



FRAGILE X ASSOCIATION FUNDRAISING KIT

Dear Fundraiser

Thank you for your interest in fundraising for the Fragile X Association of Australia as we help children and adults with Fragile X Syndrome reach their full potential.

Fragile X syndrome is a condition which results in problems with learning and behaviour. It is the most common cause of inherited intellectual disability. It is found worldwide, in all ethnic groups and throughout society. Latest statistics indicate that 1 in 3600 males and 1 in 4000-6000 females are affected and that approximately 130 - 250 females are carriers. There is currently no cure for Fragile X but special therapies, certain ways of teaching and medication can all help people with the syndrome to perform the best they can.

By fundraising for our organisation you are helping to raise awareness of Fragile X as it is estimated that 50% of people affected with Fragile X syndrome have not been correctly diagnosed.

Before you can begin to fundraise you will need to complete the registration forms following. Please return the forms and we will send you an authority to fundraise letter for you to display at all your fundraising activities.

The fundraising kit includes:

- X **Registration form**
- X **Brief for teachers and students**
- X **Fundraising ideas**
- X **Information on handling money**

Please complete the registration form and return it to the Association either by fax on 02 9949 8483 or mail to the Fragile X Association, 10 Geddes St, Balgowlah Heights, NSW 2093. We will then send you an authority to fundraise so that you can begin the fundraising!

If you have further questions please contact me on 1300 FX INFO (1300 394 636) or email support@fragilex.org.au.

Enjoy

Jocelyn Selwood
Administration Manager
Fragile X Association of Australia



REGISTRATION FORM

School Name: _____

Organiser's Name: _____

Teacher's Name: _____

Mailing Address: _____

City: _____ Postcode: _____ State: _____

Phone: (W) _____ (M) _____

Email: _____

Date of Event: _____

Brief Details of the Event: _____

Please return the form to the Fragile X Association of Australia to receive your authority to fundraise.
Fax: 02 9949 8483 or post to The Fragile X Association, 10 Geddes St, Balgowlah Heights, NSW
2093.



FRAGILE X SYNDROME INFORMATION FOR TEACHERS AND STUDENTS

What is Fragile X Syndrome?

Fragile X syndrome is a condition which results in problems with learning and behaviour. It is the most common cause of inherited intellectual disability. Latest statistics indicate that 1 in 3600 males and 1 in 4000-6000 females are affected and that approximately 1 in 130 - 250 females are carriers. There is currently no cure for Fragile X but special therapies, certain ways of teaching and medication can all help people with the syndrome to perform the best they can. The name of the syndrome comes from its location on the X chromosome. Under particular laboratory conditions, the bottom of the long arm of this chromosome can appear broken or fragile. It has been estimated that, worldwide, 50% of people affected by Fragile X have not been correctly diagnosed.

Intellectual Characteristics

Developmental delays are the most significant characteristic of those with Fragile X. The range of learning problems is wide. Some are affected in fairly small ways, while at the other end of the scale, especially with males, there can be severe intellectual disabilities. Most affected males fall somewhere in the middle. Learning disabilities are often accompanied by delays in speech and communication skills. There can also be delays in both gross motor (such as sitting and walking) and fine motor (such as holding a pencil) skills. In general, females are not as delayed as males.

Physical characteristics

People affected by Fragile X syndrome are generally healthy. They do not suffer from major medical problems because of the syndrome and have a normal life expectancy. People with Fragile X syndrome do not look very different from other people.

Behavioural Characteristics

People with Fragile X can behave differently from other people. Both males and females tend to have varying degrees of characteristics such as delayed speech, anxiety, poor concentration, hyperactivity (ADHD), autistic-like behaviours such as an unusual fixed interest in some things and dislike of change in routine.

Association Profile

The aims of the association are to help Fragile X syndrome children and adults to realise their full potential, provide information and support to those people whose lives have been affected by Fragile X, promote acceptance and integration of people with Fragile X within the community and to raise public awareness of Fragile X syndrome.

The association is a non-profit organisation.



Main objectives of the Association

To directly aid people with Fragile X syndrome through any or all of the following:

- Medical treatment
- Diagnosis and assessment
- Counselling
- Speech and language therapy
- Occupational therapy and physiotherapy, assistive technology support and vocational support
- Case management

To promote the detection, relief, treatment and prevention of Fragile X syndrome through:

- Supporting intervention and other programs in relation to Fragile X syndrome
- Supporting research into Fragile X syndrome
- Promoting awareness and education in relation to Fragile X syndrome by the holding of lectures, meetings, classes, conferences and seminars
- Advising and lobbying government and other agencies

Status of the Association

The Fragile X Association of Australia is a registered charity and has an authority to fundraise in NSW #CFN10563, South Australia #CCP1380 and Queensland #CH1758. In Victoria you can fundraise for the Fragile X Association of Victoria which is also a registered charity.