



FRAGILE X TRUST (NZ)

Supporting New Zealand families living with fragile X syndrome

FRAGILE X TRUST (NZ) NEWSLETTER

September 2011

Inside this issue:

Chairperson's Report	2
National Coordinator's Report	3
An Update from the Trust	6
Profile: Dr Andrew Marshall	7
Workshops: Fragile X and Sensory Regulation	8-10
North Island Family Gathering	11
Sensory Integration and Fragile X	12-13
Family News	14-15

Charity Golf Day

We raised \$15,000!



Thanks to Mark and Jayne Sorenson who organised the event and to the many generous supporters who participated in the tournament, donated goods, or bid in the post-match auction.

The funds raised will be used to increase the services offered as part of our new initiative: Specialist Clinical Forums for Fragile X Families.

More photos on pages 4-5 or visit us on FaceBook



Special points of interest:

Golf Day photos

Auckland Workshops

FX Clinical Forums

Cognitive Behaviour Therapy

Cheers from the Chair

What a successful few months for the Fragile X Trust! In our April Newsletter I optimistically hoped for \$10,000 from our inaugural charity golf tournament and what do you know - we raised \$15,000! We have to acknowledge the huge effort that Mark Sorenson put into this event - from securing the Shandon Golf Course, to lining up the participating teams, securing a vast amount of sponsorship and then coordinating all of the logistics on the day.



In helping to make our inaugural golf tournament such a huge success, the Fragile X Trust acknowledges the support of the following individuals and companies:

Jayne Sorenson, Janet Morgan, Jaimee Sorenson, Dave and Maureen Sorenson, Jodie Richards, Rowan Swain, Ian Klinac, Paul Kennedy, Bud Baldwin, Bill Cathie, Regan Wood, Danny Redhill, Peter Harstonge and the team at Shandon Golf Course, A1 Embroidery, Apex Print, Barlows Freight, Bayleys Commercial, Blue Star Logistics, Climatech, Construction Contracts, Datam, Dawell Furniture, DB Breweries, Faulke Property, Four Kings, GEON, GMB Watches, GNS Science, Green Gables Motel, Harcourts - Mana, Howard Transport, Lifestyle Health & Fitness - Lower Hutt, McDonald's - Newtown, Matt Hill Construction, New World - Hutt City, New World - Paremata, New World - Stokes Valley, New World - Waikanae, NZ Rugby Union, Pelorus Trust, Phil Wheelan's Commercials, Printlink, Rebel Sports - Lower Hutt, Retko Logistics, Ricoh, Sandbar, Service Printers, Shoe Clinic, Signature Promotions, Stevens Motors, STUCK, TAB, The Hire Company, The Lanes Bowling Lounge, Total Container Services, Wellington Business Forms, Wellington Phoenix Football Club, Wellington Scaffolding,

... and of course the early morning golfing team of Liam and Danielle Spier (and Judith and Phill!), Grayson Sorenson and Ben Hollis (on logistics).

In other news, we have received grants totalling almost \$22,000 from the Lotteries Grants Board, the Southern Trust and the Canterbury Community Trust, which we will put to good use by retaining the services of our now completely indispensable National Coordinator, to pay for our general administration costs and to fund the next South Island Family Gathering. *Chris Hollis*

National Coordinator's Report

Spring has just arrived and there are a number of fragile X related events to look forward to in the coming months. The next Specialist Clinic is planned for the 7th of November and again we have a full list of families wanting to take part. Before that we have Louise Gane coming from the US and a workshop planned with her and Sensory Integration specialist Kate Skinner. Over the same weekend in September, together with Louise, we will also have a Carrier Women's Workshop and a Family Get Together. The North and South Island annual Family Gatherings have been planned for November. I have been busy securing more funding for these activities and putting information and statistics together for our funders.

It seems our membership has grown by 40% in the last two years. It is encouraging to feel that there is more awareness about fragile X among professionals and more testing happening. Great news when we know great results can be achieved by specialist targeted help for our children affected by fragile X.

It's exciting also to see children having success with ORS funding applications and seeing the benefits that this brings to their school lives. Good luck to Joel, Connor, Mathew and Alex who are all starting school. Of course we all know the real gems of knowledge we receive often come from other parents of children with fragile X. That's why we continue to link families together in the same town or across the country and work to strengthen our community.

It was a highlight for me to be part of the hugely successful Charity Golf Day. Mark, Jayne, Chris and the team put a lot of time and energy into this event and what a result. We are now working to broaden our team of experts to contribute to the Specialist FX Clinic.

I look forward to see many of you over the coming months at workshops and gatherings!

Andrea Lee



Do you know we are on Facebook?

Visit Facebook and type in Fragile X Trust NZ

Charity Golf Day – publicity, event, aftermatch!



TV ONE setting up for our slot on 'Breakfast' TV



\$5 dollars a hand of poker at Hole # 9



Lucas De Jong from TV ONE with Liam, Grayson and Danielle



Rugby legend Alan Hewson receives a prize from Mark Sorenson



Chris Hollis – expert collector of golf balls from Wellington Harbour



Auctioneer Ian Klinac 'in action'



An amazing turn out and very generous support!

‘Ben’s story about the Charity Golf Day



“I had to get up early. Dad's fault! It went berserk. I ate six sausages.

Have you watched the TV interview? I'm off to watch it on my iPad.”

Ben Hollis

*Ben helps dad, Chris, with the BBQ and is obviously in charge of quality control!
Ben was part of the team that made the Charity Golf Day a success. He was a real help with many tasks and kept good track of the bottle opener for the players' beers. ☺*

An Update from the Trust...

Activities and events since our last newsletter in April.

Specialist Fragile X Clinic:

A report was written incorporating feedback gathered from the first clinic in March and suggesting improvements for next time.

The next clinic is in the planning stages with a good number of families taking up the opportunity to participate. The date for this clinic is 7th November.

The Trust has applied to join the newly formed International Fragile X Clinical Consortium.

Fundraising:

The Charity Golf Day in May raised \$15,000.

We have had grants totalling \$21,800 from the Canterbury Community Trust, NZ Lottery Grants Board and the Southern Trust.

Awareness Raising:

We are working with Tariana Turia, Minister for Disability Issues, on a letter to be sent to all GPs throughout the country in a bid to increase awareness about fragile X and encourage testing.

The Charity Golf Day was very successful in raising awareness about Fragile X through coverage on TV One Breakfast and in Wellington papers.

Mailing List Renewals:

We have updated our website with the capacity to renew your subscription online. Please renew your subscription for the 2011-2012 period if you haven't already.

Community Collaboration:

The Trust made a submission for the draft service specification for Clinical Genetic Services.

IHC has asked the Fragile X Trust to support their Start Strong project.

Family Gatherings:

There have been a number of family get togethers. Families met in Christchurch in April and Wellington in May. A group of Auckland families are meeting regularly for coffee mornings.

Our annual Family Gatherings are planned for Taupo and Hamner Springs. See details in this newsletter.

e-News:

These have been going out to families and our extended networks on a monthly basis. The goal is to keep everyone updated with what is happening on a regular basis.

Training:

Our National Coordinator, Andrea Lee, attended a recent Charities Commission Forum. She also attended a Media Workshop, and an Exult Funding Workshop.

Workshops:

We are organising workshops in Auckland in collaboration with Louise Gane and Occupational Therapist Kate Skinner. See details in this newsletter.



Thanks to everyone who has renewed your subscription to our mailing list!

If you haven't renewed your subscription for 2011-12,
we have just made it even easier for you!

Yes, we are really online now... having ironed out the glitches
You can now pay via internet banking ☺

Link: http://www.fragilex.org.nz/application_form

Or you can phone us on 0508 938 0552

Profile: Dr Andrew Marshall

Dr Andrew Marshall is a Developmental Paediatrician who works in a multidisciplinary child development team diagnosing developmental disabilities such as Autism, Intellectual Disability, physical disabilities and Fragile X Syndrome and provides ongoing follow-up of children with these difficulties. He has worked at the Puketiro Child Development team in Porirua since 2002. Dr Marshall has recently been appointed as Clinical Leader in Paediatrics at Wellington Hospital.



He trained at Otago University and then at Christchurch and Waikato Hospitals. He further specialised in Paediatrics at Starship, National Women's, Greenlane and Middlemore Hospitals in Auckland and Royal Children's Hospital Melbourne.

Dr Marshall has experience in the management of Fragile X and has presented at Fragile X workshops in New Zealand and attended the most recent International Fragile X Conference in Detroit. He also has an interest in Autism Spectrum Disorders and worked on the New Zealand Autism Guidelines, and is a member of the ASD Living Guideline group. Dr Marshall is a member of the International Fragile X Clinical Consortium and has worked with the Fragile X Trust to initiate a specialist clinical forum on Fragile X Syndrome, which is planned to be offered to Fragile X families and their paediatric team every six months.

***The next Fragile X Clinical Forum is
7 November 2011***

***Contact Andrea Lee 0508 938 0552 or
nationalcoordinator@fragilex.org.nz***

FX Workshop – 23 September 2011, Auckland

Fragile X Syndrome **Workshop**

Learn more about Fragile X with International FX expert Louise Gane and Sensory Regulation with Occupational Therapist Kate Skinner

Friday 23 September 2011

10am – 2pm

Park Lane Motor Inn, Takapuna, AUCKLAND

\$10 Families / \$50 Professionals

Guest speakers:

Louise Gane, M.S.

International expert in Fragile X Syndrome with over 25 years experience working with families affected by FX.

Louise works at the M.I.N.D. Institute in the USA with Randi Hagerman. She will speak about the affects of Fragile X.

Kate Skinner, BA (Psy) BOT (Hons) Occupational Therapist (MNZAOT; NZROT) SIPT Certified (USC/WPS)

Occupational Therapist internationally trained in Sensory Integration. Kate is part of the team at 'Sensational Kids'. She will speak about sensory regulation and Fragile X Syndrome.

Please email nationalcoordinator@fragilex.org.nz to register or Freephone 0508 938 0552 for more information.

Please bring your own lunch

Background information: Louise Gane & Kate Skinner



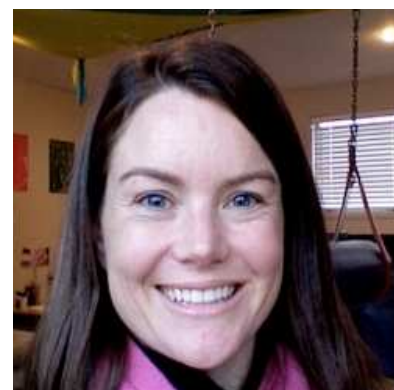
Louise W. Gane M.Sc. is a Genetic Counselor at the University of California Davis M.I.N.D. Institute Fragile X Research and Treatment Center under the Directorship of Randi J. Hagerman, M.D. Louise is nationally and internationally recognized for her work in the field of fragile X-associated disorders (FXD). She began working with patients who have fragile X syndrome (FXS) and their family members in 1984 and is currently actively involved with clinical and research work in FXD. Currently, her research work is focused on people diagnosed with FXTAS and their spouse/caregivers. Louise is also actively engaged in research pertaining to FXS and carriers of the premutation. She lectures regularly, presents at scientific conferences and family-friendly forums as well as having authored and being included on many scientific publications. Louise is a member of the National Fragile X Foundation (NFXF) Scientific and Advisory Board, the NFXF Clinical Research Consortium's Membership and

Infrastructure Committee and the International Membership Subcommittee. She is a past member of the NFXF Board and in 2004 received the Jarret Cole Clinical Services Award.

Louise also has a long history with the New Zealand Fragile X community and has helped and supported many families.

Kate Skinner's initial training was based in psychology and human development (B.A psych UNISA). She then completed a Bachelor of Occupational Therapy degree with Honours through the University of Natal, South Africa. Kate completed her sensory integration post-graduate training through SAISI in association with Western Psychological Services in 2008.

Kate worked at Livingstone Primary School for 4 years, a remedial school in South Africa, for children with learning differences such as dyslexia, dyspraxia, ADHD, Aspergers syndrome and sensory processing disorders. Since 2006 she has worked as a private paediatric therapist specialising in sensory processing. She is SIPT certified (Sensory Integration and Praxis Tests).



Kate has helped many children and parents to celebrate and accept who they are. In Kate's opinion, true therapy is creating an environment that facilitates calm-alert states in the nervous system so the brain can process the data it receives as well as giving the nervous system developmental information on which learning is built.. She considers the most amazing part of a human being is the way we are able to adapt and the neuroplasticity of the brain, whether that is a shift in thinking, neuron transmission, or helping the brain to process data in a new integrated way. By working within a sensory integration approach it targets the foundational difficulties, the sensory systems that interpret information and the regulation systems that help to focus and adjust appropriately to the environment. As each foundation becomes solid so the next layer is better established and the house of learning is built. For most children this happens naturally, however some children require further input when there is interference or some difficulty in the communication and interpretation of data in the central nervous system.

Sensory integration therapy is an important tool for O.T's and Kate is SIPT certified and qualified to provide occupational therapy with a sensory integration approach.

FX Workshop – 24 September 2011, Auckland



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Fragile X syndrome

Woman Carriers of the Fragile X Gene Workshop

***LOUISE GANE will join us for an informal workshop
for woman carriers of the Fragile X gene***

Saturday 24 September 2011

10am – 12pm

Park Lane Motor Inn, Takapuna, AUCKLAND

Afternoon activities:

Lunch at Aubergine Takapuna 12.30pm \$20 lunch special
(Two courses and glass of wine or coffee – www.aubergine.co.nz)

Followed by a choice of

- ☞ Adventure rope climbing at Tree Adventures – <http://treeadventures.co.nz>
- ☞ An afternoon spent café/bar hopping (an option requested by the less adventurous!)

**Please email nationalcoordinator@fragilex.org.nz to register
or Freephone 0508 938 0552 for more information.**

Family Gathering – 11–13 November 2011, Taupo

North Island Family Gathering Taupo 11–13 November 2011

*Enjoy fun activities for the whole family.
A chance to catch up with old friends and new, and share the
experience of raising children affected by fragile X syndrome.*

Taupo DeBretts Spa Resort

Napier Taupo Highway, Taupo Ph 07 378 8559
To book accommodation see <http://www.taupodebretts.co.nz>

We have accommodation units on hold and have organised a group discount so first in gets the first options!

(The Fragile X Trust hopes to be able to offer accommodation subsidies but won't know how much until numbers are confirmed.)

Activities:

Friday night: Shared pot luck dinner as people arrive.

Saturday morning: Enjoy the Thermal Hot Pool at DeBretts Spa Resort!

Saturday afternoon/evening: BBQ dinner and family get together for which we will use the pavilion area and kitchen at the park exclusively.

Please let us know if you'd like to attend this gathering by 16 September
Call: 0508 938 0552 or Email: info@fragilex.org.nz

Sensory Integration & Fragile X

Sensory integration has to do with how people take in and process information from all of their senses. Sensations are continuously flowing into our bodies. These include all of the inputs from our five senses, plus our awareness of our bodies in space. Sensory integration is vital to interpreting the information that confronts us at all times. This involves basic survival functions and the ability to learn from the environment. Sensory motor integration involves the connection of our sensory system with motor planning and movement.

'Sensory Integration sorts, orders and eventually puts all the sensory inputs together into whole brain function.' Ayres (1979)

Sensory disorders in people with fragile X often include several interrelated areas:

- hyper-arousal, or paying too much attention to stimuli that most people ignore (eg., the sound of fluorescent lights);
- hypo-arousal, or not responding to the most important messages that are confronting the person (e.g., the sound of the teacher's voice);
- sensory motor integration problems, including motor planning issues and fine motor weaknesses;
- tactile defensiveness, or hypersensitivity to touch.

Children and adults with fragile X syndrome may have difficulty in many new, confusing, or loud situations because of a combination of sensory integration problems, anxiety, and attention deficit disorders.

Fragile X and Arousal Levels

Problems with both hyper-arousal and hypo-arousal are seen in many people affected by fragile X syndrome. In early development, parents often notice the infant's hyper-sensitivity to sounds, light, touch, and textures. Many infants and young children with fragile X show difficulties in sleeping, with hyper-sensitivity to sounds or light. Difficulties with falling asleep or staying asleep may persist long past when other children are sleeping through the night.

Visually, people with fragile X may be overwhelmed by all the information confronting them: lights, crowds, movement, and other stimuli. High arousal levels to visually complex or crowded environments and unpredictable events may contribute to anxiety in new, unfamiliar situations. The difficulty in establishing eye contact may be tied to hyper-arousal and anxiety when confronted by too much visual input.

Auditory processing is also affected by sensory integration problems. Sounds may be given too much attention or, conversely, they may be ignored. The filtering mechanism that most children have with regard to sound seems to work less efficiently for some children with fragile X. Even very young children may become whiny in loud, crowded restaurants or when confronted with other overwhelming sounds, like fire alarms. A temper tantrum may be the result of stimulus overload. Auditory processing problems may also affect speech and language development.

Attention deficit hyperactivity disorder (ADHD) may be symptomatic of sensory integration problems.

Fragile X and Sensory Motor Problems

Sensory motor problems may cause difficulties with posture, balance, and muscle tone. Fine motor problems may be caused by difficulties in motor planning and sequencing of movements.

Proprioception involves the sense of where the body is in space. People with fragile X who have difficulties in proprioceptive processing may not have a good sense of themselves in space. Their posture, eye movements, and gait may be unusual. They may have a number of self-stimulating behaviours (e.g. hand flapping, rubbing the hands together, chewing on clothing or skin, rocking) that provide them with additional feedback from their senses. These movements seem to have a calming and organizing influence on the sensory system. All of these behaviours are typically also connected to anxiety.

Motor planning problems may be seen in the difficulties some children and adults experience learning a new motor skill or sport. Motor planning is the ability to think through a new task requiring body movements and then execute that movement.

Fine motor skills are often delayed in children with fragile X syndrome. Overall, fine motor development seems to be in keeping with cognitive level. In addition to the impact of the cognitive level, low muscle tone and joint laxity contribute to a lack of strength and dexterity in grip and movement for drawing and writing. Children with extreme tactile sensitivity may not like the feeling of a pencil or marker in their hands.

As is true with many characteristics of fragile X syndrome, females with the disorder do not seem to have as many sensory integration problems as males.

Cognitive Behaviour Therapy

I remember when the kids were first diagnosed with fragile X feeling overwhelmed by the long list of stuff that they needed support with. At some point I decided to just focus on one thing at a time. I have found that if we target one thing that the kids or us as a family are finding very difficult, we succeed and life gets a little bit more fun and easier for all of us.

The focus at the moment is to help Ben do stuff that he is very capable of doing but is currently avoiding. Ben avoids everything, answering the phone, going into a shop to make a purchase and social situations at home (except when Danielle and Liam Spier come over).

I can't remember how I came across it but somehow I found out about Cognitive Behaviour Therapy. The idea behind this therapy is that changing an individual's thoughts can change an individual's behaviour and emotional state. A child who experiences anxiety in a given situation, will avoid experiencing the same situation but if the child develops positive ideas about the experience, they will no longer avoid the event



This idea seemed to describe Ben's experience of anxiety. Direct attention from another person makes Ben feel anxious. Ben avoids the situation that made him anxious. Although avoidance makes him feel safe he is restricting his world and not developing the skills and experience he needs to do the task with confidence. Avoidance is a dead-end street that leads to nothing but the safety of staying at home. At 17 years old, Ben is at an age where he needs to become more independent.

So with a feeling of determination I found a private Cognitive Behavioural Therapist in Wellington by internet search. I have never taken the kids to a private therapist. I was a little shocked by the charge of \$150 an hour but decided to give it a go anyway.

In the first session we decided on our goal: for Ben to go into a shop and make a purchase independently. We talked about what strategies worked best for Ben and settled on using backward chaining to reduce the difficulty of the task. We also learnt about how to calm the body using breathing techniques. Breathing techniques work because they reduce the body's stress response. I liked that the therapist was really thorough and that she was very outcome focused. We went away with homework, practising the calming breathing which Ben did every night just before going to sleep.

In the next session the therapist talked to Ben about what happened when we avoid situations. I'm not sure that she quite managed to convince Ben that avoidance meant missing out. In the rest of the session we talked about strategies that would help Ben feel mentally relaxed and confident.

We came up with a phrase to say, that Ben associated with feeling relaxed, "the news at 8" (Ben watches the news at 8 o'clock each night while lying on his favourite couch - a very relaxed time for Ben). Ben was to say this to himself and do his breathing to calm himself when



he needed to. The therapist also suggested that when Ben walked into a room he could imagine he had a protective layer over him. The therapist suggested that Ben could pretend he was wearing Harry Potter's invisibility cloak. After much discussion we decided on Ben imagining he was his favourite All Black, Piri Weepu, a good choice because Piri always looks like he's in charge, cool, calm and collected.

We worked out a program to practise the target behaviour of going into a shop to make a purchase. The therapist suggested practising the behaviour everyday. We decided on an after school shopping routine; Mondays buy a packet of Cheezels, Tuesday a Crunchy Bar, Wednesday a newspaper and then repeat the sequence on Thursday, Friday and Saturday with a day off on Sunday.

We worked out how to backward chain the task so that Ben could slowly increase his confidence. At first I made the purchase and Ben completed the last part of the task - getting the receipt and saying thanks. After a week of this we moved to Ben giving the money to the shop keeper and accepting the change and receipt. After this it will be doing the whole thing with me standing back and finally Ben will go in without me and do the whole thing himself.

The first time we tried we practised the breathing before we went in and said the phrase "the news at 8". I made the purchase and Ben got the receipt. As we walked out of the shop, Ben with his loot, I saw Ben realise that it had actually been really easy. We are now up to Ben making the purchase with me alongside him. The first time we did this Ben really surprised me by initiating a conversation with the guy behind the counter. He looked at me knowing exactly how clever he was.

I am surprised at how quickly we are achieving our goal. I think setting a very specific goal, the breathing, backward chaining, practising most days and having a well set out plan that Ben has been involved in, have been the most effective strategies. It was helpful for me to be really clear about what my expectation of Ben was so that I didn't increase what I wanted Ben to do half way through the task - easy to do and not helpful for Ben.

Once we have making a purchase sorted we'll move onto answering the telephone.

Anita Nicholls

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Treasurer: Niel Smith
National Coordinator: Andrea Lee

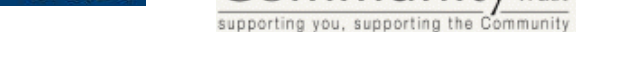
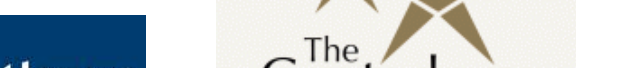
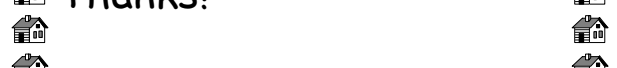
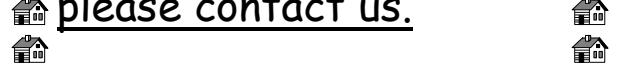
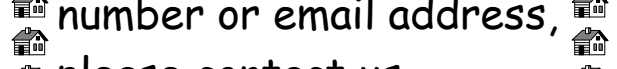
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