



Fragile X Trust (N.Z.)

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

Newsletter

AUGUST 2005

Fragile X Trust (N.Z.) Now On The World Wide Web.

The 14th of July marked a very special milestone for the Fragile X Trust (N.Z.), with the commissioning of the Trust website. After 4 ½ months of development work, the finished product was launched without a lot of fanfare and now sits quietly in the cyber-world, ready to assist those who want to know more about Fragile X Syndrome in New Zealand.

The Trust was approached back in mid February by John Forman, Executive Director of NZORD (New Zealand Organisation for Rare Disorders) and made an offer too good to refuse. At that time, information on Fragile X and the Trust could be found on a single webpage under the NZORD banner of Support Groups. Whilst that was a good start, the Trust had always harboured the desire to provide a more comprehensive picture of Fragile X in NZ, along with up-to-date contact details and support information for families to access across the country. To this end, our own website was always going to be an option that the Trust would pursue. Let's face it - these days, any organisation or group endeavouring to get information out to the masses does so through a website or similar web-based initiative.

John offered us the chance to be the first NZORD-associated organisation to develop & launch a website, at a very attractive price, and using the collective brains & technical expertise of the team that launched NZORD's own product. As I said, an offer too good to refuse!

Content for the website has been largely based on that which featured in the NZORD webpage, and segregated out under specific subject headings. The idea was to produce a website with a NZ flavour to it (you'll note the toi-toi in the top corner) and where possible, not to duplicate information already existing in cyberspace - careful use of links to other websites has successfully achieved that for us.

In assisting the Trust to reach this milestone, we'd like to acknowledge the significant part played by Chris Hollis, Wellington Regional Support Group Coordinator. Chris was responsible for authoring & supplying a large percentage of the content, and he did so in a way that ensured the editing process was quick & easy. We'd also like to thank John Forman for the opportunity & his assistance in creating the website; the vehicle that will better transport the Fragile X Trust (N.Z.) on its mission to raise the profile of Fragile X Syndrome in New Zealand.

Please encourage the people you know to visit the site at www.fragilex.org.nz and help us to increase awareness.

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The Fragile X Trust (N.Z.) Homepage.



A Word from the Chairman.

Hi to all Fragile X families across New Zealand. I hope you are all well and enjoying the early start to Spring with some nice warm days (it has certainly been nice weather in Palmerston North lately!).

Recently the Board of Trustees had an AGM in Auckland on the 6th of August and I would like to highlight the main points from my summary of events during 2004 and 2005 as follows:

- Following a general strategy meeting held in Wellington in April 2004, a new Trust Deed was later formed.
- This new Trust deed was ratified on the 19th June 2004 by the Board of Trustees with the number of trustees increased to 6 members including: Darryl Cockroft, Chris Heenan, Jenny Adair, Heather Copestake, Lynda Satherley, and Vicki Williams.
- The main thrust of the new deed is simply to re-focus on raising awareness of Fragile X Syndrome and to assist families affected by the condition.
- In June 2004 Regional Support Group Coordinators were appointed to allow for localised support groups to be formed and a healthy interaction between those groups and the Trust has been encouraged.
- On his own initiative, Chris Hollis, the Wellington Regional Coordinator, organised a seminar titled "Testing for Fragile X Syndrome: who, when, and why" and included Louise Gane as the keynote speaker. This seminar was a great success and the Trust congratulates both Chris and his wife Anita for organising this event.
- New Fragile X Trust (NZ) information packs have been designed and produced. These packs have been distributed to Genetics NZ and a copy of the new information booklet is enclosed with this newsletter for your own use. The packs have been designed for both affected families and other interested parties. They are specifically designed to give a broad overview in easy to read "layman's terms".
- A new Fragile X Trust (NZ) Website has now been established. This is the most exciting initiative of the Trust and we would like to sincerely thank John Forman for providing us with this opportunity. Please do visit the new website for a look.
- The trust has also been successful in producing a funding surplus of over \$5,000 in the past year and this has enabled the Trust to focus on the main achievements listed above in covering the costs of producing the information packs and the costs of setting up the new website. Between myself and Darryl Cockroft, we jointly raised over \$1,000 ourselves in sponsorship in completing the 100km charity bike race from Rotorua and Taupo in April (and we survived!). Many thanks to those people who sponsored us. In addition, the Trust has endeavoured to produce the "re-vamped" newsletter on a regular basis in order to keep you informed of happenings across the country.

I would also like to make special mention of two trustees who have recently finished their time with the Trust. Many thanks to both Heather Copestake (Treasurer and trustee), and Lynda Satherley for your great contributions to the Trust.

In addition, Vicki Williams stepped aside as a Regional Coordinator for the Auckland/Northland region and we thank her for her enthusiastic contribution in that region. Vicki continues on with us as a trustee. We would be interested to hear from anyone in Auckland who might like to become active as the new Regional Coordinator. Please do feel free to make contact if you are interested in this role.

You can see from my comments that we have been pretty busy and I would like to thank Darryl, Heather, Jenny, Vicki and Lynda for your contributions over the 2004/2005 year. As busy parents of Fragile X children I think that it's great to see a passionate group of people freely give their time for such a worthy cause.

The strength of course in the Trust is not only due to the trustees, but due to your support across New Zealand also. If we can stick together as a group of people who have genuine concern for our cause, then we can all help to make progress in continuing to raise awareness of Fragile X.

Best wishes to you all.

Chris Heenan

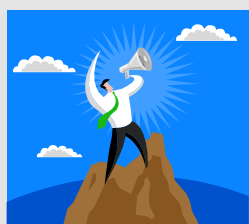
Upcoming Events



+ **ASSID (Australasian Society for the Study of Intellectual Disability) - "Out of the ordinary? Creativity, co-operation, collaboration"**.

Dates: 10 - 13 October 2005, Auckland.

More information: <http://www.assid-conf05.org.nz> .



1995-2005

Celebrating 10 Years of FXS support in New Zealand.

A weekend for families & friends associated with the Fragile X Trust (N.Z.)
29 & 30 October
Rotorua.

*More details to be advised in the next few weeks.
Contact the Secretary to register your interest.*

Wellington Fragile X Support Group

NEWSFLASH!!!

Workshop on education strategies and social skills development for children with Fragile X

Keynote speakers:

Louise Gane and Alison Schroeder

Friday November 4, Lower Hutt.

Venue to be advised

Contact Chris Hollis for details:

04 938 0552 or fxwell@paradise.net.nz

+ **"Rising to the Challenge" A symposium to advance state of the art practices in supporting families and young people where behaviour presents as challenging, provided by Standards Plus, Tautoko Services (with CCS, Southern Behaviour Support, IDEA Services).**

Dates: 9 - 10 November 2005, Brentwood Hotel, Wellington.

More information: <http://www.imaginebetter.co.nz> .

+ **DisAbility in Education Conference - 'This is the Moment'**.

Dates: 5 - 6 December 2005, Auckland.

More information: <http://www.disability.auckland.ac.nz> .

DISCLAIMER

The items in this Newsletter contain views & ideas of individuals, and are not necessarily representative of, or endorsed by, the Fragile X Trust (N.Z.)

FX CENTRAL NEWS.

An update of the activities of the Wellington Fragile X Support Group and central districts support network

Since the workshop last November it's been a fairly quiet, heads-down start to the year – hard to believe it is June already. We've only had one formal get-together in 2005, an outing to Lollipops Playland in Lower Hutt (see Judith Spier's article over the page) that my son James and I had to miss because he had a vomiting bug. Oddly enough I'm writing this now because I'm home with my other son Ben, missing a family gathering, because he's got the latest strain of vomiting bug.

In other news, special education came in for a bit of attention in April with a great article by Nikki Mandow in the Listener (April 2) on the plight of "moderate needs" children who miss out on ORRS. A string of excellent letters followed, including a grumpy one from us in which we used the case of our two children – both with similar needs but only one is ORRS funded – to point out the obvious economic benefits to the country of investing "early and generously in special needs intervention at all levels" not solely at the high to very high end. A trickle of euphoria following the Benson-Pope announcement of more special needs funding shortly afterwards, was short-lived when I realised very little was going to the biggest gap in the system – one on one teacher aide support. In the same the Listener issue as the Mandow article there was also a timely article by Veronika Meduna on PGD (pre-implantation genetic diagnosis), which included some comments from us, and in particular a comment from Anita on the hope that PGD offers to some "families with fragile X whose biggest sorrow is that they don't [want to risk having] more children". If you'd like copies of these articles or letters, please contact me.

There have been two important developments with the Wellington support group. First, we've formed a trust so that we can access local funding for a variety of workshops and programmes that we're hoping to run. The first of which will be a social skills programme for the 6-7 local fragile x children, which is running in term 3. The trustees are Senorita Laukau, Anita Nicholls, Mark Sorenson, Judith Spier and me.

Second, we've prepared a position statement on testing for fragile X syndrome. We're hoping this will be endorsed by the Fragile X Trust, and then we'll take it to Genetic Services in the hope that they will build the recommendations into their professional practice guidelines. The main aim of the position statement is to improve current practice relating to the testing of siblings of children diagnosed with fragile X. Specifically, we argue that parents' unique and intimate understanding of their children puts them in the best position to decide if and when their children should be tested. Currently, Genetic Services are very reluctant to test unless there is clear evidence of developmental delay or intellectual impairment. We've consulted widely in putting the statement together and have strong endorsement from Randi Hagerman, Louise Gane, Jonathan Cohen and John Forman (NZORD). If you are interested in this issue and would like to express a view, relate your personal experience, or look over the position statement, please contact me and I'll send you a copy of the positions statement. I'm really keen to have your input.

Chris Hollis

Secretary/Treasurer, Wellington Fragile X Support Group

Regional co-ordinator, central districts support network

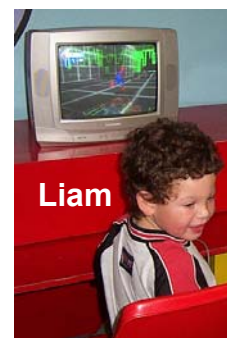
Address: 158 Oxford Tce, Epuni, Lower Hutt Email: fxwell@paradise.net.nz

Phone: 04-938-0552

WELLINGTON SUPPORT GROUP @ LOLLIPOPS PLAYLAND



Blake



Liam



Danielle

On Sunday 10 April 2005 several Wellington Fragile X Support Group families had a get-together at Lollipops Playland in Lower Hutt. The original venue was to be Harcourt Park with a picnic and games, but the inclement weather forced a change of venue. Attending were: Jayne and Mark Sorenson with their son Grayson (6); Judith and Phil Spier with their daughter Danielle (7) and son Liam (5); Nick Cuthbertson and her son Blake (5); and Anita Nicholls with her son Ben (11). It was incredibly sad/bad timing that organiser Chris Hollis and his son James could not attend as James, the night before, came down with a vomiting bug. We missed you James, but there will be a next time! It was especially wonderful to catch up again with Nick and Blake who had travelled all the way down from Levin.



Ben



Grayson

Lollipops was a very popular venue for our gorgeous FX children. The flying fox and the spinning cups were the definite favourite activities – movement, movement, movement! I was especially proud to see my 7 year old daughter overcoming her fear of the flying fox (having her feet off of the ground), and having her first ever rides! Way to go! It was so awesome to see our children all getting on so well together and having lots of fun.



While our children played away happily, the parents (in between occasionally checking out our kids were okay) were able to sit around drinking coffee and just chatting. Conversations ranged from serious stuff like the ABA programme, teacher-aide hours and child anxiety, to our wonderful Hurricanes Super 12 rugby team. I even got mistaken twice as a Lollipops employee as I was wearing my Hurricanes shirt (the same yellow colour as the Lollipops shirts!). What a laugh!

Judith Spier - *Proud FX Mum!*
(abridged)



Editor's comment. In the period between receiving this article and it being published, the group held a "mid-winter magical gathering". Another successful event by all accounts! ☺



Nick

Anita

Mark



Judith

Phil

Jayne

100K Rotorua-Taupo Charity Flyer - 6th April 2005.

As the Chairman mentioned, we successfully completed the Charity Flyer race without causing ourselves too much discomfort. The conditions were more akin to Auckland weather (four seasons in one day..), having started with brilliant sunshine, turning to chilly rain and a strong southerly wind as we travelled through the middle section of the course, and then finishing with brilliant sunshine in Taupo. Thankfully, there was no snow to contend with!

This has been a very popular event in past years, with a large turnout of riders (in excess of 3000 started the race) for the 2005 event. A large percentage of competitors are raising funds for their own organisations, or riding to support the event charity, which this year was the Cancer Society. The organizers were well pleased with the results, calculating that more than \$200,000.00 was raised for a long list of charitable groups.

Many thanks to Steve Lawson, Tony Thomas & Grant Robinson (our driver & "motivation coach") for making up Team FXS. Also, a big thank you again to all those who sponsored us on this ride. Your generous donations helped to boost the Trust coffers by more than \$1000.00.



Team FXS (L-R: Steve, Tony, Chris & Darryl) before the start of the race.

Darryl



NICHOLAS AND MATTHEW AT THE 2 DOLLAR SHOP.

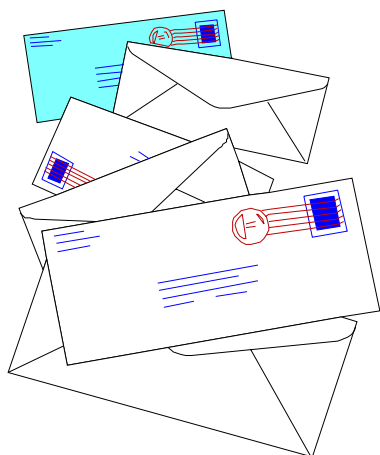
Matthew and Nicholas are in the same class at Allenvale School. They both have f/x, but they are so different in character. Nicholas's mum and I are the best of friends (we met through the Trust!).

It would be nice to meet a few more families in the Christchurch area.

Lois Smith (Matthew's Mum)
loiscarole@paradise.net.nz

*As you slide
down the
banister of
Life, may the
splinters
never point
the wrong
way.*

- An Irish Blessing



Hi everyone.

Just thought I would update you all what's been happening in regards with Craig's funding for his Vocational Work program.

As some of you are aware we have been having major problems getting Ministry of Health funding for Craig. After a lot of head banging against a lot of bricks walls trying to deal with the NASC agency here AccessAbility and the Ministry of Health here in Auckland and getting absolutely nowhere. We finally wrote to 25 MP's 's and we picked the biggest mouth MP's to see if we would resolve this problem. The letters we got back were interesting. Some passed the buck and some decided to help. This was a very interesting exercise we actually found out that Craig was still entitled to receive ORRS funding through the Ministry of Social

Development. We like many other parents thought that once your child leave school the ORRS funding stopped, but not so. If your child had received Very High Needs ORRS funding at school which Craig did because of his dual disabilities been blind and having Fragile X Syndrome also this funding was to had carried on. Craig is on a special list which the Ministry of Social Development are supposed to contact the school where your child goes and ask where is this person going after they leave school as this extra funding will help in providing extra needs which the person may require. As per usual no one had contacted anyone and Craig fell through the cracks. So Kevin & I took on the top brass of the Government, Ministry of Health here in Auckland and the NASC agency AccessAbility and won.

Now Craig receives Ministry of Health Funding plus the ORRS funding from the Ministry of Social Development so he can get the extra special help he deserves. This funding is for life and it can not be taken away.

The Government about 3 yrs ago put through a policy that kids who had very high needs ORRS funding at school and who are about to leave school are entitled to continue to receive the very high needs ORRS funding. So if any of your kids receive very high needs funding are about to leave school. Make enquires to see if your child is on the Ministry of Social Development list and also ask the school about this funding.

Make sure when your child / children before they leave school that they go to the best place there is in your area. You as parents do have the power to get the best that there is around for your child/children. Have a good look around and see what out there. Make also that the school your child/children go to help you find the best placement you think is the best and the placement suits your child/children needs. Your child/children have to happy and so to you!!!. Contact you local NSAC agency as well so they are suppose to help you as well. If you are not happy stand up and fight because our kids are special and they deserve the best.

There will become a time when you child/children to grow up and became young adults and they are not young children anymore as some of you most properly are aware of now, but a lot you all still do have young children and it is scary all of a sudden with out warning the become young adults and they are about to leave school. You wonder where have all the years gone and you are faced with different challenges and their needs start changing and go in a different direction. Kevin & I have learnt through this NEVER give up the fight even though you will bang your head against a lot of brick walls, but eventually the brick wall with start coming down.

Vicki & Kevin Williams



Kim Caffell (Dunedin) delivered the following presentation to a local Autism N.Z. meeting in late July.

The ORRS process- a parents perspective

My son Bradley has Fragile X syndrome- a genetic syndrome which has a number of characteristics, including intellectual disability. FXS falls within the ASD's. Currently Bradley, at the age of 8, has the intellectual ability of approximately a 3 ½ year old.

We were very fortunate to have a wonderful ESW and a supportive caseworker at kindergarten when we first embarked on this process. They were aware of the information that would need to be provided in presenting the initial application for ORRS. We utilized the IEP process, to discuss strategies, ensuring we had the right information when it came to the time to need to pull the application together.

We kept a diary of his behaviours, and every issue was documented (including the date, time, what else was happening at the time [to help identify potential triggers]). Many of these went into the ORRS applications to demonstrate what was meant under the individual headings.

Advice I have to give is to:

1. Ensure a detailed diary is kept at all times including
 - ⇒ Have an awareness of triggers for difficult behaviour, and document what happens to behaviour when the child is supported e.g. transition is extremely difficult for most special needs children unless well planned and supported
 - ⇒ Include issues relating to toileting, feeding, safety
 - ⇒ Take note of social relationships and support required in relation to these
 - ⇒ Take note of various curriculum difficulties- reading, maths, writing etc- and comment on the abilities of the child supported and unsupported

2. Don't go to a school just because it is the closest one to you- all children, whether special needs or not, will have individual needs in relation to schooling. I developed a list of questions (attached), and went around to 4 schools that I selected. I looked at schools either in my area, or on my way to work. I met with the principle, had a tour of the school, and asked the same questions of each principle. This gave me the opportunity to identify which school I liked the most.

3. Once you have selected a school, be actively involved in developing the transition for your child.

4. Go along to the school and talk to the teachers, students about your child's needs and how they can help. We went and spoke to our son's class, and were asked back to speak to the junior school, senior school and teachers. I have recently done this again, as his needs have changed over the past 3 years, as he has become comfortable in the environment. Target your talk to the audience you are speaking to, and be sure to tell others how they can help your child.

5. Be comfortable with your knowledge- you know your child best!

Food for thought**

No two children are the same. Do not anticipate that what has worked with one will work with another. Embrace being flexible as a teacher and receiving information from those who know the child well

6. It is a good idea to pull together information that you are willing to share about your child - I have a folder, which is usually out with someone else who works with Bradley in some way. It is my way of sharing information about my son's condition and is suitable for varying professionals.

Things you might want to consider in looking for a school for a child with autism:

- ◇ A positive accepting attitude is absolutely vital!
- ◇ A setting that is conducive to your child's needs e.g. limited opportunity for distraction (visual, auditory, tactual)
- ◇ Minimal opportunity for escape
- ◇ Adequate visual aides
- ◇ Available space for 1:1 teaching time
- ◇ Withdrawal area
- ◇ Shower or similar facilities if needed

Know what you want for your child:

One question we were asked, and still are on occasion, is 'Do you think your child should be in the school environment? Would they not be better in a school that can better cater for their needs?' For our son, one of his strongest points is to copy those around him. That is the **best** learning that can be offered to him. To be with other 'normal' children has been absolutely essential in this. Also essential in this, is the support through Teacher Aides, via the ORRS funding process.

Why inclusion?

- * To give your child the opportunity to learn social, behavioural and scholastic skills from appropriate models
- * To generalise skills learnt in the therapy setting to the real world
- * To teach your child to socialise and give them the opportunity to develop relationships.
- * To give your child the opportunity to learn routines, norms and community expectations
- * To extend academic ability
- * Long term- to teach the child adequate academic and social skills to facilitate integration into the community as an adult.

Understand the values of *inclusion* and be proud of what your child can offer others!

For you:

Comfort and reassurance of knowing that the child is accepted by the community and that the child is able to cope outside the home.

For other children:

Research has indicated that children, who are exposed at an early age to other children with special needs, are likely to be more empathetic and altruistic to such individuals in society later on.

For teachers and school staff:

The opportunity to learn new teaching skills and to modify and adapt current teaching programs, which will help them throughout their career.

For the community:

The advantage of having an adult whom is less dependent and can participate in community life!

Kim Caffell

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



JR MCKENZIE TRUST
ESTABLISHED IN 1940



Do you need to write to us ?

Chairman: Chris Heenan
578A Milson Line,
R.D. 8
PALMERSTON NORTH.

Secretary: Darryl Cockroft
6 Turi Avenue,
Whenuapai
AUCKLAND.

For general enquiries, e-mail us at:
fragilextrustnz@hotmail.com

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 ☺



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

Please send your articles to the Secretary (fragilextrustnz@hotmail.com) 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: 18th Nov 2005

www.fragilex.org.nz