Fragile X Syndrome is the leading inherited cause of intellectual disability and the most common single gene cause of autism.

Characteristics of FXS include mild to severe learning difficulties, anxiety, ADHD, delayed and repetitive speech and autistic-like behaviours.

Strengths include strong imitative skills, good memory and visual processing, great sense of humour, empathy and a desire to be helpful.

It is estimated that 1 in 800 males and 1 in 260 females are carriers of FXS.

Female carriers have a 50% chance of passing the gene mutation to each of their children. Male carriers will pass it to 100% of their daughters but none of their sons.

Some carriers may be at risk of developing fragile X-associated disorders including a late onset neurodegenerative disorder (FXTAS) and early menopause (FXPOI).

Around 12,000 New Zealanders have Fragile X Syndrome or are carriers.
What is Fragile X?

Fragile X refers to a group of genetic conditions now referred to as “Fragile X-associated Disorders”.

The disorders include:

**Fragile X Syndrome (FXS)** is a genetic disorder caused by the *full mutation* of the FMR1 gene (a change in the DNA structure) on the X chromosome. It results in a wide range of developmental and behavioural issues and is the most common inherited cause of intellectual disability worldwide. It affects around one in 4000 individuals.

**Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS)** is a condition affecting some male carriers (and in rare cases, female carriers) of the *premutation* over age 50, causing balance, tremor and memory problems.

**Fragile X-Associated Primary Ovarian Insufficiency (FXPOI)** or early menopause is a condition affecting some female carriers of the *premutation*.

Fragile X can be passed on in families with no apparent sign of the condition. In some families, multiple generations are affected.

All children with delayed development or autistic-like features should be tested for Fragile X Syndrome.

Cover photo - Edward, Trina and Sarah

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Fragile X New Zealand is a parent-led charitable organisation which aims to:

- support New Zealand families living with fragile X
- raise awareness about fragile X within New Zealand
- assist individuals affected by fragile X to reach their full potential

www.fragilex.org.nz
It was 1993 when first I heard about Fragile X. My son Ofa had been admitted to hospital for what my GP thought was an insect bite. The hospital did some blood tests and I remember picking up a letter from the Genetic Services some days later where they informed me of Ofa’s diagnosis (unrelated to the swollen arm) for Fragile X. Even now, while writing, the weight of what I felt then still make my tummy turn. Later that same year, I was invited to a presentation at the Wellington Hospital about Fragile X. This was the first time I had met Louise Gane. There were only a handful of people in the room and I was the only brown face there.

What a joy it was to attend a workshop in 2007 in Wellington for Fragile X targeting educators and Fragile X families. That’s where I met the other Hutt residents with Fragile X connections. Ever since then, although some challenges are still there, I no longer feel Fragile! I feel connected to a lot more people/families/friends and experts. In a way, my family still feel very special because we are the only known Pacific family with Fragile X!

This year we will hold our AGM on 1st November at the Taupo gathering again. Every year, I look forward to the AGM gathering because it feels like a family reunion and every year, it is awesome to see so many familiar faces as well as starting to know new faces and new families. I also note that the children who are now growing up are starting to recognise each other and us, the parents. It is great that we try our hardest to organise the Family gatherings to coincide with the AGM so we can see more of you and as well as enjoying each others company and friendship.

The work that FXNZ does is very important to me because I wouldn’t wish the lonely and horrible feeling I experienced when I first heard about Fragile X, not knowing who to turn to or how to support my own child and family. I am so looking forward to finding another Pacific Fragile X family but then it would mean mine won’t be special anymore!

‘Ofa atu – Senorita Laukau MEd, Trustee
National Coordinator’s Report

There’s lots to share in our Spring Newsletter, you’ll be amazed what’s happened over winter! Thank you to everyone who

joined us in spreading awareness over Fragile X Awareness Month in July. We used Facebook as our platform predominately and had over 13,000 views on the FXNZ page in July! This included ‘Did you know…?’ Fragile X information bites. Check it out if you haven’t already. A huge thanks to Pippa in Alexandra and Vicki and Veronica in Whangarei who held awareness raising fundraisers. You can see Vicki and Veronica later in the newsletter in the t-shirts they had especially printed!

Recently we received support from the Frozen Funds Charitable Trust to run more ‘No Longer Fragile’ workshops in schools. This is exciting news because schools are increasingly requesting the workshop and we have lacked the resources to keep up with demand. So let me know if you and your school are interested.

Currently we are preparing for our annual Fragile X Family Gathering in Taupo the first weekend of November. It looks set to be the biggest yet with potentially over 100 people. I can hardly believe it! Just goes to show how committed families are to getting together and sharing the experience of living with fragile X. Not to mention the fun to be had at DeBretts! We have also organised Tony McLean from Imagine Better to present a workshop on Future Planning. There’s still time to sign up if you haven’t yet and FXNZ can help support families who need financial assistance to get there.

It’s exciting to see families connecting around the country for coffee mornings, dinner out, and even a walking group! Isolation is often an issue when a family member has special needs. Remember support and information is just a click or a phone call away!

Andrea Lee

Fragile X Clinical Forum

The Fragile X Clinical Forum is an opportunity for a discussion via video conference link between families affected by Fragile X Syndrome, paediatricians responsible for the local care of children with Fragile X and Dr Andrew Marshall, Developmental Paediatrician and specialist in Fragile X Syndrome.

This is a free service available to all families. Families can use the service more than once as the need arises.

Please contact FXNZ for more information or to register for the next clinic.
Activities and events since our last newsletter in June;

**Fragile X New Zealand AGM**

The Annual General Meeting for FXNZ will be held 1st of November 2013 at 7:30pm in the Pavilion at DeBretts, Taupo. All are welcome to attend. Your input is important!

**North Island Family Gathering**

This annual event will take place over the weekend of the 1-3rd November at DeBretts in Taupo. Last year we had a record 28 families attend and we look set to break that record this year. We plan to hold a workshop again, with details available closer to the time. Accommodation can be booked at www.taupodebretts.co.nz or 07 378 8559. Remember to ask for the 10% discount for FXNZ families. FXNZ can help support families that need financial assistance to attend.

**Zumba Fundraiser**

Vicki and Veronica held a hugely successful awareness raising fundraiser in Whangarei. See photos later in this newsletter. Thank you from FXNZ.

**Charity Golf Day Fundraiser**

The date has been set for our next Fragile X Charity Golf Day fundraiser. If you would like to join us mark Wednesday 13th November in your calendar now! Currently we are looking for donations for prizes. Please contact Andrea if you can help.

**Facebook**

We continue to use Facebook to raise awareness about Fragile X and to share information about what’s happening in our community. www.facebook.com/Fragilexnewzealand

We now also have two additional closed groups for parents and grandparents to share their experiences of living with Fragile X in NZ. Families can contact FXNZ to join.

**Family Gatherings and Get Togethers**

Families in Wellington met in April and families in Auckland met in April and May and have also held several coffee mornings. Families in Whangarei and Nelson have also met for coffee mornings. If you would like assistance to get families together in your area let us know, we are happy to help.

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**Useful websites and links**

Useful websites for information about fragile X:

1. **Fragile X New Zealand**
   www.fragilex.org.nz
2. **The National Fragile X Foundation**
   www.fragilex.org
3. **Australian Fragile X Association**
   www.fragilex.org.au
4. **The Fragile X Society**
   www.fragilex.org.uk
5. **Imagine Better**
   www.imaginebetter.co.nz
6. For information about education and behaviour www.marciabraden.com
8. **Information about FXTAS**
   www.fxtas.org
9. **Fragile X research**
   www.fraxa.org
10. **Parent to Parent New Zealand**
    www.parent2parent.org.nz
Two years ago we made a decision to apply to enrol our son Matt, now 16 years old with a dual diagnosis of FXS and Bipolar Disorder, into Hohepa Residential Boarding School in the Hawkes Bay.

What started out as a hugely difficult journey for our family has become a very positive change for each and every one of us. Here’s a little about our journey.

The Process

On first deciding that we wanted to look at Matt attending Hohepa, I contacted the school to chat with them about the possibility.

They arranged for us to visit with Matt to look around and join them for lunch at the school. First they showed us around the school and we met with the principal to discuss how they operate, and for them to find out a bit about Matt. We had to take along any recent reports, IEPs etc. from school, paediatrician, and the psychiatrist. They also had a parent attend the meeting to answer any questions we might have from a parents’ perspective.

While we were in the meeting, two of the specialist teachers took Matt for a walk to see their rooms to see if they could engage him.

After this, we met with the director and he showed us around the boarding houses and introduced us to some of the house parents and explained a bit about the application process.

While he said they would be happy to take Matt and that they currently had a couple of places available he told us that they could only take Matt subject to Ministry of Health approval.

The first step in getting approval was to contact our Needs Assessment and Service Coordinator (NASC) provider, who then had to carry out a reassessment of Matt’s needs. The NASC are responsible for making the application to the Ministry of Health, so it required a close liaison with our case-worker. They were required to ensure that we had tried everything within our community to meet Matt’s needs, as the Ministry of Health have very specific expectations that if at all possible the young person is catered for within their local communities.

As there was little within our community we hadn’t tried our NASC provider was very supportive of our application, though they did suggest enlisting the services of a behaviour management specialist as we hadn’t used one for several years and that was one expectation the Ministry would have.

Once they had agreed to place an application for Matt to go to Hohepa, the school and paediatrician and psychiatrist were required to provide a letter of support.

Again we were very fortunate to have full support from both these services, as they both viewed Hohepa as a positive step for Matt.

While the NASC were completing this process and sending it off to the Ministry, we were also required to meet with CYFS (Child, Youth and Family Services).

CYFS role is to ascertain whether or not it is in the best interests of a child under 16 years to be put in an out of home placement. Had we sent our older son Sam to a boarding school this
wouldn’t have been a requirement, however because Hohepa is partially funded by the Ministry of Health, it was a requirement. At the close of the CYFS meetings we had to sign a Section 9 for an out of home placement.

**Transitioning Plan**

Once approval came through from the Ministry things happened pretty quickly.

With the help of a behaviour specialist who also works as an advisor to the Hohepa staff, we created a transition plan to prepare Matt for his new school.

After our visit to Hohepa with Matt, we had discussed with him how we thought it was cool to have a school on a farm, and explained that the kids at the school stayed in the houses we had looked at and went home only in the school holidays. We were very relieved when Matt piped up with “I’d like to stay there”.

To help prepare Matt further we talked to him about boarding schools and how both his granddads and his aunt had gone to boarding school and how it was an exciting thing to do. We also talked to him about how his brother Sam was leaving home next year to go to university and he would be sleeping there and that leaving home was something everyone did and it was part of growing up and becoming a young man. This seemed to appeal to him and while anxious about going he seemed to be excited about the prospect.

Matt started at Hohepa in January 2012, so we visited Napier a couple of times during the holidays to familiarise him with the area and each time we drove around the Hohepa environment.

This preparation, along with the behavioural specialist we had worked with holding a training day at Hohepa for the staff who would be working with Matt, ensured that he had a very smooth transition.

Matt has now been at Hohepa for 18 months. He is enjoying newfound independence from his family, something we had found very difficult to achieve. He has lots of friends and supportive carers there, and we are rested, and able to enjoy Matt when he is home in the holidays. He enjoys a wide range of daily activities not offered at other schools, including helping with planting, growing and harvesting of foods grown on the farms at Hohepa. He has a very healthy lifestyle including a diet based on organic and biodynamic food, much of it produced on the Hohepa farms.

Jodi Heenan

Otago

*Photos: Matt enjoying time with Mum and Dad in the school holidays.*
New Zealand FX Drug Trial

An entirely new Fragile X treatment strategy has emerged...

New Zealand-based biotech Neuren Pharmaceuticals has achieved impressive preclinical results in the Fragile X mouse model with two of their lead compounds, NNZ-2566 and NNZ-2591. These compounds are examples of a new class of drugs based on insulin-like growth factors (IGF-1).

On 29th July 2013 Neuren Pharmaceuticals Limited announced positive results using Neuren’s second drug molecule, NNZ-2591 in a mouse model of Fragile X Syndrome (FMR1 knockout mouse model).

In summary, NNZ-2591 was shown to reverse the differences between normal (wild-type) mice and FMR1 knockout mice, normalizing known Fragile X neuronal, behavioural and biochemical characteristics.

Commenting on the results, Larry Glass, Neuron’s CEO, said “We are truly excited with the outcome of this study. These results in a well-accepted model of Fragile X Syndrome are compelling and reinforce our belief that NNZ-2591 is a valuable compound with significant promise as a therapeutic for chronic neurological conditions. That both NNZ-2566 and NNZ2591 exhibit significant benefits in this model suggests a “class effect” which has not previously been reported, in which two synthetic analogues of naturally occurring neuropeptides show therapeutic potential in the same condition.

FXNZ has contacted Neuren Pharmaceuticals in New Zealand offering a congratulatory message on their success. We hope to know more soon about potential clinical trials that may follow from the preclinical success.

Education Strategies

Best Practice Supports for Children with FX in the Classroom

Environmental accommodations;
⇒ Provide structure and predictability of schedule
⇒ Provide opportunities to be included with typically developing peers
⇒ Use natural lighting wherever possible
⇒ Provide support strategies for transitions ie. transition object, job or task to move from one location to another
⇒ Remove or minimise stressful situations where possible
⇒ Plan and adapt for upcoming noisy or potentially stressful events if not avoidable
⇒ Avoid crowded areas; help students to gradually desensitise to crowded environments
⇒ Encourage opportunities to move

For FXS learning resources visit www.marciabraden.com
FX Community Events

Veronica and Vicki in Whangarei organised and held a ‘Zumba for Fragile X’ event at the beginning of August. Well done guys!

Here they are out and about Whangarei in their F.Xercise t-shirts delivering flyers. Thanks to Zumba instructor Cara Burndred for donating her time and to Rarimu Avenue School for the use of their hall and supporting the event!

North Island Family Gathering

1-3rd November 2013 Taupo DeBretts

Book accommodation at DeBretts www.taupodebretts.co.nz or 07 378 8559

Friday night  5pm family catch up, 7:30pm AGM, 8:30pm Blokes night out
Saturday  8am Breakfast out with the Mums, Grandmothers and girls
          10:30-12.30pm Workshop
          1:30pm onwards meet at DeBrett hot pools for family fun!
          5:30 onwards Family BBQ dinner at the Pavilion
Sunday  Free time and pack up

The ‘X’ is everywhere!

Zumba for Fragile X! A fun way to raise awareness and fundraise for FXNZ

All fragile X families welcome!!!
Come and join the fun!
When Ben left school at the end of last year I felt a little like I felt on his first day at school - slightly bewildered at what life would be for him and us. But this was an event I had planned for. I started looking for answers to what we could put in place for Ben several years ago and to be honest I haven’t yet found a perfect answer.

I went to a workshop by Imagine Better, an organisation who “assist families to imagine a better way of life and provide the support and encouragement required to achieve their goals”. The key points I got from the workshop were:

**Start with your children's interests and strengths. If possible find out what goals or dreams they have for their future.**

This takes bravery on our part as some days it is hard to believe our children have dreams or are capable of achieving them. Ben told me that he wants to own a farm like his grandfather and become a train driver. Although being a train driver for a NZ rail company is out of reach for Ben I realised that Ben could become involved in the local steam train society. Once Ben joined, he very quickly felt that he was one of the working team at the railway. Ben often gets to sit in the engine with the driver. One day one of the guys let Ben drive the engine. He was over the moon.

Another idea that was suggested at the workshop was to;

**Make sure your children are well connected with their communities. The best way to become involved in an organisation is to have a role that is important to the group.**

Ben felt part of the team at the railway because he found a role or way of contributing; mowing the steam train society’s lawns. The other society members are very happy for Ben to mow the lawns as it allows them to spend more time on the trains.

The next conference I went to was the Inclusive Life Choices conference. I was the only parent at this conference. It was designed to give service providers ideas to “promote an inclusive society where we realise vocational aspirations of all New Zealanders especially those with significant barriers”.

Geoff Waghorn talked about the importance of employment for maintaining people’s sense of well-being. For people with mental health issues research states that “employment is one of the most effective treatments” because it connects people with others and provides a sense of purpose. It makes sense that either employment or activity that provides purpose and connectedness is important to our children also. Geoff also reported the depressing news that work placement services frequently struggled to successfully provide work for their clients.
Two speakers discussed an alternative idea to gaining employment from others. Guy Turnbull talked about social enterprises. A social enterprise is a business set up to support a social good rather than just make money for investors. Tony McLean from Imagine Better talked about a type of social enterprise called a micro business: a small scale business that provides activity for someone with a disability. The business does not have to make money, only fulfill its aim of providing employment and activity for the person it is designed to support. The example Tony gave was a lad with Down Syndrome who loved walking dogs and started a micro business walking the neighbourhood dogs. He is paid 10 dollars a walk. Imagine Better provide advice and guidance to those who wish to set up a micro business for their family member. Guy Turnbull said that a successful social enterprise must provide a high quality product or service and have methods of monitoring the quality of service. He also said that it was OK to take risks when setting up a business. We do not have to be totally risk adverse when considering our childrens future options. Better to try and fail than not try at all. I can imagine a micro business working for Ben. Setting something like this up would be challenging.

The conference also made sense of my experience of transition services. There is a big gap between government rhetoric and practice. There are fantastic services in some areas and very poor services in other places.

Unconnected to all this I ran into Ally Attwell, whose has started up an organisation that promotes NZ sign. Check out her web site


Anita Nicholls
Wellington
FXS and Autism
Similar But Different
Clinical Insights Into The Similarities And Differences for Diagnosis and Treatment

While it has long been known that individuals with fragile X syndrome often exhibit autistic tendencies, only very recently has the possibility been raised that the two conditions may have considerably more overlap than previously thought. Scientists at various Fragile X centers are studying whether this overlap may extend beyond mere behavioral similarities but perhaps include genetic or biological components as well. That research may yet prove to have far-reaching effects. Meanwhile, parents, educators and clinicians in the FX field have continued to note the similarities and differences between the two conditions so they can plan appropriate interventions based on the specific characteristics and needs of each individual. It was in that spirit that a well-attended panel discussion at the 13th International Fragile X Conference in Miami pondered the topic: “FXS and Autism: Clinical Insights into the Similarities and Differences for Diagnosis and Treatment.”

The discussion provided clinical perspectives on the behavioral differences between fragile X syndrome and what are thought to be core features of autism. There is still much to be learned about identifying behaviors that suggest the presence or absence of autism in FXS, so much of the discussion was exploratory and tentative. As the science advances, researchers and clinicians will achieve a deeper understanding of the overlap between the two conditions, and how that overlap affects both of them. Moderator Vicki Sudhalter, PhD, led a distinguished panel of clinicians that included Tracy Stackhouse, MA/OTR Sarah Scharfenaker, MACCC·SLP, Walter Kaufman, MD, and Richard Belser, PhD.

⇒ Fragile X syndrome causes a range of functioning across domains. It is a specific, identifiable condition with a known genetic cause. Autism is identified by a cluster of symptoms rather than a specific condition, and it has many causes, most of them unknown. There is overlap, in that some individuals with FXS may have autism, and some may not. Additionally, FXS accounts for the leading known genetic cause of autism.

⇒ Clinicians must understand the differences between the two conditions in order to avoid misdiagnosis and improper treatment. Likewise, clinicians must appreciate the similarities. Harnessing what is known about autism in particular, given its larger cache of treatment strategies, can help advance treatment and educational plans as appropriate.

Characteristics common to both autism and FXS include poor eye contact (more on that below), social deficits, atypical language and repetitive behaviors. The core deficit in autism is social interaction. The core deficit in FXS is intellectual function and hyperarousal/anxiety. A key point related to these differences: People with FXS tend to be deeply desirous of human interaction, but the social anxiety that also typifies the condition often causes them to act otherwise, which prevents success. People with autism are largely unaware of the function others serve in relation to themselves, hence they rarely seek social interaction.
Eye contact is a key element of social interaction, and though “poor” eye contact is symptomatic of both FXS and autism, the type of eye contact is substantially different. People with FXS directly avoid eye contact, looking off in another direction to cope with their social anxiety, while people with autism are unaware of why they should use eye gaze as a source of information or interaction. Insisting on eye contact with those who have FXS is most always counterproductive, leading to greatly heightened anxiety. Insisting on eye contact with those who have autism simply tends to be ineffective.

Even when they are staring off elsewhere, people with FXS tend to be acutely aware of their surroundings. Like a good politician or salesperson, they “read” a room effectively, accurately gauging others’ moods and anxiety levels. They long to participate, to joke and be joked with. They want to be inside a social circle—but they typically need a great deal of acceptance, invitation and training to be successful at it. In contrast, people with autism more often really do want to be left alone, and attempts to include them in social activities thus face more severe obstacles than with FXS.

Imitation is a pivotal developmental skill that is generally a strength for those with FXS and typically impaired in people with autism. If imitation is impaired in those with FXS, it provides useful information to help determine additional diagnosis and treatment plans.

Teachers and caregivers often say they don’t need to know about FXS because they have previously had children with autism in their classes or homes. But interventions appropriate for FXS may be quite opposite those of autism.

Both FXS and autism are typified by repetitive behaviors, but in FXS, this is most commonly seen in hand-flapping and body-stiffening. Those with FXS tend to exhibit repetitive behaviors due to excitement, anxiety, or difficulty “stopping” or inhibiting their behavior. People with autism engage in those behaviors as well, but for less specific and more varied reasons. What appears to be a need for vestibular stimulation results in much spinning and jumping; what appears to be a need for sameness results in restricted repeatable actions such as rubbing a piece of wood or twirling a string; what appears to be a need for soothing results in pacing and rocking.

At base, most FXS behavioral issues are traceable to the twin challenges of managing anxiety and hyperarousal. Autism, being the cluster of conditions it is, is more complex and multi-faceted in its behavioral roots and manifestations.

We know more of what to do for FXS today than ever before, while autism remains more challenging owing to its greater variance and the much lower level of social need exhibited in the condition.

The crucial point for teachers, therapists and others involved in the care of those with FXS is not to lump them in with autism as more or less a common diagnosis requiring a common set of interventions. FXS is still best treated utilising what is known specifically about the condition.
An Assistance Dog for Matthew

Early last year we got in touch with Julie Hancox from Assistance Dogs New Zealand after talking with a man from Mobility Dogs NZ about dogs and their benefits to ASD children. We had never really thought of a dog, the kids were scared of them and I wasn’t sure how it would help Matthew. Julie explained the possibilities and the potential for Matthew, she showed us some dogs she bought on the day, which Matthew loved, and she showed us videos of kids with her dogs and what the dogs could actually do. Chris and I spoke at lengths about the pros and cons and we decided we needed to test drive one first.

After filling in a million forms about Matthew, our family and Matthew’s needs, we met Basil. Basil was a pup they had got from the Australian Guide Dogs to be their stud dog. He was a big, goofy Golden Labrador who just melted our hearts! He was amazing and that’s something coming from a cat woman! He was incredible with Matthew, Jarrod and Alicia and indeed with me too. He stayed with our family for nearly six months and in that time the kids, especially Matthew, went from being terrified of dogs to being in love with Basil.

We were suddenly able to take Matthew to the mall, to MOTAT, to school fairs and in fact many crowded places he had refused to go to before. Matthew also became instantly popular at school. Every morning we went in with Basil and Matthew showed his friends. Basil would just lay there and let thirty kids pat him. He got read to, shown the iPad and spoken about at news almost every day. Basil changed Matthew. He showed him the wow factor of having a friend; he learned responsibility, to feed Basil and he even learned to use the poopa scoopa.

Basil then went back to the farm and we had Annie come to stay. Annie was a three month old Black Labrador and very cute. Unfortunately she was also jumpy and mouthy and loved to run up to people at speed... definitely not compatible with Matthew. She stayed nearly five months and then we had a break from dogs. Meanwhile Basil’s sister Bella had given birth to nine pups and we were next on waiting list for a permanent dog.

We patiently waited for these pups to grow knowing that puppy age was definitely not for our family. In mid-August we met Chance.
He was a 10 month old Black Labrador who would be Matthew’s Assistance Dog. From the moment he moved in he was perfect for Matty. He was big and goofy, docile to the max and most of all didn’t mind Matty kissing, patting, being laid all over and being called endlessly to come. We were sold and decided Chance would become part of our family.

Next was the task of fundraising a goal of $20,000 for Chance. We held cake stalls, busking days, a garage sale and set up an online fundraising page. Family and friends donated and we couldn’t believe how fast the total kept going up! We had a few very nice surprises from family friends in Australia and even a deceased estate donation towards it of a large amount. We have currently raised approximately $14 000 and have applied for a grant for $5000. Chance will need to visit the vet soon and then will go back to the training farm to complete his training. We are hoping he will be trained to be Matthew’s companion, safety monitor when out and about, be able to do the ‘drop and hold’ technique when Matty wants to run off and most importantly be Matthew’s best friend. He will allow Matthew to catch buses, go on outings and teach Matthew responsibility and caring for someone else. Already they are best friends, but with training, he will be the best friend Matthew could ever hope for. Importantly he is great with the rest of us too. Our experience up until now has been amazing. Julie is always just a text away and all the dog food and vet expenses are covered by Assistance Dogs until they get signed over to us. We have loved our puppy walking experiences, our fundraising and most of all meeting Chance. Visit Assistance Dogs NZ on Facebook or their website and read about the amazing things they do.

Leona
Auckland
If you are moving house, changing phone or email address please contact us!

Do you have something of interest to put in this Newsletter?

Please send your articles to nationalcoordinator@fragilex.org.nz

Remember, this is your Newsletter. We want to hear about what’s happening in your household, at your child’s school or in your local community, so that we can share it with our national community.

Deadline for the next issue: 24 November 2013

Sincere thanks to our generous sponsors -