



FRAGILE X TRUST (NZ)

Supporting New Zealand families living with fragile X syndrome

FRAGILE X TRUST (NZ) NEWSLETTER

December 2007

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Special points of interest:



- James & Irene Van Dyk
- Jenny & David Beckham
- Online FX Forums
- Call FX Trust TOLL FREE
- Fragile X Conference

"2 Golds, 1 Bronze, and ... 1 Silver Fern"

Irene Van Dyk meets up with James Hoffman to get tips on winning gold medals. See page 4 to read about James Hoffman's winning haul at the 2007 Special Olympics in China.

Cheers from the Chair

Hi to you all.

It was great catching up with many of you at the Taupo family gathering. For those of you who couldn't be there, seventeen families met at the Taupo Top Ten attending a half-day workshop presented by Louise Gane, followed by an afternoon relaxing at the hot pools (see photos on page 8). The weekend was enjoyed by everyone and it was great to see the kids having so much fun together. Thanks very much to Rob Whittleton for organising the barbeque and to Louise for bringing her special magic to the weekend. At our AGM, past chairperson Chris Heenan stood down from the Trust, having overseen the transition to the new Wellington-based team, and we welcomed Barbara Shelley as new trustee.

The following weekend, Louise was a keynote speaker at the NZORD (NZ Organisation for Rare Disorders) Conference, which was held in Wellington and had a special focus on genetic screening. Louise outlined the need for a newborn screening programme for fragile X syndrome in New Zealand to an influential audience that included geneticists, members of the Bioethics Council, and the head of the National Screening Unit. It was a great speech that impressed everyone present. I will be following up the momentum for newborn screening by attending and, if my abstract is accepted, presenting at a screening symposium in Wellington in April. Thanks to Chris Hollis and Judith & Phil Spier for attending this conference. It is always good to have other families come along to these types of conferences as the more of us there are, the greater the presence and visibility we have. So if you are interested in attending a conference or helping me out to man or woman a booth at a conference, let me know. It would be great to have you attend.

In November I went to the Paediatrician Conference in Christchurch where I manned the Trust booth and presented a poster outlining the education programme successfully launched by the Trust this year. It was a good chance to remind all of the paediatricians present about fragile X syndrome and why diagnosis is important. As paediatricians rarely attend workshops run by the Trust (despite our best efforts) the Trust plans to have a presence at future Paediatric conferences. Thanks to NZORD and Lotteries Community Grant for helping to pay for the Trust's booth at this conference.

And finally I am happy to announce two exciting developments. We have taken up an offer from NZORD to set up two online fragile X forums for the NZ fragile X community, one general forum and one specifically for teenagers and young adults. This follows up on an idea hatched at the Taupo gathering that it would be great if teenagers living with fragile X (siblings, carriers or fragile X teens) had a way to network and discuss issues that concerned them. See the ad on page 3. The second exciting development is the establishment of a toll free number – which means all of you can call us free any time you want information or just need to chat. Please try it out.

0508 938 0552

Wishing you a very happy Christmas

Anita, Fragile X Trust (NZ) Cheerperson



Website changes

www.fragilex.org.nz (advice and support)

With the advent of our new toll free number, we have simplified the contact information that is listed on our website. Rather than listing this information for all our regional contacts, we've decided to channel the first point of contact through the national office. This gives us the flexibility to put people in contact with families in their area that are in similar situations, as well as preserving a bit of privacy for the regional contact people. We are still very grateful to the work that Darryl, Jenny, Chris, Lois and Kim perform in their community and for the Fragile X Trust.

On the page that previously had the regional contact information, we've added something new. We are very pleased to announce that the Trust now has four official expert advisors, who are happy to provide advice to NZ families:

- ◆ Dr Andrew Marshall, Developmental Paediatrician, Child Development Team at Puketiro Centre, Porirua, NZ
- ◆ Dr Jonathan Cohen, Medical Director, Fragile X Alliance Inc, North Caulfield; Senior Lecturer, Monash University Dept of General Practice, Centre for Developmental Disability Health Victoria, AUSTRALIA
- ◆ Louise Gane, MS, Genetic Associate, Development Officer, M.I.N.D. Institute, University of California at Davis Health System, Sacramento, California, USA
- ◆ Dr Marcia Braden, Psychologist, Colorado Springs, Colorado, USA


CALL US TOLL FREE: 0508 938 0552

Chat: Fragile X (NZ)

Do you have a burning issue you want to discuss, some exciting news you want to share, or are you after some key advice from the FX community? Why don't you try out our new online forums? Thanks to NZORD, we now have two online forums:

- ◆ **Fragile X Community** – a general forum for discussion, debate and information that is open to everyone
- ◆ **Fragile X Teens** – a forum just for teens and young adults in fragile X families, who want to debate the issues that are important to them. This forum is moderated by Anita Nicholls, but is otherwise designed to be a parent-free zone.

To get started go to www.nzordforums.org.nz and register for one or both of the forums. Because there is a high-powered spam filter in operation, it might take a few goes, and if all else fails email the NZORD webmaster Ben Chapman:

benedict.chapman@paradise.net.nz

James Hoffman – Gold Medalist



Hi there.

This is a report for James' trip to Shanghai.

James returned from the Special Olympics World Games held in Shanghai on the 17th of October where he competed in the Ten Pin Bowling events.

The first call we received from James was to tell us he had won a Gold Medal in the team's event. His team was in the top grade. The second call we had was to tell us he had won another Gold Medal, this time in the doubles. The last call we received was to tell us he had won Bronze in the singles event. Wow, we were so proud to hear this news.

The trip was very successful overall. They first flew to Hong Kong for acclimatization and training. During this time they went up Mt Victoria and also had afternoon tea at the NZ consulate. After this they flew to Shanghai and competed in the Games. They were very well looked after and when they went anywhere they had a Police escort. On the return trip back to Hong Kong after the Games they had a few days for relaxing and resting. This time they went to visit Disneyland. On their return to New Plymouth they were welcomed by the Mayor, Mr. Peter Tennent and they also received a Powhiri from a local group. They all returned home pretty proud of their accomplishments but very tired after a long flight from Hong Kong and then on to New Plymouth from Auckland.

A big thank you to you for supporting James' fundraising efforts and we also thank his coach Virginia Mills for her efforts in training James for Ten Pin and his many hours at the Gym for fitness. We would like to encourage others to take up a sport with the Special Olympics and also compete for NZ. These trips are a chance of a lifetime for anyone willing to have a go.

Regards Heather & Warren Hoffman

Family News

Hi everyone

Hope all is well with you.

Well... life has been very busy in our home. Steven and I have been on holiday. I won a trip to Los Angeles in October to meet and spend the day at the David Beckham's Academy where we got to meet and train with him. There were 60 of us from all over the world. We met a lot of nice people from around the world. I won the airfare and accommodation for two days. As we went all the way over to LA, we stayed an extra 8 days. We went to Hollywood, Disneyland and Las Vegas and out to the Grand Canyon – it was an amazing place. The whole of America is an amazing place. So this trip was something we will remember for a long time. Meeting David Beckham was a big thrill.

While we were away we set up a living plan for Kelvin and he is now in shared care where he lives with a family in Hamilton. He stays in town for 4 nights a week and comes home in the weekends. It is working well at present. I don't know how it will go at Christmas as he will have to stay home for a while, then we have to start back next year so I hope he will handle it. Have to wait see how it goes. Well that's life at the moment.

Merry Christmas to you all and all the best for 2008.

Jenny & Steven Adair

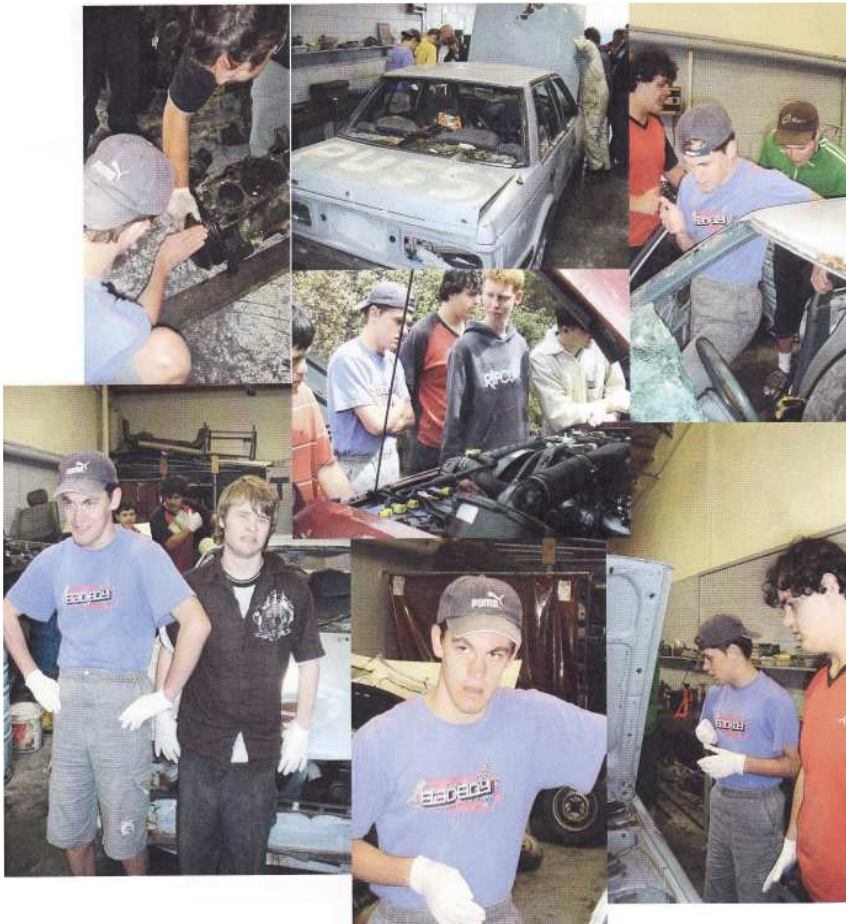


Family News

Hi. Below are some photos of my son Matthew that were taken on a course he went on from school. Matthew is the one in the blue t-shirt and cap! Also in the photos is Nicholas Tomkinson who also has FX – Nicholas is in the red t-shirt and has black longish hair!

They all had a great time and got a certificate at the end. Matthew goes to Allenvale Special School.

Warmest regards, Lois Smith



← Matthew had a great day on the Auto Course. He learnt about all the different parts of an engine – which meant a lot of standing around and listening. The boys had to wear gloves to keep their hands clean.

They learnt how to jack a car up, and learnt about things around the tyres and how to change a tyre.

↓ Matthew finished up the course with some cleaning, and an award for an outstanding performance.

WELL DONE MATTHEW!



Family News

Hi everyone

James, Sara, Saphira and myself really enjoyed the time at Taupo. It was fantastic for us as we don't usually have the money to stay at motels, so we are very grateful for the assistance we received from the Fragile X Trust to do this.

The programmes were great and it was awesome to catch up with and to meet other Fragile X families, some of whom had not been to a conference before. I thank the Hollis family so much for their organisation and structuring of this conference. I also thank all those who helped them in this as well.

As usual, Louise wowed us with all the facts and technical knowledge she gave us, and she is a lovely, caring person too – so interested in each of our families. So thanks to you Louise too.

There was only one thing in which I felt was against all I stand for, and that is when she talked of termination of a Fragile X pregnancy, and this made me very sad as I know what a blessing my Fragile X son is. No matter what tests we have during pregnancy, there is absolutely no way of determining how that child will be affected, and I am so glad I didn't give in to pressure to terminate any of my children as I have no possible way of knowing how they will turn out, and I know God has an awesome plan for each one of our children. Just because they are not what the world sees as productive humans, doesn't give us the right to end their lives, especially as Fragile X carriers can suffer from depression, and there is increased chances of depression in women who have had terminations of pregnancy. Besides, it's marvellous what we can cope with when we try. So be encouraged you Fragile X carriers, we can do it!!

Once again, a big thank you to all who organised and attended the conference. The motel was a lovely place and the trip to the pools was enjoyed by all, as was the barbeque on the Saturday night. It was great to see everyone and I look forward to next year. It's wonderful to be in an atmosphere where our children feel comfortable and they can socialise freely with others, and where we can glean ideas and strategies for better family life.

God bless and have a wonderful Christmas.

Barbara Shelley

A festive graphic with the words "Merry Christmas" in a red, cursive font. The word "Merry" is on the top line and "Christmas" is on the bottom line. There are two holly leaves with red berries: one to the right of "Merry" and one to the left of "Christmas".

Taupo Family Gathering



Message from Louise Gane

To All Trust Members

I would like each of you to know what a true joy it is to be able to join with you each year to celebrate fragile X. My time with you is the highlight of my visit "home". Getting to know each of you, your children and family members, learning from you, and being trusted by you is a real honor.

I thank you for sharing with me...

Louise

International Fragile X Conference 2008



See You in St. Louis!

The US National Fragile X Foundation presents the
11th International Fragile X Conference
hosted by The Fragile X Resource Center of Missouri
St. Louis, Missouri July 23-27, 2008

REGISTRATION INFORMATION Online registration for the 11th International Fragile X Conference will be available 31 January, 2008 at:

www.FragileX.org > 11th International Fragile X Conference

HOTEL INFORMATION The Conference will be held at the Hyatt Regency St. Louis at Union Station. Rooms are available for attendees of the conference for a special rate of \$125.00 per night, plus taxes. To make a reservation, please see the contact information below. Be sure to let them know that you are with the NFXF 11th International Fragile X Conference to get the special room rate! Hyatt Regency St. Louis: www.Hyatt.com

SCHOLARSHIPS A limited number of scholarships will be available to assist with conference registration fees from the NFXF. Applications for these scholarships will be available beginning January 1, 2008 at:

www.FragileX.org > 11th International Fragile X Conference

Applications are due no later than March 31, 2008. Priority will be given to first-time applicants. Scholarship recipients are expected to volunteer for a minimum of 8 hours at the conference.

The Fragile X Trust (NZ) hopes to have funding to assist New Zealanders to attend this conference. If you are interested in attending, please contact Anita.

**Phone 0508 938 0552 or
email fragilex.info@nzord.org.nz**

Need to contact us?

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Change of Address?



If you are moving house, changing your phone number or email address, or simply wish to be removed from the Mailing List, please contact the Secretary.

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