



FRAGILE X TRUST (NZ)

Supporting New Zealand families living with fragile X syndrome

FRAGILE X TRUST (NZ) NEWSLETTER

April 2010

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Congratulations! It's Fragile X!

"Wow!! Awesome conference! Very informative! Great speakers! Great people!"

"Marvellous, very informative, very worthwhile, most enjoyable, amazing speakers, great conference, great organisation, lots of interesting information, great job everyone"



"I really enjoyed the conference, extremely informative, excellent speakers and a nice mix of topics... I'll certainly recommend this conference to colleagues in the future"

"Meal great - entertainment fantastic!"

The **3rd National Conference of Fragile X Syndrome** held in Lower Hutt last November was a great success. The Tongan performance preceding the conference dinner was the most memorable event for many, but the real success of the conference was due to the wonderful line-up of expert speakers and their willingness to engage with the participants – who were also a terrific mix of interested and motivated parents and professionals from across the education and mental health sectors.

Sincere thanks to our speakers: Randi Hagerman, Marcia Braden, Louise Gane, Jonathan Cohen, Bev Sher, John Forman, Kerry Howard and Anita Nicholls.

Another highlight for many was the address by the Honourable Tariana Turia, Minister for Disability Issues and Associate Minister of Health, which is reproduced in this newsletter.



Special points of interest:

Tariana Turia's conference address

Fragile X Survey Results

James Shelley goes camping

NEW CONTACT INFO

A word from the chair

I take over the role of Trust chairperson from my wife Anita with a little trepidation. Anita has done such a terrific job building support for our work and engaging with families across the country that she'll be a hard act to follow. Also, I'm still in the role of coordinator and treasurer as the Trust goes through the process of defining roles for paid workers to manage a lot of the coordination and book-keeping. In another step along this path, I'm pleased to announce that we have just taken on a part-time administrator. Lindsay Cooper will staff the Fragile X Trust Office, three mornings a week from 4 May – Monday, Wednesday and Thursday. Lindsay is Anita's aunt and comes to us with knowledge about fragile X, plus a strong background in teaching and website design. The office is located within the NZORD offices in central Wellington (see last page for contact details).

2009 was an extremely busy year for our family and for the Trust. Anita started working as an early intervention teacher at the Ministry of Education, which limited the amount of work she could do for the Trust. Meanwhile we still had the national conference to organise and had also begun the path towards establishing a New Zealand fragile X clinic, with the support of John Forman at NZORD and developmental paediatrician, Andrew Marshall. Life in the Hollis-Nicholls household was fairly fraught at times, to say the least. It seemed very appropriate then that part way through the year, the primary school that our sons attended decided to establish an annual award in recognition of the "persistence" that Ben and James had shown in overcoming their many obstacles to become successful and popular students. Coincidentally, the Trust honoured me with a "hard work / persistence" award at the conference last November – a shell pendant using the impenetrable door or operculum of the Cat's Eye sea-snail.

Certainly, the awards in both cases are apt – we Hollis boys are all hard-working and persistent when it comes to issues or interests that are important to us – you could say fixated. But that hard work and the resulting successes cannot be sustained in a vacuum. We all needed and continue to need consistent support, encouragement and advice, and the occasional gentle redirection. So, sincere thanks for all your support but please keep it up. The Fragile X Trust needs to know that we are succeeding, that you value us, and we need to know about ways that we can continue to make a difference to your lives. With this in mind, it's the time of year for you to renew your membership by completing the enclosed or online form and posting it to us with your optional donation.
– Cheers, Chris

Fragile X Trust Trustees – Who are we?



Chris Hollis, Chairperson – I have two sons with fragile X. Ben is 16 and James is 13. My wife Anita is past chairperson of the Trust and is now an early intervention teacher. We've both been involved with the Trust since 2006 and before that we established the Wellington support group. Our home phone number doubles as the Fragile X toll-free helpline. Please feel free to call anytime. Don't be put off by the answer phone – just leave a message and we'll call back. And if you get "Menswear", it's just James pretending he's Mr Humphries from "Are You Being Served". I have less time for fragile X work these days than I'd like as I'm increasingly busy in my other role as a paleontologist at GNS Science, a crown research institute. So my primary goal in the coming year is to expand the

pool of workers within the Trust, including a paid office administrator, a new treasurer and a new national coordinator – with the ultimate aim of establishing a clinic fully integrated with a national support network for fragile X families.

Andrea Lee – Our family was first introduced to Fragile X in 2007 when our son Andrè was three. Dan and I also have a seven year old daughter Yasmina (who is unaffected). For the last five years we have lived in sunny Nelson after many years in the UK and Bosnia i Herzegovina. I have a BA in sociology and a background in sales, interior design and English language teaching. My goals as a trustee are to be taking an active part towards achieving the aims and objectives of the trust. I'm particularly interested in continuing to raise the profile of FX in NZ, working towards a managed clinical network specialising in Fragile X, inclusive education, and increasing support and knowledge for women carriers of FX.



Senorita Laukau – I am Tongan and migrated to NZ in 1988. I spent some of my childhood years in Niue and so I can speak Niuean, Tongan and English. Some of my secondary school years were spent in Tonga and Fiji and I was a recipient of two scholarships at the University of the South Pacific, Fiji. I've just completed my Masters in Education at Victoria University. The most influential person in my life was my mother who was widowed when I was 13. Just watching her trying so hard to make ends meet made me want to make something of my life so I could support her and be what my father would have wanted me to be. I am married to Aisea and we have 7 children (3 of them are adopted). Our son 'Ofa (18 years old) was diagnosed with Fragile X when he was 3. His most recent past-time fun is to impersonate the Tua Man and fight any willing (or unwilling) partner he can find – including me!

Judith Spier – I have two awesome children – Danielle (12ys) and Liam (10ys) - with Fragile X. Danielle loves quieter indoor play whereas Liam likes everything sport! Liam is non-verbal, but boy can he make a noise when he does his haka (frequently)! My passion is playing softball, laughing, and attending the gym. My work background is many years as a Personal Assistant. However I decided that I wanted to be readily available for my children and their high needs, so for the last five years I have been a Teacher-Aide at a decile 1 school in Taita. My children have taught me so much over the years and I want and love to share my knowledge and expertise to help others.



Jayne Sorenson – Hi there, hope this finds you all well and smiling.☺ I have just been tricked into joining this wonderful Trust (just kidding). It is my privilege to join such a wonderful dedicated bunch. I have two amazing kids, Jaimee who will be 21 in August (not affected) and finishing her 3rd year at University and Grayson - I'm sure many of you have met my entertaining happy talkative wee guy (getting bigger by day) who always starts and ends my days with a smile. I could write a whole newsletter on his fantastic achievements since starting Intermediate this year and his outstanding transition- long may it last! but I am meant to be telling you about me. I am a PA to an orthopaedic surgeon in Lower Hutt. This keeps me very busy and I am lucky enough to work with an amazing bunch of very supportive people, which allows me any time off with Grayson's needs. I was on the BOT at Grayson's primary school for 4 yrs which has taught me a great deal. Now I

hope with everybody's support and input we can continue to achieve wonderful things for our very deserving children. I look forward to working with you all.

Submission to the Special Education Review 2010 by the Fragile X Trust

The Ministry of Education is undertaking a review of special education “to ensure that policies and processes are fair, consistent, reach those most in need, make the best use of government funding, and that parents have choices.” The Fragile X Trust welcomed this opportunity to address the many areas of concern raised by fragile X families. What follows are some extracts from our submission. The full submission can be downloaded from our website.

Fragile X syndrome is a relatively rare genetic disorder that causes a wide spectrum of developmental, cognitive, behavioural, and physical problems that impact on learning. Many individuals with fragile X are on the autistic spectrum but have a distinct learning profile.

Fragile X affects around one in 4000 individuals, but around one in 400 individuals are carriers for the disorder and may exhibit mild symptoms.

The Fragile X Trust is a parent-led support group that represents around 80 NZ families who have struggled or are currently struggling to ensure that their children get the support the need to achieve their learning potential.

With no expert professionals in NZ, the Trust has taken on the role of providing advice and classroom support on educating children with fragile X, guided by international authorities in the field and our own research into best practice.

We have three primary recommendations that build on existing services and need not require significant additional funding:

Training – All education professionals and para-professionals should have an introduction to the learning needs and learning styles of children with fragile X and related disorders like autism, and opportunities for ongoing training, through successful programmes such as “tips for autism”.

Information – Educators need access to information specific to educating fragile X children in New Zealand, including online resources and “go-to” specialists with expert knowledge on fragile X (or able to access relevant information via the Fragile X Trust). This can be accomplished by ensuring that all the initiatives relating to ASD

include information about fragile X.

Funding – Fragile X children have clear ongoing resourcing needs in the areas of language, communication, motor planning, and cognition that cannot be adequately or consistently funded through SEG but many struggle to meet the narrow definitions in ORRS criteria 4, 5, 8 and 9. The definitions of these criteria should be broadened or the verification threshold lowered or the system should be restructured to take more account of recommendations from the expert teams working with individual children.

Criterion 8: Many of our children have “needs arising from a severe disorder of both language use and appropriate social communication” but do not exhibit classic autistic behaviour, which is highlighted in the criterion descriptor: “these students usually distance themselves from social situations and seem to be largely unaware of people around them”. Fragile X children, and many others on the autistic spectrum who have received appropriate early intervention, do not fit this description yet still have severe language and communication disorders.

Criterion 9: Many of our children fail to meet this criterion because although they have ongoing needs in curriculum adaptation, language development and social communication skills, they do not meet the requirement of a third area of hearing, vision or physical needs.

Anita Nicholls, Andrea Lee & Chris Hollis

Fragile X Conference Address by Tariana Turia

Over the course of my lifetime, we have shifted house more times than I like to remember. Every shift there are some special boxes that I pack my taonga in - cherished photographs; works of art; treasures of the heart. These boxes I mark: fragile - handle with care.

I am delighted to be with you today, at this third national conference to support families living with fragile x; learning how to handle your families with care. Just as those taonga bring me such joy, what brings all of you here today is the joy of your family; and the commitment you have all made to ensuring the support and services are in place about this under-diagnosed disorder.



I am really pleased to see such an emphasis on supporting families; and I want to congratulate the group of parents who have demonstrated such passion for the work of the fragile x trust. Our knowledge about the impacts of the mutation of the x chromosome - and its relationship to autistic behaviours, learning problems or developmental delay is still relatively new, and as such the information you bring together is of great value to families affected by this disorder.

As I looked over your newsletters it was really inspiring to read the stories of Jayne and Janet; Bradley and Jaimee-Kate; 'Ofa and Siasosi; Jack, Phoebe and Emily. The newsletters describe the milestones and successful achievements celebrated within families - starting a new school; performing at assembly; winning a sports award. There's Alicia dressed up as a gorgeous ballerina; Matthew at the park; James creating a pottery work of art. And then on other pages there's a report on the Fragile X Alliance Clinic in Melbourne - medical director, Jonathan Cohen and coordinator Beverly Sher - who are special guests at this conference.

There's information about an international survey and the issues surrounding the ethical, local and social consequences around the disclosure of genetic information to families. There's an invitation to a workshop on improving care and support of those with rare disorders. But the overwhelming emphasis throughout all of the information I have been able to download on the Fragile X Trust is on supporting families to be great families. Indeed, I think there was just as much focus in the conference promotions on barbeques, picnics, swimming and kayaking as there was on the actual programme! And that's exactly how it should be.

Sometimes I think so much emphasis on the medical model of health, that we forget all of the other aspects of our wellbeing. I think of the wisdom of one of the greatest writers, Katherine Mansfield, who once said,

By health I mean the power to live a full, adult, living, breathing life in close contact with... the earth and the wonders thereof - the sea - the sun.

Last Thursday I had the most wonderful night, attending the EEO Diversity Awards in Auckland. The theme of the awards was Valuing People - creating value - and it was evident throughout all of the awards just how committed each of the workplaces was to supporting their employees - employees who were tetraplegic, had mental health issues, intellectual impairment, or various forms of disability. It was really exciting. One of the employers spoke about this word - disabling - saying instead that they looked at their workplace as enabling because of the special perspectives and experiences that added value to each of their lives. It was really heart warming to see that the talents and the gifts of employees were being nurtured within workplaces as varied as the snow sports industry; an accountants office; or a fast foods processor.

What your conference is all about, is ensuring that you are able to access the right specialists and support networks to ensure clinical assessment and management is in place; education is inclusive and healthcare is effective. Its success will be in the way in which it enables you all - families, professionals, supporters - to understand how the treatments and strategies debated here, may make a difference to your lives. It will be in enabling families to understand challenging behaviours - anxiety, aggression, self-harm and to know how to manage and to maintain a supportive environment.

It is a rare privilege to have two of the foremost international authorities on fragile x - Professor Randi Hagerman and Dr Marcia Braden - both here to address this conference. All of our international guests will bring with them vast experience and up-to-the minute knowledge about the medical and allied health management, the counselling and lifestyle options, the speech therapy, occupational evaluation and educational strategies that they know have proven successful. We will be richer for their contribution and I thank them both for being here to help us.

But I want to also really acknowledge the heroic efforts of people like Anita, Chris, Judith, Senorita and Barbara - the members of the Fragile X Trust. The mammoth commitment you have demonstrated in these last five years is outstanding. Each of you, as parents of fragile x children, know the feeling of joy in seeing your children thrive, and I applaud your generosity of spirit in wanting to see more parents receive the support you know can make such a difference.

New Zealand is also proud of the experience that people like Louise Gane and John Forman bring to the treatment of the fragile X Syndrome - together all of you are helping to support families to access the right support and to navigate a future ahead where behavioural and mental health issues do not become the only focus of attention. There are some big challenges ahead.

I wonder what efforts are being made to share the information for instance with whanau, hapu and iwi - and whether Maori families are accessing the specialist support that the Trust might promote. I would suggest that there will be some very sensitive areas for debate such as around genetic testing and screening. These are all areas where Maori have particular interest in terms of the respect we place on whakapapa - the protection of the sacred seed of life; the significance of genealogy. I would be interested too in learning how widely understood the fragile x syndrome is amongst Pasifika families or other ethnic communities across New Zealand.

The Australian and NZ Fragile X Family Survey

In 2009 the NZ Fragile X Trust and the Fragile X Association of Australia teamed up to conduct the first national survey of Fragile X families in our two countries. The study replicates a similar survey completed in the United States in 2008. The survey form was available online at the Research Triangle International (RTI), North Carolina. Invitations to participate were distributed through newsletters, email requests, partner organisations and hospital databases in Australia. The data were collated by staff at the RTI. They are presently being analysed by the project team. Caution needs to be exercised in interpreting the results as some cells are quite small.

In this newsletter we present a preliminary overview of the demographics of the sample and an overview of attitudes towards testing for Fragile X. Two more overviews will be provided in subsequent newsletters: one on education and employment and the other on availability and quality of services. More detailed analysis will be placed on our two websites in due course.

Terminology

Fragile X is a group of associated genetic disorders, Fragile X-associated Disorders (FXDs), that affect individuals across generations. Fragile X-associated disorders (FXDs) include:

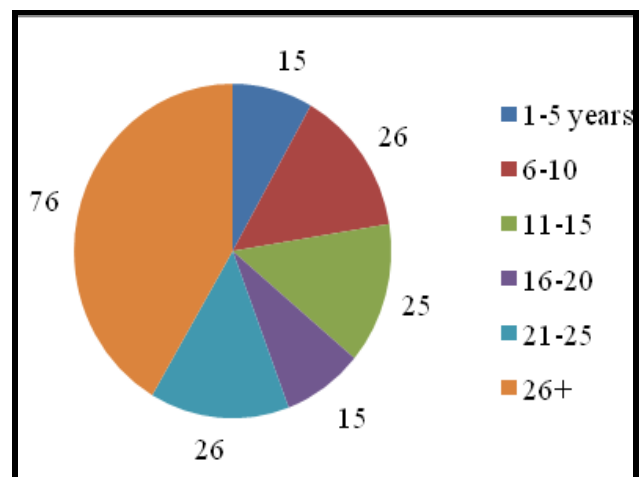
- ✘ Fragile X Syndrome (FXS) - most common cause of inherited intellectual disability, behavioural disorders and speech and language delays that manifests in early childhood in males and females;
- ✘ Fragile X-associated tremor/ataxia syndrome (FXTAS) - neurological disorder which may set in at 50 or over in both males and females, causing tremors, balance and memory problems, and cognitive decline;
- ✘ Fragile X-associated primary ovarian insufficiency (FXPOI) - causes irregular menstrual cycles, infertility and premature menopause in females.

Demographics

A total of 113 households representing 289 children responded to the survey: 16 households from NZ and 97 from Australia. Of the 289 children covered by the survey, 183 were affected by fragile X. Table 1 shows the sex and FXS status of this group of children.

Most (78%) of the 183 lived at home. As Figure 1 shows most full mutation FXS offspring are mature adults, indicating the nature of the long-term commitment of families, particularly to those with the full mutation. One third of all families had a family member who had turned down a job because of their FXS commitment. Forty nine families (nearly half) indicated their child needed either moderate or considerable assistance in day-to-day living.

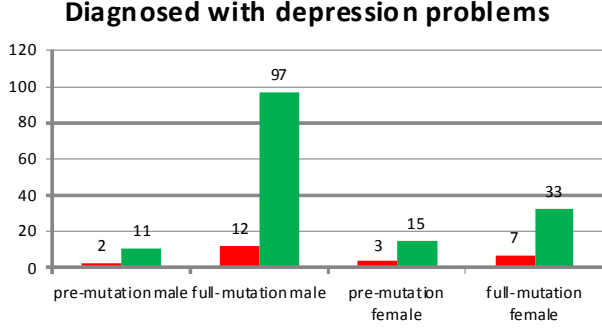
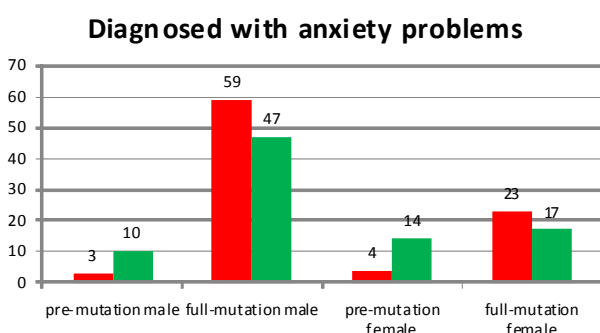
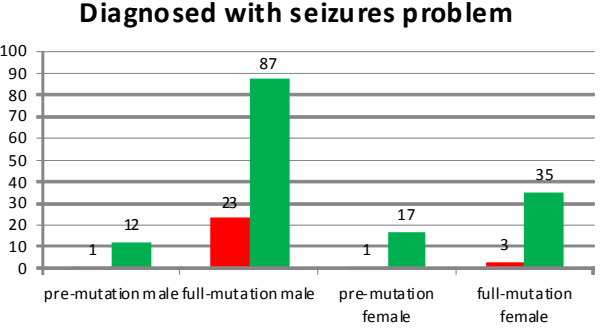
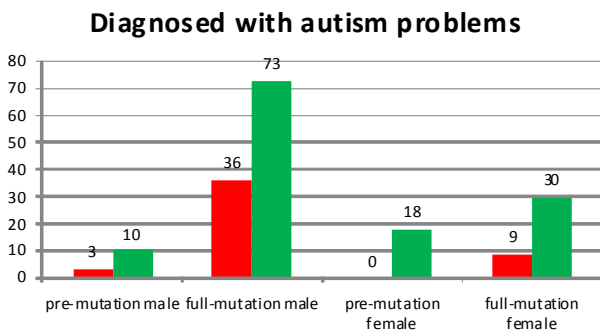
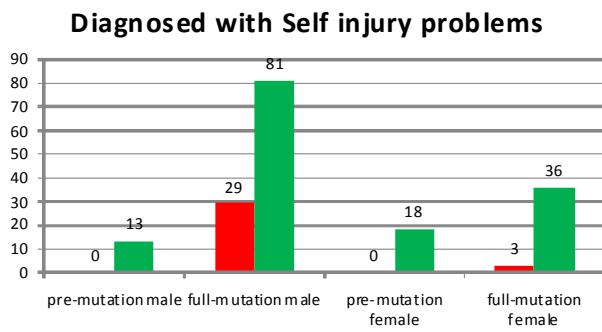
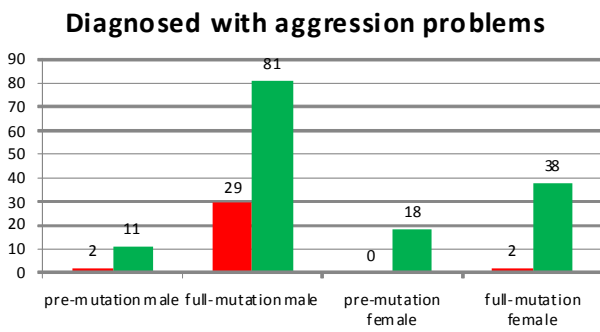
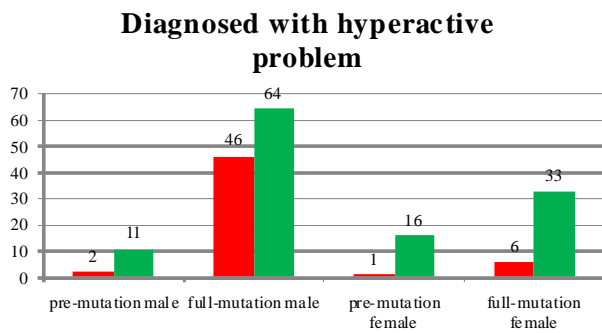
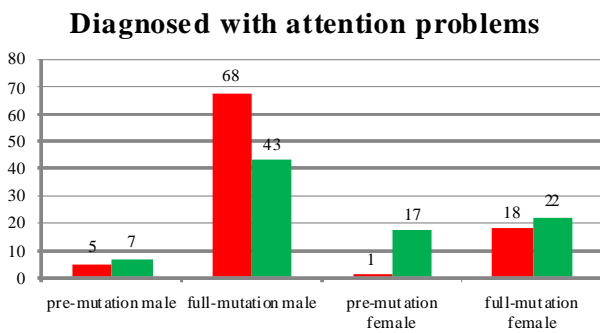
Fragile X Status of Child	No.	%
pre-mutation male	13	7.1
pre-mutation female	18	9.8
full-mutation male	111	60.7
full-mutation female	41	22.4
Total	183	100



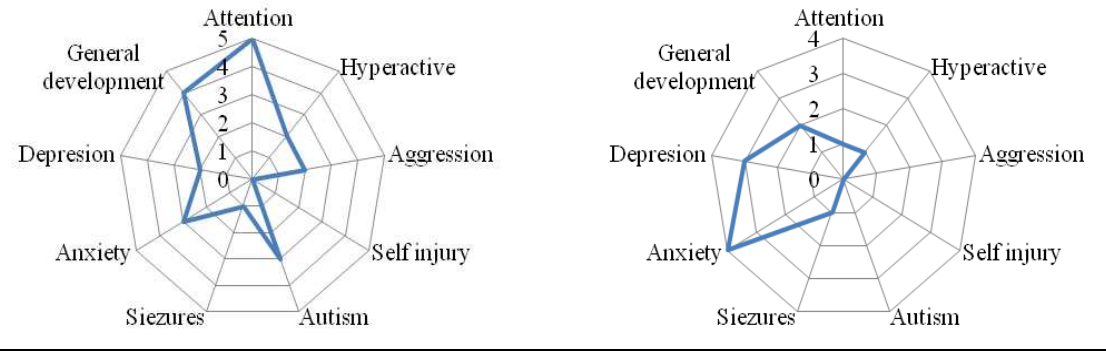
Occurrence of co-occurring conditions by sex and mutation status

The following charts show the variability of co-occurring disorders. For full mutation individuals, co-occurring conditions were quite similar though males have relatively more problems with attention, hyperactivity, aggression, self injury and anxiety. One of the important findings of the study is this difference in co-occurring conditions as experienced by *pre-mutation* FX males and females. At the pre-mutation level, while females have less difficulty with attention, hyperactivity or aggression they are considerably more prone to depression and anxiety. These differences have implications for education and behaviour management.

Charts of co-occurring conditions (number of persons) ■ = Yes ■ = No



Pre-mutation Males (n=13) **Pre-mutation Females (n=18)**

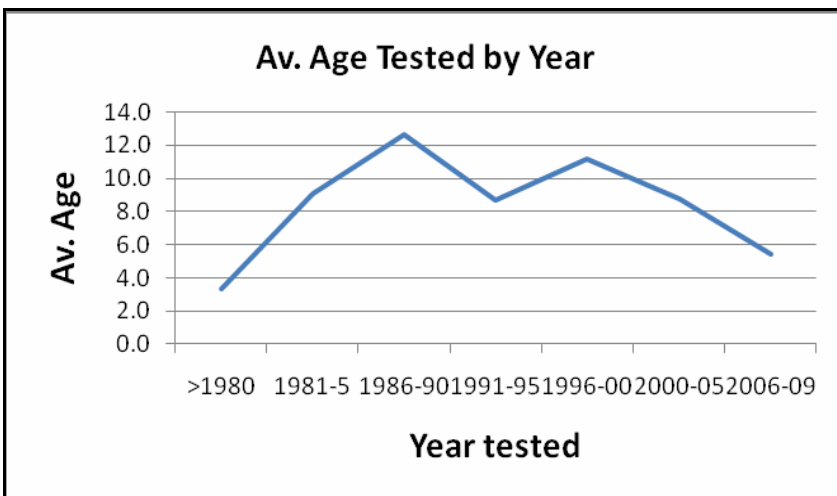


Knowledge of FXDs and attitudes toward testing

The sample data show that only 12 out of 113 respondents knew about their own or their partner’s FX carrier status before their first affected child was tested. The age of testing for FXDs has changed over time. Through the 1980s, there was an increase in the average age at which a child was diagnosed. No doubt this reflected a new awareness of FX syndrome and the technological capacity to test. More recently the average age has dropped to under 6, but this is still quite high compared to similar data from the US.

A number of questions were asked to gauge attitudes to testing for FXDs at various stages: 81% of respondents indicated that the best time to offer testing for both men and women is before a woman gets pregnant. If pre-pregnancy testing to determine carriers has not been done, most parents would prefer to know, during pregnancy, if their child was affected. A small number of respondents (9) indicated they did not wish to know during pregnancy.

Post-natal or newborn screening of all babies was even more strongly supported.



Tim Turpin
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 Centre for Industry and Innovation Studies Research Group
 University of Western Sydney

Dr Robyn Iredale, PhD
 Adjunct Associate Professor
 ADSRI
 Australian National University

Inclusive Education Action Group Conference

September 2009

Last year the Inclusive Education Action Group in conjunction with Standards Plus held their first national conference. I attended the conference as a representative of the Fragile X Trust to increase our profile, which involved being the person at our stand to give out information and chat to people about FX.

It was a multi-disciplinary conference with educators, parents, advocacy groups, academics and others involved in the world of disability. Many of the lectures and workshops were inspirational, with a strong focus on thinking about what inclusive culture and education means and what it would look like. I want to share this quote which I think many of us will relate to "To be included is not to be excluded. To be excluded is to not be included".

There was a strong political/social change focus which many of us as parents are probably to exhausted with day to day life to spend much time thinking about! Here's another quote that summed up some of the ideas expressed. Disability is "the process that happens when one group of people create barriers by designing a world only for their way of living". We need to remove barriers to change NZ "from a disabling to an inclusive society".

On a more practical note here are some of the useful ideas and pieces of information I gathered together with our FX community in mind:

1. Teacher Aides - A good practice model
 - a. Strong relationship between teacher and TA.
 - b. TA presented as a benefit for the whole class, introduced as teachers assistant for the class (to minimise stigma).
 - c. TA has clearly defined roles and responsibilities (included in the life of the school).
 - d. Designated place in the classroom for the TA.
 - e. Communication book between TA and teacher.
 - f. Home-school book between TA and parents.
 - g. Teacher does all the planning for student, TA has assistant role.
 - h. Regular meetings between TA and teacher.
 - i. TA always aiming for students to have presence, participation and achievement.
 - j. TA seen as a social facilitator, a social connector but knows when to become invisible.
2. An alternative model for assessment
'Narrative Assessment' model responds to children's learning and participation in context and enables goal setting and recording of successes. http://www.inclusive.org.nz/throughdifferenteyes/a_guide_for_teachers
3. Music Therapy
This is available as part of ORRS funding. Must be a registered music therapist. Contact; Dalphne.Rickson@nzsm.ac.nz
4. Halberg Trust
Fund up to \$1,500 to help with access to sport. eg. swimming lessons. www.halberg.co.nz
5. IHC has a library that we can access librarian@ihc.org.nz
6. IHC has a new DVD series about inclusive primary and secondary schooling and supporting families and schools. It's in our library.
7. Children's Commissioner has advocates we can access to work on our behalf to resolve issues with service providers www.occ.org.nz 0800224453 j.carroll-lind@occ.org.nz

Hope there's something useful there for you!

Andrea Lee

Excitement of First Overnight Tramp!



My 26yr old son James has Fragile X and lives at home with us. He attends a Community participation course 3-4 days a week called "Thumbs Up". Recently the outdoor recreation teacher there, a lovely lady called Jill Westenra who is an accomplished triathlete, suggested James might like to come on an overnight camp on Mt Bruce near Masterton. My first thought was one of panic to the thought of this, but James adores Jill and was really keen to go, so I told Jill I would come as a parent helper and that he could go, thinking that if I was there nothing could go wrong!

As we started to prepare for the coming trip 3 weeks away, James came down with an awful cold. He got cross every time his nose ran and was really miserable because he seldom gets colds, but after an anti-biotic he improved. Then I got sick so he was away from his course for a week. In the meantime they decided another staff member would go instead of me. Well, this sent me into quite an anxious state and I felt that I should withdraw James from the trip. But to my surprise James was still keen to go on the overnight camp which surprised me as initially he had said he wanted me to come.

I was still unwell and left the preparations till the last minute hoping the whole thing would not happen! But as the day drew nearer, I prayed for firstly strength to entrust James to others overnight and on a long tramp through the bush, and secondly for fine weather for the whole trip as James doesn't cope with changing clothes even if they're wet and I dreaded him getting another cold or flu.

Lo and behold the day of the trip dawned - a beautiful day with fine weather forecast for the next few days! Myself and other parents of clients going on the trip waved goodbye to our sons a bit gingerly, of course after checking numerous times that they had all they needed. I went home with an unusual peace about the whole trip. I believe God came through with that. I have to trust him more!

The next day I picked up a grubby, happy James who excitedly told of the long 6 hour hike they did on Mt Holdsworth, the hut they stayed in and the fun they all had, and how the hut caretaker was a very nice man etc.

James had an exciting new experience and he asked if he and I could go back up Mt Holdsworth soon! I'm now hoping we will be able to do that some day soon and I know that the hard work of the staff contributed to a successful camp and I will happily encourage James to go on the next one!

I hope this is encouraging to other parents in a similar situation and they will, like me, overcome the fear of other people being able to give the attention we give to our sons and daughters! God bless

Barbara Shelley and James

South Island Family Gathering

When: 29 - 31 October 2010

Where: Hamner Springs, Mountain View Top 10 Holiday Park

Come and catch up with all the wonderful South Island families and have some fun and relaxation in the hot pools.

Book it in your calendar now!

More details to follow as we confirm arrangements.

Contact Lindsay for more info: admin@fragilex.co.nz or 0508 938 0552 (toll free)

Caffell Family News

Hello from Dunedin! Its hard to believe that it will be April by the time you are reading this newsletter. Bradley turned 13 in March - 3 teenagers in the one house!

Xmas was a family time with 10 days in Pounawea (in the Catlins for those who don't know- I suggest you Google it - it's beautiful country). The weather was not great most of the time but as seasoned campers we made do. Following that we went to Alexandra for a week - we had 3 days with the Wellsteads - their B & B comes highly recommended! The weather was better but still not great. A weekend at Waikouiti (North of Dunedin) staying with friends saw the end of a relaxing family time.

The new year is well underway - Stacey begins her university experience this year, majoring in Japanese. Jaimee is year 10 and really enjoying the year. Bradley has taken a bit to settle this year which we are continuing to work on with the school. The information that we gained from the FXS conference last year has been very valuable in helping put together a plan for this year for Bradley.

This year will see the Independence Games (Google this - it takes place in Christchurch 10-11 April) - it is athletics and swimming events that we have a small Otago team entered in. Skiing will again be a focus for the winter months, as well as looking at other sporting options with Special O. Planning for transition for Bradley for high school in 2011 will be one of the biggest challenges for us.

I hope this finds you all well as you embark on your new years with your families. I have included a collage of photos of our Xmas break. Hope to see some of you through the year.

Kim and Adrian Caffell



Managed Clinical Networks for Rare Disorders

In November 2009, the NZ Organisation for Rare Disorders (NZORD) hosted 25 participants from paediatric specialties, DEBRA NZ, LDNZ, Rett NZ, NZ LAM Trust, Cystic Fibrosis Association, Fragile X Trust, Fertility network, Muscular Dystrophy Association, Parents of Vision Impaired, Heart Children NZ, and Ministry of Health and National Health Board officials, and the Paediatric Society, to discuss the rationale and necessity for improving clinical care for complex chronic diseases.

The meeting opened with apologies and wishes for a successful meeting from a further 21 support group leaders and officials who were unable to attend because of prior commitments. The context for the day was set by a message of support from Health & Disability Commissioner, Ron Paterson. His message included the quote: "I have sympathy with the position advocated by NZORD and its network. In my view, there is a responsibility to make reasonable provision for the needs of those with rare disorders, rather than leaving them to languish on priority lists."

The Chair of the National Health Board, Murray Horn, presented at the meeting and after open discussion he agreed that the NHB would look at two models for managed clinical networks that NZORD wished to propose, in addition to the genetic service project which is high on the NHB agenda.

Subsequently, NZORD's trustees resolved to submit Lysosomal/Metabolic diseases and Epidermolysis Bullosa to the NHB as the proposed two models of managed clinical networks. Key considerations in this decision were the background work already done on service delivery for these diseases, and the good level of collaboration already in place between the relevant support groups and the responsible clinicians. Also factored in was the relative "do-ability" of these two models given their small size, and a degree of urgency given the vulnerability of the current service arrangements for both the professionals and patients.

In March this year, John Forman was appointed to the strategic advisory group that will oversee the development of a Child and Youth Clinical Network under a Ministry of Health contract to the Paediatric Society. John has been appointed to bring knowledge of consumer participation and representation to the group's work. It is apparent from the first meeting discussion and the work plan agreed with the NHB, that initially there will be emphasis on establishment issues, and less on individual service improvement plans.

These are all positive developments for the New Zealand fragile X community. The Fragile X Trust is working with Dr Andrew Marshall, developmental paediatrician at the Puketiro Centre, Porirua Hospital, to develop a model for a fragile X clinic. In this endeavour, we will benefit from the lessons learned by the two more mature models, as well as from guidance through the international fragile X clinics initiative that is being promoted by Prof. Randi Hagerman, Louise Gane and the US National Fragile X Foundation.

Don't forget: go to <http://www.fragilex.org>

12TH INTERNATIONAL FRAGILE X CONFERENCE

JULY 21-25, 2010



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