

Down Syndrome is a chromosomal disorder occurring in about 1 out of every 800 births. Down Syndrome results when a person inherits all or part of an extra copy of chromosome 21. About 95% of people with Down Syndrome have Trisomy 21. About 4% have Translocation, where the extra chromosome 21 broke off and became attached to another chromosome. About 1% have Mosaic Down Syndrome, where only some cells have Trisomy 21.

Features and Characteristics

There are many physical characteristics that are associated with DS. Not every individual has all the characteristics. This is a list of the most common traits (and the medical terms often used to describe them):

- Low muscle tone (hypotonia)
- Flat facial profile (depressed nasal bridge and small nose)
- Flattening of the back of the head
- Small hands and feet
- An upward slant of the eyes (oblique palpebral fissures)
- An abnormal shape of the ear (dysplastic ear)
- A single deep crease across the center of the palm (simian crease)
- An excessive ability to extend the joints (hyperflexibility)
- Fifth finger has one flexion furrow instead of two (dysplastic middle phalanx)
- Small skin folds on the inner corner of the eyes (epicanthal folds)
- Excessive space between large & second toe
- Enlargement of tongue in relation to the size of the mouth
- Speech delays
- Short stature
- Mental retardation (can range from very mild to severe, however, is typically mild to moderate)

Individuals with Down Syndrome are subject to a variety of medical conditions. Heart abnormalities that may require surgery are present in about 50 percent, and thyroid

problems (underproduction or overproduction of thyroid hormones) affect 10 to 20 percent of persons with Down Syndrome, but these problems respond well to treatment. The risk of leukemia is somewhat increased, although treatment is successful in the majority of cases. There is also an increased risk of Alzheimer's disease in adults with Down Syndrome.

There is no cure for Down Syndrome, however early intervention programs and integrated education can be extremely beneficial.

Children with Down Syndrome are more like typically developing children than they are different. They look more like their families than they do one another, have a full complement of emotions and attitudes, are creative and imaginative in play and pranks. Children with Down Syndrome benefit from the same care, attention, and inclusion in community life that help every child grow. Love, attention, and stimulating chances to learn will do more than anything else to help children with Down Syndrome reach their greatest potential. Children with Down Syndrome can do what "typical" children can do, such as walk, talk, play, dress themselves, potty train, etc., however they generally do these things later than other children.

Babies with Down Syndrome benefit greatly from early intervention services beginning as soon after diagnosis as possible. Early intervention programs provide stimulating activities that often look like play but are meant to help the development of the child – communication, motor, mental, and social emotional skills are included in the programs.

Although children with Down Syndrome have a range of learning difficulties, physicians, educators, and parents now recognize that these children's achievements may be most influenced by what is expected of them. These expectations are perhaps the most important factor in determining the educational and vocational potential of children with Down Syndrome.

The Individuals with Disabilities Education Act (IDEA) says that every child must receive a free, appropriate public education in the least restrictive environment up to age 21. Children with Down Syndrome often attend regular classes and learn skills such as reading and writing alongside children who do not have Down Syndrome.

Adults with Down Syndrome are employed in a range of fields, participate in community and leisure activities and form ongoing interpersonal relationships. Some may live in supervised group homes, while others live independently. Some adults with Down Syndrome marry. Women with Down Syndrome are fertile and can have children, however men with Down Syndrome are generally sterile.

For Parents:

Down Syndrome will not be the most interesting thing about your son or daughter as they grow up. Raising any child fills a parent's life with delights and difficulties. There is great diversity in our world in terms of personality, learning styles, intelligence, appearance, compliance, humor, compassion, congeniality and attitude, and a child with Down Syndrome may fit anywhere on the scale of diversity. Youngsters with Down Syndrome grow up to live independent lives, needing varying degrees of support and accommodations. Favorite pastimes will vary from person to person and range from reading, gardening and travel to baseball, music and beyond.

People with Down Syndrome are people first. They are unique, responsive to their physical and social environments. Those who receive good medical care and are included in the activities of the community can be expected to adapt successfully – to attend school, make friends, find work, participate in decisions which affect them and make a positive contribution to society. People with Down Syndrome have the same emotions and needs as their peers.

RESOURCES available from the PIC Library

Babies with Down Syndrome: A New Parent's Guide, (2nd Edition) by K. Stray-Gundersen (1995)

Count Us In: Growing Up with Down Syndrome Jason Kingsley & Mitchell Levitz (1994)

Keys to Parenting a Child with Down Syndrome, M.T. Brill (1993)

Another Season: A Coach's Story of Raising an Exceptional Son, G. Stallings & S. Cook (1997)

Down Syndrome: Living and Learning with the Community, L. Nadal & D. Rosenthal (1995)

The Source for Down Syndrome, C. Chamberlain & R. Strode (1999)

Communication Skills in Children with Down Syndrome: A Guide for Parents, L. Kumin (1994)

Classroom Language Skills for Children with Down Syndrome by Libby Kumin (2001)

Teaching Reading to Children with Down Syndrome by Patricia Oelwein (1995)

Fine Motor Skills in Children with Down Syndrome by Maryanne Bruni, OC (1995)

Gross Motor Skills in Children with Down Syndrome by Patricia C. Winders, PT (1997)

Down Syndrome – A Promising Future Together by Hassold & Patterson (1999)

Yours to Keep (video), M & L Williams, (1989)

Your Baby Has Down Syndrome, (video) (1998)

BIBLIOGRAPHY

National Down Syndrome Society – “About Down Syndrome”

Down Syndrome WWW Page – “Welcoming Babies with Down Syndrome”

For more information about DOWN SYNDROME

CONTACT:



Parent Information Center

500 W. Lott St, Suite A
Buffalo, WY 82834
1-800-660-9742 (WY only)
(307) 684-2277 (v/tdd)
(307) 684-5314 (fax)
E-mail: tdawson@wpic.org
Website: www.wpic.org

To talk with the
PIC Outreach Parent Liaison
in your area, contact:

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Down Syndrome

Disability Brochure #6



Characteristics and Coping Strategies

Parent Information Center
1-307-684-2277

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