



FRAGILE X TRUST (NZ)

Supporting New Zealand  
families living with  
fragile X syndrome

# FRAGILE X TRUST (NZ) NEWSLETTER

September 2009

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*Congratulations!*  
*It's Fragile X!*

the third national conference  
on Fragile X Syndrome

2-3 November 2009, Lower Hutt

**REGISTER NOW!!**

Go to [www.fragilex.org.nz](http://www.fragilex.org.nz)

Or phone 0508 938 0552

Randi Hagerman, Marcia Braden, Louise  
Gane, Jonathan Cohen, Beverly Sher and  
more...



### Special points of interest:

Fragile X Conference in  
November and  
contributions from some of  
our speakers

Stories of achievement  
and survival from Michael  
Carter, Kelvin Adair and  
Bruno Smith

The National Fragile X Survey



**It's not too late to do the survey....**

**Extended to 29 October**

Please complete the survey so that we can identify the  
negative and the positives of current services for fragile X  
families in New Zealand.

Go to [www.fragilex.org.nz](http://www.fragilex.org.nz)

Or phone 0508 938 0552

## Cheers from the Chair – Anita Nicholls

Hi Everyone,

We are all hard at work organising the conference in November. There is a lot of excitement about this conference because of the prospect of having Randi Hagerman, Marcia Braden, Louise Gane and Jonathan Cohen all here together!! All have been here separately but now we have this powerhouse of fragile X knowledge here at the same time and pushing the same message: there has never been a better time to have fragile X! We know so much about the syndrome now that we can really make a difference to children's lives. We are particularly looking forward to Bev Sher's presentation on speech language therapy as there is little information in New Zealand on meeting the complicated speech therapy needs of fragile X children.

We are also extremely pleased that the Hon Tariana Turia has generously accepted our invitation to address the conference. As Minister of Disability Issues, the Community and Voluntary Sector and Associate Minister of Health, she is uniquely placed to recognise and advocate for the needs of the fragile X community.

If you haven't sent in your conference registration form, please do so before the end of September. Parents and whanau should make sure your children's teachers, therapists and care givers know about the conference. Information about the conference is on our website and updated in this newsletter. We have asked some of the speakers to contribute items to give you a taste of what's to come.

The Fragile X family gathering will take place on the weekend before the conference. This is an opportunity for families from around New Zealand to meet other fragile X families who understand the joys and sorrows of raising children with fragile X syndrome. Although this is primarily a family event, our conference speakers are warmly invited to come along to the BBQ at our house on Saturday night.

It is always very enjoyable to see how much our kids enjoy each other's company. My kids love these gatherings because they feel accepted and understood by everyone at the event. My son James still remembers playing with Todd from Gisborne, who he met four years ago at the family gathering in Napier. And of course he'll never forget the go-carts at Whanganui and the impressive spills by some of our esteemed trustees.

See you at Harcourt Park (watch out for the flying fox!)

*Anita*

## From the Office

**Sponsorship.** We have received a \$8420 grant from NZ Lotteries, through the national community committee, to support the November conference. This level of sponsorship has made it possible to offer an impressive line-up of international speakers for the modest registration fee of \$100. We have also secured the sponsorship of Wellington-based Pronto Print, which will be producing our newsletters, brochures and conference materials at a greatly discounted price.

**Membership.** Thanks to everyone who has renewed their subscription to our mailing list and sent through over \$600 in donations since April. If you haven't renewed your membership, you can download the mailing list form from our website: [http://www.fragilex.org.nz/contact\\_us](http://www.fragilex.org.nz/contact_us).

**National Fragile X Survey – Reminder:** We remind everyone to participate in this survey. This will be a very valuable source of information on the needs of New Zealand's fragile X families. We are extremely fortunate to have this opportunity as Don Bailey and his team at RTI International have put a huge amount of effort developing the survey. To have someone of Don Bailey's stature overseeing the survey and assisting with the interpretation and presentation of the results make participation in the survey even more valuable.

**Update on Fragile X Conference, family gathering and clinics.** Please register for the conference and family gathering activities as soon as possible. Clinics with Randi Hagerman, Louise Gane and Marcia Braden are now fully booked for the Sunday prior the conference, but for those able to travel to Auckland there is time available to meet with Randi and Louise on Wednesday afternoon, possibly also Thursday morning. Contact us urgently if you are interested in an Auckland clinic.

For more information, phone 0508 938 0552 (or (Wgtn) 938 0552) or email [fxwell@paradise.net.nz](mailto:fxwell@paradise.net.nz)



### NOTICE OF ANNUAL GENERAL MEETING

The Fragile X Trust (NZ) invites you to its AGM, which will be held at the Angus Inn, Lower Hutt, 6 pm, Monday 2 November.

To be followed by the conference dinner at 7 pm

All fragile X families and supporters are welcome to attend. If you cannot attend in person, you are welcome to submit agenda items to the secretary:

Judith Spier, 196 Taita Drive, Lower Hutt  
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Tel: 04 5678532



# Way to foster independence – Marcia Braden

I am often asked by parents to forecast how well their child will succeed later in life. They ask my opinion about their child's ability to live independently, marry, hold a job or go to college. Of course, the outcome is related to the impact of his or her genetic condition, emotional status, cognitive ability, family dynamics and environmental support. Offering an answer is almost impossible because the human potential far surpasses my ability to predict future success with any kind of accuracy. It is interesting, however, after spending many years in this field, to follow the changes in individuals with FXS from toddler to adulthood. Looking at the lives of many who are now adults, it is clear that there are a number of factors that seem to predict successful independence later in life. After interviewing a number of adults with FXS, these key factors were identified to play a significant role in promoting independence.

## **Encourage participation in a variety of experiences within their home communities**

These experiences can include going out to dinner, visiting relatives, attending family gatherings, traveling with the immediate or extended family, and spending time in unfamiliar settings such as camps, school functions and sports events. These encounters allow for more support from family members so that the experience is less frightening. As the child becomes more comfortable, the family supports can be faded and replaced with friends, camp counselors or teachers. Many of these experiences require decision making even if as simple as making a choice of what to order at a restaurant. This process is an important one because it helps reinforce spontaneous participation. If not addressed, it can later contribute to peer alienation and exclusion of the person with FXS.

## **Encourage participation in small groups such as girl/boy scouts, lessons, church groups or clubs**

This can be especially challenging because many younger children with FXS are socially shy and tend to avoid group activities especially at the outset. When the format, participants and environment are novel, it is especially difficult. It is easy to give in to the tantrum, defiance and fear, by acquiescing. Just remember that the longer the avoidance is reinforced (not requiring the participation) the longer it will take to build back the confidence necessary to overcome the social fear. There are a number of programs that provide an age appropriate "buddy" or a parallel activity for people with special needs. Having a sibling participate in a parallel activity can also provide the support necessary to take the first step. This is particularly important because it forms a foundation for membership, which becomes an important life skill that will transcend into adult routine.

## **Encourage the development of interests to create "common denominators"**

that make the person with FXS a more viable social partner. Many of the adults surveyed spoke about how they became interested in sports, collections, cooking, sports statistics, music and pop celebrities. These interests lead to creating a connection with others their age. For example, knowing a lot about professional football teams, players and rankings is always a good conversation starter. As a matter of fact, people with FXS can actually talk about these areas like experts and in many ways garner an elevated status with their peers.

### Require accountability for simple tasks or making a social plan

Building responsibility and stamina can be difficult for those with FXS. Several adults surveyed reported difficulty staying focused long enough to complete a job task. Gaining stamina to work a full day was something they had to work hard to attain. Holding a younger child responsible for household chores can be the first step. Making sure the task is manageable and one that can be done independently is important. As each step of the chore is taught and then expected to be completed independently it can be linked to a series of tasks to complete an entire job. Learning to follow through is very difficult and requires multiple trials in order to automatically generate a consistent response. Taking telephone messages and returning telephone calls to set a social plan can also be difficult and sometimes frustrating. This life skill is far-reaching and noted by many as difficult even as adults.

### Encourage age-appropriate dress, grooming and personal hygiene

According to the adults surveyed, having to discuss hygiene often resulted in negative feelings. Most of the adults surveyed understood after many difficult conversations that being well groomed played a large part in their social acceptance. Also, understanding how dressing in favourite clothes that might not be age appropriate (wearing a Disney Princess Tshirt when you are 20 years old) can be the target for someone who is delayed or socially strange. These factors, although difficult to address, are critical to acceptance by typical peers and are necessary to demonstrate in the world of work. Often these topics are the centre of group therapy when teaching social skills. The group dynamics can be helpful in creating allies in the quest to follow social standards. Discussing it in a group seems less judgmental or embarrassing and can prompt more honest feedback.

**Ofa Laukau (age 17)** changing a tyre – part of his hands on experience at the 2009 Coca Cola EXPO in Wellington".



**Ben Hollis (age 15)** has an after school job helping his dad's workplace reduce its waste by composting their kitchen scraps. Ben catches the bus to work and enjoys the regular interaction with Chris's workmates. Photo by Margaret Low, GNS Science



# Fragile X Alliance Clinic, Melbourne, Australia

## Jonathan Cohen is medical director of the Fragile X Alliance Clinic

The clinic was established in 1998 to meet the specific needs of families. It is currently the only FXS-specific evaluation and treatment centre in Australia, and is unique in that families and carers bring both children as well as adults to be seen. For children, the emphasis is on identifying the educational, behavioural and support options that will enhance family life and optimise the child's abilities. Adults and premutation carriers together with their families are also seen for broader issues including medical and allied health management, counselling, lifestyle issues, provision of information, monitoring of progress and follow-up. We have now seen over 60 individuals and their families and believe that we are able to supply a level of expertise previously not available in Australia.

The clinic is staffed by a multi-disciplinary, specialised team who provide the following services:

- Medical evaluation and treatment
- Psychological evaluation and treatment
- Speech and language evaluation and therapy
- Occupational evaluation and therapy
- Educational strategies
- Optometry
- Audiometry
- Genetic counselling and support
- Links to parent support groups throughout Australia



A medical consultation includes taking a full and comprehensive history and conducting a medical examination, usually over 1 – 2 hours. This first step is necessary to exclude often-missed diagnoses (for example epilepsy, flat feet etc) and many families opt for this only depending on their needs. In order to make things easier on families, we take special care to co-ordinate appointment times with the various clinicians and suggest accommodation for interstate or overseas visitors. A typical multidisciplinary assessment involves a medical consultation as described and the following. Families and carers fill out a number of detailed questionnaires sent by mail designed to both help clinicians measure a number of parameters such as behaviour, and also as an aid in clinical research. Visits to the audiologist and optometrist follow to exclude hearing and vision problems, each requiring approximately one hour. This is followed by psychological, speech and occupational therapy assessments, each taking approximately one hour, but conducted in one afternoon. The team meets prior to the assessment, and again after they have drafted their assessment reports. A comprehensive multi-disciplinary report is then composed and the findings discussed in person with the family and carers as appropriate. The cost of the multidisciplinary assessment and report is AUD \$660

Any combination of the above services can be selected according to each person's needs. Individualised treatment plans and follow up services are offered including regular reviews, home and school visits. It is a privately funded clinic that relies on the generous support of individuals and organisations, although some services are partly rebatable through Medicare and private insurance. Staff regularly conduct education programs for families, professionals and support groups throughout Australia and overseas. All staff are actively involved with research which will serve to improve the quality of care available to people with FXS.

## Beverly Sher is coordinator of the Fragile X Alliance Clinic

Since arriving in Australia in 1998, I have had the privilege of being involved with the Melbourne-based Fragile X Alliance Clinic. The clinic has provided me with the opportunity to see how different health professionals can work collaboratively to fully understand and work with the individual with FX and his or her family or carers. It has also allowed me to meet a vast range of affected clients who present with characteristic speech and language profiles. These profiles include difficulties with expressive and receptive communication, unintelligible speech, oro-motor limitations and most predominately, pragmatic deficits or impairments in using language for social communication. These pragmatic difficulties include excessive verbalisations or mumbled vocalizations, eye gaze avoidance, aggressive behavioral outbursts, perseverative responses and panic or anxiety in socially demanding environments (Braden, M 1995).



Through my private practice, I have provided regular Speech Therapy to clients both on an individual basis as well as in small groups, with an emphasis on addressing social skills. I find that I often use skills that I acquired in my training as a Speech and Drama Teacher during Speech Therapy sessions with clients. The potential benefits of including drama in language therapy when working with individuals with Fragile X Syndrome (FXS) are enormous.

Drama is an ideal tool for the FXS population, as we know that individuals with FXS learn from experiences and learn better when presented with ideas as a 'gestalt' rather than in isolation. My FXS clients view drama as a fun learning tool and they are able to use their good sense of humour and strong imitative skills (Scharfenaker, 1994). Drama provides the client with an opportunity to learn as well as rehearse appropriate speech/language behaviours in a variety of realistic situations whilst being in the comfort of familiar people and familiar surroundings. Inappropriate behaviours can be analysed and improved upon in a non-threatening environment. 'Experiencing' an unfamiliar or socially demanding situation through role-play may aid in reducing the associated anxiety or serve as a basis for discussion. Drama allows the individual access to both auditory and visual information, thereby aiding in comprehension.

Over the years, being involved with individuals with Fragile X and their families has been challenging yet enormously rewarding. It has provided me with great insight into so many others with communication difficulties. I look forward to being able to share my experiences with you in November at the conference and I thank the organizers for providing me with this opportunity.

### Edward Elwood and "Hairy Bear"

Hairy bear belongs to room one and gets to have stay overs with the children in the class. Edward had done really good work with his teachers so he was chosen by Hairy Bear to have a sleep over at Edward's house.



## *Congratulations! It's Fragile X!*

### Family Gathering Events

#### Saturday 31 October

##### Barbeque

**Time:** 3 - 8 pm

**Place:** Anita and Chris's house, 20 Golders Rd, Upper Hutt

**Cost:** Free, but let us know if you are coming – we don't want to run out of food

**Details:** Come and join us for a BBQ dinner. Have time to talk to other parents while the kids spend time together. There will be a bouncy castle if the weather is fine, DVDs, balloons, pool and table tennis if wet.

#### Sunday 1 November

##### Picnic at the Park

**Time:** 10 am – 1.30 pm

**Place:** Harcourt Park Playground

**Cost:** Free

**Food:** Chippies, bottled water and sausages in bread provided. Bring your own extra food and drink

**Activities:** large playground suitable for a wide range of ages, cricket, frisbees, bubbles, balls, face paint, kites, fly a paper plane, bikes, trolleys and balls. Fun and games at the park and more time for the adults to talk.

##### Silver Stream Railway

**Time:** 1.45 – 4 pm

**Place:** Silver Stream Railway, Silverstream

**Cost:** Free. But booking is essential so please phone or email to confirm your attendance.

**Details:** Have a ride on a diesel train and a steam train. We have our own Fragile X carriage. Each ride is a short 10 minutes up and back but you can ride as many times as you want. Bring your own food and drink.

#### Fragile X Conference – accompanying children's programme

Two activities have been organised for children of parents attending the conference. Your child must be accompanied by an adult. We'll provide minivans transport to and from the venues. Bring your own food and drink or buy at the venues. There is a cost of \$5 per child per day. **Bookings are essential. Contact Anita.**

#### Monday 2 November

##### Tumeke Te Papa! Te Papa tour for kids

**Time:** 10 am to 2 pm

**Location:** Starts in Te Papa Foyer at 10.30 am.

**Tour 1:** Designed for younger children or children who like hands-on activities

**Tour 2:** Designed for older children who are able to focus and listen

Get to know what's in Te Papa. Tumeke Te Papa! is a one hour fun-filled introduction to our national museum. The programme is adapted to suit our kids' needs and interests

#### Tuesday 3 November

##### Swim and Kayak at H<sup>2</sup>O Xtream

**Time:** 10.30 – 2.00 pm

**Location:** H<sup>2</sup>O Xtream, Corner of Brown and Blenheim Street, Upper Hutt

**Details:** Entry covers use of all pool facilities (unlimited hydro slides). Visit H<sup>2</sup>O Xtream and experience a fun-filled, action-packed, aquatic day out. Three exciting hydro slides, beach area, wave pool and rapid river, outdoor trampoline and café.

**Kayak Lessons:** Available if there is sufficient interest for an additional fee of \$3. Small group sessions adapted to the level of the child – How to hold a paddle, moving through the water, races. Children must be taller than 1.2 m or 9 yrs or older.

**? Saturday BBQ / Sunday Picnic / Sunday Trains / Monday Te Papa / Tuesday Swim ?**

Please let us know which of these activities you or your children will be attending.

**Call or email Anita: 0508 938 0552 (toll-free) or fxe@paradise.net.nz**

## *Congratulations! It's Fragile X!*

### Conference Programme

#### Monday 2 November

8.00 am	Registration	
8.30	Welcome	
8.40	Introduction to Fragile X	Randi Hagerman
10.10	Ministerial address	Tariana Turia, Assoc. Minister of Health, Minister of Disability Issues, Community & Voluntary Sector
10.30	<i>Morning Tea</i>	
11.00	New Zealand clinical networks	John Forman, NZ Organization for Rare Disorders
11.20	New approaches to treatment	Randi Hagerman
12.30 pm	<i>Lunch (not provided)</i>	
1.30	Australian perspectives	Jonathan Cohen
2.15	Supporting families	Louise Gane
3.00	<i>Afternoon Tea</i>	
4.00	Females with fragile X	Jonathan Cohen
5.30 pm	<i>Wrap-up</i>	

#### Tuesday 3 November

8.30 am	New approaches to education	Marcia Braden
10.00	Parent's perspective	Anita Nicholls, Chairperson, Fragile X Trust (NZ)
10.30	<i>Break</i>	
11.00	Speech language therapy	Beverly Sher
12.30 pm	<i>Lunch (not provided)</i>	
1.30	Inclusive education	Kerry Howard, Teacher, Central Normal School, Palmerston North
2.00	Transition to school	Marcia Braden
3.30	<i>Break</i>	
4.00	Transition to adulthood	Marcia Braden
5.00 pm	<i>Wrap-up</i>	

#### INVITATION: Workshop on managed clinical networks

NZORD, the New Zealand Organisation for Rare Disorders, is holding a workshop in November with representatives of several support groups to discuss solutions to the assessment and management issues associated with rare disorders. The Fragile X Trust had been invited to attend and share experiences about difficulties getting access to the right clinical expertise. Several support groups are experiencing similar difficulties getting access to the right specialists, because of restrictions on referrals across District Health Board boundaries, and there is momentum developing to find practical solutions to these bureaucratic barriers so families get the best clinical assessment and the right interventions for them.

The workshop will build upon work NZORD has been doing for many years on this topic, and on momentum that is occurring at the political level and within the Ministry of Health, to ensure that patients and families are not disadvantaged by access problems, delays or inadequate assessments, simply because of the area they live in. The Paediatric Society and the Health Ministry have indicated they will be attending.

The expected outcome of the workshop is the development of managed care models that can be applied to a variety of rare disorders, and the presentation of these to the Ministry in ongoing negotiations that NZORD will pursue, to improve care and support of those with rare disorders.

Anyone interested in attending should contact Anita – 0508 938 0552, [fxwell@paradise.net.nz](mailto:fxwell@paradise.net.nz)

# FAMILY NEWS

## Michael Carter – Special Olympics Swimming

My name is **Michael Carter** and I am involved in Special Olympics Waitakere. I train once a week at West Wave for my swimming. At the moment I am working really hard improving my backstroke and freestyle because I am training to go to the National Games in Palmerston North in December. During the year I participate in several ribbon days where I compete against other clubs. Also I attend Regional Days which is usually a two day event. I have lots of fun. I also meet lots of other people. The photos show me during and after a Regional Event held out at Mangere. I got Player of the Day. My mum usually takes me to training and competition days.



## No More Nappies!

I'm laughing and celebrating. Bruno has recently given up nappies because we ran out. Silly me, I'd forget to buy some time and time again, and anyway they were all crap and really too small for his bum was getting bigger. Does it sound like I was manipulating my son? Well, probably not more than the average parent of a potty trainer... We've had the odd wet sheets in the morning, but actually, it's less annoying than leaky nappies everyday (they were really getting too small...)

Next item: now if Bruno was able to take himself to the toilet in the morning, it should follow in my logical mind that we should be able to sleep in a little longer than he did (or a lot longer if possible). How should we go about this? Visual is the answer, if you ask Anita. So here are the pictures strategically placed so that they are the first thing that our sunshine son sees in the morning. And guess what? It works! He still is roaming around in the house, playing in his bedroom and checking the clock every so often, but it's all whispers now, instead of banging and crashing, and singing at the top of his voice...

**Anne and Niel Smith**



## Kelvin Adair – “Lucky to be alive”

Kelvin and I were in a road accident on 25 January this year. A landcruiser failed to give way and struck our car at an intersection near Te Awamutu and forced us off the road into a paddock. This cost Kelvin extensive injuries and four weeks in Hospital; one week in intensive care unit, one week in HDU (high dependency unit) and two weeks in the ward. Kelvin had a brain injury, a broken nose, fractured left cheek and jaw, a tracky in his neck, fractured skull, multiple fractures to his left arm and a broken right wrist. He had 12 hours of surgery; 6 hours on his face and 6 on his arm. We were very grateful to the two teams of doctors that worked on him and repaired his face and arm.



Kelvin's Fragile X condition makes him a challenging hospital patient. He was under the wing of trauma team at Waikato Hospital who set up a care programme for him. Hospitals can be under resourced for special needs patients and it can be a strain on staff who do their best. He had 24 hour care with a person with him all the time he was in there. He was forever trying to get out of bed and go home. One day he fell out of bed trying to go home. I was in hospital for four days, it took me three days to go see Kelvin and every time I went in I cried all the time thinking he was going to die but he pulled through. I don't remember anything about the crash, just coming to in the car. I suffered concussion, cuts, grazing, bruising and a fractured left arm. I remember looking for Kelvin but couldn't see him next to me. I just heard him gurgling which wasn't nice. I was then helped out of the car and we were taken to hospital.



Kelvin has a lot of steel in his left side of his body, having had a crash four years ago in a school van; steel rods in his leg and now two rods in his arm and a rod in his right wrist. I have a rod in my left arm also. I have had two more operations on my stomach which I am getting over now. In a few weeks I should be able to return to work after been off for almost 7 months. So to date we are coming along slowly. Kelvin is doing physio every week and has more movement in his arm now. He is also looking forward to October as we are taking him to Bathurst V8's in Sydney. My quote of the year is “Make every day a good day” and we looking forward to the end of the year. And in Kelvin's words I'm lucky I'm still alive and happy to be home.

*Jenny & Kelvin Adair*

# Contact Information

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## Change of Address?



If you are moving house,  
changing your phone  
number or email address,  
please contact the  
Secretary.

Thanks!



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