percent in people over the age of 65.

# Facts About Down Syndrome

- 1 in every 733 births will be a child with Down syndrome.
- There are 400,000 individuals with Down syndrome living in the United States.
- 5,000 babies are born with Down syndrome each year.
- The average lifespan of a person born with Down syndrome today is 55-60.
- 45% of individuals with Down syndrome will have a congenital heart condition.
- All people with Down syndrome will experience some level of cognitive delay.
- Individuals with Down syndrome benefit from early intervention services which include speech, occupational and physical therapy.



Prenatal screening and diagnostic tests may detect Down syndrome in the womb. A karyotype test is typically done shortly after birth to provide parents a definitive diagnosis. Chromosome variations occur among people with Down syndrome. They are as follows:

**Trisomy 21** 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.

**Translocation** 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.

**Mosaicism** 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.

## People First Language

The words we use have the power to help or hurt. It's imperative that people who support individual with Down syndrome use People First Language at all times. People with Down syndrome have the same rights as everyone else and should be treated with respect. Remember to use People First Language in all your interactions to convey respect and to model by example.

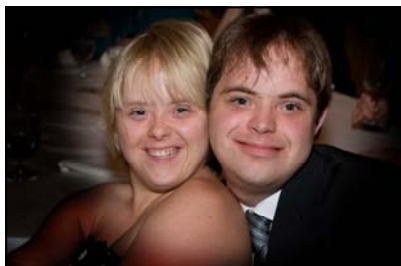
### Spelling

The correct spelling is Down syndrome. There is no apostrophe 's' following Down. Dr. John Langdon Down provided the first formal description of the syndrome, but he did not have Down syndrome and therefore no possessive is used. Also, the 's' in syndrome is not capitalized.

### A Developmental Disability

Down syndrome is a chromosomal disorder that is present at conception. Using the term 'birth defect' or 'disease' in relation to Down syndrome is incorrect. There is no known cause or cure for Down syndrome so these terms are inaccurate.

People with Down syndrome usually experience mild to moderate physical and intellectual delays. When referring to a person with Down syndrome, the terms mental retardation and mongoloid are considered outdated, offensive and should be avoided.



### People First Language

Individuals with Down syndrome are people first. The emphasis should be on the individual, not the disability. For example: a baby, child or adult with Down syndrome, not 'Down syndrome child' or 'Down's baby. If mentioning a person has Down syndrome is not relevant to the discussion, why even bring it up at all?



### Generalizations

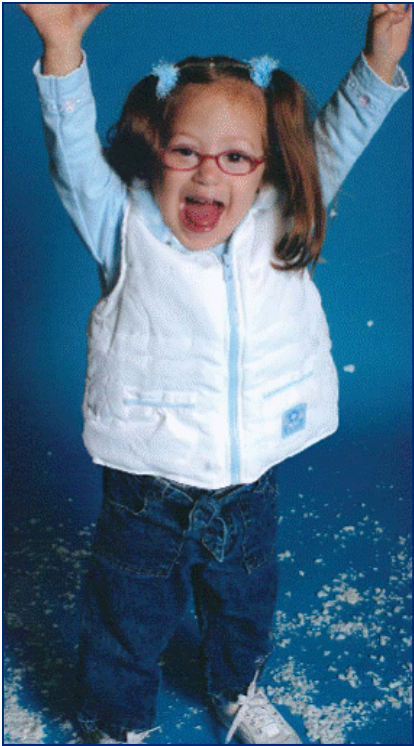
Avoid generalizations about people with Down syndrome such as 'they are always loving', 'always smiling', or 'perpetually happy'. People with Down syndrome are not all alike.

The abilities and characteristics among individuals with Down syndrome can be best described as the same for those in the general population.

### Judgment

Please avoid judgmental terminology. A person with Down syndrome does not "suffer from", and is not "a victim of" or "afflicted with" Down syndrome. Down syndrome is not a disease and these references only diminish a person's dignity.

Alternate suggestions for describing the syndrome include 'living with Down syndrome' or he/she has a medical condition known as Down syndrome.



## Down Syndrome Guild of Greater Kansas City

- Formed in 1984 by a group of parents seeking to support one another
- Welcomes approximately 50 new babies with Down Syndrome each year
- Serves more than 1,100 families in the Greater Kansas City area
- Provides administrative and funding support to 15 community groups
- Partners with 22 local hospitals to provide information to new families
- Provides support and assistance to educators in 45 school districts
- Seeks to be the number one resource on Down syndrome in Kansas City
- Hosts one of the largest Down syndrome awareness walks in the nation
- Facilitates social and educational opportunities for throughout the year
- Offers community awareness presentations to breakdown stereotypes
- Envisions a world where all people with Down syndrome are valued



10200 W 75th Street  
Suite 281  
Shawnee Mission, KS 66204  
P: 913.384.4848  
F: 913.384.4949  
[www.kcdsg.org](http://www.kcdsg.org)  
[info@kcdsg.org](mailto:info@kcdsg.org)