fx info

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From the President …

I am pleased to be able to provide details of the Fragile X Association of Australia Endowment Fund in this newsletter. The Association receives no government funding and the Endowment Fund will help to ensure that the Association will be able to continue to provide much needed information support and assistance to people with Fragile X, their families and carers.

I would like to thank Freehills which has provided invaluable pro bono legal advice in relation to the establishment of the Fund.

John Kelleher

Securing the future - the beginning of the Fragile X Endowment Fund

Since its early days it has been a priority of the Association to ensure that its long term future is secure, that it continues to support families and the Fragile X community, and carries on working to raise awareness of Fragile X Syndrome.

With the inception of the Fragile X Association of Australia Endowment Fund (EF) we are one step closer to achieving this.

The EF will provide a conservative and prudent framework within which the Association may grow its capital and earn a steady income to support its core activities. It is maintained and accounted for separately from the Association's other funds and is managed by an Advisory Board comprised of up to seven members appointed by the Board of the Association to be known as the Fragile X Association of Australia Endowment Fund Board.

The Association's Board formally resolved that the Endowment Fund would be established in 2011. Since that time much work has been done and we are delighted to report that the Endowment Fund will commence operation in mid 2012 and that its Advisory Board will hold its first meeting in April of 2012. The inaugural members are David Bassingthwaighte (Chairman); Martin Davey, Bill Evans, John Kelleher and John O'Connor.

Contributions to the Fund are tax deductible as with all donations to the Association. All bequests made to the Association will be paid into the Endowment Fund unless the terms of the bequest otherwise specify.

The Endowment Fund provides supporters of the Association an opportunity to contribute to the Fragile X community now and long into the future within a formal and carefully managed framework.

If you would like any further information on the Endowment Fund please do not hesitate to contact the Association at support@fragilex.org.au or on 02 99770074.

Member's Story

The McRae Family – a united front!

Hear their story and others in *Understanding Fragile X*, the DVD produced by the Association.

Two sisters based in Brisbane, Shelley MacRae and her sister Nyleta McRae, had their world turned upside down over a year ago when Nyleta's first baby, a gorgeous little boy called Connor, was diagnosed at 2 years old with mosaic Fragile X syndrome and autism.

Nyleta had initially decided to seek help for Connor with the encouragement of her sister Shelley as he was slow to reach his developmental milestones and she was concerned. When a diagnosis of autism was given they naturally thought that they had reached a conclusion and were beginning to think about how they would manage this in the future. When the diagnosis of Fragile X came through a week or two later due to the delay in the blood test results Nyleta was taken completely unawares.

Not having ever heard of the condition Nyleta and Shelley started their research. This is how the Association first came to meet them and share in their story.

The sisters quickly discovered that Fragile X syndrome was a genetic condition passed down through the generations of a family. Armed with this knowledge they set about informing other members of the family and Shelley decided to be tested as well as her three beautiful children.

Shelley and Nyleta discovered through this process that they were both carriers and that Shelley's two year old son Bryn (Connor's first cousin) was fully affected. This began to explain what had previously been diagnosed as developmental delay in Bryn and provided an explanation for a host of other challenges he had so far faced.

Shelley and Nyleta's story is not uncommon in our community and highlights perfectly how Fragile X syndrome can affect not just a single individual but an entire family. Until Bryn's diagnosis, brought about by Nyleta's unerring quest for help and an astute paediatrician who sought a blood test, the family had no knowledge of Fragile X let alone that past generations had also been affected.

They have generously agreed to tell their story, although still unfolding, in the newly produced DVD *Understanding Fragile X* in an effort to help other families and mothers undergoing a similar journey to theirs.

Both Bryn and Connor are beautiful little boys who are essentially like all other children in that they love to play and laugh. Although they face many challenges in their daily lives, and will continue to, they are happy and beginning to reap the benefits of their early diagnosis with strategies and therapies that are designed to help them learn and make sense of their world in a way that is unique to each of them.

Through their commitment, Shelley and Nyleta and their families are paving the way to a future in which both Bryn and Connor will reach their full potential.

In addition to the McRae family we would like to acknowledge Mary Cox and her 12 year old son William who also share their story in the DVD. It provides an insight into the unfolding future of families with Fragile X.

The Association is delighted to have now completed production of the *Understanding Fragile X* DVD. If you or anyone you know is interested in receiving a copy of this free DVD please contact

the Association on 1300 394 636 or support@fragilex.org.au. We also hope to soon make it available through download from our website.

Australia's leading experts as well as Dr Randi Hagerman, one of the world's leading Fragile X experts, also feature in the DVD giving advice and information.

Understanding Fragile X is a professionally produced resource that will be used in a variety of ways most importantly providing an initial insight for newly diagnosed families into the world of Fragile X. We would like to acknowledge the funding from St George Foundation and Genea which made this possible.

NetBuddy

Net Buddy (www.netbuddy.org.au) is a British website for swapping tips and bright ideas from parents, carers, teachers and therapists with experience of learning disability. It's a place for sharing advice and ideas, a place for overcoming problems and celebrating successes within a community that understands.

Although it is not Fragile X specific and some of the tips relate to services in the UK it still offers a broad range of information that you may find helpful. Some of the subjects that contributors have offered tips on include teeth cleaning, medical appointments and behavioural issues. Contributions are welcome from around the world .

Thank you to The Fragile X Society (UK) for highlighting this site.

Fragile X Library - a resource for all members

The Association has a long established library of resources on Fragile X syndrome and intellectual disability that members can borrow. Comprising approximately 150 different resources it is a helpful place to understand and find out more about general disabilities and Fragile X specifically, its genetics, beneficial treatments and management strategies for classroom and other settings.

Stocked with textbooks on genetics, casual reading information, parent guides and DVD resources, please do not hesitate to contact the Association for a listing of our current resources .

Our most recent additions include Robyn Iredale's firsthand account of living with and bringing up a child with Fragile X to adulthood called G*rowing Up with Fragile X Syndrome – The Road to Marty Campbell* and the Association's DVD *Understanding Fragile X*.

Fragile X Blogs

There are an increasing number of blogs written by parents and grandparents of children with Fragile X where they record their thoughts, feelings and experiences. As you will see many of them are American but we are pleased that two of them are written by members of the Association.

While we are sure that you won't agree with everything that each of these bloggers write they offer a personal view of living with Fragile X.

- http://awarenexs.blogspot.com.au/
- http://www.fragilexfiles.com/
- http://www.basicallyfx.com/
- http://mrsrogersfxneighborhood.blogspot.com.au/
- http://loveandsurvivalwithfragilex.blogspot.com.au/
- http://fragilexjourney.wordpress.com/
- http://myfragilexboy.blogspot.com.au/

We would love to hear about any blogs that you follow or if you have your own blog. Please email support@fragilex.org.au and we will include them in our next newsletter.

Janie Roberts—Counsellor

Counselling at Fragile X Association

How can Counselling help me?

Sometimes people are reluctant to 'burden' their friends and relatives with their problems and can benefit from sharing them with a caring and empathic professional. This can reduce their sense of isolation, relieve some of the stress and strengthen their ability to cope.

Families have also found it helpful to have an unbiased, gentle person to mediate in tricky areas or to assist in working out and facilitating family goals.

Most people feel at least slightly nervous when they initially attend a counselling session as they do not know what to expect. They may also feel that there is something really wrong with them as they need counselling. This is not the case. We all need help at times. We also need to be understood and cherished to feel ok with ourselves.

The counselling relationship offers this through unconditional, empathic and non-judgmental support.

Counselling is available over the phone, via email or face to face in the Manly office. I can also visit individuals and families in the Sydney region.

Counselling is free. You can contact Janie Monday, Tuesday and Friday on (02) 9977 0074, 1300 394 636 or by email at janie@fragilex.org.au

Thoughts around shame and disability

One thing that seems to keep cropping up from my discussions with people is the concept of shame and its influence on peoples' lives.

The dictionary definition of shame is ' the painful feeling arising from the consciousness of something dishonourable, improper, ridiculous, etc done by oneself or another." How does that then relate to disability? Is disability something that we have actively 'done' or was it 'done' to us?
It seems that we can sometimes internalise society's views on not fitting into normal guidelines of development and behaviour. We can experience public stigma and rejection as a result and this has the effect of closing us down and silencing us.

I would like to know who made up these rules about what is 'normal' and why we need to experience a form of punishment for not fitting in.

Studies have shown that the shame and stigma of having a child with disability is particularly strong in Asian communities. It is noted that there are reduced hopes, aspirations and expectations for a child's education, employment and lifetime achievements. Many Aboriginal carers of people with a disability do not wish to access disability services and do not identify with having a disability.

The stigma – often of religious basis – associated with having a child with a disability can sometimes extend to the whole family. There are some in the community who still hold the belief that this is 'God's punishment', 'the will of Allah' or 'bad luck'. Feelings of shame have stopped some people with Fragile X informing other family members, who could be unknowingly affected, of the condition.

For people growing up with an intellectual disability there is often an underlying sense of shame. For some it is a great relief to have a diagnosis but for others a label just serves to stigmatize them. Sadly these feelings of shame can result in people trying to hide their difficulties. Rather than risk being labelled as stupid or accused of being lazy, some people cope by denying their learning disability.

By internalising negative labels of stupidity and incompetence we often suffer from lack of confidence and self-esteem. Would this be such an issue if, in society, we did not emphasise and exalt the importance of intellect?

Shame can also stop carers and family members from reaching out for help. In a culture where people value self-sufficiency and individualism it can be extraordinarily difficult to seek government assistance.

It is important to note that carers are entitled to help and that it does not mean that they cannot cope or that they are weak in some way, it just means they are human. If we accept that suffering is a part of life then perhaps we can also acknowledge that shame can prolong suffering by isolating and silencing.

Maybe there are opportunities to challenge some of the prevailing judgments about what is important and valuable in life. Susan Cohen, a mother of a boy with Fragile X, writes that her son's condition "has caused me to examine myself and others in ways I wouldn't have thought of doing if it hadn't been for him. It's made me realise how narrow the criteria of parental pride can be, if we buy into society's expectations." She felt a sense of liberation from not having the pressure of competing with the "overachievers" in her circle of acquaintances.

If you have thoughts or ideas on this topic or any other issues, I'd be delighted to hear from you so please email me on Janie@fragilex.org.au

MyTime

Parents, grandparents and carers might be interested in the MyTime groups available across Australia. Although they are not Fragile X specific they provide facilitated peer support for mums, dads, grandparents and anyone caring for children with a disability, developmental delay or chronic medical condition.

My Time offers the chance to socialise and share ideas and information with others who understand the rewards and intensity of caring for a child with a disability. Each MyTime group is supported by two workers – a facilitator and a play helper.

Facilitators work with group members, helping them get to know each other and learn more about the services and supports in their area. Members choose what they would like to discuss in their groups, with help from the facilitator. Depending on what the group wants to do, the facilitator might guide group activities or provide resources.

Facilitators are workers from local organisations. They have qualifications and experience in disability, parenting or family support and bring to the MyTime group a good understanding of local resources and support services.

Play helpers keep children, including under school aged siblings, busy and active in activities such as singing, drawing, playing with toys, blocks or sand so members can spend time catching up with one another.

Mothers, fathers and other family carers of children who are eligible to receive the Carer Allowance (Child) can join MyTime. For more information go to http://www.mytime.net.au or call 1800 889 997.

Joan MacDonald - Caseworker

Fragile X Clinics - Adult and Children Sydney

We still have some clinic places to fill in June and October this year (see below). The clinics are always very successful and the feedback from families has been very positive.

After a visit to the clinics, families receive written reports from the doctors and therapists providing recommendations based on the clinic process. They will also make referrals to other professionals and services where appropriate.

Adult Clinic - 3 spaces, one in June and two in October

The adult clinic is a joint venture of the FXAA and the NSW Developmental Disability Health Unit held at the Royal Rehabilitation Centre in Ryde, Sydney. The adult clinic is available for individuals aged 17 years and older.

A family member who recently attended our adult clinic with her brother told us -

"Dr Law at the Clinic was amazing; she knew just how to handle my brother and he was on his very best behaviour. The Clinic was great and very helpful; Dr Law gave us some tips for getting through to Ageing, Disability and Home care to get the ball rolling for my brother's accommodation. I will follow her advice".

Children's Clinic – one space in June

The Children's clinic is run from the Children's Hospital in Westmead. The fantastic team there is headed up by Dr Natalie Silove.

A mother who recently attended the clinic with her son said -

"We found the clinic great, we got more info in 2 hrs than we have in 3 years. We wish it went for longer or that we could have regular visits or contact because it made such a difference to deal with people who knew about FXS".

If you know of anyone who would benefit from attending either clinic please let me know. If you need any additional information or have any questions please contact me on 02 9977 0074, 1300 394 636 or email me at joan@fragilex.org.au

Clinic and workshop - Perth

Perth Clinic

We have three adults with Fragile X syndrome and two children with Fragile X syndrome attending the Perth Fragile X clinic on 26 April. They will be seen by Dr Jonathan Cohen and his team of experts. We are grateful to the Newman's Own Foundation for funding this clinic. We would also like to thank Activ for providing rooms for the clinic.

Perth Workshop

The final workshop funded by the Newman's Own Foundation will be held at the Conference Centre, Perth Zoo on Friday 27 April 2012. The seminar has been incredibly popular and is now nearly booked out so please contact us on 1300 394 636 or by email support@fragilex.org.au if you would like to attend.

We are pleased that as well as the families of people with Fragile X, medical professionals, teachers and workers from the disability sector will be attending the workshop. We believe that a better understanding of Fragile X Syndrome can only improve the services and supports available for people with Fragile X and their families.

Joan, Linda and Janie from the Association's office will also be attending and are looking forward to the opportunity to meet with our members and supporters and well as people interested in learning more about Fragile X syndrome.

Thanks to the Newman's Own Foundation and Genetic Support Council WA for their support of this Workshop.

Margot Stolle- Communications Officer

The Fragile X syndrome DVD

Although the early part of the year is often a quiet period it seems that lots is still happening in the world of Fragile X. As you have read in our member's story, the DVD has been printed and is now in circulation.

If you are interested we would love you to watch it and provide your feedback. It promises to be a valuable educational tool for newly diagnosed families, educational and medical professionals, the media and corporate supporters.

New projects loom on the horizon including the creation of a suite of information products to match with the DVD which will incorporate information sheets and a revised version of the brochure.

I also have some news of a personal nature to share. I am pregnant with my third child and therefore will be taking leave at the end of July.

Linda Blair- Office Manager

We have recently made some changes to the newsletter. We have changed the format which allows us to reduce printing and postage costs but include the same amount of information.

We have also established an Editorial Committee which will make decisions about the content of each newsletter. I am one of the members of the Editorial Committee together with Doug Rodgers, Board Member/Treasurer and Margot Stolle Communications Officer.

If you would like to submit anything to the newsletter please contact one the members of the Editorial Committee at support@fragilex.org.au or telephone on 1300 394 636.

The deadlines for submissions to the newsletter are

Winter Issue	15 May
Spring Issue	15 August
Summer Issue	15 November
Autumn Issue	15 February

We would love to hear from any members interested in telling their story. You can either write your story yourself or contact Margot or me and tell us your story and we will write it up for you.

The Association has successfully applied for an exemption from fees for interpreters from the government Translating and Interpreting Service. This means that we are able to access an interpreter at no cost where someone contacts us who would feel more comfortable speaking in a language other than English.

We have also recently been advised that Google has accepted the Association into its Google Grants program. Promotional ads for the Association will appear on the side of the screen when someone searches for Fragile X. The ads will direct them to our website. We hope that this will help more people find the information that they need about Fragile X.

Opportunity for parents to contribute to research on disability

Parents of children with disability aged between 2 and 16-years are sought to complete a 20-minute, anonymous, online survey.

The survey includes questions relating to your family, your child's behaviour, the parenting strategies you use and your own wellbeing. The goal of this important research is to develop a new questionnaire that will be used in the development and evaluation of programs to support families of children with disability. Details may be found at http://exp.psy.uq.edu.au/parentingdisability or by contacting the project coordinator Dr. Trevor Mazzucchelli at t.mazzucchelli@uq.edu.au or 08 6468 5020.

Other services that can provide assistance

The SMILE Foundation was launched in July 2007 to assist families of children with rare diseases and provide much needed funding into medical research.

Its Family Relief Program was established in October 2008 to give immediate funds to Australian families in dire need. SMILE provides $1,000 grants which assists families in meeting medical expenses and other costs associated with the challenge of raising a child with a rare disease.

To date, SMILE has provided assistance to over 550 families including families with a child with Fragile X, who in many cases do not receive other forms of assistance. The Social Workers at the Children's Hospitals around Australia help identify families and SMILE is proud to be able to provide quick relief. The following stories give examples of the ways that the Foundation can help families.

> A three year old boy from country NSW contracted Bacterial Pneumonia in his heart and had to have heart surgery which in turn caused a stroke coupled with a bone marrow transplant. He has since been diagnosed with left middle artery thrombosis. This little boy is cared for by his single mother who has now had to relocate to the city in order to be closer to medical assistance. The grant was used to pay for a mobile phone bill as well as costly medicines.

> A family from Queensland have two children who both suffer from a rare medical condition and therefore SMILE was able to support both girls, ages 9 and 6. Both girls suffer from Danlos Syndrome and due to the large ongoing expenses, the grant was used to provide ongoing physio and occupational therapy for the children.

For more information contact the Foundation by email info@smilefoundation.com.au or by telephone on 02 9409 4860, or go to http://www.smilefoundation.com.au.

Research

Are you the parent of an adult child with a disability?

ARTICLE DELETED

Research

Latest research on newborn testing

Dr David Godler

Released in mid January, a paper written by Dr David Godler and other researchers from the Murdoch Children's Institute, details the development of an innovative new test that could revolutionise the way Fragile X syndrome is screened and diagnosed.

The Murdoch Children's test uses a DNA region that was previously thought to have no function. Researchers say the new technology could be used as an early detection test for both male and females, and could be included in newborn screening tests, leading to improved quality of life for thousands of children and their families.

Early identification and intervention improves outcomes for children with Fragile X syndrome but until now it has been difficult for doctors to diagnose the disorder until the age of three years or older.

In a world-first, the researchers have shown that the new test can detect both the type and severity of symptoms in Fragile X syndrome with unparalleled accuracy in DNA samples from 154 females, with 18 of these having the 'faulty switch' in the FMR1 gene.

Lead researcher, Dr David Godler, from Murdoch Children's said that in the study the test was shown to be superior to others available in predicting developmental disability particularly in females, and that the discovery could pave the way for a simple, accurate and inexpensive test for Fragile X syndrome that could be used for population screening.

"The test is especially advantageous for diagnosis and screening in females, because it can specifically and accurately identify those individuals who are expected to develop cognitive impairment and can therefore potentially identify those most likely to benefit from early intervention," Dr Godler said.

John Kelleher, President of the Fragile X Association of Australia has welcomed the finding, saying the test has the potential to benefit thousands of Fragile X patients by providing earlier detection and intervention, leading to better treatment and improved outcomes.

"This test has the potential to become one of the most powerful tools to be discovered this decade for accurate diagnosis of children with Fragile X syndrome. With it we may be able to test and treat affected individuals earlier on in their lives giving them the best chance to live to their full potential and to save parents the anguish of spending years searching for a diagnosis. The association has spent several years lobbying for the inclusion of FXS testing within the heel prick test and now Dr Godler and his associates have developed the technology."

The research, gained much news coverage including radio and newspaper articles nationally.

The test was developed by Murdoch Children's researchers Dr David Godler and Dr Howard Slater in collaboration with Dr Danuta Loesch from the School of Psychological Science at La Trobe University.

Larger studies are now underway internationally to further validate the findings. The paper was published in leading clinical journal Clinical Chemistry.

Media related articles and activity can be found on the Association website www.fragilex.org.au.

Research

FXTAS: A New Study May Shed Light on the Syndrome in Carriers of Fragile X

A group of researchers led by A/Prof Julian Trollor at the University of New South Wales (UNSW) has commenced a study of the effects of the "premutation" of the Fragile X gene on health. The study is part of a collaborative effort led by Professor Kim Cornish at Monash University.

The Fragile X gene is present in all of us, but is expanded in length in some people. The length of expansion of the gene determines its effect on health. If the gene expansion is small, it functions well and has no obvious effects on health. If the gene is considerably expanded, it results in Fragile X syndrome, the most common inherited cause of intellectual disability.

Individuals who have only a moderate expansion in their gene are referred to as having a "premutation". Recent research has suggested that premutations of the Fragile X gene may cause a specific dementia syndrome in mid or late life in some people. The syndrome has been called Fragile X Tremor Ataxia Syndrome (FXTAS) and presents with tremor, balance problems and decline in memory. The syndrome may be found in parents or grandparents of children affected by Fragile X syndrome and is more common in older men than women. However, not everyone with the premutation will show symptoms.

As yet, we do not know why some people who carry the premutation are affected and others are not. The researchers are performing detailed health, balance and memory tests on adult men and women over the age of 18 who have confirmed status (through genetic testing) as premutation carriers.

The research team includes A/Prof Trollor and Dr Wei Wen (UNSW), Dr Anna Hackett and Carolyn Rogers (Genetics of Learning Disability Service), Professor Kim Cornish and Dr Darren Hocking (Monash University), and Professor Stephen Lord (Neuroscience Research Australia). The study is funded by The Australian Research Council and The Dementia Collaborative Research Centre (Assessment and Better Care), and is based at the University of New South Wales.

If you would like to participate in this study, or would like some further information, please call the research team on (02) 9931 9160.

NSW

Card Day

The eighth Annual Card Day was held on 14 March at Dural Country Club. This wonderful fundraising event was once again organised by Trish Piper and Barbie Barratt and was attended by over seventy five people. This event is not only a day to raise much needed funds but it also raises awareness of Fragile X. Janie Roberts, our Counsellor attended and spoke about the impact of Fragile X on families.

We would like to thank the Bendigo Bank Galston for their sponsorship of the event. Dural Country Club, Rays Florists and Gifts and Ross and Muriel Smith. Thanks also to Donna Warren, Lesley Blackett and the Chat-a- lots, Waterford Wedgewood Royal Doulton, Bunnings and Woolworths for the fantastic raffle prizes and Glenorie Pharmacy for lucky door prizes. Our biggest thank you of course goes to Trish and Barbie for organising this event.

Family support news

Queensland

Newly diagnosed families get together

With several Queensland families being diagnosed with Fragile X, over a short period of time and all wanting to meet other families with children with Fragile X, we decided to organise a small get together for these families to meet.

Everyone had a fantastic time and I am sure that life-long friendships were formed. Jayne an experienced Fragile X mum attended to share her insights on what it has meant for her family. Jayne's experience was very much appreciated.

One of the dads of a newly diagnosed little boy with Fragile X said that he was very glad that he attended He said he had felt as though he had had a plaster taken off his leg. I think he hit the nail on the head.

Once the shock of diagnosis reduces, I don't think it ever goes away, I think that part of the healing process is to meet other families who are going through exactly what you have or are going through. I believe that through meeting other families who have the diagnosis of Fragile X the diagnosis begins to feel less isolating. You learn that you are not alone on this journey and unexpected life-long friendships are formed.

Talisha with her brothers

Congratulations Talisha

Talisha's hard work and dedication has been recognised by the Smith Family and she has been awarded a scholarship. The scholarship will assist with the costs of attending high school. As well as being an excellent student Talisha is also working part-time at McDonalds. Talisha's mum Rose would like to thank Centrecare for the support they are giving Talisha with her job.

Mel Mikkelsen
QLD Family Support

Victoria

Christmas Lights

For the past nine years Arnold Pacifico has supported the work of the Association through his annual Christmas lights and sausage sizzle. Over this time the lights have become a major event in the local community.

We would like to sincerely thank Arnold and the generous individuals and businesses who donated to this tremendous event.

What's on?

Queensland

28 April - Bunnings Sausage Sizzle Cannon Hill
A Bunnings sausage sizzle at Cannon Hill has been organised for the Fragile X Association by the Kianawah Freemasons. If you can, please head on down to Bunnings on 28 April and buy a sausage sandwich to support the Association . A huge thank you to the Kianawah Freemasons, for their support

NSW

Open Garden 5-6 May 10-4.30
Trish and Graham Piper's garden "L'hirondelle" will be open for inspection on Saturday 5 May and Sunday 6 May 2012 from 10am until 4.30pm.This award winning garden has a parklike setting featuring large mainly deciduous trees, rolling lawns, rose gardens and herbaceous borders. There is a very productive vegie garden and a chicken yard with a variety of hens and a rooster. You may even catch a glimpse of the four resident peacocks.

This is a family friendly garden (you could even bring a picnic lunch and enjoy it on the terrace). Tea, coffee and cool drinks will be available. Fragile X families are most welcome and all proceeds will be donated to the Association.

The address: 25 Harrisons Lane, Glenorie (off Old Northern Road) Cost $6.00 per adult. Children are free!



26 May - Bunnings Sausage Sizzle - Belrose
We will once again be holding a sausage sizzle at Bunnings at Auslink Corp Park, Niangala Cres Belrose. Christine will be organising the sausage sizzle and would love to hear from you if you would like to volunteer for all or part of the day. Contact Christine on 0409 987 012. If you can't volunteer come along and buy a delicious sausage sandwich and support the Association.

USA

25-29 July 2012 - 13th International Fragile X Conference - Miami Florida
The National Fragile X Foundation's biennial international brings together researchers and parents .

The majority of the conference sessions are "Family-Friendly" and cover all three Fragile X conditions (FXS, FXTAS, FXPOI), with the greatest number of sessions focusing on FXS. In addition to the family-friendly sessions there are many scientific and technical sessions. For further details go to http://www.fragilex.org

Volunteers needed

The Association is grateful to our volunteers who provide family support and organise events for much needed funds. If you are interested in volunteering to assist the Association in any way please contact us at support@fragilex.org.au or 1300 394 636.