



FRAGILE X TRUST (NZ)

Supporting New Zealand families living with fragile X syndrome

FRAGILE X TRUST (NZ) NEWSLETTER

MAY 2009

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Congratulations!
It's Fragile X!

**the third national conference
on Fragile X Syndrome**

with

**Randi Hagerman
Marcia Braden
Louise Gane
Jonathan Cohen
& Beverly Sher**

2-3 November 2009, Lower Hutt

See page 5 for details



Special points of interest:

- 1st National FX Survey
- 3rd National FX Conference
- Vote for us @ SOVEREIGN sunshine

The National Fragile X Survey



In collaboration with the Fragile X Association of Australia and a leading US health research organisation, the Fragile X Trust is undertaking the first national survey of New Zealand families.

We want to learn how fragile X has affected your family, so that we can advocate for improved support and services. Tell us what's being done well and what needs to be done better. Have your say!

See pages 3-4 for details

Cheers from the Chair

Hi everyone,

Since the last newsletter, we have run two family gatherings in Christchurch and Wanganui. It was great to finally host an event in the South Island. The family gatherings continue to be a great time to catch up with other families and Louise Gane. We all keep an eye out for each other's children while parents talk and the kids have a great time hanging out together. In Wanganui I awoke to the big smile of Bruno who appeared at the doorway with a newspaper. Bruno had charmed the Top Ten owner into allowing him to ride on the motorized cart and help deliver the morning newspapers. On Saturday we went on the Steam Boat up the Wanganui River and in the afternoon the kids rode around on camp go-carts.

In Christchurch, Louise spoke to a packed hall of parents and professionals on a range of fragile X topics, spanning infancy to adulthood. Thanks to Trina for organizing the event, Senorita for running a terrific session on hyperarousal at both Wanganui and Christchurch, Jayne, Nic, Judith, Andy and Isobel for organizing food for the barbeques. Special thanks to Louise for all of the effort she continues to invest in supporting New Zealand families, both at the family gatherings and with follow-up phone calls and emails throughout the year. For more on these events, see pages 6-9.

This year we will run our first national Fragile X conference since 2003. The conference will celebrate the amazing advances in treatment and knowledge of fragile X over the last few years. We are very pleased to offer an all-star line-up including Randi Hagerman and Marcia Braden. Randi's visit is part of a collaborative effort between the Fragile X Trust and the Fragile X Association of Australia.

In another major collaboration with our Australian colleagues, we are undertaking a national survey of fragile X families. This is the first such survey to be undertaken in either country and will provide information on the needs of fragile X families, which we can use to advocate for better services in education and health care. The survey has been developed by Dr Don Bailey who specialises in the ethical and social issues associated with genetic testing, especially in the context of newborn screening for fragile X. The survey has already been undertaken by over 1000 families in the United States and some of the initial results were presented at the Fragile X Conference in St Louis. I encourage you all to participate in the survey. See page 4 for details

Jodi and I continue to make presentations on fragile X at schools around the country, supporting the teams working with fragile X children in their care. This year presentations to schools are planned for Kapiti, Gisborne and Auckland

So, another busy year for the Fragile X Trust. I look forward to seeing you all again at the November conference, if not before.

Anita

From the office

Hutt Valley expansion continues. The Fragile X Trust has been invited to establish an office in a new complex being developed by Hutt Valley RDA (Riding for the Disabled) in Silverstream. Within the next 12 months we expect to have a office and part-time administrator.

Funding. We have received \$21,320 from the JR McKenzie Trust to assist with our education and advocacy programmes and also to contribute to the costs of the administrator. This is the largest single grant the Fragile X Trust has received and a clear sign that our funders are appreciating the value of our work. Increased funding means increased responsibility, however, so we have engaged a local accounting firm to review, upgrade and monitor our financial management systems.

Membership. We received \$2020 in mailing list subscriptions and donations in the last financial year. We very gratefully acknowledge two personal donations of \$400 and \$1000! All donations, however, of any size are of immense value to the Trust. They demonstrate that the fragile X community values our work. Also, they provide funds that we can use for purposes outside the criteria of many of the grants we receive. For instance, it is very difficult to get funds for overseas travel. So, this year your donations will go to help bring international speakers to the fragile X conference. If you haven't renewed your subscription yet, please do so now.

EVERY DONATION HELPS!!

National Fragile X Survey. We encourage everyone to participate in this survey. It does take quite a bit of time and effort but it 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 for US families, supported by substantial US funding. We and our Australian colleagues then had a relatively simple task of adapting the survey to local conditions. 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.

Some information on Don Bailey. Dr Bailey is a Distinguished Fellow at RTI International. For 27 years, he was on the faculty of the University of North Carolina at Chapel Hill, where he was Director of the Frank Porter Graham Child Development Institute. Dr Bailey's research has focused on early identification and early intervention for children with disabilities, as well as a family adaptation to disability. For the past 20 years, much of his work has focused on children with fragile X syndrome and their families. He has an extensive record of publications, with more than 170 peer-reviewed articles, chapters, and books on a wide variety of topics related to early education, early intervention, and family support. Currently, Dr Bailey directs several projects funded by the National Institutes of Health and the Centers for Disease Control and Prevention on various aspects of fragile X and broader issues surrounding the ethical, legal, and social consequences of genetic discoveries and the disclosure of genetic information to families, including newborn screening. In 2006, he received the Career Research Scientist Award from the Academy on Mental Retardation. He is President of the Board of Directors of the National Fragile X Foundation (www.fragileX.org).

For more information: Phone 0508 938 0552 (or 938 0552 in Wellington)
or email fragilex.info@nzord.org.nz

The National Fragile X Survey

fragile X

What is the national fragile X survey?

The first national fragile X survey was carried out in the United States in 2008. The survey is now being extended internationally to Australia and New Zealand. The information that has begun to come out of the US has already had a significant impact. Survey results from Australia and New Zealand will provide researchers with important internationally comparable information on how fragile X syndrome affects families, including the medical and nutritional needs of fragile X children, the use of educational services and supports, and the cost of raising a child with fragile X in our countries. All families with a fragile X child, either a carrier or with the full mutation, is encouraged to participate.

Why is this study important?

This study is the first national survey of fragile X families in Australia or New Zealand. The survey results will be shared with fragile X organisations, researchers and legislators to help change policy and improve practice.

Why should I participate?

Although many studies have been conducted with families of children with fragile X, this study will be the first in Australia or New Zealand to survey a large number of families. Your participation will provide researchers with a national picture of the needs of families with a fragile X child.

What does my participation involve?

The survey will run from May to September 2009. In the first section of the survey each family is asked to provide information about each child in their family, regardless of whether they live in the household. For each child, we will ask their age, gender, whether they have been diagnosed with fragile X, and some general health information, such as have they ever had a seizure. We will ask similar questions about each adult living in the household. The second section will include more in-depth questions about your family. It will take about 35 minutes to 40 minutes and can be completed online or by telephone. You are able to take a break at any time and resume later.

Will the information I provide be kept confidential?

All information collected will be kept confidential. Your answers will be combined with the information we get from other families. Individual answers and names will not be published in any study report or disclosed to any individual or organisation.

Where can I learn more about my rights as a study participant?

Participation in the study is voluntary and you have the right to stop your participation at any time. In addition, you may choose to skip any questions that you do not want to answer. If you have questions about your rights as a survey participant, please contact the Fragile X Trust on 0508 938 0552

Who is doing the study?

The study is directed by Dr. Don Bailey at the RTI (Research Triangle Institute) International. RTI is collaborating with the Fragile X Association of Australia and Fragile X Trust (NZ) as well as several US Fragile X organisations, researchers, and the US Centers for Disease Control and Prevention, the primary funding agency for the study. Don Bailey is a leading authority on fragile X and the broader issues surrounding the ethical, legal, and social consequences of genetic discoveries and the disclosure of genetic information to families, especially in the context of newborn screening. He is president of the National Fragile X Foundation.

Who do I contact if I have questions?

If you have questions about the study please contact Chris Hollis or Anita Nicholls on **0508 938 0552** (toll-free) or email fragilex.info@nzord.org.nz.

To participate, simply visit the survey website from May to August 2009 at

<https://fragilex.rti.org>

To complete a phone survey, call 0508 938 0552

Congratulations!

It's Fragile X!

The third national conference on Fragile X Syndrome

The Little Theatre, 2 Queens Drive, Lower Hutt

WELLINGTON

2 - 3 November, 2009

Congratulations it's Fragile X Syndrome! There may still be no cure, but there is now a wealth of knowledge on the detection and treatment of Fragile X and associated disorders. This knowledge provides families, educators and health professionals with treatments and strategies to help the affected individuals in their care. Our two keynote speakers – Randi Hagerman and Marcia Braden – are at the centre of this new vision for Fragile X. This conference is a celebration that will span extraordinary new developments in genetic testing and screening, huge advances in medical treatments and the global and local initiatives being used to provide specialised care and education for Fragile X children.

For more information on speakers and programme: www.fragilex.org.nz

Registration

Send a registration fee of \$100 per person to Fragile X Trust, 196 Taita Drive, Avalon, 5011, Lower Hutt, by **30 September**. Include name, postal address, phone number and email address for all registrants.

Conference Dinner

The conference dinner and fund-raising gala will be held at the Riddiford Hotel Chinese Restaurant on Monday 2 November. Tickets \$50. Please include this money with your registration.

Accommodation

We have arranged two types of discounted accommodation. For families, we recommend **Harcourt Park Holiday Park**, 43 Akatarawa Rd, Upper Hutt. Although a 20 minute drive from the conference venue, it's an affordable, comfortable and quiet environment with many child-friendly activities nearby. We will arrange transport if required. Cabin, tourist flats and motels range from \$35-100 per night for two persons, with \$5-10 for additional children, See: www.harcourtholidaypark.co.nz. For single, twin-share or double accommodation at \$90 per room we recommend the **Riddiford Hotel**, 21-29 Knights Rd, just across the road from the conference venue. See: www.riddifordhotel.co.nz. **Contact us to reserve your accommodation.** There are also several motels close to the conference venue, e.g. Camellia Court and Motel 22 in Pharazyn St. Please make bookings for these yourselves.

Family Gathering

The conference will be preceded by a family gathering from 31 October to 1 November. Activities will be planned around Harcourt Park in Upper Hutt, adjacent to the holiday park on the Sunday.

Clinics

Marcia Braden and Randi Hagerman are willing to provide individualised clinics for families while they are here, either on Sunday or Wednesday. **Anyone interested should contact us.**

Contact us: 0508 938 0552 or fragilex.info@nzord.org.nz or 196 Taita Dr, Lower Hutt 5011



Fragile X Family Weekend, Wanganui

31 October - 2 November 2009

Once again Blake and I headed off to the annual gathering we so enjoy, where we catch up with other Fragile X families that come from around the country to spend the weekend together.

This year Wanganui was lucky enough to host us, and of course we had a great time. The Top 10 Holiday Park, located on the banks of the Wanganui River, was a lovely place to stay. At times the lack of fences along the riverbank presented a few stressful moments, as Blake would chase the friendly camp ducks right to the very edge! But it was great to have all the wildlife around us, the camp had their own goat, and some very large bunny rabbits that roamed around free, and of course those ducks. Blake was delighted when they chose to visit us on the doorstep of our cabin.



It is always a pleasure to reunite with Louise Gane who so generously gives up some of her holiday back to New Zealand to come and give a talk and spend time with us all, and pass on her amazing amount of knowledge, advice and expertise. It was wonderful to learn how research is progressing on a 'cure' for FX, and to hear what has been learnt about FX in the past year. One of the parents,



Jodi Heenan, had brought along two staff from her son's school in Palmerston North. They were able to tell us what great progress can be made with our kids, when there is a willing school, with staff who are so passionate about making school the best experience they can for both family and child. They were a real inspiration, so thanks Jodi for letting us all see how it can be. Friday night was a good time just to catch up with those we hadn't seen for a year, and a chance to meet some new families too. We were also able to hear from the families who attended the International Fragile X conference in

St Louis in July 2008. What a great experience, and something so worthwhile - Maybe something to aspire to in 2010?



On Saturday morning we were off to cruise down the Wanganui River on the 'Waimarie', the lovely old paddle boat steamer. The crew were just awesome. Some of the kids got to load coal into the fire down below, steer the steamer, and they also put on a great buffet of food for us too. The afternoon was spent either back at the Top 10 park, or swimming in the great new pools they have in Wanganui. The campsite



had bikes/trikes to hire, and these proved to be a great way to burn off some excess energy. Unfortunately the Jumping Pillow we were all hoping for was out of action, much to the disappointment of both adults and children!!



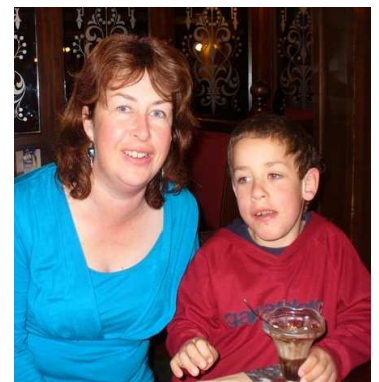
Jayne, her sister Janet, and myself, along with very willing helpers Grayson and Danielle, went off to the supermarket to get some food for our BBQ tea. There was rather a hairy moment when the trolley got left unattended, with Jayne's handbag still sitting in it somewhere in the supermarket. After a few very stressful minutes the trolley was



found left in an aisle, with all our goodies and Jayne's handbag still safely intact!!! We had a great meal Saturday night, a very relaxing affair, and it seems that most of the males got left to watch an All Black game on the big screen in the lounge, while women and children headed back off to their cabins. It was really a great, and very relaxing weekend. I hope everyone who attended had a good time too, and we look forward to seeing everyone in Wellington in November for our next catch up.



Nic Cuthbertson
from Levin



Caffell family news & Christchurch Fragile X Family Gathering

Hi from Dunedin

Well- it's hard to believe that we are into April already. The year has started with a rush, but will be full of many exciting things. It has been hard to stop and think about the year that was in 2008! Bradley had a busy time in the later part of the year. He was fortunate to be chosen as one of the children to go to the Gold Coast with Koru Care- what a fabulous opportunity! Josh Kronfield was the celebrity on the trip- he is dancing in Dancing with the Stars and his chosen charity is Koru Care (so don't forget to watch Tuesday nights and text to vote- Bradley certainly is!). He returned from that to head to school camp for a couple of days- it was his last year at the primary school which he had been at for 6 years.



(Adrian and Bradley - feeding giraffes at Orana Park)

I suppose one of the highlights for us, was directly after this, when we headed to Christchurch to catch up with other families, for a FXS workshop and gathering. It was fantastic to meet new families and see old friends again. As always the workshop was informative, and congratulations to those who presented and worked hard behind the scenes to make it the successful event it was. It

was great to meet up with Louise Gane who is an amazing resource and support for the families in New Zealand. The day at Orana park was a good way to unwind, and spend time chatting with each other (even though it did get a bit stressful when James Hollis went missing!). It was great to meet other children and see how they are doing plus provide support to others who have younger children. All the activity was a bit much and Bradley came home for a few days rest before heading back to school.

2009 has seen both Bradley and Jaimee-Kate transition to new schools. With lots of planning, this has gone extremely well. We have used the information from working with Anita and Jodi last year, in developing Bradley's education profile to inform his new school about his needs. He has settled in very well including putting his name up for class captain, which required him to present to the class on what attributes he had for the role. He did this in the form of a power point presentation (his teacher aide actually did this, but he identified what was to be included) with the key points being:

☞ Things about me:

- I am a ninja turtle so I can protect room 5 (and Mr Herden) from bullying
- I know all the Star Wars movies and I'm pretty awesome with a light sabre
- "Grease Lightning" is my favourite song- here is an example

☞ Vote for me!!- because I am strong and tough like King Kong and Josh (Kronfield)

We were so proud, and thought it was fabulous.

(Bradley and Jaimee- Kate ready for their new schools!)



What else is in store for us this year? Well- the next focus is the Independence Games in April in Christchurch. It is a fantastic opportunity for the children to compete and we have met some great people through this. While in Christchurch, given it is school holidays, we thought it would be a great thing to have another catch up for those who want to. Fliers were sent to everyone in the South Island who is on the mailing list. The details are (see Page for photos of this event)

If we don't see you there, we hope to see you in Wellington in November. It is exciting to have Randi Hagerman, and Marcia Braden coming to New Zealand again.

Kim and Adrian Caffell

Byrne Family Visit to Melbourne Fragile X Clinic

Last November Chris and I took Alicia (5) and Matthew (2) over to Melbourne to visit the Fragile X clinic, run through Fragile X Alliance. I had joined the Australian Fragile X forum and there I chatted to several lovely ladies about these clinics. Chris and I decided that this is what we as a family needed to do. So we saved up and went over in November for one week.



The words Fragile X Alliance sound very formal but the clinics are a very friendly place for adults and kids alike. Jonathan Cohen who runs them has a young adult son with FX himself and since his diagnosis about 15 years ago he has put huge efforts into not only learning everything there is to know about FX but also in educating other medical professionals and getting the message out about FX. He runs the clinics from his medical practice in Caulfield, Melbourne and has a team of people, medical specialists and therapists who are knowledgeable and experienced in FX. This includes his wife Shelley, who is lovely and a developmental optometrist and deals with the vision issues in FX.



We also met with Astra King, a Psychologist, who spent most of the day with us. She worked with both children, chatted to Chris and I separately and together, then did a Vineland assessment on both children. She was amazing. She could tell us exactly which behaviours were FX and which were autistic. She confirmed that Alicia was Autistic but Matthew was just a classic FX male, which was a relief.

We had full OT and Speech assessments done, as well as hearing and vision tests. We were able to see all Fragile X specialists, people who knew exactly how we felt, knew exactly what we needed to hear, see and do for the children and made us feel more in control of the Syndrome and our family.

It was a very busy week and not much free shopping time either, which was a shame as the whole place was on sale. On Friday Afternoon we had what was known as a group conference, where all the specialists got together to discuss us, each met with us one more time to check if we had any further questions, and then we all sat around a table and discussed the results, outcomes and goals for the children. It was an amazing experience... and very worthwhile.

About a month or two later we received print out reports for each assessment, follow up notes and goals and more information to ensure we were able to access help back in New Zealand. Our trip was not cheap....but it was so worthwhile and we both feel very lucky to have been the first New Zealand family to visit the clinic.

It is one of our hopes that New Zealand can formulate and operate a clinic similar to this one. A place were families can visit not just once, but also for follow ups, and actually sit in a room full of professionals who know about our kids needs and special requirements. I hope I can work with our trust to make this dream a reality. I am more than happy to discuss the trip, costs involved or any thing else anyone may have.

I wanted to let you know about a few web sites I have found useful both for Autism and Fragile X. They are in no particular order. I highly recommend the Fragile X forum in Australia. There are men and women who have various age children, as well as women who are carriers and just going through thinking about having children, and even a few medical people. There have been several articles published recently in Australia and I have also included them for you to read.



<http://www.fragilex.org.au/forum/index.php>

<http://www.fragilex.org.au/>

<http://www.fragilex.org.au/news/>

<http://www.time.com/time/magazine/article/0,9171,1818268,00.html>

<http://www.do2learn.com/games/learninggames.htm>

<http://www.zacbrowser>

Hi from the Wellstead family

2008 was a big year for us with moving from Balclutha to Clyde. Jack amazed us all with settling into his new school with no problems at all. At the end of his first week there was the usual assembly which I attended. Jack was called upon by the principal to stand up, in front of 150 pupils. I was at the back thinking what on earth are you doing, that will be his worst nightmare! But, to my amazement, Jack did as asked and beamed from ear to ear as the whole school sang "Consider yourself one of the family." I think it was me with the anxiety issues that day! He has done so well since. He rides to school on his trike or rides his scooter yelling hello to all the people he passes knowing all the names of the children and who their siblings and parents are. He has had the opportunity to snow ski and iceskate as part of the winter sports programme and to sail, kayak, go out on a boat and be pulled behind it on the biscuit and to swim every day for 5 weeks all as part of the summer programme.

In October the school began their practice for the end of year performance. Jack was asked to learn the words to two songs, We're on the road to nowhere, Talking Heads was one of them. I copied the words and every morning at breakfast I played the song and we attempted to sing along. He was adamant it was too hard and never seemed to participate. However, on the day we were all gobsmacked as we went along to the performance and Jack was up there singing along at the top of his voice, word perfect! He even got the dance moves right.



In November we attended the Fragile X Conference in Christchurch. It was a fabulous weekend and great to meet so many other families and too share stories. It is quite easy to get wrapped up in every day life feeling like you are the only one with daily issues to contend with. I came away from the family BBQ feeling like a huge weight had been lifted from my shoulders, just knowing there are other families going through similar problems.

Needless to say, the move has been a good one for us and we look forward to another one which will hopefully be just as good! Regards.

Pippa and Mark Wellstead

Parents of Jack (aged 10 - affected) and Phoebe (4) and Emily (2)

Peter Judge's busy life



Peter at the age of 46 leads a very full and interesting life in Christchurch. He has lived twenty years at our family home in Belmont, Lower Hutt, and about twenty years in a flat with his brother Graham, in Berhampore in Wellington. Now he has recently moved from Wellington to Christchurch and has chosen to live in a fully staffed Idea Services house which he shares with four others including his brother.

On Mondays and Tuesdays he goes by van to a day base in the Travis Conservation wetlands. Here he helps with weeding, mowing, etc. Conservation days are the highlight of his week and he has asked to go more often, but that would mean giving up other things which he enjoys. On Wednesdays he goes to Richmond base which is his home day base. From there he goes out all over the city with the camera club.

Of course he had to have a new digital camera. Any good photos are made up into gift cards and sold for fund raising. On Thursdays Peter travels by bus, changing from one bus to another at the bus exchange. This brings him to another day base in Woolston where he does woodwork under an instructor, returning home via the bus exchange. On Fridays Peter has a quieter day mostly sorting stamps and envelopes at his home day base in Richmond.

One sporting interest Peter had developed when he lived in Wellington was that of Ten Pin Bowling and he has continued this in Christchurch. He gets up early on Saturday mornings to go to the Ten Pin Bowling Centre as part of the Ramblers Club. He is entered for the Regional Games for Special Olympics.

To finish his week Peter gets up early on Sunday mornings to join with us, his parents, to attend our local church. Whenever possible he calls in at our home, we live nearby, for a coffee and snack for afternoon tea. Also to meet any family who may be there.

Peter enjoys life and makes the most of any opportunity to socialize.

Frances and John Judge

Hutt Valley news



In Naenae College's 2008 end of the year prize giving, 'Ofa Laukau was the proud recipient of the Barclay Cup for an excellent attitude in Special Education Physical Education. He is seen here with his brother Siasoi.



James Hollis cleaning his kick wheel before working on another creation. James has recently joined the Wellington Potters' Association where he is receiving plenty of praise and useful advice. The pots shown are examples of his early work.



The Fragile X
Association of
Australia

Check out the new look website for the Fragile X Association of Australia. There is a wealth of information and lots of interactivity.

Read about Don Bailey's visit to Australia in the latest newsletter. See the page on "Fragile X in the News" for links to terrific articles on a young woman's experience with fragile X (Cleo), a Queensland fragile X family (That's Life) and the issues surrounding genetic screening for fragile X (The Australian).

Got to www.fragilex.org.au

Christchurch Family Day



Frances and John Judge in conversation with Maretta Beeke

Spurred on by the success of our first South Island family gathering last November, seven families met up again at Trina and Arthur Elwood's house in Christchurch for an impressive spread of cakes and savouries, intense conversation and the obligatory Wiggles appreciation session. Thanks to Trina and Kim for organising it.



Jack Wellstead (Clyde), Bradley Caffell (Dunedin) and Isaac Beeke (Waimate)



Joel, Edward and Bradley (and Anthony)

BREAKING NEWS!!

This month, the Fragile X Trust is one of 6 charities shortlisted for a \$15000 grant from *SOVEREIGN sunshine*, a fund-raising initiative funded by Sovereign Insurance. For us to win this grant, we need you, your families, friends and associates to log on to the *SOVEREIGN sunshine* site, register and vote for us during the month of May. The grant will be the first step in our plan to establish the first Fragile X Clinic in New Zealand.

Please vote for us!! Go to: www.sovereignsunshine.co.nz

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