



FRAGILE X TRUST (NZ)

Supporting New Zealand families living with fragile X syndrome

FRAGILE X TRUST (NZ) NEWSLETTER

October 2008

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The International Fragile X Conference special issue: reflections from the New Zealand delegation



Visting the MIND Institute: Seniorita Laukau, Judith Spier, Anita Nicholls, Randi Hagerman, John and Christine Kelleher (Australian Fragile X Association).

Six New Zealand parents were able to attend the 11th International Fragile X Conference in St Louis, Missouri, thanks to the support of the Lottery Minister's Discretionary Fund, the Rehabilitation Welfare Trust, the US National Fragile X Foundation, and the Fragile X Trust.

On the way they called into the MIND Institute, University of California at Davis, the leading international centre for research and treatment of Fragile X Syndrome and related disorders and met up with Randi and Paul Hagerman and Louise Gane. This newsletter includes reflections on the experience from Anita, Judith, Jodi, Seniorita and Anne and Niel Smith.



Special points of interest:

- Reflections on the International Fragile X conference and visit to the MIND Institute
- Fragile X Trust AGM in Wanganui
- Family news from the mainland

Cheers from the Chair – Anita Nicholls

Hi to everyone

Since the last newsletter, Judith, Jodi, Seniorita, the Smith family and I traveled to the fabulous International Fragile X conference in St Louis, USA.

The fun began with a night in San Francisco. We spent a happy afternoon shopping without men or children to slow us down, ate cheese cake for dinner and zoomed around on the cities famous trams. At Fishermen's Wharf we saw flocks of pelicans, Alcatraz and the Golden Gate Bridge while Seniorita went to a great street market with her American relatives. The next adventure was to get to Sacramento by train. Judith saved the day by figuring out how to purchase tickets from a noncompliant vending machine. US trains are two stories high and lurch very slowly along stopping at times for no apparent reason, which was great as we were not in a hurry and wanted to see the countryside.

In Sacramento, Louise Gane scooped us up in her car and drove us out to Paul Hagerman's research centre. Paul showed us around and we got to chat with him about his latest research. I came away with the feeling that fragile X research is in very good hands. It's nice to know that somewhere in the world very clever, well resourced people are working day and night on research that will make a difference to our children's lives. Next stop was the MIND Institute. I loved that the building is designed specifically to meet the needs of the children who come in to be assessed, which includes an entrance-way designed to ease the anxiety of transitioning from outside and a play space that somehow had all of my boys' favorite toys. And then we got to talk to Randi Hagerman. By this time I could understand why our kids hand-flap because I was pretty close to hand-flapping myself. Randi talked about her plan of passing on expertise about fragile X through fragile X clinics located around the world. We discussed setting one up in New Zealand. Randi also talked to Seniorita about setting up a clinic in Tonga.

Our next stop was the week long fragile X conference in St Louis. It was great meeting up with John and Christine Kelleher from the Australian Fragile X Association, Jonathan and Rashelle Cohen and Marcia Braden. I saw lots of great presentations including Marcia Braden speaking on behaviour intervention for elementary school-aged children, Gary Martin providing information about speech and language, and Randi Hagerman speaking about new treatments. Jodi and I gave a presentation on how we have supported educators working with Fragile X children. This was very well received.

In summary, we learnt and saw lots, had great conversations with people who know and care about fragile X from all over the world and we had a huge amount of fun. Thanks to Jodi, Judith, Seniorita and the Smith family for being the best travel companions a girl could ask for. I hope our reports of the trip in this newsletter tempt you to attend the next conference in Detroit in 2010.

Anita with Judith, Jodi, Louise Gane and Seniorita at the conference gala dinner



A Learning Experience – Jodi Heenan

During my trip to the St Louis conference, one main idea kept coming through no matter who I was listening to. That was, to create a team around the child that will enable you to teach them new skills using a multidisciplinary approach. Teams need to include: parents/family, a speech language therapist, an occupational therapist, classroom and specialist teachers, pediatrician, and sometimes a psychologist. Input from all these people is vital as each has important information about the child that will enable successful strategies to be developed by the team.

A multidisciplinary approach involves using the knowledge of all of the team to plan a structured learning programme to suit the needs of the child. It is important to remember that the methods the team use need to suit the Fragile X learning style. The team needs to consider and agree on what are the most important goals to work on, not just in the school setting but also at home and in the community. Discussing concerns and needs as they arise, rather than waiting till the next IEP meeting, make it much easier to nip a behavior in the bud, by making a slight change in routine, rather than having to create a full behavioral intervention plan where a behavior has become a big problem and fully established.

This got me thinking about how as a parent I could help to facilitate a better team-based multidisciplinary approach for my son in the New Zealand system. What I now aim to do is:

- speak to all team members personally rather than waiting to hear from the school about what the OT and SLT have said;
- set my own goals for what I want my son to achieve and share them with the team;
- make more phone calls to team members requesting knowledge or information about areas of concern for my son;
- pass on information, ideas, and strategies that I have acquired without assuming they already know (this may be particularly important where teams are not meeting regularly or where there have been relationship breakdowns between team members or where teams do not have access to a SLT or an OT and because parents are the only ones receiving information from pediatricians);
- have questions ready for when I do speak to specialists. If I have no other questions I can ask what do you plan to do, why and how;
- share successful strategies.

After attending the conference I am now more empowered to consider what my son's needs are and to ask questions of the team members. Consider such things as:

- learning life skills – how does my child's deficits in motor planning affect his ability to perform in everyday skills?
- are we using enough strategies to help him counteract these weaknesses?
- are we using the right strategies? (if they are not helping then maybe not)
- hyperarousal – is my child in the right space for learning?
- are we using Fragile X learning styles when we are planning his programme?
(these include: imitation, cloze technique, simultaneous learning, high interest learning)

A multidisciplinary approach to teaching should ensure that all areas of need/concern are dealt with and enable the child to be much more receptive to their learning environment. Parent facilitation can aid the team to work more effectively for the child by ensuring information from all team members is included in the planning of strategies.

FROM THE OFFICE:

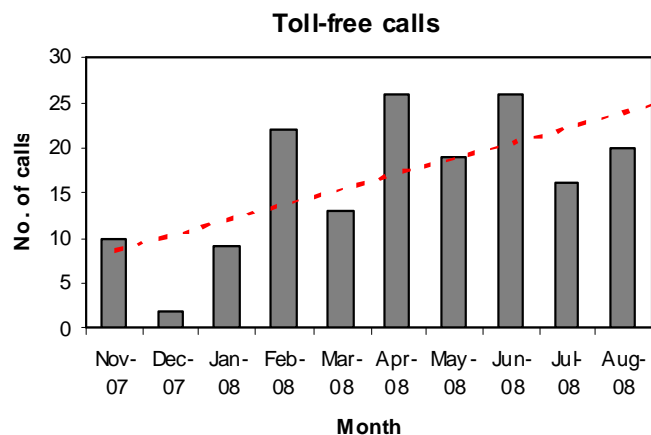
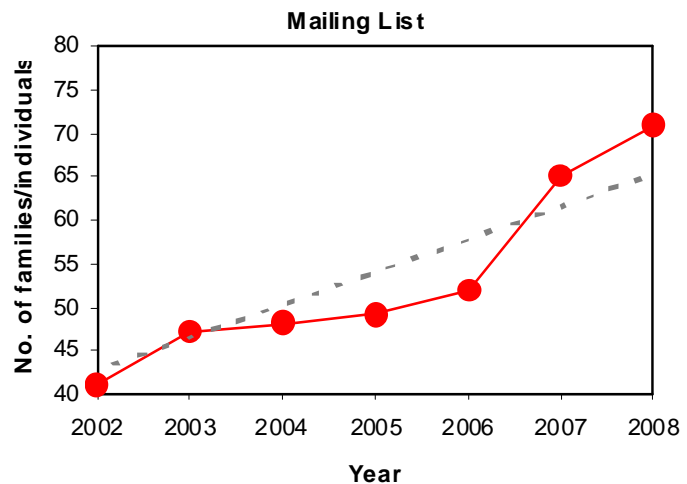
Hutt Valley expansion. Anita, Chris and the boys have moved from their ex-State house in Lower Hutt to a more spacious home in Upper Hutt. So, the executive team of the Fragile X Trust now spans the entire Hutt Valley! Other lifestyle changes for the family include the delights of dog ownership – Jack the Jack Russell, bus commuting to work and school for Chris and the boys, and Anita getting a new job as an Early Intervention Teacher for the Ministry of Education – based in Otaki!

Membership. It's great to see a steady increase in families joining the Trust mailing list, which appears to be the result of our attempts to raise awareness among professionals and the wider community. Our active membership has almost doubled from 41 families in 2002 to 71 families today. A big surge in 2007 is linked to the Marcia Braden workshops and the roll-out of the No Longer Fragile education programme. More people are also contacting us via our website, which continues to be maintained by the NZ Organisation

for Rare Disorders at no cost to us. Our drive for increased donations from members has also been very successful, with the generous flood of donations now totalling \$640 for the year to date. If you haven't yet renewed your subscription, please do so now. **Every donation helps!**

Communication. We continue to receive regular news and photos from families and hope to launch photo pages on our website before the end of the year. Email is a common way for new families to contact us although it's great to see how successful the toll-free number has been. We are getting about 20 calls per months, both from regular and new callers. In contrast, the online forums have not proved that popular, so may be discontinued.

Family Gatherings and Seminars. We have around 15 families attending each of the family gatherings in Wanganui and Christchurch and so far 40 people have signed up for the Christchurch seminar. It's still not too late for registering.



Funding. We received \$6,885 and \$2000 from the Lottery Minister's Discretionary Fund and the Rehabilitation Welfare Trust, respectively, to support six NZ parents attending the International Fragile X Conference in St Louis (see the reports throughout this newsletter). We were also awarded \$6100 from the Lottery Grants Board national community committee, which will be used for general operating expenses and costs associated with the two family gatherings. We were not successful in our request for funds for an office administrator, something we feel we desperately need as the Trust's activities expand, but we're trying again with an application to the JR McKenzie Trust.

Fragile X Conference in November 2009. We are working with the Australian Fragile X Association to bring Randi Hagerman to Australia and NZ next year. Randi is the director of the leading international fragile X treatment and research centre, the MIND Institute in California, and last visited NZ in 1998. We plan to use this opportunity to hold a Fragile X conference, probably in Wellington, in November next year.

For more information, phone Chris or Anita on **0508 938 0552** (or 938 0552 in Wellington) or email fxwell@paradise.net.nz

NOTICE OF ANNUAL GENERAL MEETING

The Fragile X Trust (New Zealand) invites all fragile X families to our AGM, which will be held on Saturday 1 November 2008 from 4.00 to 5.30pm at the Whanganui River Top Ten Holiday Park, 460 Somme Parade, Wanganui.

If you can't attend in person, you are welcome to submit agenda items to the secretary:

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 Tel: 04 5678532 or Anita and Chris on
 0508 938 0552



Fragile X Conference reports

MY USA TRIP DIARY – by Judith Spier



Day 1: The day has finally arrived. Anita Nicholls, Senorita Laukau, Jodi Heenan and myself started our travels to USA to the International Fragile X Conference in St Louis, Missouri. Anne and Niel Smith and kids are already in the US. So excited!

Day 2: Arrived safely in San Francisco! After eventually getting through customs we are off shopping, hanging off the side of the cable car, visiting Fisherman's Wharf and seeing a musical. Cold in San Fran!

Day 3: We caught a double decker train from San Francisco to Sacramento. It was a scenic, but slow, 2 hour trip. Yay, it was warm here! We spent two nights in a lovely old hostel. Tonight we met up with Louise Gane (who lives in Sacramento) and had dinner at a nice restaurant and had a good chat!



Day 4: One of my favourite days in USA. Louise collected us in her car and drove us to Davis University, 20 minutes away, where Paul Hagerman works. Paul gave us (and Christine and John Kelleher from Australia) a tour of his research labs and chatted to us for about an hour on the latest developments in research on Fragile X. Paul's passion for "finding a cure" for FX is amazing. I could listen to him forever! Louise then drove us to the MIND Institute back in Sacramento. We met up with Randi Hagerman and she and Louise give us a

tour of the incredible MIND Institute. My first thoughts were "I would love for my kids to come here!" Randi generously took us all out to lunch at a local Mexican restaurant. A great opportunity to chat. We then went back to Randi's office at the MIND Institute and spent an incredible 30 minutes with her answering our questions. I was so grateful to get some advice from her about medication - and she even wrote her recommendation on letterhead so I could then show it back in NZ to my paediatrician. Brilliant! I was one happy woman! We then sat in on Randi and her team of professional's weekly 2-hour meeting with FX research students. Fascinating! I felt so privileged to be there!



Day 5: We left Sacramento and flew to St Louis Missouri. We arrived at night time. Staying at the hotel/venue of the conference - Hyatt Regency, Union Station. The hotel is GORGEOUS - very opulent! Union Station is a huge indoor shopping centre as well as the hotel. Bed about 1am!

Day 6: The International Fragile X Conference started midday today. We collected our registration packs, which included the large folder that had the full agenda of the conference. We headed straight to Einstein's bagels, which is inside the Union Station complex, had a bagel for breakfast and started devouring with our highlighters the sessions we wanted to attend. Today I went to sessions on "FX Females Maths Abilities", "Migraines in Premutation Carriers", "Panel of Experts - Premutations". The day ended with a Welcome Reception with nibbles and drinks, and then watching a fabulous DVD called "Living with Fragile X" in the huge ballroom. A few hundred people attended both these events.

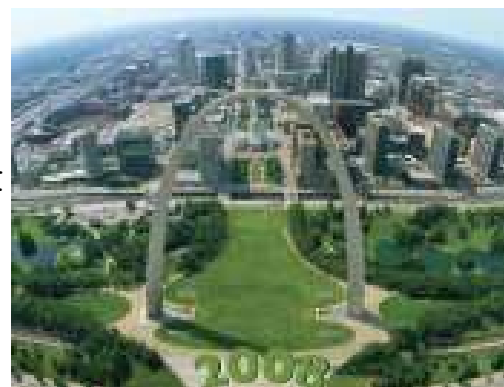
Day 7: Great first session "New Treatments on the Horizon", by Randi Hagerman and Elizabeth Berry-Kravis. Huge turnout - hundreds! Other sessions today of highlight were "Promoting Fine Motor Skills in Children with FXS", "Harnessing the Power of Play", "Speech and Language Intervention", "Self Regulation and Sensory Diets", and a key session for me "Females with FXS". This was a panel of 4 girls (19-27 years) with full mutation FX who spoke about their lives, moderated by Marcia Braden. They were really honest about their ups and downs over the years, and gave me a real sense of hope of what FX girls could accomplish. Anita and Jodi also gave their presentation "No Longer Fragile: An Educational Programme for School-Aged Children with FXS". They received fabulous feedback. The day ended with a bus trip to the St Louis Science Center, where we were able to explore the hands-on exhibitions before enjoying a sit down buffet dinner with a projection of the night sky and the constellations on the ceiling above us.

Day 8: 7am breakfast for invited international representatives, hosted by Robert Miller. Great networking opportunities. First session today was watching a DVD called "Including Samuel". This was a quality production by Dan Habib, and once again hundreds attended. My sessions of interest today were "Managing the Behaviour Problems of Children with FXS with Medication", and "Behaviour Intervention Workshop". There was a luncheon hosted by Don Bailey. Awards were given out at this luncheon to people who have tirelessly worked for the FX cause.



Day 9: The last full day of the conference. I wish this conference could just keep going as there is an incredible atmosphere here with all the families and professionals all here for the same reason. Session highlights were "Managing Hyperarousal", "Communication Challenges of Youth with FXS", "Seizure Disorders" which Elizabeth Berry-Kravis presented brilliantly (I could listen to Elizabeth for hours!). The day ended with a flash dinner, live auction and dancing.

Day 10: The last half day of the conference. Most conference attendees have started travelling home. This last day consisted of two panel sessions, but I felt that I had all my questions answered by the previous days and our private discussions with Randi Hagerman in Sacramento. Senorita and I decided to visit the famous Gateway Arch affectionately known as the "Gateway to the West". We arrived by 8.30am to avoid the queues. The interior of the steel Arch is hollow and contains a unique transport system (an egg-shaped tram) which takes you to an observation deck at the top of the Arch where there are small viewing windows. A great photo opportunity. Warning - do not take the tram inside the Arch if you are in any way claustrophobic! Then back to the hotel where I collected Anita, and the two of us continued our US adventure by spending a few days in New York before travelling home to New Zealand. Bring on the next conference in Detroit, Michigan in 2010! I highly recommend this international FX conference to all!



Fragile X Conference reports

Senorita Laukau

What an experience it had been and although it was only for 10 days, every minute of it was well spent and worthwhile.

I had heard from others who had been to previous FX conferences that it is a life changing experience and I suppose I went with the intention to find out why that would be so. I do agree wholeheartedly and would like to encourage everyone else to make plans to be at the next one planned for Detroit in 2010.

The three broad factors I think that have contributed to making Fragile X conferences an awesome experience are:

- ☞ The family friendly atmosphere
- ☞ The range of information shared and available is up to date, practical and relevant.
- ☞ The energy, interest and motivation that drive the people behind the activities and research related to Fragile X sends off a sense of hope for FX children, their families and support groups.



Fragile X is like a 'global phenomena' – in that as it has touched local families/communities/countries; it requires a global response to effect treatment, understanding and change.



Some of the participants at the International Breakfast. Countries represented: New Zealand, Australia, Hong Kong, Switzerland, Brazil, Holland, Canada, Germany, Guam, Scotland, South Africa and many from the different states of America

Jodi Heenan

For those of you who considered going but didn't quite make it I recommend that you do make the trip to the 12th International conference in Detroit, Michigan in 2010. What an experience! To have the Fragile X worlds' most knowledgeable and experienced people under one roof for four whole days, willing to be accosted, questioned and hounded is, to put it mildly, AMAZING! They must have gone home even more exhausted than we were.

After a quick overnight stopover in San Francisco, in which we managed to cram in a show, a trip to the famous cheesecake shop, a tramride to Fishermans Wharf to view Alcatraz and the famous Bay Bridge, (hanging off the sides while going downhill and around corners was pretty exciting), and a couple of hours doing some serious shopping in the Nike and Levis shops, we caught a train around the coast to Sacramento home of the MIND Institute.



WOW! The whole building was architecturally planned and designed with the needs of Autistic and Fragile X people in mind. I'm sure as we walked around with Louise we were all observing with our own childrens' reactions in mind. We had a very enlightening hour with Randi solely to ourselves, and were able to each ask a question of her about our own child. We also spent time with Paul Hagerman hearing about the exciting new developments, which I've no doubt Louise will share at the upcoming family gatherings. Thanks to Louise for transporting us to and from the MIND and the university and for showing us around.

As I mentioned before the conference itself was incredible, from the amazing speakers, right down to Union Station the fantastic venue where everything we needed was under one air-conditioned roof.

Anita and I were able to share Anita's initiative the "No Longer Fragile" programme that we have put together and which some of you have already experienced in your child's school. This was very successful and we had quite a bit of positive feedback with several people excited about doing something similar in their country.



A huge thanks must go to The Fragile X Trust, for the financial assistance they provided us with, this was a huge help. Also to Anita and Chris for organizing and planning the travel and accommodation. And of course, to my travel companions who made the trip so much more enjoyable.

Fragile X Conference reports

Anne, Niel, Charlotte & Bruno Smith

The Visit to the Mind Institute: we thoroughly recommend it. Here's why:

To start off we thought the kids would have to do lots of tests and we could go and have a nice coffee somewhere nice....in my dreams!

First of all if you want a nice coffee, you're in the wrong country, better go to Italy...Secondly, a university campus just lacks the ambience.... And lastly, once the team over there have got you in their clutches, they'll make the most of every minute, and you will have time for lunch only if you brought it with you and go hide in a corner, otherwise it's pretty much all work, work, work.

So, the kids did have to do a million tests, three days of it, in fact, but as far as Bruno is concerned, he couldn't get enough of "playing with the ladies", as he calls it, the process was so smooth I wish I had brought everyone who works with Bruno, just so they could witness his life and mood as good as it gets. Even the waiting room is made for FX children, cubicles with TVs and fishtanks, toys and couches, and there are always some medical students miraculously appearing when you're wondering how you're going to do the next transition, or concentrate on what the lady is saying.

God knows (and Louise Gane, probably) what all those tests were about. As far as I can figure, they measured EVERYTHING, the ears, the toes, the thumbs (Bruno measured his own nose...), the intelligence or lack of it, and how it works on different tasks, the eye tracking, recognition of emotions on faces, anxiety and stress levels, you name it...

Charlotte had a brain scan, Magnetic Resonance Imaging, if you like clever words, which means that they took 194 pictures of her brain in action, when she was watching a video, doing some thinking, solving math problems, etc... She is now the owner of a video proving she has a brain, and she took it to school to show her teacher.

While the children were happily "playing with the ladies" we had to talk to other ladies, and answer about a million questions about ourselves, medical conditions, emotions etc... and the kids' life, last month, four years ago, and the family history and this and that and the other, and often the questions were similar but the answers were not the same coz after all these questions and all that thinking about it, well, we had changed our minds!!!

That's the beauty of the whole experience: going to the Mind Institute is being part of a process that makes us think and helps us to see stuff about our children that we never would have suspected. Of course, the professionals also suggest things that could be helpful, change the medications, add a bit of counselling here, a lot of occupational therapy there, and explain all the things we want to know more about.



And, last but not least, they give us hope for the future, each in their own way, the Randi Hagerman team is committed to find the miracle cure for FX, the drug that will make all the symptoms disappear, (and to be honest I think they will, coz Mrs Hagerman sounds like a dog with a bone, just won't let go). They've already got some medication out there a lot more efficient than what's accessible here in the outback... hang in there, we'll get it some day.

There is also a team working on computer games as a way of developing brain areas for the perception of time and space, which are the stepping stones for most of our human interactions, that's a medication the kids are going to like...



Just another couple of things to add to my advertisement for the Mind Institute. They sent us a report, which was all Chinese to me, containing all the numbers related to the various tests and a summary of the recommendations that they had already told us (and believe me, we were taking notes!), great stuff to show the professionals who work with our children!

The best bit is that it's all free, coz it's part of a research program and the team is happy to have as many participants in their research as possible. I mean, almost free, you're still gonna have to drag yourself and your kids halfway across the planet, go through customs (and hope you don't get searched...), pay for your accomodation and your hamburger... but all that is not part of the ad.

Look at all the space I've taken up already, if you wanna know about the conference, go ask someone else... there was another four of us there...



Family News and Photos

The Caffell family's skiing journey

As we are half way through our second season with Disabled Snow Sport in Otago, we have been reflecting on the skiing journey so far.

Bradley has Fragile X Syndrome - FXS is a genetic disability which has a wide variation in presentation. For Bradley it includes fine and gross motor issues, intellectual disability and other behavioural characteristics.

2007 was full of excitement as we recognized that Bradley could access a sport that he was interested in and have support provided to him that we were not able to provide as a family. As a family we are highly motivated for Bradley to have choices in all aspects of his life. We appreciate that this is so for all children, however our focus is on intellectual disability which poses its unique challenges.

It has been with great enthusiasm that we have returned for the 2008 ski season. The conditions are fabulous and it is exciting to see more skiers involved this year. We have met some stunning people (both those who have disability and those who support them) in our brief time in the sport.

What we are now realizing is that it may be useful to understand more fully what considerations those working with some one with an intellectual disability may need to think about to provide the best opportunity for that individual to achieve their best potential. Whilst I will focus on FXS, many of the comments apply to others with intellectual disability.

Behaviourally FXS children generally have a good sense of humor and enjoy jokes and humorous situations. They are also distractable and impulsive with short attention spans meaning it can be difficult for them to stay on task. Instances of this can be in situations where someone is trying to work with him, yet his instincts are telling him to just get on with what he wants to do. Other behaviours are mentioned below.

Speech and language - in Bradley's case, his speech is excellent. What is not so apparent, is that his pragmatic/ conversational abilities are reasonably limited, characterised by echolalia and cluttering. Whilst he is very good at looking for other subtle prompts and cues to enable him to better understand what is being said to him, his comprehension is not as good. Things such as multiple/ abstract meaning and limited attention span do impact on his level of understanding.

Bradley (on the right) and Jack Wellstead (from Clyde on the left) - skiing at Cardrona



Anxiety is a key issue, which is not apparent, but does manifest in some physical signs - red ears, gaze aversion and agitation are common features. There is a strong difficulty in sequencing steps in a task which make it difficult for him to understand and follow instruction.

Sensory issues are important to understand - Bradley does not manage lining up in cues, and the wait can frustrate him. He sees the person in front of him as a barrier to him moving on and doing what he wants, and has indicated that he wants to hit them to get them to move. He is on medication for anxiety, but it also understanding the triggers, monitoring them, reminding him of appropriate behaviour, and if things escalate, removing the stimulus e.g. he has to be removed from the cue. He also has tactile and hearing issues, so if the cues are large it may cause a sensory overload, which again can manifest in varying behaviours which to some may seem "naughty". You also see Bradley mouthing objects- this reflects the need for additional input to sort out sensory information.

Physical characteristics - the key impact from the FXS disability in relation to sport is connective tissue problems. Loose connective tissue in joints causes problems - for Bradley he has fine motor issues in holding pens, and is unable to write or draw very well. In his arms and legs it means that his abilities to manage activities is affected eg. climbing, getting up after falling on the ski field.

Cognitive development - whilst Bradley has an intellectual disability, it is also important to focus on his strengths. Bradley learns well when shown things many times, rather than learning in the abstract context. He learns well with visual cues which can be used in a number of ways e.g. as prompts within activities. Success with learning and memory tasks is improved significantly when the information has a significant meaning for Bradley e.g. he is more likely to be compliant if it is something he is interested in.

Understanding the issues for the person in the first instance can allow everyone working with the individual to agree on management strategies in the various areas that are an issue. Consistency in applying these is one of the best ways for the individual to clearly understand what is required, and be more likely to be the best out of the day!

I encourage anyone working with someone in sport who has an intellectual disability, to seek as much information as possible. Parents are generally a wealth of information and are generally able to give you some reasonably quick and simple guide - what are the benefits? To see someone achieve their greatest possible potential in sport!

We are looking forward to the 2009 ski season and are always looking for other sporting opportunities! Thank you to those who are continuing to work with Bradley and our family in opening up his opportunities.

Kim and Adrian Caffell

Family News and Photos



Muffin loving Alex Norton (2y) with his sister Madison (1y) & brother Connor (4y)

Photos contributed by Christchurch mum Suzanne, who joined the fragile X community in 2007. She says if you want the recipe please email Alex



Edward "the artist" Elwood (4y) & his sister Sarah (2y)

Photos contributed by parents Trina and Arthur Elwood, who also joined the fragile X community in 2007, and are helping to organise the Christchurch gathering.



My Spider



My Car



Like My Hat?

Lawn Mowing Time



Helping Dad



Contact Information

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