



Pediatric/Adolescent Resource List

WEBSITES

http://www.njcfsa.org	NJCFSA, Inc., Youth Corner, Scholarship
http://www.cfids.org/youth/asp	CFIDS Association of America, Youth
http://www.dynakids.org	Dysautonomia Youth Network of America, Inc.
http://www.iacfsme.org	IACFS/ME, Pediatric Case Definition, 2007
http://www.yellowpagesforkids.com/help/nj.htm	Resources for Parents
http://www.wrightslaw.com	Educational related resources for Parents

FEDERAL GOVERNMENT ME/CFS WEBSITES

http://orwh.od.nih.gov/cfs.html	Office of Research on Women's Health, Trans-NIH Working Group
http://www.hhs.gov/advcomcfs	U.S. Department of Health & Human Services Advisory Committee
CDC- not yet included here.	CDC is gathering updated pediatric data to replace the present info which is outdated.

NEWSLETTERS

New Jersey CFS Association, Inc.

P.O. Box 477, Florham Park, N.J. 07932

888-835-3677 (toll free) Membership \$30

International Association for CFS/ME

IACFS 27 N. Wacker Drive, #416, Chicago, Ill. 60606
847-258-7248 Membership-Profession.\$100Assoc.\$40

MANUAL & PRIMERS

A Pediatric Case Definition for Myalgic Encephalomyelitis and Chronic Fatigue Syndrome,

Jason, Leonard A. et al. Co-published simultaneously in Journal of Chronic Fatigue Syndrome (The Haworth Medical Press, an imprint of The Haworth Press, Inc.) Vol. 13, No. 2/3, 2006, pp. 1-44; and: Pediatric Chronic Fatigue Syndrome (ed: Kenny L. De Meirleir, Neil R. McGregor, and Elke L. S. Van Hoof) The Haworth Medical Press, an imprint of The Haworth Press, Inc., 2006, pp. 1-44.

A Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome

Edited by Joseph F. John, Jr., M.D. & James M. Oleske, M.D., MPH, The Academy of Medicine of N.J., The University of Medicine and Dentistry of N.J., The N.J. Department of Health & Senior Services, copyright 2002, the manual is now out of print but it is available **free** by download,

<http://www.njcfsa.org>

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A Primer for Clinical Practitioners

International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).2001. Online <http://www.iacfsme.org/Home/Primer.tabid/509/Default.aspx>

Myalgic Encephalomyelitis-Adult & Paediatric: International Consensus Primer for Medical Practitioners, The International Consensus Panel 2012 Online

<http://www.hetalternatief.org/ICC%20primer%202012.pdf>

BOOKS ON PEDIATRIC/ADOLESCENT ME/CFS

A Parents' Guide to CFIDS, How to Be an Advocate for your Child with Chronic Fatigue Immune

Dysfunction Syndrome, David S. Bell, M.D. FAAP; Mary Z. Robinson, MSEd; Jean Pollard, AS; Tom Robinson, MS, CAS; Bonnie Floyd, MA (1999)

The Doctor's Guide to Chronic Fatigue Syndrome, Understanding, Treating, and Living with CFIDS

David S. Bell, MD (1995)

Harnessing the Wind, Chronic Fatigue Syndrome and My Son, Shanon McQuown, (2005)
Adolescence and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Journeys with the Dragon
Naida Edgar Brotherston, MSW, RSW (2001)
When I am Weak, A Teenager's Struggle with Chronic Fatigue Syndrome, Jacki Schirmer (1994)
Finding Strength In Weakness, Help and Hope for Families Battling Chronic Fatigue Syndrome
Lynn Vanderzalm (1995)
Zoe's Win Jane Colby (1999)
TEACH-ME: A Sourcebook for Teachers of Children with ME/CFS/FMS National ME/FM Action Network,
Canada(2002) <http://www.mefmaction.net>

BOOKS ON SPECIAL EDUCATION LAW AND ADVOCACY

Wrightslaw: Special Education Law, 2nd Edition Peter and Pamela Wright (2007)
Wrightslaw: From Emotions to Advocacy: The Special Education Survival Guide Peter & Pamela Wright
(2006)
The Complete IEP Guide: How to Advocate for Your Special Ed Child Lawrence M Siegel, (2009)
IEP and Inclusion Tips for Parents and Teachers, Handout Version Anne Eason and Kathleen Whitbread
(2006)
Better IEPs, How to Develop Legally Correct & Educationally Useful Programs Barbara Bateman, Mary
Anne Linden (2006)
*How to Compromise With Your School District without Compromising Your Child: A Field Guide for
Getting Effective Services for Children With Special Needs* Gary Mayerson (2004)

A more comprehensive list of materials is available in the Youth Corner at www.njcfsa.org

Note: The NJCFSA maintains current healthcare provider and lawyer/educational advocate referral lists.

03/16/2014