

# 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 60years.

## 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.
- Children with Down syndrome qualify for Early Childhood Intervention (ECI)\* up to age 3 (link below). ECI provides services for children with developmental delays, such as occupational and speech therapy.
- 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 they have friends and intimate relationships.



\*<https://www.hhs.texas.gov/services/disability/early-childhood-intervention-services>



## 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.pdsg.org

### 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  
P.O. Box 11194  
College Station, TX 77842  
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: info@downsyndromedallas.org  
Website: www.downsyndromedallas.org

### Edinburg

Rio Grande Valley Down Syndrome Association  
801 E. Fern Ave Suite #127  
McAllen, Texas 78501  
Phone: (956) 314-0821  
Email: info@rgvdsa.org  
Website: www.rgvdsa.org



### El Paso

Down Syndrome Coalition for El Paso  
P.O. Box 272  
El Paso, Texas 79943  
Phone: (915) 521-7229  
Email: info@dscep.org  
Website: www.dscep.org

### Ft. Worth

Down Syndrome Partnership of North Texas  
P.O. Box 766  
Ft. Worth, Texas 76101  
Phone: (682) 316-2970  
Email: info@dspnt.org  
Website: www.dspnt.org

### Hallettsville

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

**Galveston-Houston Families Exploring  
Down Syndrome**  
PO Box 891093  
Houston, Texas 77289  
Phone: (281) 736-8008  
Email: admin@ghfeds.org  
Website: www.ghfeds.org

### **Longview**

**East Texas Down Syndrome Group**  
PO Box 6604  
Longview, Texas 75608  
Phone: (903) 740-3843  
Email: info@etdsg.org  
Website: www.etdsg.org

### **Lubbock**

**BUDS - Better Understanding of Down Syndrome**  
P.O. Box 53063  
Lubbock, Texas 79453  
Phone: (806) 241-5800  
Email: buds@budsonline.net  
Website: budslubbock.org

### **Paris**

**Red River Valley Down Syndrome Society**  
505 Lamar Ave.  
Paris, Texas 75461  
Phone: (903) 783-1922 or (877) 273-4045  
Email: info@rrvdss.org  
Website: www.redriverdss.org

### **San Antonio**

**Down Syndrome Association of South Texas**  
1127 Patricia  
San Antonio, Texas 78213  
Phone: (210) 349-4372  
Email: info@dsastx.org  
Website: www.dsastx.org

### **Waco**

**Heart of Texas Down Syndrome Network**  
PO Box 21869  
Waco, Texas 76702  
Phone: (254) 230-9782  
Email:  
support@hotdsn.org  
Website:  
www.hotdsn.org

Resource contact information such as addresses, phone numbers, and email addresses may change over time. Please contact [birthdefects@dshs.texas.gov](mailto:birthdefects@dshs.texas.gov) for assistance.

## **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”**

By Nancy McCrean Iannone and Stephanie Hall Meredith, Down Syndrome Pregnancy, [www.downsyndromepregnancy.org/books/](http://www.downsyndromepregnancy.org/books/). *A book and website with information for new and expectant parents anticipating the birth of a child with Down syndrome.*

**“Facts about Down Syndrome”** Centers for Disease Control and Prevention (CDC), [www.cdc.gov/ncbddd/birthdefects/DownSyndrome.html](http://www.cdc.gov/ncbddd/birthdefects/DownSyndrome.html). *A website with facts about Down syndrome.*

**“Babies with Down Syndrome”** Edited by Susan J. Skallerup, Woodbine House, Books on Disabilities. *An extensive book for new parents of a child with Down syndrome.*

**“Bebés con síndrome de Down”** – *Spanish edition.*

### **“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.*



“What Parents Wish They’d Known: Reflections on Parenting a Child with Down Syndrome” Edited by Kathryn Soper, Woodbine House, Books on Disabilities. *Book with personal essays and quotes by new and expectant parents of a child with Down syndrome.*

“Health Care Information for Families of Children with Down Syndrome” American Academy of Pediatrics, [www.healthychildren.org](http://www.healthychildren.org). *Guidelines focused on recommended healthcare and treatment of a child with Down syndrome.*

“Planning for a Loving Future” National Down Syndrome Adoption Network, [www.ndsan.org/about-ndsan/](http://www.ndsan.org/about-ndsan/). *Pamphlets and website for parents considering adopting a child with Down syndrome.*

“A Loving Choice: Making an Adoption Plan for a Child with Down Syndrome” National Down Syndrome Adoption Network, [www.ndsan.org/adoption-process/birth-parents/](http://www.ndsan.org/adoption-process/birth-parents/). *Pamphlets and website for parents considering placing their child for adoption.*



## State Down Syndrome and Disability Organizations

- For Education and Job Training: Texas Workforce Commission, [www.twc.texas.gov/jobseekers/training-education](http://www.twc.texas.gov/jobseekers/training-education)
- For Health Care Information: Navigate Life for Texas, [www.navigatelifetexas.org](http://www.navigatelifetexas.org)
- For Support, Information, and Education: Texas Parent to Parent, [www.txp2p.org](http://www.txp2p.org)
- For Early Childhood Intervention Services: Early Childhood Intervention, [www.hhs.texas.gov/services/disability/early-childhood-intervention-services](http://www.hhs.texas.gov/services/disability/early-childhood-intervention-services)
- For Services: Children with Special Health Care Needs, [www.hhs.texas.gov/services/disability/children-special-health-care-needs-program](http://www.hhs.texas.gov/services/disability/children-special-health-care-needs-program)

## National Down Syndrome Organizations

- Focused on Research: Global Down Syndrome Foundation, [www.globaldownsyndrome.org](http://www.globaldownsyndrome.org)  
Lumind Foundation, [www.lumindfoundation.org](http://www.lumindfoundation.org)  
DS-Connect, <https://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 Adoption: National Down Syndrome Adoption Network, [www.ndsan.org](http://www.ndsan.org)
- Focused on Education: Down Syndrome Education USA, [www.dseusa.org](http://www.dseusa.org)
- International Mosaic Down Syndrome Association, [www.imdsa.org](http://www.imdsa.org)

## National Disability Organizations

- American Association Of People With Disabilities – [www.aapd.com](http://www.aapd.com)
- The Arc – [www.thearc.org](http://www.thearc.org)
- Association of University Centers on Disability – [www.aucd.org](http://www.aucd.org)
- March of Dimes – [www.marchofdimes.org](http://www.marchofdimes.org)
- Special Olympics International – [www.specialolympics.org](http://www.specialolympics.org)