

The Fragile X
Association of
Australia



Annual Report

2010/2011

PRESIDENT'S REPORT

To improve the health and wellbeing of those affected by Fragile X Syndrome (those affected include: full mutation, carriers, parents, caregivers, siblings, extended family and significant others)

2010/11 has been a year of tremendous growth but also consolidation and although there is always more to do I am delighted with the Association's achievements this financial year.

FUNDING:

Overall revenue has increased by more than 120% to \$376,000, which is the biggest increase in our history as well as the largest amount raised to date. Each dollar raised is very important and equally valued. I would like to acknowledge John and Margaret Cunningham who identified that for the Association to offer services on an ongoing and professional manner it must have a full time office with requisite staff. Through their tremendous support we have been able to achieve this; we now have 4 part time staff and are operating 5 days a week.

The Newman's Own Foundation granted US\$36000 for us to provide regional workshops and clinics. This, along with grants from the Brenda Best Charitable Trust and Sydney IVF (Genea), has enabled the Association to run 4 workshops in this financial year in 4 states/territories. We have run these regional events with the support of two specialised Fragile X medical teams – the Fragile X Alliance Inc in Melbourne and the Fragile X clinic team from the Children's Hospital at Westmead in Sydney.

The St George Foundation has granted \$15,000 for the production of a DVD which will be completed by the end of the year.

Fundraising, through events such as the annual card day, which is organised by Trish Piper and Barbie Barratt, and various fun runs throughout Australia, has increased by over 30% in this financial year. Through our members and supporters we have received funds from groups such as Kianawah Masonic Lodge, MasoniCare and Sydney IVF. Supporter fundraising not only provides much needed funds but also increases awareness of Fragile X syndrome. We thank all of those who have supported us through fundraising.

SERVICES:

CLINICAL AND SUPPORT SERVICES:

In 2011 our range of services was offered to those affected by Fragile X. The Association expanded its clinical and care services which now include a counsellor and a caseworker. Services offered:

Fragile X Clinics:

The emphasis at the clinics is to identify effective treatments and intervention strategies that will optimise the person's abilities and enhance their life. This year 9 people were seen in Melbourne and 12 in Sydney. The children's clinic in Sydney is booked out 6 months in advance.

Counselling

The FXAA offers counselling to individuals and families that are affected by Fragile X syndrome. The counselling is free and confidential and is held on the premises of the Association.

Counselling is appointment based and can be conducted through the telephone, Skype and face to face.

Counselling is available and appointments or queries can be made through email and phone.

Casework:

Casework is offered to all families and individuals that are affected by Fragile X; the caseworker provides professional direction and case management to high needs families and carriers.

The caseworker manages the case and acts as an advocate, referral and support for individuals and families.

Parent support:

The parent support arm of Fragile X is through telephone support and social gatherings for families that are affected by Fragile X. The social gatherings operate 2-3 times per year.

Carrier support:

The carrier support service of Fragile X is through telephone and email support.

All of the services offered are free and confidential with the aim of improving the health and well being of those affected by Fragile X.

REGIONAL WORKSHOPS AND CLINICS

Our regional workshops have been extremely successful with an average of 100 allied health professionals, teachers and parents attending each workshop. The first of these was held in Taree, NSW, in August 2010 to support a member family with 4 children with Fragile X syndrome. We had a request from the attending paediatrician, Dr Dylan Wesley, to bring the Sydney team to Taree to assess the children and to also provide an opportunity for the local practitioners to increase their knowledge on Fragile X syndrome. The Sydney team also held a workshop/clinic in Canberra in April 2011.

In March 2011, along with the team from the Fragile X Alliance in Melbourne, we held a regional workshop/clinic in Shepparton in response to a request to support another family with 4 adults affected with Fragile X syndrome. The financial year ended with a successful regional workshop and clinic in Townsville which was attended by Senator Claire Moore.

AWARENESS

One of the major issues confronting the Association is the ongoing challenge of increasing awareness of Fragile X syndrome within the general community as well as medical, allied health, education and government organisations.

July 22nd is Fragile X Awareness Day and in 2010 we were fortunate to have Virginia Nichols provide pro bono media and PR services. Her excellent work culminated in segments on national news on the ABC and channels 9 and 7.

In October, we updated our "Fragile What" brochure and 65,000 were distributed to doctors' surgeries throughout Australia via INFO MED. INFO MED provided free distribution and management of the brochures. This distribution was so successful that we refilled the brochures in NSW and Victorian surgeries in April this year.

RESEARCH:

In the last few years there has been an increase in the number of research projects being undertaken in Australia and we are proud to be working closely with Australian researchers. In August I was asked to attend the Molecular Genetic Society meeting at Cradle Mountain which was a great opportunity to highlight the human side of Fragile X syndrome.

NATSEM:

Following the success of our national survey in 2009 we are working with NATSEM (The National Centre for Social and Economic Modelling) who are currently undertaking research into 'Modelling the Lifetime Social and Economic Impacts of Fragile X Syndrome and the Benefits of Early Diagnosis and Intervention'. Professor Laurie Brown has received an ARC grant and we are providing funds toward a PhD student. The results of this econometric study will help us to demonstrate to the government the benefits of providing better services to our families.

TESTING:

Currently there are 2 studies being undertaken in Australia on testing, the New Born Screening study by the GOLD service researchers in Newcastle and Pre-pregnancy Population Screening by the Murdoch Children's Institute in Melbourne.

NOVARTIS:

Australia has been selected to be part of the worldwide clinical trial currently underway into Fragile X syndrome medication by Novartis. 150 people affected with Fragile X syndrome worldwide are to be part of this trial and we are very excited that Australia has 27 of these places. There are 3 sites conducting the trial, 1 each in Melbourne, Sydney and Newcastle.

BOARD:

This year saw the development of the Committee into a Board and with this development the inclusion of medical professionals. This gives the Board a good representation of families as well as professionals who can add their expertise to the governance of the Association.

At the 2010 AGM a new constitution was passed which updated the original constitution. Thank you to Bruce Donald who gave so much of his time and expertise to ensure that the constitution reflected the Association's values and needs.

The Board for 2010/11 financial year comprised:

John Kelleher	President and Parent
Doug Rodgers	Treasurer Parent
Robyn Iredale	Secretary Parent and Research

Medical & Research:

Dr Kim Cornish	Psychologist
Dr Michael Field	Geneticist
Dr Helen Heussler	Developmental Paediatrician
Prof. Tim Turpin	Sociologist

Other:

Bruce Donald	Lawyer and Parent
Will Delaat	Chair of Medicines Australia
John O'Connor	Investment manager
Mel Mikkelsen	Family representative and Parent
Christine Kelleher	Family representative and Parent

Two of our Board have decided that, due to other commitments, they will not be continuing on the Board so I would like to take this opportunity to thank both Bruce Donald and Mel Mikkelsen for their support over the last few years.

Bruce has been on the Board since 2006 and has been a great asset with his legal knowledge. During his time on the Board Bruce has provided us with legal advice as well as working on achieving a sustainable future for the Association.

Since her move back to Brisbane in 2008 Mel has invigorated the Queensland branch of the Association with many get-togethers at her family home and developing a close relationship with the Kianawah Masonic Lodge which has made the Fragile X Association one of their chosen charities. She has worked tirelessly often providing phone support to Queensland families in need.

LOBBYING:

Over the past two years representatives of the Board have met with the then Parliamentary Secretary of Disability and Carers, Bill Shorten, MP, the Health Minister, Nicola Roxon, and department heads from FAHCSIA to educate them about Fragile X syndrome. This culminated in children with Fragile X syndrome being included in the Better Start Initiative along with other more well-known disabilities which are Cerebral Palsy, Downs syndrome, vision and hearing impaired. The Fragile X Association was represented on the Advisory Board and the Specialist Board of the Better Start Initiative.

We have also forged an alliance with the other disability groups included in the Initiative and this group became the First Step Alliance.

In March this year we met with the new Parliamentary Secretary of Disability and Carers, Senator the Honourable Jan McLucas, to further discuss issues that face our families.

Through our close alliances with stakeholders including the Fragile X Alliance Inc, Ryde Developmental Disability Clinic, the specialised Fragile X clinic team at the Children's Hospital at Westmead, Sydney IVF, Queensland Centre for Intellectual and Developmental Disability (QCIDD), and the Association of Genetic Support of Australia (AGSA) we have developed a strong network to achieve our goals.

We also work closely with the other national groups, specifically, the United States National Fragile X Foundation, the Fragile X Society in the UK and the Fragile X Trust in New Zealand.

All of these achievements would not have been possible without the commitment and passion of our board members and staff. The longest serving member of the Board is Doug Rodgers, our Treasurer, who works tirelessly for the Association and is a great support to our small team in the office.

Thank you to two of our new members of the Board, Drs Michael Field and Helen Heussler who have contributed their extensive medical knowledge. Also, to the members of the Board who are involved in research, Drs Kim Cornish, Robyn Iredale and Prof. Tim Turpin.

The research into Fragile X syndrome that is happening in Australia is quite extensive and has led to these board members hosting an inaugural Fragile X Research Symposium in Brisbane in October 2011. This will give Australian researchers an opportunity to discuss their findings and look toward the future of Fragile X research.

Will Delaat has been in the forefront of lobbying the federal government and John O'Connor has shared his business experiences and worked closely with the office team. Bruce Donald's contribution has previously been acknowledged however his legal knowledge and the writing of the new Constitution have been of great value to the Association. Christine Kelleher and Mel Mikkelsen are our family representatives, ensuring that the needs of the families are never far from our thoughts. They have both been of great assistance to our members through family days and telephone support.

John Kelleher
President