

Tariana Turia

2 November, 2009

Third National Conference: Fragile X Syndrome

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 Siaosi; 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 Nicholls, Chris Hollis, Judith Spier, Senorita Laukau and Barbara Shelly - 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.

I understand there is also a call for a fragile x clinic in New Zealand and I heard that twice today.

I will be interested in hearing back from the conference how these issues were addressed, and any others that emerge.

Finally, I want to wish you a fantastic few days together, as you strengthen your networks and the support you offer each other. I want to leave with a final message of hope that really struck me on the back of the pamphlet, 'have you heard about fragile X?'. It said

"Those of us who live with fragile X have learned to treasure these gifts: an engaging smile and brilliant sense of humour; an eagerness to please; a great imagination; an incredible eye for detail; a terrific memory for hard facts, and a warm loving heart".

I suddenly understand where the term 'the X factor' comes from! It is these gifts that will continue to motivate us all as we search for the solutions and strategies to make the difference that is required. Have an enjoyable time and I look forward to hearing back on the solutions you think would be good going forward.