



**FRAGILE X TRUST (NZ)**

*Supporting New Zealand families living with fragile X syndrome*

# FRAGILE X TRUST (NZ) NEWSLETTER

April 2011

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Special interest:



points of

**New National Coordinator**

**New Treasurer**

**Family Gatherings**

**Fragile X Clinics**

**Time to renew memberships**



## *Rotorua Gathering - Family Fun November 2010*



# Chairperson's Report



I find it hard to believe that it's been 9 months since our last newsletter. Where has all the time gone and what have we been doing that we've left it so long. Well, as you'll gather from this newsletter, we haven't been sitting on our hands. Through a funding glitch we lost our administrator Lindsay - which is certainly the main reason there has been a hiatus in newsletters. But then a funding reversal meant we gained a national coordinator and what a difference that has made to our operations! Where would we be without Andrea Lee! She has taken on this challenging job with huge enthusiasm and flair and travelled the country meeting families, hosting gatherings, organising speakers and spent quite a lot of time on the phone! And she is having a real impact. New families are joining our mailing list weekly. Our advice to families is helping children get ORRS funding. And our new collaborative initiative with Dr Andrew Marshall - clinical assessments and training via video conference - has been a resounding success. If you haven't done one, get your name on the list for September.

One clear highlight of the last six months has been the development of local support group activities in Auckland and Christchurch. A key role for a national coordinator is to foster such initiatives and I acknowledge the efforts of Mirela and Leona in Auckland and Trina, Kim and Paula in Christchurch and Dunedin in making these activities so successful.

Another important development for the Trust has been appointment of a new treasurer. Niel Smith has generously offered to take on this key job and will work with his accountant Michelle Gilmour to ensure our finances are kept in order. Michelle's office will also become the new registered office for the Fragile X Trust, although our postal address for regular communications remains the same (see back page).

Finally, we are about to hold our first charity golf day. Through the efforts of Mark and Jayne Sorenson, we have 30 teams lined up to play the Shandon Course in Petone. We are on track to raise over \$10,000 to put towards further developments with specialist clinical services. What a great time to have fragile X!!

*Chris Hollis*

# National Co-ordinator's Report

What an exciting time it is in the world of fragile X!

I started this role as we began to plan our first Fragile X clinical sessions with Dr Andrew Marshall, in conjunction with local paediatricians and the Ministry of Health. This has been many years in the planning in fact. We are extremely fortunate to have Andrew Marshall, a specialist neurodevelopmental paediatrician, taking a particular interest in Fragile X. With the help of video conferencing technology, the session took place all over the country from Whangarei to Dunedin on the 29<sup>th</sup> of March and I am delighted to report it was deemed a great success by all who took part. We have received good feedback from both paediatricians as well as from the families who participated. The scope and format of this clinical assessment and training forum has also generated both national and international interest.

A highlight of last year for me personally was representing the Trust at the 12<sup>th</sup> International Fragile X conference. You'll find more about this later in the newsletter.

Another highlight has been getting to know more of our member families. We have had several Auckland gatherings, including a trip to the zoo and a Family Get Together. I had the great pleasure to meet both Vicki Williams and Heather Carter, founding members of the New Zealand fragile X community. Leona Byrne has now taken on the job of organising regular get togethers in Auckland. We have something similar planned for Christchurch in April. I would like to plan gatherings in other parts of the country so let me know any ideas you have and we can plan together.

An important part of the role is getting regular updates out to our member families about what is happening in our community. The E-News is a way of doing that, along with emails about particular events as they happen. Let me know how that is working for you.

I believe together we are stronger and together we can support one another to dream big and create a good life for individuals and families affected by fragile X.

Finally many thanks for the kind words of support I have received from families in my first months in this role. Your support is much appreciated.



*Andrea Lee*

## Hamner Springs Gathering – October 2010



# International Clinic Consortium Forum

## 12th International Fragile X Conference, Detroit, USA



I attended this conference in July last year. What an amazing experience being part of a conference with over 800 people attending and the sole focus being fragile X! Here are some of the many highlights I would like to share with you. Of the many presentations I attended, all of a very high standard, some stood out.

Marcia Braden was, as always, fantastic with great insights and ideas about behaviour management and FX.

I saw Tracey Stackhouse and Sarah (Mouse) Scharfenaker (occupational therapist and speech language therapist respectively) speak for the first time and was very impressed. I came away understanding the significance of how anxiety, or hyperarousal as they often referred it as, really impacts on our son André and I guess all our children. They talked about when people are 'in the zone', a comfortable place where you are focused, alert and able to really attend to what you're doing, and when we get 'out of the zone', or hyperaroused, and feel disorientated, can't think straight, have difficulty focusing etc. They suggested that anxiety is in many ways one of the most significant issues for individuals affected by fragile X. This had a big impact on me and helped me understand our son's world more. They also talked about the benefits of sensory diets for people affect by FX.

I came away from the sessions on speech

language therapy with increased determination to get André more help in this area. It was very clear that there is a body of knowledge around patterns of speech that are common in people affected with FX, and that effective therapy can significantly help. It seems the model that is often used in the US is OT and SLT working together, which makes sense for our children with obvious sensory needs.

Randi Hagerman's presentation was also impressive. There was a lot of talk about different research currently happening and also the use of medication.

I was part of the International Clinic Consortium forum together with Dr Andrew Marshall and we talked about what was happening in New Zealand currently and our goals for the future. This forum was a chance for people from different countries to share their experiences and give an update on where they were at in terms of specialist FX clinics.

Overall the conference was a fascinating experience which interestingly left me feeling that in fact we are in many ways doing very well in New Zealand. There are few countries in the world outside of the US doing better. I think our size and adaptability means we are in many ways leading the way in inclusive education models (although we still have a long way to go!) and there is much to celebrate.

I would definitely encourage others to go to the next conference in 2012.

# Auckland Family Gathering

## 27 March 2011

On 27

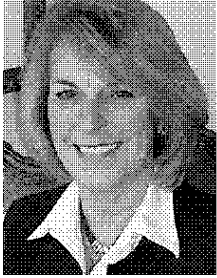
March our family went up to Albany for the first Auckland gathering for some time organised by Andrea and Mirela. There were talks given by CCS Disability Action, Parent to Parent and Renaissance Group. It was great to meet the new families, catch up with old friends, and have a really nice and relaxed afternoon. The kids were able to use the gym upstairs to play and watch movies. It was awesome to see all the kids getting along and having a great time. We finished off the afternoon with pizza... which we all enjoyed. I for one always love these gatherings as it is a time to compare notes, hear new ideas for our kids and to share little tips that we have learned.

After chatting to a few of the mums there I have organised a coffee morning in Auckland on April 12<sup>th</sup> for anyone in the surrounding area who wants to come along. After that the next Auckland family gathering will be Saturday May 21<sup>st</sup>. The venue is still being organised but I will be in touch soon with the details. Pencil in the date though!! I hope you enjoy the photos and can't wait for the next one!

*Leona Byrne*



# Braden on Behaviour (by Marcia Braden, PHD)



Being part of the behavior  
symposium at the International

Conference in Detroit proved to be both interesting and enlightening. During the symposium there was a fair amount of discussion about the importance of behavior intervention. Behavior management continues to be of tremendous importance to parents and professionals.

I have thought a lot about this and have decided to make it the topic of this column. In my opinion, understanding the etiology of behavior in people with FXS is critical when creating proactive strategies to successfully manage that behavior. Knowing the triggers and manipulating the environment can often succeed in preventing the person with FXS from engaging in problem behavior.

This became apparent recently when consulting with a family whose son engaged in self-injurious behavior (SIB), which included hitting his forehead with his fist when he was in noisy or crowded environments. The trigger was not obvious because he loved going to restaurants and looked forward to going—until he got to the door. The obvious remedy was to avoid all crowded and noisy places, but how realistic is that? Not only is it unrealistic, but it is not a good way to increase independence.

Best practice would be to identify the antecedent and develop ways in which the person with FXS can be desensitized to the environment. We would call this a lesson in self-regulation. In other words, the person would learn that before he enters a noisy environment, he would put on his ear pods and play music on his I-pod, or wear headsets that would muffle the sound. This would teach replacement behaviors that could help him throughout his lifespan.

The other part of the discussion coming out of the behavior symposium was the emphasis on the consequence— especially when the consequence could in fact help maintain the behavior.

Taking the example above, removing or avoiding loud environments could be construed as a consequence. When the person enters the noisy environment and engages in SIB by hitting his head, he is removed from the environment. This has the effect of rewarding him for hitting his head by removing him from a situation he considers aversive. I contend that it is

generally preferable to teach him how to handle noisy

***Understanding the etiology of behaviour in people with FXS is critical when creating proactive strategies to successfully manage that behaviour***

environments via effective behavior shaping strategies rather than reacting by avoiding those environments.

This example provides a revealing contrast between proactive and reactive strategies. While both may be necessary at given times, putting more energy and emphasis on figuring out the

antecedents makes more sense in the long run, because it leads

to a more adaptable individual who can better manage his or her responses to stimuli in a wider variety of settings.

The example above is not unique. After getting background information and observing a number of behaviors, there appears to be similar antecedents that relate directly to the behavioral etiology. In an attempt to make sense of the problem behaviors, I have comprised a list from 50 intake forms and clustered them into categories. The chart that follows lists a variety of behaviors most often presented during the intake. The chart clusters the behaviors and lists corresponding remedies. Although some of the behaviors occur mostly in boys, girls may also engage in variations of each behavior, though in a less direct manner (especially in the area of self-abuse). ®

*Marcia Braden is a psychologist and special education consultant in Colorado Springs who specializes in Fragile X. She is the author of Fragile: Handle With Care, and creator of the Logo" Reading System.*

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<p><b>Behavioral Cluster: Change in Routine</b></p>	<p><b>Remedy or Intervention</b></p>
<ul style="list-style-type: none"> <li>• Difficulty reacting to changes</li> <li>• Shows strong reaction to changes in routines</li> </ul>	<ul style="list-style-type: none"> <li>• Set a visual schedule; if a change is scheduled, train the child to anticipate it by placing a question mark in the schedule to prompt the changes</li> <li>• Write a social story about the schedule and changes in routine</li> </ul>
<p><b>Behavioral Cluster: Transition</b></p>	<p><b>Remedy or Intervention</b></p>
<ul style="list-style-type: none"> <li>• Acts out when we arrive at places of high interest and preference</li> <li>• Stalls when entering a building</li> <li>• Gets in the car but won't get out when we arrive at our destination</li> </ul>	<ul style="list-style-type: none"> <li>• Crossing the threshold creates much anxiety because child cannot anticipate what is happening on the other side; give a task or job to do when crossing the threshold or getting out of the car</li> </ul>
<p><b>Behavioral Cluster: Self-Abuse</b></p>	<p><b>Remedy or Intervention</b></p>
<ul style="list-style-type: none"> <li>• Bites hand when stressed</li> <li>• Pounds head with hand</li> <li>• Slaps own face very hard when told "no"</li> <li>• Obsessively picks at scabs or sores</li> </ul>	<ul style="list-style-type: none"> <li>• Provide calming activities within a sensory diet; consult an OT</li> <li>• Redirect or teach a replacement behavior</li> <li>• Restructure the way child is told "no"</li> <li>• Use band-aids to cover, wear bracelets or hair bands on wrists to provide alternative</li> </ul>
<p><b>Behavioral Cluster: Sensory</b></p>	<p><b>Remedy or Intervention</b></p>
<ul style="list-style-type: none"> <li>• Stuffs mouth with food</li> <li>• Pushes mouth against my face and then might bite me</li> <li>• Chews sleeve or shirt</li> <li>• Covers ears</li> <li>• Won't wear shoes or pants; has to wear sweats</li> </ul>	<ul style="list-style-type: none"> <li>• Require swallowing before subsequent bites</li> <li>• As child approaches turn your face away very quickly and offer a chewy</li> <li>• Offer a chewy</li> <li>• Encourage using ear pods, or earphones</li> <li>• Introduce sandals and flip flops, encourage wearing softer tailored pants</li> </ul>
<p><b>Behavioral Cluster: Inattention</b></p>	<p><b>Remedy or Intervention</b></p>
<ul style="list-style-type: none"> <li>• Seems distractible when required to sit for long periods of time</li> <li>• Shows poor impulse control, which usually gets worse when under pressure</li> </ul>	<ul style="list-style-type: none"> <li>• Use a token board to summon attention and to provide a tangible way to show how long child needs to attend</li> <li>• Provide self-regulation to slow down; introduce deep breathing exercises, counting to 10</li> </ul>

# Ministry of Health: Consumer Forums

The Consumer Forums held throughout the country were an opportunity to hear about proposed changes to the Ministry of Health (MoH) disability services and ask them questions. A brief summary follows:

**Individualised Funding (IF):** This is a key priority

- ⇒ There are now 12 Host Providers throughout NZ. These include places such as, Manawanui In Charge, Presbyterian Support Northern, Lifewise Homecare Services, Vision West & Healthcare NZ Ltd.
- ⇒ Currently IF is limited to Home and Community Services. The MoH will look at IF for Respite Care next.

Respite:

- ⇒ A respite trial is to go ahead shortly in Nelson, giving families 3 options for respite: out of family, in-home & host families (or a combination of these). Pending the outcome of this trial, this could be rolled out throughout NZ.
- ⇒ Respite review will take place in 2nd half of 2011, including a review of distribution.  
(MoH knows that some areas currently don't have enough/any)

Behaviour Support:

- ⇒ MoH have contracted this work out & a recommendation is due in June 2011.

Child & Youth:

- ⇒ Child Development Services have been contracted to District Health Boards – not consistent yet throughout NZ.
- ⇒ The review of the Equipment & Therapy protocols is complete.
- ⇒ Autism Spectrum Disorder (ASD) work programme: Implementation of the NZ ASD Guideline continues, the priority areas are assessment and diagnosis, support to strengthen families, interventions, respite and coordination of services. The Werry Centre now delivers an education course on ASD for professionals.

Carer Support:

- ⇒ MoH acknowledge that this is cumbersome and not working well. Their objective for 2011 is to get the guidelines reviewed.

New Model:

- ⇒ OLD WAY – Someone else makes decisions about what support you get and when you get it.
- ⇒ NEW WAY – With support, you decide what's important to you to have a good life.
- ⇒ Being trialled in Tauranga for 1-2 years.

Community Living Options:

- ⇒ By June 2011 MoH will have a model, then will go out to tender in August.

Supported Living:

- ⇒ MoH is rewriting the guidelines.

Details of these and other Key Projects are available online <http://moh.govt.nz/moh.nsf/indexmh/disability-keyprojects>

A full report of the MoH Consumer Forums will also be available at the website shortly.

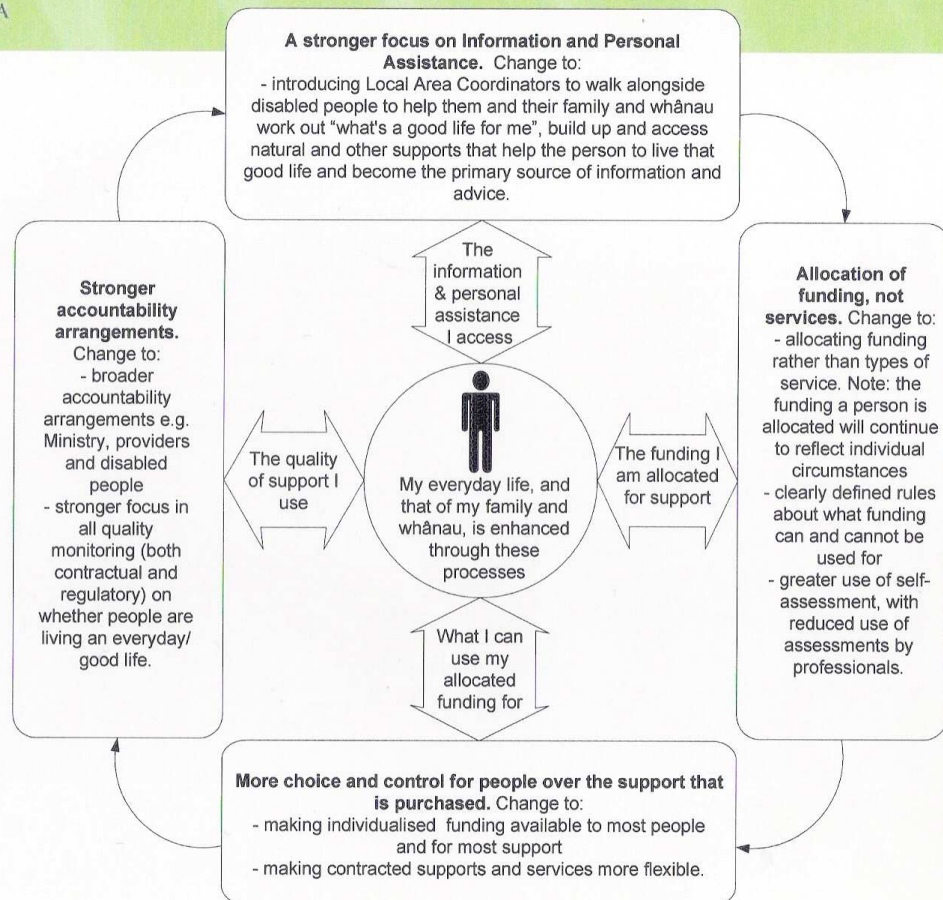
# The New Model



## Disability Support Services

### The New Model

This is the model  
Cabinet approved



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# Family Feedback – Clinic with Andrew Marshall

We were fortunate enough to participate in the first sessions that were held between our own physicians and Andrew Marshall late March. For those of you who are not sure whether you need this, I strongly encourage you to seek an opportunity to participate in future sessions.

We went along with a few concerns about Bradley's incessant talking, and need for constant touch. I felt that we had good strategies in place and there was unlikely to be anything more that we could do at this time other than weather the next few years as puberty takes hold! The other thing I wondered was that maybe it was our perception that Bradley had become more hyperactive.

The session involved meeting with our paediatrician, Andrew Kelly and using a teleconference facility at Dunedin Hospital, which allowed us to "meet" with Andrew Marshall. We completed a questionnaire prior to the session, which allowed us to identify what it was that we wanted to cover as part of the session. We had just completed Bradley's IEP at school a few days earlier as well, so I was able to use information from this to feedback. Both doctors noted Bradley's constant touching and moving things around and his need to be tactile and interactive, particularly with Adrian. Andrew Kelly noted that Bradley's behaviour had indeed changed since we saw him last, and following discussion regarding medications, it was suggested that some change may (or may not) be useful.

Presently Bradley is on clonidine (for hyperactivity) and citalopram (for anxiety). A change from clonidine to strattera was suggested as it may more effectively deal with the ADHD symptoms. So, we came away from the session finding that our thoughts were acknowledged, and some potential solutions identified. It was great to have the opportunity to speak with someone who has taken on the challenge of becoming an expert in New Zealand that can support our children. We would like to say a very big thank you to our paediatrician for being responsive to the idea and making himself available. We are also very grateful for Andrew Marshall for making himself available to provide this support to us all. And lastly a huge thank you to the trust- particularly Andrea for making this happen.

*Kim and Adrian Caffell*  
Dunedin

# Lydia Whittleton... You are an IronKid!



What a momentous day for our family. Lydia who turned 10 in December participated in and completed Iron Kidz, Taupo - the children's version of Ironman on Taupo Lakefront, the week before the main event (incidentally run by Waipahihi School where Lydia attends as a year 6 pupil).

The Whittleton's were out in force to support. Mum, Dad and brother Elliot, Gran and Grandad and Teacher Aide too. We were all surprised and held our breath expecting her to back out at the last minute. She didn't seem to be phased at all by the mass of people, loud PA system and uncertainty of what was going to happen.

Lydia led the decision to participate, which surprised us all. She still hasn't mastered the art of riding a bike totally and the bike leg of the triathlon would prove taxing. How could I make this happen for her? She is so competent on her scooter, maybe she could scooter instead. She was determined to be like everyone else and tried to master her bike for the occasion but on the day the scooter was the mode of transport.

Participation is the order of the day. Lydia could participate at whatever level she could manage and we would support her all the way - so did the rest of the community in true Waipahihi spirit. She was cheered on all the way.

She swam/crawled 100m in the lake, scootered 4km and then ran 100m.

The determination of our girl made me so proud. As soon as the event was finished she took off the medal and hid the T-shirt. She did not enjoy the attention that was being drawn to them at all. In true Lydia style she only enjoys attention when it is on her terms!!!

# Kindy Fun – Connor Fowke



These are pictures of me at Onerahi Kindy in Whangarei. I like going to Kindy and ask my Mum if I can go every day even in the weekends.

I like painting, playing in the sand pit, swing and running around with my Kindy mates. I have a very cool teacher aide called Susan, whom I like very much. I am very good at mat time especially when we sing and dance. I like to go first when it is time to wash my hands and have afternoon tea. Yum, yum, food.

I bet everyone wishes they could go to Onerahi Kindy. ☺

**Connor Fowke (4 years)**  
as told to my Mum



# More family fun in Rotorua



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