

NEWSLETTER

FEBRUARY 2005

2005 Marks 10 Years of Fragile X Syndrome Support in New Zealand.

Original Support Group founded in Auckland 1995

Vicki Williams, Founder of the Fragile X Support Group N.Z. (1995) tells us how it began.....

Hello,

As it is the 10th anniversary of a Fragile X group starting up here in New Zealand in April this year, I thought I would write to the newsletter and give you some background information on how it all came about.

When we first got the diagnosis of having Fragile X in my family in 1982, I had always wondered if there were any other families here in New Zealand with the same condition. It took me 13 years later to actually do something about it. So in 1995 I decided to start some sort of group up or join a group if something had been already done here. So I contacted the various organisations and put my details out there. I had learned prior to starting up the group here in 1992 that there was a group in England called the Fragile X Society. So I wrote to them asking for information as there was very little information on Fragile X here. I joined the Fragile X Society and I am still a member today. So when the group started up here at least I had more than half a page of information. So I went mad and photocopied every bit of stuff I had just in case I was ever contacted by anyone.

Well the day came when I got my first ever phone call. I nearly fell over. At last there was another family out there. Who knew what I was talking about. The person was Cheryl Voller from Wellington. Not long after that more and more families made contact which was great.

When we actually found out that

there was a Genetic Service department at Auckland Hospital, I rang them to see if they would see us. So we made an appointment and Craig and myself had our DNA test done. No surprises there! I asked the Genetic Services to put together a booklet of some kind on Fragile X for me so I could pass it on to other families, which they did. Not long after that, the phone rang - it was the Lab Technician from Auckland Hospital, a lady named Karen Snow (who by the way is a very good friend of Louise Gane). Karen put both Louise and I in contact with each other. That's when I learned that Louise was coming out to New Zealand for a holiday. I thought "Wow" a specialist in Fragile X, our first ever workshop here in New Zealand. So after a few letters to Louise, I put together a workshop in Nov 1996 so other families could come along at hear this person. I was over the moon at the turn out. I finally was able to put names to faces of families I had spoken to and written to. In the mean time, Louise had put me in contact with Jonathan Cohen in Australia and I was also put in contact with the Fragile X Association in Sydney. Louise's talk at the workshop was just mind blowing, you could hear a pin drop in the room.

I remember putting out the groups first ever newsletter - one page. As time went on, the newsletter grew in size as I went mad with the photocopier and printed out every bit of new information around that I could get my little hands on.

As time went on the group became too much for me. My energy levels became low and I just couldn't find the extra time

needed to do all the work on my own. So I decided to stand aside and let other people continue to run the group. That's how Jenny Adair, Heather Copestake and Darryl Cockroft became involved. This was in 1999. In 2000, Jenny, Heather and Darryl formed the Fragile X Trust (NZ) known today. They were able to do a lot more than I could and put in the hard yards needed to carry on. Hence the two wonderful conferences here, first one in Hamilton and the second one in Wellington. It is no easy feat to arrange these conferences. A lot of time and effort went to each one. A lot of work was done behind the scenes for both conferences which others don't see and realise, or appreciated the huge amount of effort that goes in arranging these conferences we have had thus far. Congratulations to Jenny, Heather & Darryl. A job well done.

Now the Fragile X Trust (NZ) has changed again. There are now 6 Trustees, including myself. Fragile X Syndrome is now recognised as the leading hereditary cause of developmental and learning disabilities known today. Not this so called "rare disorder" we were told about all those years ago. Funny how things change with time.

I know this isn't everything but you all now have an idea of what went on in the early days and what's happened thus far. I am very proud of this group. Well done.

Vicki



Fragile X Trust (N.Z.)

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Chairman's Comment.

I hope you have all had a good start to 2005. Things have been pretty busy in my household after the Xmas break, settling the kids back into school, and of course settling myself back into work!

This newsletter contains some very interesting reading. 2005 is quite a milestone as it is the 10th anniversary of the Fragile X Support Group starting in NZ (now the Fragile X Trust, NZ).

It is interesting to note the changing awareness of disabilities in NZ over the past 10 years and no doubt this will continue in the future as we become a much more inclusive society.

I very much enjoyed reading the article by my niece, Stacey Caffell- A Sibling's Perspective. Despite the difficulties of living with Fragile X, "each FX child has their own humour and personality which makes them kind a cool". This rings so true and shows how important it is to spread the word and help improve the understanding of Fragile X.

A big objective of the Trust is to help raise the awareness of Fragile X Syndrome and ultimately this leads to greater acceptance and recognition within our society. To that end, you will notice the revised wording in the Trust logo which emphasises this as our primary focus.

Many thanks to Chris Hollis and Anita Nicholls in running a very successful workshop in Lower Hutt back in November last year. It was very pleasing to see a large and quite diverse group learning about Fragile X and the need for genetic testing. I always find Louise Gane to be such a wonderful source of knowledge and very uplifting with her personal approach. Thank you for your continued support Louise. Thanks also to the other speakers who participated.

The Trust has recently developed new information packs specifically designed for newly diagnosed families and these will soon be made available to Genetics NZ as well as our Regional Co-ordinators.

Another initiative the trust is currently working on is to develop our own website over the next few months ahead.

Darryl Cockroft and I will soon be participating in the Rotorua 100km Flyer - a cycle race from Rotorua to Taupo on the 2nd of April. It is a charity event and we have elected to raise funds for the Trust. Please feel free to pledge monetary support by emailing either Darryl or myself. (*see advertisement on the back of this newsletter*).

I trust this newsletter is well received and as always we welcome any feedback you might have.

Regards,

Chris Heenan
Chairman



Do you live in the Auckland area?

Would you like to get together for coffee & a chat?

Give Tracey a call on 416-3118

Report on Fragile X Workshop, Lower Hutt.

On November 19, 2004, the Wellington Fragile X Support Group ran a half day workshop entitled "**Testing for Fragile X: who, when and why**". The workshop was aimed at raising awareness among professionals and volunteers in the education, social service and health sectors. We had 122 participants, virtually all from the special education, education, specialist therapy and social services sectors. There was a truly impressive turnout from Group Special Education. Many local fragile x families attended, and it was terrific to have Vicki Williams travel down from Auckland and Chris Heenan from Palmerston North. It was also great to meet a new parent – Senorita Laukau - whose family lives just around the corner from us. We now have four fragile x families with school age children in Lower Hutt – forming the core of the support group.



The workshop included presentations by Louise Gane, genetic associate at the MIND Institute, University of California, Alice Christian, genetic associate at Central and Southern Genetic Services, Andrew Marshall, developmental paediatrician, at Puketiro Child Development Centre and Anita Nicholls who provided the parents' perspective. We distributed an evaluation form and had 50 responses. All aspects of the workshop scored highly on the questionnaire. Highest scores were given to: value of workshop, increased interest in fragile X, general information on fragile X, information on intervention, parent's perspective, and choice of topics. Louis gave two passionate and highly informative keynote presentations – one that covered the basics of fragile x and the other on cognitive issues and intervention strategies. Feedback from one (GSE?) participant summed up the latter: "Louise Gane's 2nd presentation on cognitive and learning was the most practically useful summary of successful interventions for the classroom I've ever seen and in my role as special education advisor I will be trying hard to spread the word and ensure that as many teachers as possible work towards greater understanding, acceptance and provide practical support for children with fragile x/autism."

Inevitably, we had too little time left for a decent panel discussion at the end of the workshop. However, thanks to Jayne Sorenson, the discussion did succeed in raising a key issue – the need for fragile x families to prepare a position statement on "who, when and why to test for fragile x" to present to Genetic Services. We received lots of positive feedback and clearly got the message out to a wide spectrum among the target professional groups, and we got lots of great suggestions for future workshops – so watch this space!

The workshop would not have been possible without the generous financial and logistic support of our sponsors:

- ◆ CLANZ (Community Learning Aotearoa New Zealand)
- ◆ Institute of Geological and Nuclear Sciences, Lower Hutt
- ◆ Next Stop Earth, Newtown
- ◆ ASB Bank, Lower Hutt
- ◆ Progressive Enterprises (Countdown & Foodtown, Lower Hutt)
- ◆ Warehouse Stationery, Petone

& the comprehensive advertising campaign of our supporters:

Fragile X Trust (NZ), Cloud 9 Children's Foundation, NZORD, Learning and Behaviour Charitable Trust, Porirua Healthlinks Trust, IHC and GSE.

A special thanks goes to Louise Gane who donated her valuable holiday time to make this event truly memorable for organisers and participants alike.

Chris Hollis, Wellington Fragile X Support Group

**Lesson Planning Guide for Students with
Fragile X Syndrome:
A Practical Approach to the Classroom**

The National Fragile X Foundation has created a great new educational resource and it's available free on their website or you can purchase the print version. The two hundred page planning guide not only describes fragile x children's specific learning needs but also provides ideas for preschool, primary and secondary curriculum adaptations. The guide's many authors (including Marcia Braden) discuss a wide range of topics such as literacy, communication, maths and science. This resource is a "how to" guide that will be invaluable for teachers and parents in planning and implementing curriculum at school and at home.

Find it at www.fragilex.org

(go to Education, Lesson-Planning Guide)



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 (peeandbee@actrix.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:
27th May 2005**

The following snippets were taken from the January 2005 issue of *PARTICIPATE*, a Newsletter from Hon Ruth Dyson, Minister for Disability Issues.

+ UN convention on rights of disabled people draws closer.

New Zealand is again represented at a two-week meeting that began in New York on 26 January in a bid to finalise a United Nations convention on the rights of disabled people. Draft articles in the convention include living independently and being included in the community; respect for privacy, the home and family; security; freedom of expression and opinion; and freedom from violence and abuse.

Our delegation includes representatives from the Office for Disability Issues, Ministry of Foreign Affairs and Trade and New Zealand Permanent Mission to the United Nations in New York, along with 'Like Minds Like Mine' national advisory group co-chairperson Chris Hansen and Robyn Hunt from the Human Rights Commission.

I endorse the partnership approach with the disability sector in these negotiations, and support continuing leadership from New Zealand on the international stage in developing the convention.

For more information on the convention, go to:

<http://www.odi.govt.nz/whats-happening/working-programmes/un-convention.html>

+ Tertiary education code launched.

Late last year, I launched a new code of practice to encourage tertiary education providers to develop inclusive environments for students with impairments. The code covers the different activities of a tertiary institution, including policy and planning; admission and enrolment; support services; funding; services for Maori; facilities and equipment; teaching and learning; assessment; staff development, complaints procedures; monitoring and evaluation. Each activity has a vision for creating an inclusive environment, best practice standards, and examples to help the readers' understanding.

The code has been endorsed by then Tertiary Education Commission Minister Steve Maharey and is supported by our government. I have encouraged all parties involved in tertiary education to value and use it.

More information is available at: <http://www.achieve.org.nz>

+ Disability Advisory Council to be set up.

The Office for Disability Issues is setting up a Disability Advisory Council, made up of disabled people and their families, to provide advice on issues facing disabled people and help monitor the implementation of the NZ Disability Strategy.

Information on the council's membership and operation will be released by the office early this year, and will be available at: <http://www.odi.govt.nz>

Snippets from the January 2005 issue of *PARTICIPATE* continued....

+ Extending employment support services.

The Ministry of Social Development continues to expand its support services for people with ill health or disability. Recent developments include:

- The Providing Access To Health Solutions (PATHS) initiative, which brings employment, training and health services together into one package, is now available in Wellington and will be extended to the Western Bay of Plenty.
- All case managers have been trained in Enhanced Case Management to improve their support to individual clients receiving a sickness or invalid's benefit to find out what their aims and aspirations are in terms of employment and community participation.
- Case manager to client ratios have been reducing in 14 areas, to enable more time to assist clients, rather than just focus on paying a benefit.
- Preparing for Work assessments are being trialled to help case managers identify people's skills and abilities, and work with them to find and stay in employment.
- Work has started on a service to employers about the barriers they face hiring and retaining people with ill health or disability.

More information, including a regular email newsletter, is available at:

<http://www.msd.govt.nz/work-areas/people-with-disabilities/sbib-strategy/index.html>

+ Survey on experience of discrimination.

'Respect Costs Nothing' reports the findings from a survey of 785 people with experience of mental illness. Carried out in 2003 by the Mental Health Foundation, the survey reveals that people who experience mental illness often also experience discrimination in all aspects of their lives, from employment and housing to discrimination from friends and family and the community, leaving them feeling socially excluded.

More information is available at: <http://www.mentalhealth.org.nz/page.php?113> .

HOW TO GET PARTICIPATE.

Participate is available in hard copy or by email (Word and text-only).

You can subscribe at:

<http://list.beehive.govt.nz/mailman/listinfo/dyson-participate> .

To receive or respond to the newsletter, please write to Office of Hon Ruth Dyson, Parliament Buildings, Wellington; or email:

sharyn.haigh@parliament.govt.nz.

Living with Fragile X: A sibling's perspective.

The following article was written by Stacey Caffell (13 years) as a school speech. Stacey is the daughter of Kim & Adrian Caffell of Dunedin.

Have you ever wondered what it is like to have a disabled brother or sister. Bet ya haven't! You may have said "Oh my God! Look at that guy- he looks so retarded!", but no one likes to be disabled- I know I wouldn't.

My brother and sister have Fragile X syndrome (FXS). I think they are annoying but what is it like for them? I'm going to tell you what FXS is and what impact it has on our family.

Firstly I will tell you what FXS is. FXS is one of the most common causes of autism. Even though it is one of the most common causes of autism, not many people know about it. Those affected by FXS are generally healthy, but have a few medical problems.

Some of the physical characteristics are:

- * Long face
- * Broad forehead
- * Large ears
- * Poor muscle tone (causes them to be clumsy and less coordinated than others of the same age)
- * High arched palate- causes sucking problems in babies
- * Extremely flexible joints- my brother can bend his fingers way back
- * Ear infections

People with FXS can behave differently from other people. Both males and females tend to have:

- * Delayed speech
- * Short attention span
- * Autistic like features e.g. hand flapping, stims (repetitive behaviours), poor eye contact, echolalia (saying the same word or phrase over and over), poor social skills, tantrums/emotional outbursts.



Bradley Caffell.
Hoping to land the "big one", Lake Te Anau, Christmas 2004.

Now I will tell you a little bit about my brother and sister. My brother is really floppy. You can't go to town with him because he gets bored after like 5 minutes, and then you won't be able to find him, or his rolling around on the ground, or wanting to go up and down the escalator. He never lets you watch TV cause he stands in the door way and tries to kill you with his star wars lightsaber - but you don't die, so he gets annoyed and hits you. Bradley has a teacher aide at school 15 hours a week. Even though he is 7 ½ he probably has most skills of a 3 year old.

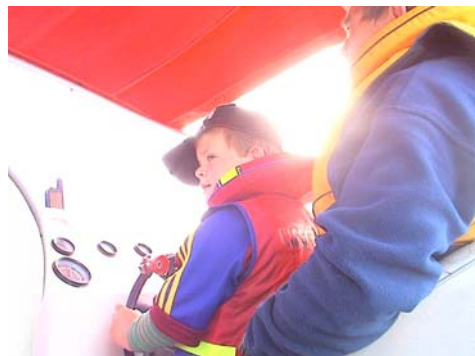
My sisters FXS isn't as bad as Bradley's, but seems so much worse. Say me and my friends are reading a magazine or watching a movie she'll come and start annoying me and laugh at stuff that isn't even funny. I tell her to shut up so she hits me- I hit her back and she goes crying to mum- and I get told off!!! She has to watch with us- it's so unfair!- Or so it seems- my sister doesn't make friends very easily and is very shy. She has trouble with school work and as she gets older she might need more support (from me as well) with social things. I tried to interview my sister, but all I got was tears (she understands she is a bit different).

In the past mainstream schools haven't let disabled kids in, so they had to work with other disabled people and never learnt "normal" behaviours. But since they are great copiers they learn better off normal people by copying them.

Each Fragile X child has their own humour and personality which makes them kind a cool.

Now that I am used to them I wouldn't want them any different. We don't really know what the future holds - we just take things one day at a time.

Stacey



Bradley Caffell.
Helping Dad to steer a safe course, Lake Te Anau, Christmas 2004.

National Contacts:

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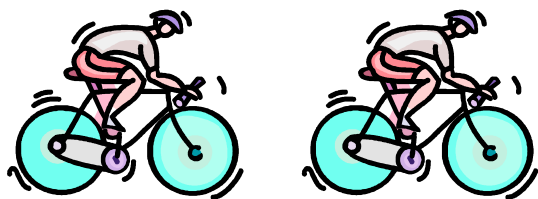
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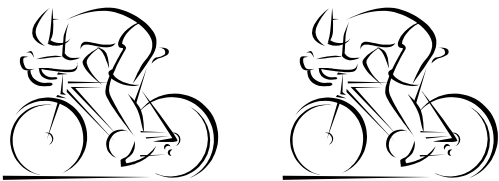
Fax: (03) 379-1343



On Saturday 2nd April, the Chairman & Secretary will be participating in the annual **Rotorua to Taupo 100K Charity Flyer**, to raise money for the development of the Fragile X Trust (N.Z.) website.

If you'd like to support our cause by sponsoring these riders, please contact the Secretary for further details.

Any and all support is gratefully received.



Do you need to write to us ?

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