

February 2007



Fragile X Trust (N.Z.)

"Raising awareness of
Fragile X Syndrome
in New Zealand."

NEWSLETTER

Inside this issue:

Chairman's Comment.	2
Executives/Trustee Profiles.	3
10th Intl. Fragile X Conference, Atlanta.	4
Upcoming Conferences & Workshops.	5
Marcia Braden Workshops.	6
Napier Family Weekend (Nov 2006)	8
Contact Details & Sponsors.	11

Fragile X Bowler selected for Beijing Special Olympics.

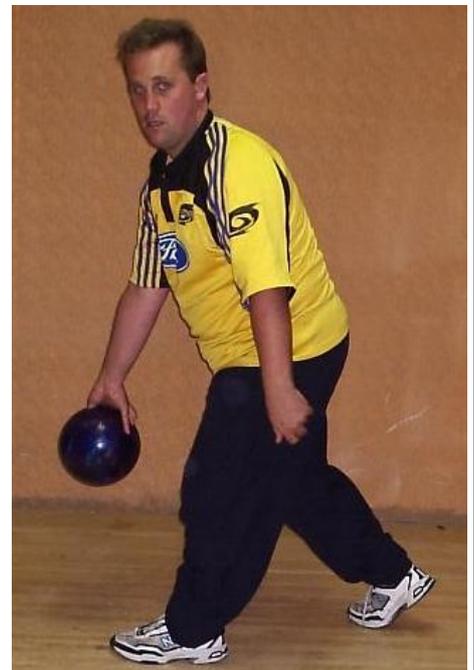
New Plymouth.

James is now 26 years old and living with us at home here in New Plymouth. For a number of years now he has been playing Ten Pin Bowling for the Special Olympics. He has been away to various tournaments around the North Island with one trip to Christchurch for the Nationals just before Christmas last year. The nomination for the Special Olympics to be held in Beijing this September-October came in the middle of last year so he had an anxious wait for quite some months before finally been told of his acceptance and selection. He went to a camp in Wellington where the final selections were made.

James works at Atawhai Industries where they do various contracts for firms around town and he also works for the Horticultural crew doing section clearing and gardening. On Fridays you can find James at Jones & Sandford Mitre10. He loves working there where he is useful in all of the departments. He spends most of his time however in the Gardening Department. He is also helpful making a few home deliveries. He is very busy on these days and comes home worn out but loves every minute of being part of the team. At the moment a Mega Store is being built and James is really looking forward to going out to the valley when it opens. Jones & Sandford are very supportive of James and they are going to help with the fundraising for Beijing.

James has begun intense training to get fit for the trip to China. He goes off with his coach at 7.30 am Tuesdays and Thursdays to the gym at the Aquatic Centre. He is also walking and there will be extra training ahead for Ten Pin Bowling.

2007 will be a busy time for James with training and fund raising but very rewarding with the trip to China at the end. James needs to raise \$5,000 for the trip. A raffle has already been done and a garage sale is to be the next fund raiser and a few other ideas are in the pipeline.



James displaying the form that has seen him selected to represent New Zealand at Beijing.

Can you help?

If you would like to support James in his efforts to get to the Beijing Special Olympics, the Fragile X Trust (N.Z.) has set up a 0900 number through NZORD that you can call to make a \$20 donation. Phone 0900 NZORD (0900 69673) and leave your name, address and the number you are calling from (to get a receipt) and say that you are supporting James Hoffman to get to the Beijing Special Olympics.



Special points of interest:

- Look out for the photos from the Napier Family weekend on page 9.
- New addition to the Fragile X Trust (N.Z.) library on page 10.
- A couple of letters from Regional Coordinators in the north and south.

Heather Hoffman

Cheers from the Chair.....

Hi to all the fragile X families around New Zealand and to the professionals that work with our children. I hope you all had a very pleasant summer holiday and that all of our children have made a successful transition back to school, work or post-holiday life.

2007 brings change to the Fragile X Trust with all but one of the previous trustees deciding it is time to step down. I would like to thank Vicki William, Jenny Adair and Darryl Cockroft for all of the hard work they have contributed over many years, introducing fragile X to many professionals, running conferences and most importantly bringing fragile X families together. Chris Heenan continues as a trustee but has handed over the chairperson role to me. We appreciate Chris staying on to help us newbies to continue on the good work of the trust. We also appreciate Darryl Cockroft continuing to play a vital role within the trust as both our newsletter editor and our representative for Auckland. Welcome and thanks to our new trustees: National Coordinator - Chris Hollis, Treasurer - Senorita Laukau and Secretary - Judith Spier.

This will be a busy year for us all beginning with Marcia Braden presenting workshops in both Auckland and Wellington. This is a must-see workshop for anyone caring for or working with our children as Marcia Braden is the leading authority on educational strategies and behavioural issues in fragile X syndrome. Marcia may not return to New Zealand for some time, so I recommend that you register for this workshop if you haven't done so already. In May, Jodi Heenan and I will begin a series of education seminars designed to present an overview of best teaching strategies for primary school-aged fragile X children. This is an exciting new initiative that received a \$20,000 start-up grant from the Todd Foundation.

July will bring the Human Genetics Society of Australasia Annual Science Meeting to Auckland where we will present a parent's perspective on fragile X syndrome to the many medical professionals present. And finally following the great success of the Napier gathering we hope to run another family get-together in an as yet to be decided destination. If you didn't get to Napier you have to make it to this year's event. You will be sure of a warm welcome, great company and lots of kids and adults who understand fragile X.

Please get in contact with us and let us know if we can help you in anyway. The Fragile X Trust (NZ) is dedicated to supporting all of you that live and work with fragile X.

Cheers, Anita

Fragile X Trust (NZ) Chairperson



Do you have something of interest to put in this Newsletter?

Please send your articles to the Editor (doodlibug@xtra.co.nz) either as an e-mail or as a Microsoft Word attachment. There's no limit to the size or shape of your submissions and photos are very welcome.

Remember, this is *your* Newsletter. We want to hear about what's happening in *your* household, at *your* child's school or in *your* local community, so that we can share it with our national community.

Deadline for the next issue: 20th Jul 2007

Fragile X Trust (N.Z.) Executive Committee & Trustees.

At the November AGM a new team of trustees were appointed:



Anita Nicholls, Chairperson

Chris and I are the parents of 13 year old Ben and 9 year old James. Both of our boys have fragile x syndrome. Ben is very passionate about rugby and is the rugby expert of the house. James loves cooking, trains, flying fox rides and fishing. When I'm not fishing with James or talking about rugby with Ben I'll be watching a movie, reading a book or at the gym with Judith Spier.

I love working with children and their families. I am both an early childhood teacher at a community childcare and a parent presenter for "tips for autism" - a training programme on autism. I am passionate about supporting families and their children, recognizing and building on every child's strength.

As Chairperson of the NZ Fragile X Trust I wish the trust to not only raise awareness of Fragile X in the wider community but also to support families so that our children can flourish both at school and in the wider community. By ourselves the task often seems overwhelming but together we can make it happen.

Judith Spier, Secretary

I am 37 years young and am married to Phil. We have two gorgeous kids – Danielle is 9 and Liam is 7 – both have Fragile X Syndrome. Danielle loves music, dancing and drawing, and Liam who is non-verbal is a big fan of rugby, cricket and horse-racing. When I am not with my children you will probably find me on a softball diamond or at the gym - sport is my passion.

I have worked many years in personal assistant/secretary roles for Justice/Corrections Head Office. For the last 1 ½ years I have been teacher-aiding at a local decile 1 school. My children have taught me so much over the years and I want to share my knowledge and expertise to help others.

I am fortunate to live in Lower Hutt, close to several families who are also affected by Fragile X. As families we have learnt so much by generally spending time together, and of course attending workshops and conferences over the past few years. I am keen to support the Fragile X Trust (NZ) in whatever ways I can, and would love to meet and support other families around New Zealand.



Seniorita Laukau, Treasurer

I am Tongan and migrated to NZ in 1988. I spend some of my childhood years in Niue and so I can speak Niuean, Tongan and English. Some of my secondary school years were spent in Tonga and Fiji and I was a privileged recipient of two scholarships at the University of the South Pacific. I currently work for the Tertiary Education Commission in the Wellington Area Office as Senior Advisor Pacific. I also do part time postgraduate studies.

Aisea and I have 7 children (3 of them are adopted). Our son Ofa Laukau who will be 16 this year was diagnosed with Fragile X when he was 3.

My passion is in education and I have recently focused on the education of and for Pacific communities in New Zealand, exploring the reasons for the consistent poor performance of Pacific children in the New Zealand education system.

I have taken on the challenge of being the treasurer for the Fragile X Trust because I see it as part of my own learning and development. While I do not have an accounting background, I am involved as part of my current job in

assessing the financial viability of tertiary training organisations and provide advice on purchases of programmes based on value for money and relevance to the labour market demand.

Chris Hollis, National Coordinator

Anita and I were introduced to fragile X syndrome 8 years ago when Ben was 5 and James was 3. After the initial shock the diagnosis was a huge relief – first, because our concerns for our children were confirmed and second, because there was a clear diagnosis, a treatment path and maybe even a cure. This is why I'm having a crack at this job. I believe having a diagnosis is important – so I want to do what I can to raise awareness about the syndrome and provide support to affected families.

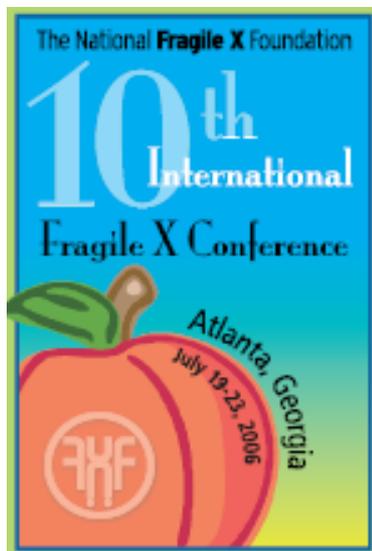
I've been a research scientist for 15 years and am now a mixture of scientist and science manager for a crown research institute – GNS Science. While my job is fairly challenging and absorbing, it gives me some useful skills for this role in the Fragile X Trust – communication, planning, organisation and nit-picking in particular.



Chris Heenan, Trustee (former Chairman)

I'm 41 yrs old and live in Palmerston North. I'm married to Jodi and have two boys, Sam 12 yrs, and Matt 9 yrs who has Fragile X. Both Jodi and myself come from rural backgrounds in the Otago/Southland region. I'm a rural banker and Jodi is a qualified primary school teacher. We live on a 12-acre lifestyle block and find this to be ideal for the boys who enjoy the space to "do their own thing".

I fully support the cause of the Fragile X Trust (NZ). I see that the two key roles of the trustees are to: raise the profile and understanding of Fragile X in NZ; and to provide as much assistance as possible to those individuals and families affected by Fragile X. Both Jodi and myself have thoroughly enjoyed getting to know the families who have been involved with the Trust and have gained a tremendous amount from the two Fragile X conferences held in NZ in recent years. I'm looking forward to working closely with the other trustees and I'm very pleased to be taking an active part towards achieving the aims and objectives of the Trust.



Report on the 10th International Fragile X Conference in Atlanta, Georgia, July 2006

Anita Nicholls and Chris Hollis had the privilege of representing New Zealand at last year's international fragile X conference. It was the first time that New Zealand families were represented but we are confident it won't be the last! It was a wonderful life-changing experience. In New Zealand, we struggle to bring 20 families together – but this conference brought 800 researchers, health and education professional, social service providers and families together for five days of learning and networking. A family atmosphere prevailed, with fragile X children and adults included in all social and many formal parts of the proceedings. The conference was arranged as a mixture of informative family-friendly sessions and professional scientific sessions. Each day began with a plenary session before breaking into four or more concurrent sessions. With both of us attending, we were able to attend different sessions and swap information at the breaks. More New Zealand families should endeavour to attend these conferences. Aside from the wealth of information, they leave you with a strong sense of community and common purpose. Session summaries, handouts, presentations and abstracts are included in the 2006 Proceedings volume that is available at: http://www.fragilex.org/html/2006_proceedings.htm

Follow-up

We presented a PowerPoint summary of the conference highlights to six families from the Wellington region, with a focus on behaviour and education strategies for fragile X children. Books and resources purchased at the conference are now available for fragile X families to borrow through the Fragile X Trust library. The group discussion led to a decision to prepare a programme for educators working with fragile X children based around strategies and resources developed in the US. We succeeded in getting a \$20,000 grant for this programme from the Todd Foundation and Anita has been working hard to prepare it over the summer holidays.

Acknowledgements

Attendance at the Atlanta conference was made possible by generous grants from the NZ Organisation for Rare Disorders (NZORD), the Lottery Minister's Discretionary Fund, and the US National Fragile X Foundation.

The Fragile X Trust aims to secure funding for several more New Zealanders to attend the next conference in St Louis, Missouri, in 2008. If you are keen to attend, please contact us.



Fragile X Awareness Rally, 20 July 2006, Centennial Park, Atlanta

Upcoming Conferences & Workshops.

19 March 2007. Marcia Braden workshop, Wellington (see next page)

20 March 2007. Marcia Braden workshop, Auckland (see next page)

21-23 March 2007. SCERTS workshop, Auckland. SCERTS is a framework developed by Barry Prizant and his colleagues for working with children with autism spectrum disorders (ASD). The SCERTS framework places emphasis on Social Communication, Emotional Regulation and Transactional Support. The Marcia Braden workshop is at the same venue, with the aim of encouraging those attending the SCERTS workshop to come a day early and learn about fragile X. For more information email anna.kelly@minedu.govt.nz

16-19 July 2007. Human Genetics Society of Australasia Annual Science Meeting, Auckland. An important opportunity to raise the profile of fragile X syndrome amongst geneticists and genetics researchers in Australia and New Zealand. The Fragile X Trust will have a booth there and aim to raise funds to bring Jonathan Cohen to present his latest research findings on carrier testing options. Conference website: <http://hgasa.com.au>

Late August- early September 2007 (dates to be confirmed). NZ Organisation for Rare Disorders (NZORD) conference, Wellington. This year's conference will have a theme on genetic screening. The Fragile X Trust will be represented and we will be seeking views on this topic from fragile X families.

Mid or Late November 2007 (dates and venue to be confirmed). Fragile X family gathering, seminar, and Fragile X Trust AGM. Following on from two successful family gatherings, we aim to target another holiday park with a jumping pillow (see Napier report) for a weekend of fun, information and networking.

26-28 November 2007. Paediatric Society of New Zealand Annual Scientific Meeting, Christchurch. The theme of this meeting is "future trends" and one of the plenary speakers is Dr Hillary Cass a specialist in autism. The Fragile X Trust did not manage to get Drs Randi and Paul Hagerman invited to this meeting and we are currently unsure if we have the resources to send a delegate. Conference website: <http://www.paediatrics.org.nz>

23-27 July 2008. 11th International Fragile X Conference, St Louis, Missouri, USA. Anita Nicholls and Chris Hollis attended the last conference in 2006 and found it to be an incredible experience. The Fragile X Trust is keen to have New Zealand represented again and will be looking at options for funding soon. If you are interested in attending this conference, please contact us: fragilex.info@nzord.org.nz

***** Registration Deadline extended until 2 March *****

FRAGILE! Handle With Care!

One-day workshops by Dr Marcia Braden in Wellington and Auckland



MARCIA BRADEN is the leading international authority on educational strategies and behavioural issues in fragile X syndrome. A psychologist in private practice in Colorado Springs, Colorado, Marcia specializes in the evaluation and treatment of children with fragile X, autism, Asperger's syndrome, ADHD and related disorders. She is adjunct professor at the Colorado School of Professional Psychology and author of numerous articles and books on fragile X and autism, most notably "Fragile: Handle with Care" an indispensable guide to fragile X and its treatment. For more information visit Marcia's website: www.marciabraden.com

**WELLINGTON: Monday, 19 March, Sharella Motor Inn Conference Centre
12 Glenmore Rd, Thorndon (opposite Botanical Gardens)**

This workshop is divided into two parts. A morning seminar (9.00-12.30) will provide a general introduction to fragile X, with an emphasis on behavioural issues for children and adolescents, learning styles, educational strategies and resources. The afternoon (1.15-5.15 pm) will be on advanced behavioural intervention and will introduce a new team-based system for approaching intervention, termed the Etiological Specific Pyramid (ESP).

COST: \$80 for professionals, \$40 for family members and support workers, \$200 for teams (up to 4 members); morning seminar only \$40 (does not include lunch)

**AUCKLAND: Tuesday, 20 March 2007, Waipuna Hotel and Conference Centre
58 Waipuna Road, Mt. Wellington**

This workshop will provide a general introduction to fragile X with an emphasis on behavioural issues for children and adolescents, learning styles, educational strategies and resources, including Marcia Braden's "Logo Reading System" and "Social Compass" – a new comprehensive social skills programme.

COST: \$80 for professionals, \$50 for families and support workers

Registration, payment, accommodation

- Register by 2 March 2007 by email: fxwell@paradise.net.nz, phone: 04 938 0552 or post: 158 Oxford Tce, Eponi 5011, Lower Hutt.

- Post cheque payments by 9 March 2007 to the Fragile X Trust (NZ) at the above address

Accommodation: Reduced room rates are available at Sharella Motor Inn and Waipuna Hotel. Please book ASAP and quote Fragile X workshop)

For more information email : fxwell@paradise.net.nz or phone 04 938 0552

Marcia Braden Workshop Programmes

WELLINGTON

- 8:30 Registration
- 9:00 Introduction to Fragile X (behavioural overview – children and adolescents, hyper arousal, differential diagnosis)
- 10:30 Break
- 11:00 Educational Profile, intervention strategies and demonstration of learning tools (self-regulation, logo reading, social compass)
- 12:30 LUNCH
- 1:15 Behavioural profile, behaviour assessment, function of behaviour
- 2.45 Break
- 3.15 Advanced behavioural intervention. Application of the Etiologic Specific Pyramid. This segment will include designing pyramids for specific students – be prepared to bring in case studies to use in this process
- 5.15 Workshop ends

AUCKLAND

- 8.30 Registration
- 9.00 Introduction to Fragile X: a general overview
- 10.30 Break
- 11.00 Educational profile, intervention strategies and demonstration of learning tools (self regulation, logo reading, social compass)
- 12.30 LUNCH
- 1.15 Behaviour profile and management
- 2.45 Break
- 3.15 Adolescents and sexuality
- 4.45 Wrap up question and answer session
- 5.15 Workshop ends

Hello to everyone.

It is the start of a new year- each year I comment that it will get easier, but now I am beginning to doubt that. This year, we have 3 children at 3 different schools! Other parents comment they are busy with the normal things as school gets underway. The routine sorting of uniforms, and books is the easy bit. As you all know it is the transition to a new school, class, teacher etc that poses the challenges for a child with FXS. I am thankful that the planning we have done has paid off, and the children seem to have settled well into their school year. The xmas break has gone by in a blurr!

The last 2 1/2 weeks we had a great family time, with a holiday in Hawea (near Wanaka for those who don't know). We spent quite a bit of time fishing and out in the boat. The biggest thrill for us, is the fishing reel that we bought Bradley, now means he can fish independently - he is so pleased with himself, and it was a bit hard stopping him once he got going. The reel has a button, which reduces the number of steps in casting out the line.

It is great to find these little things that can help us integrate our children into the world around them. I am looking forward to meeting another family who live in Otago over the next several weeks. There don't appear to be many families in this region- I am unsure whether it is due to a lack of testing for FXS, or what the reason maybe. If you live in Otago/ Southland- please don't hesitate to give me a call- I look forward to hearing from you.

Take care as you all ease into the year.

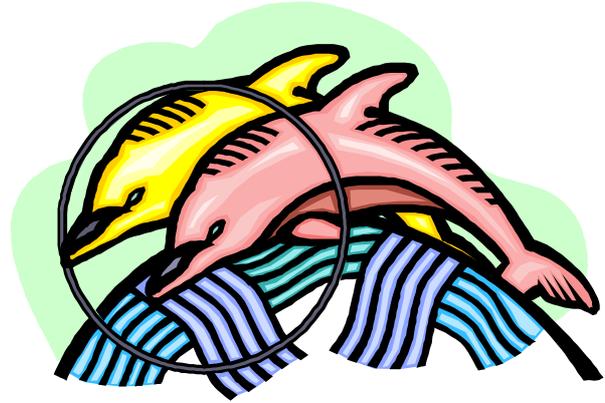
*Kim Caffell
(mother of Bradley 10 years, Jaimee- Kate 11 1/2 years)*



Above. The reel that is making Bradley's fishing expeditions more enjoyable.
Left. The fisherman himself.

Napier Seminar and Family Weekend

In November last year, 17 fragile X families converged on Kennedy Park for a weekend of information, recreation and conversation. Once again, Louise Gane generously combined her annual New Zealand holiday with a fragile X seminar for families and local professionals, followed by a weekend of informal counselling. The link that Louise provides New Zealand families with the international leaders in research and treatment at the MIND Institute, University of California at Davis, is invaluable.



For the kids though (and parents too at times), the jumping pillow was the truly invaluable thing at Kennedy Park. It's hard to think of better way of chilling out fragile X children and getting them to interact than a giant bouncy pillow - except perhaps Hi5 videos. The other weekend's activities were well also well-received. As the accompanying photos illustrate (see next page), the visit to the aquarium was the highlight for many.

The weekend was funded in part by grants from the McKenzie Trust and Pelorus Trust, and was made that much more memorable by the help and consideration given by the staff at Kennedy Park, the National Aquarium, Ocean Spa aquatic centre, and by our Napier contact person Biff Waddel and her able team of child minders.

We are now looking for a venue for this year's gathering - and are open to suggestions so long as they include a jumping pillow!



On Friday morning I went to Napier. On Saturday I went to the Aquarium. At the Aquarium I touched an orange starfish and saw a crocodile. After the Aquarium my family had a picnic lunch at the park. Then we went to Ocean Spa and the water was warm. When we got back we had a barbecue dinner.

By Danielle Spier
9 years old



Families enjoying the amenities provided at Kennedy Park, Napier.....



... and the aquarium visit was a big hit!



Hi everyone

Well things in our house have been in turmoil. On the 18th of August Kelvin was in a van accident - it was his school bus that he goes and comes home on, but not on Friday. The driver drove off the road we live down and went down a bank, through a fence and side ways in to a tree. Hitting the front of the left side of the van where Kelvin was sitting and smashed the whole side around him. He was very lucky that the van didn't go into the river which was just behind where the van stopped. He was trapped for a while until the firemen cut him out. He had a 5-hour operation, he has broken his femur, tibia and his heel. The pad on his heel has come away and we are not sure if it will re-attach; have to see. He also had a blood transfusion as he lost a lot of blood and had to have two more pints two days later. He also had a cut on his left eye which has stitches. Well as I said, it was one a hell of a week but at least he is alive which we thank our lucky stars for. As if Kelvin needed this with his fragile x it wasn't a good thing to have a boy with FX in hospital and trying to make him understand what is happening, but we got through and we are home and on the road to recovery for Kelvin and us, which is going to take a very long time.

Kelvin has to wear a moon boot which keeps his leg in place. He also has a pressure sore on side of his ankle and on the back of his heel which isn't healing - the nurse is coming out every second day to dress it.

Well that was 6 months ago and things are a lot better, the leg and heel have healed well and the scars are healing slowly but look good Kelvin is returning to school for the first term and will leave school in April. He is to start at Gracelands which is a service provider where he will start a day program and start work. He is so looking forward to this so this year is going to be a good one (I hope). All the best to you all out there for the next year

Cheers Jenny, Steven, Kelvin and Dean



X Stories

The Personal Side of fragile X syndrome
(2006)

Charles Luckmann and Paul Piper have compiled a heart-warming and eloquent collection of essays in which "people who have been touched by fragile X tell in their own word how it has transformed their lives. There are stories about family before and right after diagnosis and stories that span generations, as fragile X carriers and fully affected individuals move into adolescence, adulthood and old age. These essays by parents, grandparents, siblings, caregivers and professionals X will strike a chord with anyone who lives or work with people affected by fragile X."

As Katie Clapp (executive director of FRAXA) says "*with honesty, love, tears and sometimes humour, the writers bring alive their experience of caring for a child, sibling or patient with a serious disability... I found the essays riveting and ultimately uplifting.*"

The Wellington Fragile X Support Group has purchased two copies of this book and has donated them to the Fragile X Trust library. You can borrow them by contacting the Trust Librarian, Tracey Cockroft, Ph. 09-4128035, email: doodlibug@xtra.co.nz



Need to contact us?

Web: www.fragilex.org.nz

E-mail: fragilex.info@nzord.org.nz

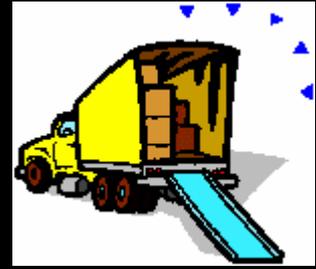
Snail mail:

Chairperson - Anita Nichols
58 Oxford Tce,
Epuni 5011,
Lower Hutt.

Secretary - Judith Spier
196 Taita Road,
Avalon,
Lower Hutt.

National Coordinator -
Chris Hollis
58 Oxford Tce,
Epuni 5011,
Lower Hutt.

Change of Address.



If you're moving house, changing your phone number or e-mail address, or simply wish to be removed from the Mailing List, please contact the Secretary ☺

The Fragile X Trust (N.Z.) acknowledges the generous financial support of the following organisations:



JR MCKENZIE TRUST
ESTABLISHED IN 1940



**THE
TODD
FOUNDATION**