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## **Down Syndrome Resources**

This month we are featuring books, videos, children's books, and websites about Down syndrome.

## **Down Syndrome - Books**

Another Season: A Coach's Story of Raising an Exceptional Son. Gene Stallings and Sally Cook, 1997. (800.1 S782 1997). In this biography, the author shares with honesty, perception, and compassion the challenges and joys of raising his only son who has Down syndrome.

Babies with Down Syndrome: A New Parents' Guide. Karen Stray-Gundersen, 1995. (226.11 Str82 ECI).

This book provides information on prenatal testing, early intervention, legal medical issues, and resources. Written for parents by parents, doctors, nurses, educators and lawyers, it covers everything parents need to know about raising their child with Down syndrome.

Bebés con síndrome de Down: Guía para Padres. Karen Stray-Gundersen, 1995. (226.11 S913b 1998 ECI).

This is the Spanish language version of *Babies with Down Syndrome: A New Parents' Guide.* 

Changed by a Child: Companion Notes for Parents of a Child with a Disability. Barbara Gill, 1997. (271.4 G41 ECI).

The mother of a son with Down syndrome provides affirmations and encouragement for parents of children with disabilities.

Cómo Favorecer las Habilidades Comunicativas de los Niños con Síndrome de Down. Lubby Kumin, 1994. (226.11 K96c 1994 ECI). This is the Spanish language version of *Early Communication Skills in Children with Down Syndrome: A Guide for Parents*.

Continuity and Change in the Social Competence of Children with Autism, Down Syndrome, and Developmental Delays. Marian Sigman and Ellen Ruskin, 1999. (226.5 S577c 1999 ECI).

This monograph describes the results of a longitudinal study which aimed: 1) to assess the continuity and change in diagnosis, intelligence, and language skills in children with autism, Down syndrome, and other developmental delays, 2) to specify the deficits in social competence and language skills in these children, and 3) to identify precursors in the preschool period of gains in language skills and of peer engagement in the mid-school years.

## Down Syndrome - Books (continued)

**Count Us In: Growing Up with Down Syndrome.** Jason Kingsley and Mitchell Levitz, 1994. (800.1 K55 1994). Two boys with Down syndrome discuss their life experiences growing up with Down syndrome and share their innermost thoughts, feelings, hopes and dreams, and their lifelong friendship.

**Down Syndrome: A Promising Future, Together.** Terry J. Hassold and David Patterson, 1999. (226.11 H355 1999 RHB).

This book summarizes the highlights of a four day national conference on Down syndrome.

**Down Syndrome: Birth to Adulthood: Giving Families an Edge.** John E. Rynders and J. Margaret Horrobin, 1996. (226.11 R995 1996 ECI).

This book provides a collection of longitudinal perspectives on experiences of individuals with Down Syndrome, from birth to adulthood.

**Down Syndrome: Living and Learning in the Community.** Lynn Nadel and Donna Rosenthal, 1995. (226.11 N124 ECI).

This book, a tool for parents and health care professionals, contains an overview of medical advances, information about the programs and services available, and commentaries by young adults with Down syndrome who describe in their own words their feelings and accomplishments.

The Down Syndrome Nutrition Handbook: a Guide to Promoting Healthy Lifestyles. Joan E.G. Medlen, 2002. (226.11 M491 2002 ECI).

This book presents information on nutrition and healthy living for children with Down syndrome. It encourages parents to start teaching healthy habits early in their child's life but also stresses that it is never too late to begin healthy habits.

Early Communication Skills for Children with Down Syndrome: A Guide for Parents and Professionals. Libby Kumin, 2003. (226.11 K96 2003 ECI).

This book focuses on speech and language development from birth through the stage of making 3-word phrases. It contains an explanation of speech-language assessment and descriptions of what to expect when a child enters school. Numerous home activities are included.

**Early Education for Children with Down Syndrome.** Valentine Dmitriev, 2001. (226.11 D628 2001 ECI). This book is intended as a reference, textbook and a manual for parents, teachers, and other professionals who wish to accelerate the development of children with Down syndrome.

**NEW!** Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals. Maryanne Bruni, 2006. (226.11 B896f 2006 ECI).

This book explains the best practices and procedures for helping children master the finger and hand skills needed for home and school activities. It is written by an occupational therapist who has worked extensively with children with Down syndrome.

**Genetics and Mental Retardation Syndromes: A New Look at Behavior and Interventions**. Elizabeth M. Dykens, Robert M. Hodapp, and Brenda M. Finucane, 2000. (226.1 D996 2000 RHB).

This book presents a comprehensive guide to the genetic and behavior characteristics of nine specific genetic mental retardation syndromes explaining how they affect individuals' behavior.

**Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals.** Patricia C. Winders, 1997. (226.11 W723 ECI).

Children with Down syndrome master gross motor skills, everything from rolling over to running, but need additional help and encouragement to maximize development. In this book, the author, a physical therapist, shares her expertise and experience. She provides parents and professionals with essential information about motor development including the impact of temperament and the effect of physical and medical conditions associated with Down syndrome.

## **Down Syndrome - Books** (continued)

**Improving the Communication of People with Down Syndrome.** Jon F. Miller, Mark Leddy, and Lewis A. Leavitt, 1999. (226.11 M648i 1999 ECI).

This book provides a framework for assessing and treating speech, language, and communication problems in children and adults with Down syndrome.

Life As We Know It. Michael Berube, 1996. (226.11 B463 ECI).

This book tells the story of the first four years in the life of James Berube, who was born with Down syndrome, and the issues he faced at each stage in his development.

Medical and Surgical Care for Children with Down Syndrome: A Guide for Parents. D.C. Van Dyke, Philip Mattheis, Susan Schoon Eberly, and Janet Williams, 1995. (226.11 V288 ECI).

This book, written by a team of twenty-five experts in the fields of medicine, dentistry, rehabilitation, psychology, nursing, and nutrition, gives parents an overview of specific medical conditions that are common among children with Down syndrome. These conditions include: heart disease, immune system concerns, endocrine conditions, eye conditions, skin conditions, ear, nose, and sinus conditions, gastrointestinal problems, orthopedic conditions, leukemia, dental concerns, reproductive issues, and neurological problems.

A Parent's Guide to Down Syndrome: Toward a Brighter Future. Siegfried M. Pueschel, 2001. (226.11 P977 2001 ECI).

This guide for new parents of a child diagnosed with Down syndrome, identifies what parents should expect as their child grows and what they can hope for in terms of health, schooling, and the child's life in the community.

**Síndrome de Down y Educación.** Jesus Florez and Maria Victoria Troncoso, 1991. (226.11 F663 ECI). In this book, written in Spanish, several experts in the field of education of children with Down syndrome share their ideas and theories.

**Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers.** Patricia Logan Oelwein, 1995. (226.11 Oe6 ECI).

Children with Down syndrome can be taught to read using an approach that provides for their unique learning styles and needs. This book describes a nationally known reading program that ensures success by presenting lessons which are both imaginative and functional and which can be tailored to meet the needs of each student.

## Down Syndrome - Children's Books

The Best Worst Brother. Stephanie Stuve-Bodeen, 2005. (805.1 S937b 2005 ECI).

Older sister Emma tries to be patient while teaching three-year-old Isaac, who has Down syndrome, how to communicate using sign language. The book includes questions and answers about sign language.

**Big Brother Dustin.** Alden R. Carter, 1997. (805.1 C323 1997).

A boy with Down syndrome helps his parents and grandparents get ready for the birth of his baby sister and chooses the perfect name for her.

I Can, Can You? Marjorie W. Pitzer, 2004. (805.1 P692i 2004 ECI).

Come along with these babies and toddlers with Down syndrome as they discover their world and enjoy new experiences. This board book is filled with colorful photographs.

My Friend Isabelle. Eliza Woloson, 2003. (805.1 W866m 2003 ECI).

A young boy named Charlie describes the activities he shares with his friend Isabelle, a girl with Down syndrome.

My Sister Annie. Bill Dodds, 1993. (805.2 D661).

This book presents the story of growing up, trying to be accepted, and having a sister with Down syndrome, which at times makes life a challenge for Charlie.

## Down Syndrome - Children's Books (continued)

Russ and the Almost Perfect Day. Janet E. Rickert, 2000. (805.1 R539 2000).

Russ, a student with Down syndrome, is having a perfect day until he realizes that the five-dollar bill he has found probably belongs to a classmate.

Russ and the Apple Tree Surprise. Janet E. Rickert, 1999. (805.1 R539 1999).

After Russ, a five-year-old with Down syndrome, picks a basket of apples and helps his mother and grandmother bake a pie, his grandfather invites him into the backyard for a surprise.

Russ and the Firehouse. Janet E. Rickert, 2000. (805.1 R539 2000).

Russ, a five-year-old with Down syndrome, visits his uncle's firehouse and gets to help with the daily chores.

## **Down Syndrome - Audiovisuals**

**NEW! Discovery : Pathways to Better Speech for Children with Down Syndrome.** 81 minutes, 2005. (DD0081).

This DVD provides an overview of language development in youngsters with Down syndrome from ages 2 and up. It shows the techniques developed by experts such as Dr. Libby Kumin and Professor Sue Buckley. By integrating spoken language, sensory input, text and reading, and sign language, children with Down syndrome can improve their understanding of the world around them long before they can speak clearly. That knowledge pays off when they do start to speak, because they have a head start on language while their talking skills are catching up. Knowing letter sounds and sight words helps children fine-tune pronunciation and lays the ground work for true reading.

## Down Syndrome: A Parental Perspective. 20 minutes, 1995. (VT1441).

This video presents positive, real experiences and discussion by a group of parents of individuals with Down syndrome.

#### NEW IN DVD! Down Syndrome: The First 18 Months. 108 minutes, 2003. (DD0079).

This video, which is organized around four chapters: the newborn, health concerns, therapies, and new expectations, presents interviews throughout with nine international medical experts on Down syndrome and several parents of children with Down syndrome discussing their children.

# Early Use of Total Communication: Parents' Perspectives on Using Sign Language with Young Children with Down Syndrome. 22 minutes, 1991. (VT0127).

To overcome the obstacle of slow communication development in children with Down syndrome, many parents and professionals are using a total communication approach that combines speech with sign language. On this tape parents speak candidly about their initial fears as well as the benefits and drawbacks of using total communication with their child.

## ECI Teleconference: Down Syndrome What's There to Know. 110 minutes, 2005. (VT0603).

Presenter Chris Simon, a parent of a child with Down syndrome, gives an overview of Down syndrome. She defines Down syndrome, reviews the common physical features, and its developmental aspects while providing facts about the condition. Typical parent reactions are explained so that caregivers can respond in ways that are helpful to the new parents and child. This video offers details about current interventions, controversial therapies and research.

## Educating Peter. 30 minutes, 1993. (VT0507).

This video, the winner of the 1992 Academy Award for Best Documentary Short Subject, is the story of a child with Down syndrome and his third grade classmates. It chronicles the frustrations and achievements during the school year of Peter, his family and fellow students.

## Down Syndrome - Audiovisuals (continued)

## Graduating Peter: Down Syndrome in the Inclusive Classroom. 75 minutes, 2003. (VT2304).

This documentary video features Peter's educational experiences in sixth grade, eighth grade and high school as he adds speech therapy and life skills classes and on-the-job training to his academic coursework. Interviews with Peter's parents, teachers, fellow students, aides, and doctors demonstrate the broad-based, ongoing support mobilized to help him fight depression, improve his ability to communicate, and move ahead in building a meaningful life for himself.

## Journey of a Lifetime: Beginning with the End in Mind. 66 minutes, 1998. (VT2482).

In this video, Karen Gaffney presents her life growing up with Down syndrome by sharing how her parents, younger brother and doctors helped her to live a fulfilling life.

## Like Any Child: Raising a Child with Down Syndrome. 22 minutes, 1995. (VT1442).

It is far easier to see the similarities between a child with Down syndrome and his or her peers than it is to focus on the differences. In this video, parents who are expecting their first child who has been diagnosed with Down syndrome, relate their feelings and anticipation of the birth. Later interviews reveal that many of their worries have been unsubstantiated.

## **Lily: A Sequel.** 15 minutes, 1998. (VT2484).

This video tells the story of the author's daughter's life growing up with Down syndrome and shows the three years from her senior year in high school (age 20) through her first 2 1/2 years in a group home. Because of Lily's openness in discussing her situation, she gives insights to the full life possible for those with Down syndrome, and for their families.

## Raymond's Portrait. 27 minutes, 1997. (VT2488).

This video presents the life of 19 year old Raymond Hu, a Chinese brush painter born with Down syndrome, through home movies and interviews with both parents, his brother, art teacher and Raymond himself. Raymond's sensitivity and passion for life is manifested in his paintings of animals.

### Your Baby Has Down Syndrome. 27 minutes, 1995. (VT1437).

This video presents several families of babies with Down syndrome who share the emotions, both positive and negative that they experienced learning their baby had Down syndrome. It shows the joy and positive effects this child had on their lives.

## **Down Syndrome - Selected Websites**

The National Down Syndrome Society's mission is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy. This website is immense and attempts to be the comprehensive information source on Down syndrome. See <a href="http://www.ndss.org">http://www.ndss.org</a>

The National Institute of Child Health and Human Development has information about Down syndrome at <a href="http://www.nichd.nih.gov/health/topics/down\_syndrome.cfm">http://www.nichd.nih.gov/health/topics/down\_syndrome.cfm</a>. An electronic pamphlet, "Facts about Down Syndrome" is available at <a href="http://www.nichd.nih.gov/publications/pubs/downsyndrome.cfm">http://www.nichd.nih.gov/publications/pubs/downsyndrome.cfm</a>.

More links to information and resources about Down syndrome are available at MedlinePlus, a website provided by the National Library of Medicine. See <a href="http://www.nlm.nih.gov/medlineplus/downsyndrome.html">http://www.nlm.nih.gov/medlineplus/downsyndrome.html</a>

## Local Texas Associations:

Down Syndrome Association of Central Texas: http://www.dsact.com/index-2.html

Down Syndrome Association of Houston: <a href="http://www.dsah.net/">http://www.dsah.net/</a>
Down Syndrome Association of San Antonio: <a href="http://www.dsasa.org/">http://www.dsasa.org/</a>
Down Syndrome Guild of Dallas: <a href="http://www.downsyndromedallas.org/">http://www.dsasa.org/</a>
Down Syndrome Partnership of Tarrant County: <a href="http://www.dsptc.org/">http://www.dsptc.org/</a>

Down Syndrome Support Group of Bryan/College Station: http://www.downsyndromeofbcs.com/

East Texas Down Syndrome Group: http://www.etdsg.org/

Panhandle Down Syndrome Guild: <a href="http://www.panhandledsg.org/">http://www.panhandledsg.org/</a>

## **New Addition - Video**

Understanding Traumatized and Maltreated Children: The Core Concepts. 157 min. 2004. (DD0127) This series consists of 7 programs hosted by Bruce Perry and Art Linkletter on 2 DVDs. Program 1 Challenging Our Beliefs: Dr. Perry challenges us to evaluate existing childcare systems, and urges us to consider their effectiveness; Program 2 The Amazing Human Brain: Dr. Perry covers the basics of brain anatomy and function; Program 3 How the Brain Develops: The Importance of Early Childhood: Bonding and attachment are stressed as the cornerstones of early childhood optimal development; Program 4 Neglect: How the Poverty of Experience Disrupts Development: Severe neglect and missed caregiving opportunities cause various degrees of brain effects and behavior problems in maltreated children; Program 5 The Fear Response: The Impact of Childhood Trauma: Caregivers learn to effectively recognize the behaviors and physical reactions of children in the various stages of the fear response; Program 6 Living and Working with Traumatized Children: In depth information and effective skills for those who care for traumatized and maltreated children; Program 7 Violence and childhood: Insufficient brain cortex modulation and primitive brain stem impulsivity can lead to acts of violence.

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## Journal of Early Intervention

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## Fall 2007

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