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Medical Diagnosis: Cerebral Palsy, Cleft Palate, Cystic Fibrosis, Fetal Alcohol Syndrome, Seizure Disorders, Sickle Cell Disease, and Spina Bifida - Updated

This month we are featuring resources on cerebral palsy, cleft palate, cystic fibrosis, fetal alcohol syndrome, seizure disorders, sickle cell disease, and spina bifida.

Check out the new additions to the collection on page 8!

Cerebral Palsy - Books

Caring for Children with Cerebral Palsy: A Team Approach. John P. Dormans, 1998. (203.21 D736 ECI).

This book describes the collaborative approach used to provide care for children with cerebral palsy by a team of pediatricians, orthopedic surgeons, physical and occupational therapists, speech-language pathologists, social workers, and educators. The book offers information on the diagnosis, treatment, and support of these children within the context of team-based caregiving.

Cerebral Palsy: A Complete Guide for Caregiving. Freeman Miller and Steven Bachrach, 1995. (203.21 M614 ECI).

This book provides an overview of this condition along with practical advice for both physicians and parents.

Developmental Disabilities in Infancy and Childhood: Volume II: The Spectrum of Developmental Disabilities. Arnold J. Capute and Pasquale J. Accardo, 1996. (226.5 C255 1996 ECI).

This book covers the continuum of motor disorders and disorders of higher cortical function, cerebral palsy, the spectrum of motor dysfunction, mental retardation, the spectrum of language and communication disorders, the spectrum of disorders of learning and attention, and associated deficits.

Expect the Unexpected: My Dreams and How I Got There. Larry P. Espling, 1998. (800.1 E77 1998).

Mr. Espling, a man with cerebral palsy, shares his life story. He recounts experiences from his childhood in New Sweden, Maine and his adulthood in Boston, Massachusetts. He also provides readers with cerebral palsy with specific strategies for living life to the fullest extent possible.

From Where I Sit: Making My Way with Cerebral Palsy. Shelley Nixon, 1999. (800.1 N736 1999).

In this autobiography, the young author tells of the obstacles she has overcome to lead her life on her own terms.

Cerebral Palsy - Books (continued)

NEW! My Perfect Son Has Cerebral Palsy: A Mother's Guide Of Helpful Hints. Marie A. Kennedy, 2001. (800 K36m 2001 ECI).

This is a mother's story of her life with her son who has cerebral palsy. It shares the thoughts, concerns, joys and sadness of sharing a life with her special child.

NEW! The Official Parent's Sourcebook on Cerebral Palsy. James N. Parker and Phillip M. Parker, 2002. (203.21 P241o 2002 ECI).

This sourcebook has been created for parents who have decided to make education and Internet-based research an integral part of the treatment process. Although it gives information useful to doctors, caregivers and other health professionals, it also tells parents where and how to look for information covering virtually all topics related to cerebral palsy, from the essentials to advanced areas of research.

The Question of David: A Disabled Mother's Journey Through Adoption, Family, and Life. Denise S. Jacobson, 1999. (800.1 J17 1999).

The author, who has cerebral palsy, writes about her life as the mother of a child with cerebral palsy and as an activist.

Cerebral Palsy - Audiovisuals

A Day at a Time. 58 minutes. 1992. (VC5339).

The film makers follow a family with four children, including a set of twins with cerebral palsy. They show how the love of the family has turned a difficult situation into an affirmation of life. The challenges of parenting children with special needs are documented.

The Flowering of a Child with Disabilities: Micah's Story. 58 minutes. 1998. (VT2492).

This video, produced and filmed by Micah's father, shows the daily activities and adventures of Micah and his family. It also documents how inclusion in an elementary school has helped Micah and his classmates.

If I Can't Do it. 57 minutes. 1998. (VT2480).

This is the story of Arthur Campbell who developed cerebral palsy as a result of a difficult birth. Campbell grew up in poverty in the hills of Kentucky with a dysfunctional family, but in spite of his disability and the environment in which he was reared, he grew up to seek independence and to work as an advocate for people with disabilities. This contains frank, although not explicit, discussion and language.

King Gimp. 50 minutes. 2002. (VT2489).

This is a documentary portrait of an artist with cerebral palsy. The film makers document thirteen years in the life of Dan Keplinger as he graduates, progresses in his education and develops his artistic talents.

Movin' On. 24 minutes. 1995. (VT1870).

This video documents the educational and professional accomplishments of six people with disabilities who have overcome challenges to succeed. The video profiles people who have cerebral palsy, hearing and visual impairments, spina bifida and post-polio syndrome.

Same Walk, Different Streets. 30 minutes. 1993. (VT1865).

Geri Jewell uses humor to explain cerebral palsy and other disabilities to a live audience.

Cerebral Palsy - Children's Books

NEW! Nathan's Wish. Laurie Lears, 2005. (805.1 L438n 2005 ECI).

A boy with cerebral palsy helps out at a raptor rehabilitation center and is inspired himself when an owl that cannot fly finds another purpose in life.

Cerebral Palsy - Children's Books (continued)

NEW! Rolling Along: The Story of Taylor and His Wheelchair. Jamee Riggio Heelan and Nicola Simmonds, 2000. (804 H458r 2000 ECI).

This children's book explains how having cerebral palsy affects Taylor and how getting a wheelchair makes a big difference in helping him get around, do things by himself, and even play basketball with his twin Tyler.

Cerebral Palsy - Websites

United Cerebral Palsy: <http://www.ucp.org/>

MedlinePlus: <http://www.nlm.nih.gov/medlineplus/cerebralpalsy.html>

Cleft Palate - Books

Cleft Palate Speech Management: A Multidisciplinary Approach. Robert J. Shprintzen and Janusz Bardach, 1995. (201.2 Sh82 ECI).

This book, meant to be used in the clinical setting, discusses what the clinician should do when treating a patient with a communicative impairment related to clefting. Several concepts are presented, several tried and true procedures are discussed, and some widely accepted procedures are challenged.

Cleft Palate: Interdisciplinary Issues and Treatment. Karlind T. Moller and Clark D. Starr, 1993. (201.2 M726c 1993 RHB).

This textbook provides direct instruction and practical knowledge to speech pathologists for helping patients with clefts. Information from multiple disciplines is presented.

Communicative Disorders Related to Cleft Lip and Palate. Kenneth R. Bzoch, 1997. (201.2 B863 1997 ECI).

This textbook presents research on the general and diagnostic aspects of cleft palate along with information about early preventive and later rehabilitative speech therapy. Contributors include speech pathologists, surgeons, physicians, dental specialists and scientists.

A Curriculum for Infants and Toddlers with Cleft Palate: Developing Speech and Language. Bonnie Brookshire, Donna Fox, and Joan I. Lynch, 1993. (201.2 L987 1993 ECI).

This is a curriculum suggested to be used weekly or biweekly in close cooperation with a child's parents or caregiver. The material is divided into five sections: curriculum, determining entry levels and progress, essentials for interaction, and information for parents.

Don't Despair Cleft Repair. Karen S. Lipman and Rick Lipman, 1996. (800.1 L764 1996).

The authors present basic information about cleft lip and palate and photos to document their son's progress through the reconstructive surgery.

Cleft Palate - Audiovisuals

Face First. 29 minutes. 1998. (VT2486).

This video looks at the social isolation four individuals, each with a facial birth defect, felt as children. Their stark anecdotes about the pain of corrective procedures, coupled with the sting of ridicule and rejection, reflect the reality faced by many who are seen as different.

The Special Touch Babies Need: Caring for the Infant with Cleft Lip/Palate. 16 minutes. 1996. (VC7180).

This video is intended for parents of babies born with a cleft lip or cleft palate and health clinicians involved in the care of these infants. It gives practical and crucial information for helping parents adjust to their special needs situation. It also shows the importance of breastfeeding the baby and instructions on providing breastmilk to the baby before and after surgery. Help and information for bottle-feeding are included.

Cleft Palate - Websites

Cleft Palate Foundation: <http://www.cleftline.org>

MedlinePlus: <http://www.nlm.nih.gov/medlineplus/cleftlipandpalate.html>

Cystic Fibrosis - Books

Cystic Fibrosis: A Guide for Patient and Family. David M. Orenstein, 1997. (208.4 O66 1997).

This book presents clear explanations and practical advice on cystic fibrosis and its management.

Understanding Cystic Fibrosis. Karen Hopkin, 1998. (208.4 H793 1998 RHB).

This book charts the progress that has been made since the discovery of the genetic mutations that cause cystic fibrosis and in understanding how these genetic anomalies cause the disease.

Cystic Fibrosis - Audiovisuals

Breathing. 20 minutes. 1995. (VT1308).

This program begins by looking at a typical day in the life of a young girl with cystic fibrosis. The structure and function of the lungs are seen through a combination of computer graphics and video. The program also provides an introduction to the lungs and associated topics; causes and symptoms of this disease; and genetic diseases and gene therapy.

NEW! Cystic Fibrosis: A Day in the Life. 26 minutes. 2004. (DV0188).

For a young person living with cystic fibrosis, each day is a struggle just to breathe. The lungs are clogged with thick mucus requiring constant medication and intrusive therapies. There is no cure. Without a lung transplant the disease can become a death sentence. This program follows the story of a young woman with cystic fibrosis and a young man whose life was saved by a lung transplant.

Diagnosing and Treating Cystic Fibrosis. 21 minutes. 1999. (VT 1314).

This video examines the presentation, diagnostic testing, treatment, and biochemistry of cystic fibrosis.

Jeremy Bishop Explains CF. 17 minutes. 1995. (VC6000).

This video dramatizes a day in the life of a 10-year-old boy with cystic fibrosis by chronicling his difficulties with his therapeutic regimen and the concerns his disease raises among his peers. The boy is shown the inside of the body of a child with cystic fibrosis via computer animation. Once he understands why the bodies of persons with cystic fibrosis are different, the boy changes his behavior and becomes more compliant, which resolves many of his problems.

Living with Cystic Fibrosis. 25 minutes. 1997. (VT 1315).

Patients, healthcare professionals and scientists answer commonly asked questions about cystic fibrosis and provide an in-depth look at the lives of people with the disease.

Cystic Fibrosis - Websites

Cystic Fibrosis Foundation: <http://www.cff.org/home/>

MedlinePlus: <http://www.nlm.nih.gov/medlineplus/cysticfibrosis.html>

Fetal Alcohol Syndrome - Books

The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. Ann Streissguth, 1997. (201.4 Str83 ECI).

This book presents a summary of findings and recommendations by a team who conducted the largest study ever done on people of all ages with fetal alcohol syndrome and fetal alcohol effects. More than twenty experts from the fields of human services, education, and criminal justice describe their solutions to this disability that targets the brain and has lifelong consequences.

NEW! Damaged Angels: An Adoptive Mother Discovers the Tragic Toll of Alcohol in Pregnancy. Bonnie Buxton, 2005. (201.4 B991d 2005 ECI).

Part heartfelt memoir, part practical guide, this book recounts the author's struggles to raise an adopted daughter whom she did not realize was afflicted with fetal alcohol syndrome. The book offers guidance to parents who have children with fetal alcohol syndrome.

Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome. Judith Kleinfeld and Siobhan Wescott, 1993. (201.4 K673 ECI).

This book presents case studies of children affected by alcohol and three optimistic messages: (1) Existing negative stereotypes of these children may be misleading; (2) Early diagnosis and intervention, together with excellent family care and schooling, make a great difference in these children's success and happiness; (3) Specific educational strategies help children affected by alcohol succeed.

Fetal Alcohol Syndrome: A Guide for Families and Communities. Ann Streissguth, 1997. (201.4 St84 ECI).

A completely preventable disability, fetal alcohol syndrome changes the life course of thousands of babies each year. This book, using case studies, photos, illustrations, and validated empirical research, will help physicians, psychologists, social workers, and families of children and adults with fetal alcohol syndrome work toward an educated community, a supportive network and better futures.

NEW! Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis. 2004. (201.4 F419 2004 ECI).

Guidelines for the diagnosis of fetal alcohol syndrome and other negative birth outcomes resulting from prenatal exposure to alcohol are listed in this publication. Guidance about medical, educational, social and family services appropriate for individuals with fetal alcohol syndrome and their families are reviewed. Research on programs aimed at preventing fetal alcohol syndrome and recommendations for identifying women at risk are also presented.

Fetal Alcohol Syndrome - Audiovisuals

NEW! Fetal Alcohol Exposure: Changing The Future. 31 min. 2006. (DD0087).

Viewers will learn how fetal alcohol spectrum disorders are diagnosed. They will understand the primary and secondary disabilities associated with fetal alcohol spectrum disorders and the human cost of these disorders.

David with Fetal Alcohol Syndrome. 45 minutes. 1996. (VC7251).

David and his adoptive family describe what is like to grow up and live with the effects of fetal alcohol syndrome.

Fetal Alcohol Syndrome and Other Drug Use During Pregnancy. 19 minutes. 1994. (VT1196).

This video profiles an eight-year-old Apache boy born with fetal alcohol syndrome, showing how alcohol ingested by his mother crossed the placenta and entered the bloodstream of the fetus, remaining long after it left the mother's bloodstream. The program also examines the plight of babies born to cocaine-addicted mothers.

Fetal Alcohol Syndrome: Life Sentence. 24 minutes. 1998. (VT1197).

This program examines how early identification of and intervention with infants and children with fetal alcohol syndrome can help prevent extreme antisocial behavior in adulthood.

Fetal Alcohol Syndrome - Multimedia

Fetal Alcohol Syndrome Tutor. 1999. (CD0002).

This is interactive software that assists in the screening and diagnosis of fetal alcohol syndrome using descriptive text, video clips, animations and illustrations.

Fetal Alcohol Syndrome - Websites

The FASD Center: <http://fasdcenter.samhsa.gov/>

National Organization on Fetal Alcohol Syndrome: <http://www.nofas.org/>

MedlinePlus: <http://www.nlm.nih.gov/medlineplus/fetalalcoholsyndrome.html>

Seizure Disorders - Books

Epilepsy and Seizures: Everything You Need to Know. Donald Weaver, 2001. (203.11 W363 2001 RHB).

This book discusses what is currently known about this unpredictable disorder, and gives detailed, practical advice to understand and cope with seizure disorders.

Seizures and Epilepsy in Childhood: a Guide for Parents. John M. Freeman, 1997. (203.11 F877 ECI).

This is a resource for parents in need of medical information about their child with epilepsy. It provides information about drugs, diet, and surgical treatments as well as routine health care.

The Brainstorms Family: Epilepsy in Our Terms: Stories by Children with Seizures and Their Parents.

Steven C. Schachter, 1996. (WL 385 S291f 1996). Medical and Research Library.

In their own words, children and parents describe the experiences of handling the crisis of the initial seizure, adjusting to the diagnosis of epilepsy, coping with seizures, managing medications and side effects, and dealing with health care providers, siblings, and friends.

Seizure Disorders - Audiovisuals

NEW! Epilepsy: One In One Hundred Kids. 26 min. 2004. (DD0088).

Children and adults with epilepsy are the focus of this DVD. Two young siblings who live with the condition are interviewed along with leading experts in this field.

Seizure Disorders - Websites

Epilepsy Foundation: Information for parents: <http://www.epilepsyfoundation.org/about/quickstart/parents/index.cfm>

Kids Club from Epilepsy Foundation: <http://www.epilepsyfoundation.org/kidsclub/nonflash/home/index.html>

MedlinePlus: Information on epilepsy: <http://www.nlm.nih.gov/medlineplus/epilepsy.html#cat8>

MedlinePlus: Information on seizures: <http://www.nlm.nih.gov/medlineplus/seizures.html#cat8>

Sickle Cell Disease - Books

Understanding Sickle Cell Disease. Miriam Bloom, 1995. (207.22 B623 ECI).

This book was written for people with the disease, their families, carriers of the gene, and those who work with them. It also includes discussion of the symptoms and emotional aspects of the disease.

Sickle Cell Disease - Audiovisuals

Care for the Child with Sickle Cell Disease. 13 minutes. 1995. (VC5956).

This video discusses the symptoms of sickle cell disease in children and the extra care parents must provide. It emphasizes that these children should be encouraged to lead normal lives and to reach their full potential. It also describes the many programs and types of specialists available to treat this disease.

Sickle-Cell Anemia. 16 minutes. 2000. (VT1306).

This video provides a thorough overview of the sickle-cell phenomenon by presenting the symptoms, treatment, possible complications, screening methods, and the biochemical reasons for the characteristic shape of sickle-cell.

Sickle Cell Disease - Websites

Sickle Cell Disease Association of America: <http://www.sicklecelldisease.org/>

MedlinePlus: <http://www.nlm.nih.gov/medlineplus/sicklecellanemia.html>

Spina Bifida - Books

Answering Your Questions about Spina Bifida. 1995. (201.1 C437 ECI).

This book, which is a guide from The Spina Bifida Program Department of General Pediatrics, answers commonly asked questions about spina bifida. It also includes information on specific medical and social issues of interest to families of those with spina bifida.

Children with Spina Bifida: A Parent's Guide. Marlene Lutkenhoff, 1999. (201.1 L973 1999 ECI).

This book provides parents with information, guidance, and support to meet their child's often intensive needs from birth through childhood.

Living with Spina Bifida: A Guide for Families and Professionals. Adrian Sandler, 1997. (201.1 Sa56 ECI).

This guide covers pregnancy, childbirth and each developmental stage of childhood. The key medical, rehabilitation, and emotional issues of spina bifida during each stage are explained.

Spina Bifida - Children's Books

All Kinds of Friends, Even Green! Ellen B. Senisi, 2002. (805.1 S477 2002).

Seven-year-old Moses, who has spina bifida and uses a wheelchair, reflects that his neighbor's disabled iguana resembles him because they both have figured out how to get where they want to be in different ways than those around them.

Spina Bifida - Websites

MedlinePlus: <http://www.nlm.nih.gov/medlineplus/spinabifida.html>

Spina Bifida Association: <http://www.sbaa.org>

Comprehensive Audiovisuals

Syndromes Associated with Multiple Congenital Anomalies. 116 minutes. 1990. (VC7255).

This video presents an overview of congenital disabilities with examples of individuals at different ages. It includes descriptions and examples of 23 syndromes, associations and sequences, including cleft palate, Down syndrome, neurofibromatosis, Marfan's syndrome, and fetal alcohol syndrome.

Comprehensive - Multimedia

NEW! Developmental Disabilities Faces Patterns Possibilities. 2002. (CR0013).

This CD-Rom gives basic information about autism, cerebral palsy, epilepsy and intellectual and developmental disabilities. A glossary of related terms, bibliographies and interactive quizzes are provided.

Comprehensive Website

The **March of Dimes** provides web pages on many conditions of interest in this issue of the newsletter:

<http://www.marchofdimes.com/pnhec/4439.asp>

New Additions - Books

Child Maltreatment 2005. U.S. Dept. of Health and Human Services, Administration on Children, Youth and Families, 2007. Book. (130.5 C536 2007 ECI)

This report summarizes case-level data from the states to the National Child Abuse and Neglect Data System. It presents national statistics on child abuse and neglect.

Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis. National Center on Birth Defects and Developmental Disabilities, 2004. Book. (201.4 F419 2004 ECI)

Guidelines for the diagnosis of fetal alcohol syndrome and other negative birth outcomes resulting from prenatal exposure to alcohol are listed in this publication. Guidance about medical, educational, social and family services appropriate for individuals with fetal alcohol syndrome and their families are reviewed. Research on programs aimed at preventing fetal alcohol syndrome and recommendations for identifying women at risk are also presented.

Summary Health Statistics for U.S. Children: National Health Interview Survey, 2004. National Center for Health Statistics, 2006. (906 D528 2006 ECI)

This book summarizes data from the 2004 National Health Interview Survey which provides national estimates for a broad range of health measures for the U.S. civilian noninstitutionalized population of children under 18 years of age...classified by sex, age, race/ethnicity, family structure, parent's education, family income, poverty status, health insurance coverage, place of residence, region, and current health status. It covers these topics: asthma, allergies, learning disability, Attention Deficit Hyperactivity Disorder, use of medication, respondent-assessed health status, school-loss days, usual place of medical care, time since last contact with a health care professional, selected measures of health care access, and dental care.

New Additions - Videos

Mastering the Tasks of Toddlerhood. 24 min. 1990. (DD0118)

Mastery experiences, oral language development and emotional growth are among the topics handled in this DVD that reflects the charm and liveliness of this stage of life.

Promoting Children's Social Competence: A Guide for Family Child Care Providers. 23 min. 2007 (DD0119)

This DVD contains three sections: Setting up the Environment to Support Social Development; Guiding Children's Behavior; Understanding and Dealing with Challenging Behavior. This program gives child care providers tips on how to teach children to cooperate, play positively, share and take turns.

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Early Childhood Report - September 2007

Early CHILDHOOD Report

Children With Special Needs & Their Families

VOLUME 18, ISSUE 9

SEPTEMBER 2007

LEGAL SPOTLIGHT

You Be the Judge

Does a discontinuation of IFSP services entitle a child to comp ed? **Page 2**

Washington Watch

Find out when Supreme Court justices will hear the case regarding private placement before a child has an IEP; also learn about potential changes to Annual Performance Reports. **Page 3**

Decisions & Guidance

View the latest judicial rulings and SEA decisions, including a case on conductive ed. **Pages 10-12**

Part C Primer

Section 303.344(e)(2) of the proposed IDEA Part C regs would retain the requirements for service coordinators to identify on the IFSP medical and other services that the child needs, but are not required by Part C, and the steps that will be taken to secure those services. Service coordinators would no longer be required to identify and coordinate funding sources for these services.

COVER STORY

OSEP: Stay-put regs on Part C services may not shield you from FAPE claims

While the final IDEA regulations do not require school districts to provide Part C services to children transitioning from Part C to B during the pendency of due process disputes, a recent **OSEP** letter suggests certain states may want to consult with their attorneys before denying such services. This can help ensure they will not be vulnerable to FAPE claims. School districts nationwide also should consider the benefits of offering some services similar to children's early intervention services during a dispute. **Full story, page 4.**

Placement

See why the **Education Department** states children at age 3 do not have a 'current educational placement' that qualifies them for stay-put, pending a due process dispute. **See page 4.**

HIGHLIGHTS

Take charge to ensure smooth Part C to B transitions

Find out how school districts can ignite communication between Part C and B to better plan for and execute early childhood transitions. **Page 5**

Eye on Autism: Create a multidisciplinary preschool

Learn how you can create a comprehensive, inclusive preschool program for children with autism by accounting for the latest research and parents' concerns. **Page 6**

Be open-minded about natural environments

See why you should consider more than a child's home and child care center as his natural environment to avoid due process complaints. **Page 7**

Prepare parents for their child's special ed evaluations

Discover how you can prevent misunderstandings by educating parents about the nature of their child's impending special needs assessments. Also learn why specialists may want to document their individual findings. **Page 8**

Review, document children's biting behavior

Find out why you should pay attention to when and with whom children engage in biting behavior to uncover potential developmental or emotional causes and determine effective interventions. **Page 9**

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Exchange - September/October 2007

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Infant Mental Health Journal - September/October 2007

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Cover photo: Department of Defense

www.zerotothree.org/journal