

# down syndrome guild resources

## *Down Syndrome Guild of Dallas* **New Parent Checklist**

- ✓ Get connected with the Down Syndrome Guild of Dallas to receive a new parent packet and begin receiving the newsletter to learn about local support services, events and information. Membership is free to parents with children 12 months or younger. 214-267-1374; [www.downsyndromedallas.org](http://www.downsyndromedallas.org)
- ✓ Contact your local Early Childhood Intervention (ECI) provider to arrange for services. To determine which agency services your home area, see the list of agencies at the back of the Down Syndrome Guild phone directory or call the ECI Care Line at 1-800-628-5115
- ✓ Make an appointment for you and your child to visit the Down Syndrome Clinic at Children's Medical Center Dallas - call 214-456-2357. See enclosed brochure. There is typically a three month wait to get an appointment.
- ✓ Find a good pediatrician. Contact the Down Syndrome Clinic at Children's Medical Center Dallas (Joanna Spahis 214-456-2327) or the Down Syndrome Guild for a referral. The American Academy of Pediatrics document entitled "Health Supervision for Children with Down Syndrome" is included in this guide and is designed to assist your pediatrician in caring for a child diagnosed with Down syndrome.
- ✓ Attend a new parent gathering sponsored by the Down Syndrome Guild of Dallas. These are informal gatherings for parents/families of children with Down syndrome ages 0-18 months, yet families with children of any age are welcome. They occur once per quarter generally in the months of February, May, August & November. You will receive an invitation in the mail.
- ✓ Familiarize yourself with the government programs available. See the "Programs in Texas offering Family Support and Services" document in this guide. Other than ECI, there are programs available to families of children with Special Needs. Because some of these programs have long waiting lists, it is beneficial to sign your child up for these services as soon as possible.
- ✓ Community Living and Support Services (CLASS). Provides a broad array of services to individuals with physical disabilities and related conditions occurring before the age of 21 years. Telephone number for information and to place a name on the waiting/interest list: (877) 438-5658.

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- ✓ Home and Community based Services Program (HCS). Provides a broad array of services to both children and adults who have mental retardation and certain related conditions. To find the center nearest you call (512) 794-9268, or go to the web at <http://www.dads.state.tx.us/contact/mra/index.cfm>.



# down syndrome guild resources

## BIBLIOGRAPHY FOR PARENTS OF NEWBORNS

### PARENTING

**Cunningham, Cliff.** *Understanding Down Syndrome: An Introduction for Parents.*

Cambridge, MA: Brookline Books. 1999. (3<sup>rd</sup> printing).

An overview for new parents and professionals of children with Down syndrome.

[www.brooklinebooks.com](http://www.brooklinebooks.com).

**Kidder, Cynthia and Brian Skotko.** *Common Threads: Celebrating Life with Down Syndrome.* Rochester Hills, MI: Band of Angels Press. 2001.

An essay and photographic celebration of inspirational accomplishments of people with Down syndrome. 800-963-2237; [www.bandofangels.com](http://www.bandofangels.com).

**Meyer, Donald J. (Ed.).** *Uncommon Fathers: Reflections on Raising a Child with a Disability.* Bethesda, MD: Woodbine House. 1995.

Written for fathers, by fathers of diverse backgrounds. 800-843-7323;

[www.woodbinehouse.com](http://www.woodbinehouse.com).

**Pueschel, Siegfried M. (Ed.).** *A Parent's Guide to Down Syndrome: Toward a Brighter Future.* Baltimore: Brookes Publishing. 2001.

A comprehensive reference book especially for new parents, but useful and informative for "seasoned" parents as well. Topics include: history of Down syndrome; developmental expectations; early intervention; the school years; recreation; adolescence and adulthood; vocational training and employment. 800-638-3775; [www.pbrookes.com](http://www.pbrookes.com).

**Stallings, Gene.** *Another Season.* New York: Broadway Books. 1998.

Gene Stallings recounts his life as a football coach and a father, focusing on his relationship with his son Johnny, who has Down syndrome.

[www.randomhouse.com](http://www.randomhouse.com).

**Stray-Gundersen, Karen. (Ed.)** *Babies with Down Syndrome: A New Parent's Guide.*

Bethesda, MD: Woodbine House. 1995 (2<sup>nd</sup> Edition).

A comprehensive guide for new parents, covering all aspects of care for babies and young children. 800-843-7323; [www.woodbinehouse.com](http://www.woodbinehouse.com)

**Zuckoff, Mitchell.** *Choosing Naia: A Family's Journey.* Boston: Beacon Press. 2002.

A routine ultrasound reveals that the baby Tierney carries has a major heart defect, leading doctors to suspect Down syndrome. This book follows the Fairchild family and the decisions they must make regarding their unborn baby. 617-742-2110; [www.beacon.org](http://www.beacon.org).

# down syndrome guild resources

## DEVELOPMENT

**Bruni, Maryanne.** *Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals.* Bethesda, MD: Woodbine House. 1998.

A practical and accessible guide to understanding and developing fine motor skills in children with Down syndrome. 800-843-7323;  
[www.woodbinehouse.com](http://www.woodbinehouse.com).

**Kumin, Libby.** *Early Communication Skills for Children with Down Syndrome.* Bethesda, MD: Woodbine House. 2003.

Focuses on speech and language development from birth through the stage of making three-word phrases. Covers problem areas and treatment. 800-843-7323.  
[www.woodbinehouse.com](http://www.woodbinehouse.com).

**Winders, Patricia C.** *Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals.* Bethesda, MD: Woodbine House. 1997.

Provides parents and professionals with essential information about motor development associated with Down syndrome. 800-843-7323;  
[www.woodbinehouse.com](http://www.woodbinehouse.com).

## FAMILY SUPPORT

**Rynders, John E. and J.M. Horrobin.** *Down Syndrome: Birth to Adulthood: Giving Families an Edge.* Denver: Love Publishing. 1995.

Case studies of families woven in a clear, readable fashion, followed by practical suggestions to help both parents and professionals alike. 303-757-2579;  
[www.lovepublishing.com](http://www.lovepublishing.com).

## MEDICAL ISSUES

**VanDyke, Don C. and Philip Mattheis, Susan Eberly, Janet Williams (Eds.).** *Medical & Surgical Care for Children with Down Syndrome.* Bethesda, MD: Woodbine House. 1995.

A guide for parents providing detailed, easy-to-understand information on a wide range of medical conditions. 800-843-7323; [www.woodbinehouse.com](http://www.woodbinehouse.com).

## BOOKS FOR CHILDREN

**Rickert, Janet Elizabeth.** *Russ and the Apple Tree Surprise.* Bethesda, MD: Woodbine House. 1999.

A day in the life of Russ, who happens to have Down syndrome. 800-843-7323;  
[www.woodbinehouse.com](http://www.woodbinehouse.com). (other titles in this series are: Russ and the Firehouse and Russ and the Almost Perfect Day.)

**Shriver, Maria.** *What's Wrong with Timmy?.* New York: Little Brown. 2001.

A mother helps her daughter understand that a child who looks or acts differently, is much more like her, than different. [www.twbookmark.com](http://www.twbookmark.com).

# down syndrome guild resources

**Stuve-Bodeen, Stephanie.** *We'll Paint The Octopus Red.* Bethesda, MD: Woodbine House. 1998.

A simple repetitive story told with warmth and directness puts young siblings minds at ease, and helps them develop a positive outlook for their brother or sister with Down syndrome. 800-843-7323; [www.woodbinehouse.com](http://www.woodbinehouse.com).

**Woloson, Eliza.** *My Friend Isabelle.* Bethesda, MD: Woodbine House. 2003.

Isabelle and Charlie are friends who don't have to be just alike to enjoy being with each other. Isabelle has Down syndrome. [www.woodbinehouse.com](http://www.woodbinehouse.com).

For additional resources, please contact the National Down Syndrome Congress at 1-800-232-6372 or [www.ndscenter.org](http://www.ndscenter.org)



A small group of thoughtful people  
can change the world.

Indeed, it is the only thing  
that ever has.

- MARGARET MEAD

