

December 2005



**Fragile X Trust (N.Z.)**

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

# Newsletter



*Wishing the New Zealand Fragile X Community  
a very, Merry Christmas and safe, Happy New Year!*

*Warmest regards  
The Fragile X Trust (N.Z.) Trustees*

## 10-YEAR CELEBRATION OF FRAGILE X SUPPORT IN NEW ZEALAND

A small celebration to mark 10 years of Fragile X Syndrome support to families in New Zealand, took place in Rotorua on the weekend of 29/30 October 2005. 30 people, including children and young adults, gathered at the Holdens Bay Holiday Park to share a few stories and enjoy each others company. Those attending came from as far east as Gisborne, and as far south as Levin. The park provided an ideal location for such an event, with plenty of room for children to “express” themselves, and enjoy the playground activities or pool.

Guest of honour for a buffet dinner held on the Saturday evening was Louise Gane, M.S. — a Genetic Counselor with the M.I.N.D. Institute, USA, and a long-time associate of the Trust & friend to many Fragile X families in NZ. Louise spoke of the achievements that the group had made over the many years she had been traveling back and forth between NZ and the States, and encouraged people to continue to cherish the special “gift” that the Fragile X person has. She also described some of the developments that were occurring with Fragile X within the research field, and touched on her hopes for the future.

The gathering concluded on the Sunday morning, with people enjoying the opportunity to partake of coffee & cakes, and further those conversations started the previous evening.

We now look forward to the 15-year celebration (where-ever that may be) and the chance to mark another milestone for Fragile X support in New Zealand.



*You can't have a celebration without chocolate!*



*(L-R) Louise Gane, Chris Heenan (Chairman) & Vicki Williams, founder of the original Fragile X Support Group, cut the cake.*



*A quiet drink and a chat with friends, old & new.*

### Acknowledgement



*Special thanks go to Hannalie & Ernest Albertyn, owners of the Holdens Bay Holiday Park and our hosts for the weekend. They generously provided the dining facilities for both days free of charge, and assisted with arranging the catering through a local company.*

*For more information on the park, accommodation & facilities, call them on (07) 3459925 or visit them on-line at [www.holdensbay.co.nz](http://www.holdensbay.co.nz)*



Well what a year 2005 has been. It has your had it's up's and downs.

The fight we had with the NASC agency Assess ability and the Ministry of Health over Craig's funding and having to end up going to the Government for help sure took it's toll on both Kevin & I. How ever we did get the best outcome and won the fight. No parent should ever have to go through what Kevin & I did to get what Craig was fully entitled to and to stay with the service provider where he is happy, safe and which catered for all of Craig's needs. So to all of you parents never, ever give the fight for your child/children. 9 times out of 10 you will get the result you are looking for. Don't worry about the 100 or so brick walls you might hit. The brick wall does come down eventually.

In May of this year we all went to Perth for a special occasion. It was our 25th wedding anniversary. Can't believe where the 25 years have gone. Craig had a wonderful time and sure got spoiled. We went to a Wife life park in Perth where Craig as able to feed and touch the animals which he really enjoyed doing. We saw a huge snake for the first time, put it this way glad we haven't got them here. Of course we went to quite a few pubs and restaurants along the way and shopped until we dropped as one does on holiday.

Then there was the 10<sup>th</sup> Anniversary in Rotorua to celebrate a Fragile X Group starting up here in New Zealand. It was good to see some new faces and catch up with the old ones. The night went well and both Kevin & I had a good time. Now that I have actually officially retired after 10 years of service's to Fragile X in New Zealand. It is time for other families to put up their hand and get involved with the trust and to help others and make a difference.

Kevin, Craig and myself wish you all a very merry Christmas and all the best for 2006.

Vicki.



Hi everyone, hope you all are well. Thought I would send in an item for the newsletter. In September our family trip to Fiji with Kelvin for a week. We stayed out on an island name Plantation Island one of the many there are around Fiji.

We left from Auckland airport and flew to Fiji with not too much drama, but on arriving in Fiji after leaving the plane to go though customs the things didn't go to plan as far as Kelvin was concerned. He had had enough of being on a plane for 2 hours and had done him in. All he wanted to do was leave the airport, go to the hotel and have a swim. On arriving at customs it was time for a melt down. He hates waiting in lines: its all to much. So here is this 18 years old throwing his shoes one way and the passport other, sitting on the floor saying he has had enough and I am going to walk out of here now and being told he couldn't do that as the people at customs won't let you do that. He was not happy and "I don't care and too bad" in a loud voice. Lucky for us airport staff allowed us to go though the gate for the Fiji residents. Managed to escape without too much more trouble.



*The Indy car circuit is next. Lookout Scott Dixon!*

We were taken to our hotel where we stayed for the night. Next day we were taken out on a catamaran to the island and spent the week swimming, boating, snorkelling and kayaking. Kelvin did all the water sports. We hired a golf cart for a few days and Kelvin drove around in it and loved it (we had to have someone with him when driving as "we" don't look where we are going. We all had a lovely time and returned home a week later. Back at the airport, we were taken straight through and didn't have to wait too long in Fiji. Arriving back in Auckland, we had a small melt down when the bags on the conveyer didn't come out as fast as he would have liked and we had a few funny looks but we coped. Had to wait in a small line to go out, but it didn't take too long. Once out, it was "lets go home now" and "are we home yet?" was what we got all the way home! Kelvin was very happy to be home and in his own bed (as he talks to him self we could hear him going over what had happened that day). Can't help but laugh: the joys of a Fragile X teenager.

Best wishes for the New Year  
Cheers Jenny & Steve Adair

# Wellington Fragile X Support Group

## Mid-Winter Magical Gathering

On the 7<sup>th</sup> of August the Wellington Fragile X Support Group organised a mid-winter get-together at the Sorenson's house. Attending were: Mark and Jayne



Sorenson with son Grayson (6); Judith and Phil Spier with their daughter Danielle (7) and son Liam (5), Anita and Chris Hollis with their sons Ben (11) and James (8), Senorita Laukau with son 'Ofa (13) and Nick Cuthbertson with son Blake (5) who travelled all the way from Levin to be with us.

It's always good to catch up and have those conversations that you can only have with other parents like yourself. The children had a great time playing together too; Grayson very kindly shared his toys with everyone. Grayson's four wheeler motor bike was a big hit and was ridden until its

battery went flat and I think it was Grayson's idea to play a Hi 5 DVD, which all the kids enjoyed. Our kids always seem to get on so well, perhaps because they have such similar interests and understand each others reactions.



After a great afternoon tea (organised by Jayne) it was time to be entertained by Magician Nigel Kennedy. Nigel's first question to the kids "who likes surprises" was answered unanimously by the kids

"not me!" probably not the response he was expecting. Despite the kids dislike of surprises all of our children were able to enjoy the show in the relaxed and safe atmosphere of the Sorenson's comfortable lounge. Grayson, Danielle, Liam and James were brave enough to take a turn at being the

Magician's helper. All the kids were given a magic trick to take home and a very cool balloon animal.



*Anita Nicholls*



## Social Skills Group

In August and September I ran a social skills group for six of our local fragile x children aged between 5 and 13 years old. I organised the sessions because parents within the Wellington Fragile X Support Group (myself included) felt that our children have limited access to social skills training.



The social skills group ran over seven weeks. I ran the first four and my focus was on having fun together with lots of practise of the interaction skills our kids need to learn, such as turn taking, greeting, listening, leading play, and asking and answering questions.

I was helped in my task by Diane Ward, who has been teacher aid to both my children so she has plenty of experience with fragile X children. The last three sessions were run by an educator from family planning who covered topics such as body

awareness and the difference between public and private places.

This was very much a trial run to see what was possible with lots of good will and very limited funds. The kids enjoyed the sessions and got to know each other better in a fragile X-friendly environment. There were some memorable moments, such as when Grayson 'read' a book (he made up his own story based on the book's pictures, clever boy) to the other kids who all sat and listened, enjoying Grayson's story. Liam who is not yet talking surprised us all by answering a question appropriately with a very definite "yes". I think one of the best things to come out of the sessions was that by meeting once a week we all got to know each other better, kids and parents.



*Anita Nicholls*

## Fragile X Workshop – Fragile: Handle with Care



On November 4, the support group held its second half-day workshop. The first one about the same time last year served as a general introduction to fragile X and attracted 120 participants that included an impressive range of special education professionals, teachers and volunteers. This one focused on early intervention, education strategies and social skills training. Ironically, this was a theme proposed by Anita who belatedly discovered she had a university exam on the day and couldn't attend the workshop! Nevertheless the workshop was another great success – thanks to terrific presentations from our two speakers

Louise Gane and Alison Schroeder. Louise gave us an update on carrier issues, especially in relation to FXTAS, before launching into a typically passionate exposition on effective education strategies for fragile X children. Alison, a Christchurch-based speech language therapist and author of "socially speaking" and "time to talk", two effective social skills and language development programmes, was a ideal choice for the stuffy room in the late afternoon – mixing dry humour and plenty of audience participation into a superb presentation of social skills strategies.

Feedback from the 80 participants was pleasingly positive. The support group can be satisfied that it has effectively raised awareness about fragile X in the greater Wellington region – especially among GSE staff – and provided some valuable information to the teams working with fragile X children in the region. The 80 participants included representatives from all of the nine school-based teams working with known fragile X kids in our region and in some cases almost the entire team turned up – teachers, teacher aides, RTLBs and GSE specialists. It was also heartening to meet three new terrific families – with the Shelley family and Louise joining us for a very relaxed and enjoyable post-workshop barbeque at the Sorenson's.

With two great workshops behind us we have grand plans for next year!

*Chris Hollis*

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



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*Do you need to write to us?*

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*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](mailto: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: 31st Mar 2006**

**[www.fragilex.org.nz](http://www.fragilex.org.nz)**