

Resources Available from the National Fragile X Foundation

Books

9th International Conference Proceeding (2004) Summaries and handouts of many of the professional and parent presentations in a three ring binder format.

Boys with Fragile X Syndrome (1995) by Rebecca O'Connor, MA. This children's book is designed to enlighten and educate siblings, friends, classmates, and educators alike about the characteristics of Fragile X. The author is a developmental specialist and has over ten years experience in the development of treatment plans for children with Fragile X Syndrome.

Children With Fragile X Syndrome: A Parents Guide (2000) Edited by Jayne Dixon Weber. Written by leading professionals in the field and experienced parents. Up-to-date information helps families adjust, understand their child's strengths and weaknesses, and seek further help and expertise.

Lesson-Planning Guide for Students with Fragile X Syndrome (2004) Edited by Marcia L. Braden, PhD. and the Education Project Team of the National Fragile X Foundation. This workbook is intended for classroom teachers who may have little or no exposure to Fragile X Syndrome. Includes a wealth of practical information that includes background on Fragile X, descriptions of behavior and learning styles, discussion of educational and community resources, and sample lesson plans for children with Fragile X at a variety of developmental levels. NOTE: This guide replaces and extensively incorporates Dr. Marcia Braden's "Curriculum Guide."

Educating Boys with Fragile X: A Guide for Parents and Professionals (1994) by Gail Spiridigliozzi, and others. This 20-page volume provides an excellent overview and introduction to those issues impacting the education of boys with Fragile X. Sections include: Planning; Interventions; Social & Emotional Development; Behavior Management.

Fragile: Handle With Care – More About Fragile X Syndrome Including Adolescents & Adults: (Revised Edition 2000) by Marcia L. Braden, PhD. This book captures the essence and the characteristics of Fragile X at all developmental stages. Good for parents and those who want a basic thorough introduction to Fragile X by a well-known expert.

Fragile X Syndrome – A Handbook for Families and Professionals (2002) by Brenda Finucane, MS, CGC, Allyn McConkie-Rosell, PhD, CGC., and Amy Cronister, MS, CGC. This newly revised 25-page booklet includes information on the characteristics of Fragile X, the basics of heredity and genes, diagnostic testing, and sections on special education and the impact Fragile X has on families.

Fragile X Syndrome – Diagnosis, Treatment, and Research (2002) by Randi Hagerman, MD, and Paul J. Hagerman, M.D., PhD. The third edition of this book answers nearly all the questions that parents or clinicians might raise about Fragile X

Syndrome. “It includes updated chapters on the cytogenetic and molecular biology of the FXS mutation and pre-mutation. The first half addresses the diagnosis and research aspects and is well referenced. The latter half is dedicated to treatment and intervention. The chapter that emphasizes an integrated approach to intervention could easily qualify for continuing medical education credit.” *Journal of the American Medical Association*. *Note: This is a book written primarily for professionals and can be very technical in nature. Nonetheless, it can still be an invaluable reference for parents.*

Medication Guide for Fragile X Syndrome (2004) by Michael Tranfaglia, MD. This book is provided by the FRAXA Research Foundation and is a supplemental guide for parents who want comprehensive information about medications in an accessible format. It is written to help parents make informed decisions with their physician about the care of children with Fragile X Syndrome.

My Brother has Fragile X Syndrome (1998) by Charles Steiger. Written by eight-year-old Charles, this book describes his life and experience with his older brother who has Fragile X syndrome. A personal expression, this book makes a great addition to any family’s reading list as they cope with a child with Fragile X Syndrome.

My eXtra Special Brother (2003) by Carly Heyman. From the inspiration of a high school teacher, sixteen-year-old Carly Heyman writes about living with and loving her older brother who has Fragile X Syndrome. With complete candor, the young author entertains and teaches the reader about many of her experiences with her brother. She shares, in a most honest way, her struggles, frustrations, and finally her exhilarations as she learns the skills to cope with her brother’s limitations.

The Source ® for Fragile X Syndrome (2004) by Gail Harris-Schmidt, PhD and Dale Fast, PhD. An excellent book for explaining the nature of fragile X, its effect on speech-language development and related issues. Chapters cover physical characteristics, cognitive development, sensory issues, speech & language development, behavior and emotional issues, academic intervention, biological basis, future directions, education placements and programming. Dr. Harris-Schmidt is an Associate Professor in the field of Communication Sciences and Disorders as well as the parent of a son with Fragile X. Dr. Fast is an Associate Professor of Biology.

Transitioning “Special” Children Into Elementary School (1994) by Jayne Dixon Weber. Written by a parent of a child with Fragile X syndrome, this is a warm yet practical guide for families and educators.

Multi-Media

9TH International Conference Proceeding (2004) Summaries of many of the professional and parent presentations in a CD-PDF format.

Faces of Fragile X (2000) – Video: A 17-minute video showcasing nearly 20 children and teenagers, from 11 months to 20 years, affected by Fragile X. Filmed during clinical evaluations, at home and during therapy. Narration covers basic physical,

developmental, cognitive and behavioral characteristics – *no genetics*. This video is helpful as an introduction for teachers, therapists, and others who work with children affected by Fragile X.

Females and Fragile X Syndrome (2002) – Video or CD. In this 20-minute presentation, created by renowned Fragile X psychologist, Dr. Marcia Braden, you will find scenes of females from preschool through adulthood. The genetic basis of Fragile X females and inheritance is described along with interviews and scenes depicting girls and women in school, at play and at work. Throughout, a voice-over narration provides key points regarding the needs of females as well as the most appropriate interventions.

Fragile X Syndrome – Clinical and Molecular Aspects (2004) – CD; (for students or professionals) Fragile X Syndrome is a stand-alone interactive CD-ROM integrating the genetics and clinical features of Fragile X syndrome. The program covers clinical diagnosis, laboratory diagnostics, and personal perspectives. The program uses high quality media such as videos, animations and interactive images. Multiple choice questions, glossary of terms and references are also included. This program will be useful for students studying human genetics, medical and biomedical courses, and for continuing professional education. Distributed in the US by the NFXF for the University of Melbourne and Fragile X Alliance, Inc. of Australia.

Vocations – Video: This 15-minute video, produced by Pekin Hospital Progressive Health Systems, presents the various aspects of employing an adult with Fragile X syndrome through interviews with family members, neighbors, co-workers and supervisors. It provides a dynamic model for setting attainable goals and illustrates that incorporating individuals with different abilities into the workplace can be stimulating and rewarding for all involved.

Resource Sets

Educational / Clinical:

This set has been compiled for educators, therapists and parents.

- Faces of Fragile X – video
- Fragile, Handle With Care – book
- Lesson Planning Guide – book
- The Source for FXS – book

Medical:

This set has been compiled for medical professionals.

- Fragile X Syndrome: Diagnosis, Treatment and Research – book
- Medication Guide for Fragile X Syndrome – book

Each Resource Set also Includes the Following:

- Fragile X Syndrome: A Handbook for Families and Professionals
- Understanding Fragile X Syndrome: An Overview – an educational pamphlet suitable for copying

**Resources can be ordered by calling
1-800-688-8765
or via the Internet at
www.fragilex.org/html/resources2.htm**