

Fragile X Alliance Inc

(Incorporation No A0036906U, ABN. 78965364337)
263 Glen Eira Rd, Nth Caulfield 3161, Tel (03) 9528 1910, Fax (03) 9532 9555
www.fragilex.com.au, email: jcohen@travelclinic.com.au



Thank you for contacting the **Fragile X Alliance Inc**. This is a non-profit organisation whose mission statement is to promote education and research into fragile X syndrome, as well as disseminate information and new findings about fragile X syndrome. The **Fragile X Alliance Clinic**, in Melbourne, offers families a multidisciplinary specialised assessment and evaluation including medical consultation, hearing, vision, speech, occupational therapy and psychological services for individuals of all ages.

Fragile X syndrome is the most common inherited cause known of intellectual disability, developmental delay, learning disabilities and autism spectrum behavioural disorders. Diagnosis is important because it can influence medical and interventional strategies and allow informed decision making by carriers. Diagnosis of the fragile X gene is by DNA blood testing.

The Fragile X Alliance's main purpose is to disseminate information and new findings about fragile X syndrome. The **annual educational membership subscription fee is \$44.00 and includes membership of the Fragile X Association of Victoria**. This entitles you to an information brochure on fragile X syndrome, copies of policy statements on diagnostic testing and health surveillance as well as a full set of multidisciplinary information files available as either printed materials or electronic file. These files, suitable for parents and professionals, are prepared through the collaborative efforts of numerous physicians, researchers, clinicians and parents, all with firsthand involvement in fragile X syndrome. If you have concerns for your child or a family member, we encourage you to share this information with your family doctor, teacher or other interested professionals.

In addition, we have other educational supplies and information available for purchase. Information is available regarding conferences, parent contacts, regional resource centres and professionals with expertise in fragile X syndrome.

The Fragile X Alliance Inc provides expert medical and allied health services, in-servicing and presentations for professionals and families. These are at reasonable rates and all proceeds are used to fund further educational activities. Please contact us for appointments, information or for any questions you might have.

Yours sincerely,



Jonathan Cohen
President, Fragile X Alliance Inc
Medical Director, Fragile X Alliance Clinic
Senior Lecturer, Department of General Practice, Monash University

Fragile X Alliance Inc

263 Glen Eira Rd, Nth Caulfield 3161, Tel (03) 9528 1910
Fax (03) 9532 9555 email: (Incorporation No A0036906U, ABN. 78965364337)
263 Glen Eira Rd, Nth Caulfield 3161, Tel (03) 9528 1910, Fax (03) 9532 9555
www.fragilex.com.au, email: jcohen@travelclinic.com.au

Educational items - books, CDs and DVDs

The following is a list of educational aids produced by or available through the Fragile X Alliance Inc. These resources are invaluable for parents, professionals, educational and medical institutions and organisations. Please use the order form at the end of this brochure.



1. Fragile X Alliance Clinic Handbook

(Recommended for initial overall guide for families and professionals)

This is the most up to date Australian guide for professionals and families. Prepared by the Fragile X Alliance Clinic staff, topics include medical and genetic issues, speech and language strategies, occupational therapy and sensory integration, vision and hearing issues, the use of medications and behaviour management strategies.

Available from the Fragile X Alliance Inc for **\$27.50**



2. Educating Boys with Fragile X Syndrome - A Guide for Parents and Professionals

Gail A Spiridigliozzi, Ave M Lachiewicz, Cynthia S MacMurdo, Andrea D Vizoso, Constance M O'Donnell, Allyn McConkie-Rosell and Debra J Burgess, Child Development Unit, Duke University Medical Centre.

(Recommended for primary teachers and families)

This excellent booklet provides information and ideas to parents, educators and therapists who work with boys with fragile X syndrome. It is of great value in the initial development of an appropriated education program for children with fragile X syndrome.

Available from the Fragile X Alliance Inc for **\$16.50**



3. Fragile X Syndrome. Diagnosis, Treatment and Research 3rd edition 2002

Edited by Randi J Hagerman and Paul J Hagerman. John Hopkins University Press.

(Recommended for professionals)

This superb 480 page book is a must for the professional with any interest in fragile x syndrome. Topics covered in part one include epidemiology and the associated cytogenetic and molecular findings, present research regarding protein studies and neuropsychology of the fragile X syndrome. The second part of the book covers treatment and management strategies including genetic counselling, medical follow up,

psychopharmacology, psychotherapy, education, occupational therapy, speech and language therapy and protein and gene therapy. This new third edition is not only a very current review but in addition makes for fascinating reading. It is the one definitive text about fragile x syndrome.

Available from the Fragile X Alliance Inc for **\$88.00**.



4. A Medication Guide for Fragile X Syndrome - Michael R Tranfaglia MD.

(Recommended for professionals and carers)

This wonderful guide by the founder of the FRAXA Research Foundation is intended to serve as background to help parents, caretakers and others to communicate with their physicians regarding medications. The medications are only to be used under the supervision of a qualified physician and almost all are available only by prescription.

Available from the Fragile X Alliance Inc for **\$33.00**



5. Fragile: Handle With Care. Understanding Fragile X Syndrome.

Marcia L Braden, PhD.

(Recommended for families and professionals)

This is an exceptional book written by a master in the field of special education and behavioural psychology. Combining case studies and a handbook approach, the author gives us insight and understanding of the behavioural and cognitive profile that constitutes fragile X syndrome and which is unique among children with developmental disabilities.

Specific behavioural management strategies are presented in a highly accessible manner for the management of patterns of learning and behaviour and thus allows us to both understand the child as well as implement effective intervention across a wide range of ages and situations. Issues generally not dealt with elsewhere are well developed here and include adolescent and sexuality issues, females issues, vocational training and adult living. Highly recommended.

Available from the Fragile X Alliance Inc for **\$55.00**



6. Lesson Planning Guide for Students with Fragile X Syndrome (2004) by the Education Project Team of the National Fragile X Foundation.

(Recommended for teachers and parents)

NEW!

Whether your initial exposure comes through study, a friend, a relative, your own child, or a new and unique student who shows up at your classroom door the first day of school, you must begin somewhere in seeking to understand the challenges posed by children with FXS. This workbook is intended for classroom teachers who may have little or no exposure to FXS. Our goal is to help make the teaching and learning environment from preschool through high school more effective, more efficient, and more rewarding for teachers and the student(s) with FXS who come under their care. We look to accomplish that goal by

providing a wealth of practical information that includes background on FXS, descriptions of behavior and learning styles, discussion of educational and community resources, and sample lesson plans for children with FXS at a variety of developmental levels. NOTE: This guide replaces and extensively incorporates Dr. Marcia Braden's "Curriculum Guide for Individuals With Fragile X Syndrome"

Available from the Fragile X Alliance Inc for **\$33.00**



7. Females and Fragile X Syndrome (2004) – DVD

(Recommended for families and professionals)

NEW!

In this 20 minute DVD, 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.

Available from the Fragile X Alliance Inc for **\$33.00**



8. Fragile X Syndrome- Clinical and Molecular Aspects (2004) – CD

(Recommended for students or professionals)

NEW!

FRAGILE X SYNDROME is a stand-alone interactive CD-ROM integrating the genetics and clinical features of fragile X syndrome. It is produced by Associate Professor Sylvia Metcalf from the University of Melbourne and Dr Jonathan Cohen from the Fragile X Alliance. The program covers clinical diagnosis, laboratory diagnostics, and personal perspectives and includes high quality media such as

videos, animations and interactive images from Australian families. 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.

Available from the Fragile X Alliance Inc for **\$22.00**

Please contact us for further information on the following:

- **Computer** software recommendations and suggestions
- **Parent support groups** - VIC, NSW, SA, WA, TAS, QLD and other community resources.
- **International resources and contacts**
- **Web sites** – www.fragilex.com.au (see links)

Fragile X Alliance Inc

263 Glen Eira Rd, Nth Caulfield 3161, Tel (03) 9528 1910
 Fax (03) 9532 9555 email: jcohen@travelclinic.com.au



Order form

| | ITEM | PRICE \$ | Quantity | TOTAL \$ |
|---|--------------------------------------------------------------------------------------|--------------|---------------------------|----------------|
| 1 | Fragile X Alliance Clinic Handbook | 27.50 | | |
| 2 | Educating Boys with Fragile X Syndrome - A Guide for Parents and Professionals | 16.50 | | |
| 3 | Fragile X Syndrome. Diagnosis, Treatment and Research 3rd edition 2002 (Hagerman) | 88.00 | | |
| 4 | A Medication Guide (Trafanglia) | 33.00 | | |
| 5 | Fragile: Handle With Care. Understanding Fragile X Syndrome (Braden) | 55.00 | | |
| 6 | Lesson Planning Guide (Braden) | 33.00 | | |
| 7 | Females and FXS DVD (Braden) | 33.00 | | |
| 8 | Fragile X Syndrome CD – Clinical and Molecular Aspects (University of Melbourne) | 22.00 | | |
| | | | | |
| | | | | |
| | | | | |
| | | | PACKAGE & POST | \$11.00 |
| | All prices inclusive of GST | | TOTAL | |

I do not need educational materials at this time but I would like to make a contribution to the Fragile X Alliance Inc. I have enclosed \$ for this purpose.

1. I enclose **cheque** for \$ payable to “**Fragile X Alliance Inc**”
POST to **Fragile X Alliance Inc, 263 Glen Eira Rd, North Caulfield 3161** or

2. Please **charge this to my** Visa / Mastercard / Bankcard (*please circle*).
FAX this form to **(03) 9532 9555** or mail it to **Fragile X Alliance Inc, 263 Glen Eira Rd, North Caulfield 3161**

Card no:

Expiry date: **Signature:**

First Name **Last Name**

Address **Postcode**

Phone **Fax**

Profession **E-mail**