Information about Down Syndrome for New and Expecting Parents

Your baby has or may have Down syndrome. It is natural for you to have questions, concerns or fears. You are not alone in your feelings or on the journey ahead of you. Know that the outlook for people with Down syndrome has improved over time because of advances in medical care, education and public attitudes. This brochure has facts about Down syndrome and a list of places where you can go to find more information and support.

About Down Syndrome
Each cell in the human body has 23 pairs of chromosomes; babies get half of each pair from their mom and the other half from their dad. Down syndrome is a genetic condition that is usually caused by an extra copy of the twenty-first chromosome. It is not caused by anything either parent did or did not do.

About 250,000 people in the United States have Down syndrome. Down syndrome does not usually run in families.

Children with Down syndrome will grow and develop like other babies, but may meet milestones later than a typical child. The mental, behavioral and developmental progress of people with Down syndrome varies widely and cannot be predicted before a person is born. Currently, the average life expectancy for people with Down syndrome is about 60 years.

Your Child with Down Syndrome
You can help your child fulfill his or her potential by having high expectations. Nurture and relate to your child like any other, and create a supportive and caring environment to help your child thrive.

People with Down syndrome are active and valued members of their community. This includes children who are involved in social and school programs, and adults who have jobs and live independently or with some support.

- Children with Down syndrome are more like other children than they are different.
- Babies with Down syndrome usually have developmental delays. Early intervention like occupational and speech therapy helps babies meet their milestones.
- Most babies with Down syndrome have low muscle tone at birth. This usually improves with time, and physical therapy can help.
- Half of babies with Down syndrome will have health issues. This could include heart or gastrointestinal conditions that may require surgery. Babies with Down syndrome have higher chances for feeding and digestive issues, hearing loss, vision impairments, and respiratory infections. Most of these conditions can be treated with good health care.
- People with Down syndrome can do all the things a typical person can do, including participate in sports and have a job.
- People with Down syndrome usually have a mild to moderate range of intellectual disability.
- Children with Down syndrome often attend regular schools in regular education classes with differing levels of support. There are now many college programs for people with intellectual delays.
- People with Down syndrome can have regular jobs or ones with support.
- People with Down syndrome can live independently or in a group home, and have friends and intimate relationships.
Texas Resources

There are organizations across Texas that offer support, programs and resources to help families learn more about Down syndrome and connect with each other.

Amarillo
Panhandle Down Syndrome Guild
PO Box 20783
Amarillo, Texas 79114
Phone: (806) 670-1568
Email: panhandleDSG@yahoo.com
Website: www.panhandledsg.net

Austin
Down Syndrome Association of Central Texas
3710 Cedar St., Box 3
Austin, Texas 78705
Phone: (512) 323-0808
Email: admin@dsact.org
Website: www.dsact.org

Brownsville
Down By the Border
15 W. Madison St., Suite A
Brownsville, Texas 78520
Phone: (956) 541-2085
Email: sergio@downbytheborder.com
Website: www.downbytheborder.org

Bryan
Down Syndrome Association of Brazos Valley
1802 Wilde Oak Circle
Bryan, Texas 77802
Phone: (979) 778-7010
Email: dsabv@dsabv.org
Website: www.dsabv.org

Dallas/Richardson
Down Syndrome Guild of Dallas
1702 N. Collins Blvd., Suite 170
Richardson, Texas 75080
Phone: (214) 267-1374
Email: jennifer@downsyndromedallas.org
Website: www.downsyndromedallas.org

Edinburg
Rio Grande Valley Down Syndrome Association
2124 Katherine Ave.
Edinburg, Texas 78539
Phone: (956) 314-0821
Email: info@rgvdsa.org
Website: www.rgvdsa.org

El Paso
Down Syndrome Coalition for El Paso
333 North Oregon St., 2nd Floor
El Paso, Texas 79901
Phone: (915) 521-7229
Email: dsaofelpaso@yahoo.com
Website: www.dsaelpaso.org

Ft. Worth
Down Syndrome Partnership of North Texas
1300 W. Lancaster Ave., Suite 227
Ft. Worth, Texas 76102
Phone: (817) 390-2970
Email: info@dspnt.org
Website: www.dspnt.org

Halletsville
Down Syndrome Foundation of South Texas
PO Box 856
Halletsville, Texas 77964
Phone: (361) 772-6053
Email: dsfstx@yahoo.com
Website: www.dsfstx.blogspot.com

Houston
Down Syndrome Association of Houston
7015 W. Tidwell Road, Building K, Suite 106
Houston, Texas 77092
Phone: (713) 682-7237
Email: info@dsah.org
Website: www.dsah.org
Recommended Resources for New and Expectant Parents

The following materials have been reviewed by medical experts and are included in the “National Society of Genetic Counselors practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome.”

“Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome”


“Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives”
Edited by Kathryn Lynard Soper, Woodbine House, Books on Disabilities. Mothers’ stories describing the gifts that children with Down syndrome have brought into their lives.


State Down Syndrome and Disability Organizations
- For Education and Job Training: Texas Workforce Commission, www.twc.state.tx.us/jobseekers/training-education
- For General Resources: Texas Department of Assistive and Rehabilitative Services, www.dars.state.tx.us
- For Health Care Information: Navigate Life for Texas, www.navigatelifetexas.org

National Down Syndrome Organizations
- Focused on Research: Global Down Syndrome Foundation, www.globaldownsyndrome.org
  Lumind Foundation, www.lumindfoundation.org
  DS-Connect, www.dsconnect.nih.gov — *Research on cognition and health can also greatly improve outcomes for people with Down syndrome in the future. DS-Connect, sponsored by The National Institutes of Health (NIH), is a voluntary registry for families who want to participate in research opportunities, receive updates on research initiatives, and be included in the collection of data about Down syndrome.*
- Focused on Education: Down Syndrome Education USA, www.dseusa.org
- International Mosaic Down Syndrome Association, www.imdsa.org

National Disability Organizations
- The Arc — www.thearc.org
- Association of University Centers on Disability — www.aucd.org
- March of Dimes — www.marchofdimes.org
- Special Olympics International — www.specialolympics.org

Texas Department of State Health Services
Texas Birth Defects Epidemiology and Surveillance Branch
PO Box 149347, Austin, TX 78714-9347
www.dshs.state.tx.us/birthdefects/downsyndrome/
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