

The facts about **DOWN SYNDROME**

What is Down Syndrome?

Down syndrome is a genetic variation causing delays in physical, intellectual and language development. Approximately one in every 733 children born has Down syndrome. The cognitive impact ranges from mild to moderate mental retardation for most individuals. Behavior and physical development in children with Down syndrome varies, as do their unique personalities, capabilities and talents. Early intervention, inclusive education, appropriate medical care, positive public attitudes, and loving homes live productive and fulfilling lives. In adulthood, many people with Down syndrome have jobs, live independently, and enjoy recreational opportunities in their communities. More than 400,000 people in the United States have Down syndrome.

Cause of Down Syndrome

Down syndrome is caused by an error in cell division resulting in an extra 21st chromosome, thus it is sometimes referred to as Trisomy 21. A sperm or egg with an extra 21st chromosome merges with a mate that has the typical single chromosome, resulting in the child with 47 instead of 46 chromosomes.

Maternal age influences the chances of conceiving a baby with Down syndrome. Women between 35 and 39 have a one in 214 chance of giving birth to a child with Down syndrome. At age 45, a woman's risk increases to one in 19. However, due to higher birth rates among younger women, 80 percent of infants born with Down syndrome have mothers younger than 35 years of age.

Characteristics

Down syndrome has physical and physiological characteristics. Distinct facial and body features as well as a number of potential medical conditions can be associated with the syndrome.

- Low muscle tone
- Small stature
- Upward slant to the eyes
- Single deep crease across center of palm
- Increased risk of congenital heart disease
- Hearing impairment
- Vision deficits
- Increased risk of leukemia
- Increased risk of Alzheimer's disease
- Lowered resistance to infection

In addition, some individuals with Down syndrome may have a condition known as Atlantoaxial Instability. This misalignment of the top two vertebrae increases the risk of severe injury during activities where the neck may be overextended or flexed. Children must be examined by a physician to identify this condition and prevent serious injury.

Medical Needs

The child's pediatrician will help the family assess the need for various medical treatments. Surgery may be required for congenital heart disease and gastrointestinal anomalies. Medication may be prescribed for sleeping difficulties and respiratory problems. Different types of therapy may be used to improve a child's muscle tone, mobility, motor skills, and speech.

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Intervention Options

Early intervention services help children with Down syndrome reach their full potential. Therapists and educational professionals not only work with the child directly, but they also help parents learn ways to work with their child at home. For instance, language development is usually delayed in children with Down syndrome, but incorporating language into daily interactions and facilitating communication with the use of sign language can promote language development.⁽¹⁾ Positive behavior management techniques may be helpful in addressing behavior challenges which, though not necessarily more prevalent than in typically developing children, may appear later, last longer, and be complicated by communication issues.⁽²⁾

To provide the most effective treatment options for a child with Down syndrome, family members and professionals must work together early to understand the child's strengths and weaknesses and determine the best intervention treatments.

Next Steps

Learning that a child has Down syndrome can be a difficult emotional adjustment. Parents may need time to work through feelings of grief, disappointment or anxiety. Although no one is ever to blame for the diagnosis, parents sometimes report feeling guilty or in some way responsible. These emotions must be addressed for the parents to move past them and become a continuous source of inspiration and support for their child. A counselor or family therapist can help parents and other family members work through these feelings and create a healthy, nurturing home environment. Most families of children with Down syndrome report that they are stronger and closer as a result of the experience.⁽¹⁾

Parents may have concerns about the affect that a new sibling with Down syndrome will have on the other children in the family. A family therapist can help parents learn strategies to promote healthy relationships among siblings. In fact, research shows that siblings of children with Down syndrome are impacted more positively than negatively. They often show more maturity, better social skills, and more tolerance for diversity than their peers.⁽¹⁾

It is helpful for parents to reach out and connect with other families of children with Down syndrome. Networking with other families provides a wonderful source of support and guidance as parents begin gathering information they will need to raise their child. A number of organizations provide parent mentors, community resources, support services, and social events for children with Down syndrome and their families.

According to the Individuals with Disabilities Education Act (IDEA), children with Down syndrome are eligible to receive special education and related services. For children birth through two years of age, the child's state early intervention agency needs to be contacted for more information on eligibility and services. For children three years and older, the local educational system will assess eligibility and provide services.

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Looking to the Future

Siskin Children's Institute is here to serve as a resource to families as they learn about their child's diagnosis. Please contact our Outreach and Resource Center to learn more about Down syndrome and take advantage of the resources, referrals, and training programs that we can provide to your family.

Lending Library Resources on Down Syndrome

- Babies with Down Syndrome: A New Parent's Guide (Skallerup, ed.)
- Common Threads: Celebrating Life with Down Syndrome (Kidder, Skotko)
- Dakota's Pride: One Father's Search for the Truth about Down Syndrome [DVD]
- Discovery: Pathways to Better Speech for Children with Down Syndrome [DVD]
- Down Syndrome: The First 18 Months [DVD]
- Early Communication Skills for Children with Down Syndrome: A Guide for Parents and Professionals (Kumin)
- Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives (Soper)
- A Parent's Guide to Down Syndrome: Toward a Brighter Future (Pueschel)
- Road Map to Holland: How I Found My Way through My Son's First Two Years with Down Syndrome (Groneberg)
- We'll Paint the Octopus Red (Stuve-Bodeen)

Helpful Websites

- National Association for Down Syndrome (www.nads.org)
- Down Syndrome Association of Greater Cincinnati (www.dsagc.com)
- On this website you can find a DVD entitled "The Journey Ahead...Consider the Possibilities". It was created for expectant and new parents to highlight the joys and rewards of raising a child with Down syndrome.
- National Down Syndrome Congress (www.ndsccenter.org)
- There's a touching booklet available through the National Down Syndrome Congress called "Down Syndrome." In addition to providing general information it highlights individual stories of persons with Down syndrome and their relationships with those they love. A section on support from grandparents is included as well as a list of resources.
- National Down Syndrome Society (www.ndss.org)
- National Center on Birth Defects and Developmental Disabilities of the Center for Disease Control (www.cdc.gov/ncbddd)
- Contact the NCBDDD for a brochure entitled "Your Baby and Down Syndrome: Answers to Questions You Might Have." Collaborating partners were the University Centers for Excellence in Developmental Disabilities and the Association of University Centers on Disabilities.
- Brighter Tomorrows (www.brightertomorrows.org)

1. Bonnie Patterson
2. National Down Syndrome Society (2009)