



ANNUAL REPORT 2014-2015

WWW.FRAGILEX.ORG.AU
1300 394 636

Who are we?

Fragile X Association of Australia (FXAA) is a national member-based charitable organisation dedicated to improving the health and wellbeing of those affected by Fragile X syndrome and associated disorders.

We have been serving this community which includes families, carers, educators and health professionals, for 25 years by offering support, knowledge, connection and resourcing.

FXAA now provides specialised information, counselling services, research findings, diagnostic guidance, referrals, networking, advocacy, awareness raising, a voice for Fragile X, educational workshops and assessment clinics.



We receive no government funding and are therefore reliant on donors, grants and substantial volunteer input to sustain these activities. FXAA continues to work towards understanding, empowerment and inclusion of those we serve, within their communities.

Our commitment is to be responsible and responsive, operating within our means to help meet the needs of members and participate in emerging initiatives for disability, wellbeing and the particular issues of genetic conditions.

UNDERSTANDING FRAGILE X

Fragile X-associated Disorders include Fragile X syndrome (resulting in developmental disability), FXTAS (Fragile X-associated Tremor Ataxia syndrome, a degenerative condition often confused with Parkinson's disease) and FXPOI (Fragile X-associated Premature Ovarian Insufficiency, often leading to early menopause). **They are caused by an expansion or lengthening of the "FMR1" gene on the X chromosome.** When the gene lengthens, it switches off production of a protein vital for normal brain development and other functions.

Fragile X syndrome (FXS) is the most common known cause of inherited intellectual disability and the most common known single gene cause of autism spectrum disorder.

People living with FXS experience the effects throughout their lifetime. These effects will vary from person to person and may include:

- ♦ intellectual and learning disability
- ♦ speech delay or minimal speech
- ♦ fine & gross motor delay, coordination difficulties
- ♦ low muscle tone
- ♦ anxiety, hyperarousal, ADHD, depression
- ♦ autistic-like behaviours
- ♦ aversion to touch, loud noises, bright lights & strong smells
- ♦ avoidance of eye contact
- ♦ mood instability

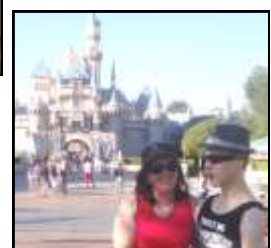
People with FXS often have a good visual memory, a great sense of humour, empathy, strong ability in mimicry and a friendly nature.

Men and boys with FXS may appear to be more affected than women and girls, but this is not always the case. It is estimated that 1 in 3600 males and 1 in 4000-6000 females have FXS.

Every week in Australia one child is born with FXS, and 20 are born who carry the changed FMR1 gene which means they have the potential to pass it to their children. Approximately 100,000 people in Australia are affected by Fragile X in some way.

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Board 2014-2015



Robyn Iredale, PhD President (NSW)
Migration and Human Rights Researcher
Robyn is a carrier of Fragile X, and parent of two FX-affected adults. Eight other family members are affected by Fragile X.



Bruce Donald AM Treasurer (NSW)
Lawyer
Bruce is a parent of two young women with Fragile X. Seven other members of his wife's family are affected by Fragile X.



Tim Turpin, PhD Secretary (NSW)
Sociologist
Tim is a specialist in science, technology, innovation, industrial change and human resource policies. He is a step-parent to children affected by Fragile X.



Judith Lenart Executive Committee member (NSW)
Investment consultant and community volunteer
Judith is qualified in urban valuation, natural health and school trusteeship and is trained in governance



Cathy Love Board member (VIC)
Consultant Occupational Therapist and Author
Cathy has worked with children and families affected by Fragile X for a number of years, and was a member of the BetterStart reference group.



Pam Montgomery, PhD Board member (VIC)
Psychologist
Pam has substantial experience in management of professional medical development programs and in policy development



Jeremy Sweeney Board member (WA)
Community services worker
Jeremy has a young son with Fragile X syndrome.



Candice Stingel Board member (QLD)
Real estate consultant
Candy is a carrier of Fragile X. Two of Candy's young children have Fragile X syndrome, and other family members are affected by FX.

OUR TEAM

Our office remains in Sydney, at Suite 6, Level 3, 39 East Esplanade, Manly NSW. Our small team comprises 3 staff, and one consultant, which combined is the full-time equivalent of 2 people.



Wendy Bruce Executive Officer

Wendy manages the general operations of the Association, with particular responsibility for managing our compliance obligations, writing the quarterly newsletter, updating our website and social media channels. Wendy also provides support to members, and assists with fundraising.



Janie Roberts Counsellor (part-time)

Janie has a Masters degree in Counselling and Psychotherapy and has worked with **the Association for 4 years. Janie's focus is on encouraging families, couples, individuals and siblings from the Fragile X community to contact her for face-to-face support or phone/skype-based support.**



Liz Russell Accountant (part-time)

Liz is a qualified accountant. Liz prepares the Association's budget and financial statements, processes donations and membership subscriptions, and manages the Association's financial compliance processes.



Katrina Weir Medical Communications Project (part-time)

Katrina is responsible for identifying opportunities to increase the degree of knowledge of Fragile X-associated disorders within the medical and healthcare community, such as Fragile X representation at conferences, and writing articles for publications, our website and social media.

Our supporters

Fragile X Association is extremely grateful to a number of corporate, business and community groups who have provided funding and other support throughout 2014-2015. This support is key to our ability to provide support and programs to our member base, and the Fragile X community.



Milton Corporation Foundation



www.stephenbaric.com

Galston Garden Club (Sydney)



PRESIDENT'S REPORT

Our Annual Report provides a great opportunity to review the past year. It has been an interesting one with many highlights and successes, but also some challenges along the way.

Three areas I would particularly like to highlight:

- Our emphasis on working with the support of other organisations to achieve our goals
- The increased exposure for Fragile X in a wide range of medical and allied health settings
- The willingness of international FX experts to visit Australia and support and connect with our Fragile X community



Through a FXAA member, Leigh Riddell, we were fortunate to receive funds for key projects. First, a donation from ICAP Charity Day 2014 provided support workshops/ clinics with Dr Marcia Braden. We ran these in partnership with **Dr Cohen's Fragile X Alliance Clinic in Melbourne**. **Marcia has a unique understanding of the behavioural and educational characteristics of people with Fragile X, and we're grateful that she could visit Australia again.**

Second, a 'social inclusion' grant from BNP Paribas was used to develop a pilot project on the way Disability Employment Agencies operate with their FX clients. The resulting video formed part of our submission to a government inquiry into the Disability Employment Framework. (Launch later)

These and other partnerships have contributed much-needed funds to provide services and have broadened our knowledge and sphere of connection.

The initiative to generate increased awareness of Fragile X in the medical community, made possible by the generous support of the Cunningham family, has been very successful due to the work of Katrina Weir. Our goal is to ensure that knowledge of the ramifications of Fragile X-associated Disorders becomes widespread.

FXAA was represented at a recent Newborn Bloodspot Screening (NBS) consultation workshop that considered the policies and practices required to support a national NBS program. We will continue to be involved in the NBS consultation and the Board has agreed to support a test for Fragile X to be included in the NBS program.

We have continued to provide clinic places through the support of A/Prof Natalie Silove and her team at Westmead **Children's Hospital (Sydney)**, **Dr Jonathan Cohen's Fragile X Alliance clinic (Melbourne)** and **Dr Marcia Braden**. **We are currently exploring ongoing and mainstream clinic options for families in several states.**

We continue to function as a lean, efficient organization and we have been told that we 'punch above our weight'. Much of this is due to the work of the staff in the office, the Board members and everyone who assists in so many other ways.

I would also like to expressly thank our supporters who have raised funds or made donations over the past year. We continue to be very generously supported by several families and other private donors. Our Endowment Fund is growing, and I would like to thank our Treasurer, Bruce Donald, for his foresight in establishing the Fund and for his perseverance in continuing to promote it.

Our members, their families and supporters, medical professionals, researchers, community organisations and businesses are important as supporters and promoters of the work of the Association. They help to give a voice to the Fragile X community and to ensure that people living with a FXD have the best life that they possibly can. We thank you all and ask that you continue to work with us into the future.

Our next big challenge is informing and supporting people through the general implementation of the National Disability Insurance Scheme (NDIS) in NSW, Victoria and Queensland from 1 July 2016.

On behalf of the Board and the team in our office, it is our great pleasure and privilege to serve the membership of the Association and continue to work towards our goals.

Your President,

A handwritten signature in black ink, which appears to read "L. Riddell".

July – fragile x awareness month

Each year Fragile X Awareness Day on July 22 presents an ideal platform to build awareness of Fragile X-associated Disorders in the general community. This year opportunities for media exposure came through several of our members who have contacts in media. The highlight was a powerful 10 minute profile of Rachael Clements and her family, on the *Studio Ten* (Network Ten). Rachael shared her story of the challenges and joys she and her family face with two young boys with Fragile X. The video has since been viewed more than 4,000 times on youtube.



Rachael Clements, July 22 2014



Social media proved to be a fantastic way to share the orange ribbon!

Many thanks to newsreader Sandra Sully for tweeting a photo to her 75,000+ followers, and to Sydney radio hosts Amanda Keller and Jonesy for doing the same!



An interview with Dr Cynthia Roberts, whose young adult son Dan has FX, was aired on ABC radio 702 AM in Sydney on July 22.



This year we asked State politicians to support the FX orange ribbon campaign. With great results!

We provided the Fragile X brochure and a poster for their electoral offices, and asked them to share a photo of themselves wearing the Fragile X ribbon.

Many thanks to NSW Premier Mike Baird MP and Victorian Premier Denis Napthine MP for leading the charge!



Workshops



Dr Marcia Braden with Cathy Love, Dr Jonathan Cohen, Wendy Bruce, Astra King, Bev Kadish in Melbourne



Fragile X Alliance Inc



In March Fragile X Association partnered with Fragile X Alliance to host the visit to Australia of Dr Marcia Braden. Dr Braden, from the US, is a renowned expert in education and behaviour management for children and adults with Fragile X.

1-day workshops were held in Melbourne and Sydney, each attended by around 80 family members, carers and educational professionals. Dr Jonathan Cohen, psychologist Astra King and occupational therapist Ben Kadish also presented at the Melbourne workshop. Dr Braden also conducted 18 individual assessment clinic sessions for children and adults affected by Fragile X, in Melbourne and Sydney.



Katrina Weir interviewed Dr Braden in a 1-hour Q&A video about educational and behavioural perspectives of Fragile X. Available on our youtube channel, the video had over 200 views.



Many thanks to ICAP Charity Day 2014 for providing a grant for the specific purpose of Fragile X workshops and clinics for families.

CLINICS

In 2014-2015 we funded 9 assessment clinic places for children and adults with Fragile X syndrome, and facilitated access to 18 additional clinic places with Dr Marcia Braden.

We are actively reviewing the availability of mainstream services in NSW which provide assessment clinics for adults and children affected by Fragile X, and the availability of specialist Fragile X or mainstream developmental disability clinics in other states.

Counselling

In the period July 2014 through June 2015 the office attended to more than 750 phone contacts about Fragile X from our members and the general community. 322 counselling sessions by our qualified counsellor, Janie Roberts, were recorded in that period. The counselling sessions ranged from formal hour-long face to face, Skype or telephone sessions through to informal telephone or email sessions, dependent on need.

These counselling sessions were around supporting people with Fragile X and their families and supporters. Some of the common issues raised were coping with a new diagnosis of Fragile X, difficulties with employment, problems associated with Fragile X-associated Tremor Ataxia syndrome and Fragile X-associated Primary Ovarian Insufficiency, concerns around behaviour, feelings of anxiety, depression, isolation and grief, experiences of domestic violence and other abuses, and challenges adapting to changes in relationships.



Janie Roberts

The counselling service is provided at no charge to people affected by Fragile X and is a valued and essential service. Education and advice on supporting people with Fragile X is also given to employment, social services, health and education practitioners.

FUNDRAISING

Our members and supporters have done a wonderful job in using community events to increase awareness of Fragile X and to fundraise. Highlights included an “orange army” at the Bridge to Brisbane fun run and walk, a Gala Dinner in Brisbane organised by FXAA Board member Candice Stingel and supporter Deborah Forshaw, an amazing fundraising achievement in the Sydney City2Surf by Dr Cynthia Roberts and her daughter Amy, and the instigation of the annual Virtual Walk to raise awareness of Fragile X.



Luciana in Sydney!



Gala fundraising dinner in Brisbane, July 2014 with Andrew Powell MP as guest of honour



Teams in Launceston and Ballarat took on the Virtual Walk

The annual *Bridge to Beach* in Sydney is one of Australia's largest open water paddling events. More than 400 paddlers took part, with Fragile X profiled as charity partner for the race for the second year in a row. Many thanks to local Manly business Oceanpaddler!



Expanding the fx knowledge base of healthcare professionals

In June 2014 *Katrina Weir* was appointed to the new role of FXAA *medical communications officer*. This role was created to address the perceived lack of knowledge of Fragile X-associated disorders among healthcare professionals including general practitioners, selected specialists, professional bodies and allied health practitioners.

Ultimately, the objective is to raise awareness of Fragile X and ensure that families affected by Fragile X-associated Disorders are being quickly and appropriately referred and accurately diagnosed.

The role is funded through a donation from the Cunningham family, long-term members of the Association.

The first stage of the project was to conduct interviews with a wide range of professionals working in this area including GPs, genetic counsellors, psychiatrists, paediatricians, intellectual disability specialists, OTs and a range of others health professionals.

This exercise highlighted some of the existing knowledge gaps as well as some of the opportunities available to educate various health professionals about Fragile X-associated Disorders.

Over the past 12 months we have been involved in a number of targeted medical education activities including:

- ❑ Providing information on Fragile X to delegates at the Australian Association of Special Educators conference (September 2014) and Faculty of Child and Adolescent Psychiatry conference (October 2014).
- ❑ Securing Dr Lesley Powell as a speaker at the biennial national Maternal Child and Family Health Nurses conference in April 2015 in Perth and providing the FXAA *Fragile X* brochure to all 600 delegates.
- ❑ Participating in the Early Childhood Intervention Australia (NSW) conference in May 2015 in Sydney with an exhibition stand and providing the FXAA brochure and information about the role of early **intervention for children with Fragile X syndrome** to 330 delegates.
- ❑ Preparing promotional materials for the visit to Australia in March by American educationalist and psychologist Dr Marcia Braden, and developing a Q&A video resource featuring Dr Braden for families and healthcare professionals on educational and behavioural aspects of Fragile X.
- ❑ Approaching convenors of special education courses at NSW universities and offering support and information, including materials and presentations.
- ❑ Writing several FX family stories and articles for various newsletters, including Genetic Alliance Australia, Genetic & Rare Disease Network (WA) and Genetic Support Network of Victoria, and for the FXAA website.

During the year considerable time was also spent planning and preparing for several opportunities scheduled for the back half of calendar year 2015 including:

- ❑ Negotiating the opportunity and securing expert speakers for a GP Education Day being held by HealthEd in the 5 major capital cities from August – **November 2015. The presentation topic for each conference is “What GPs need to know about intellectual disability” using Fragile X syndrome as an example.**
- ❑ Preparing wide range of materials to support these events including a new *Understanding Fragile X* brochure, a version of the *Understanding Fragile X* DVD tailored for GPs, and articles about various aspects of Fragile X.
- ❑ Arranging an exhibition stand and appropriate educational materials for delegates at the Neurodevelopmental and Behavioural Paediatricians Society of Australia conference in August 2015.
- ❑ Scheduling meetings with tertiary hospital neurologists and preparing for the visit to Australia in August 2015 of American world leaders in Fragile X, *Professors Randi and Paul Hagerman*.

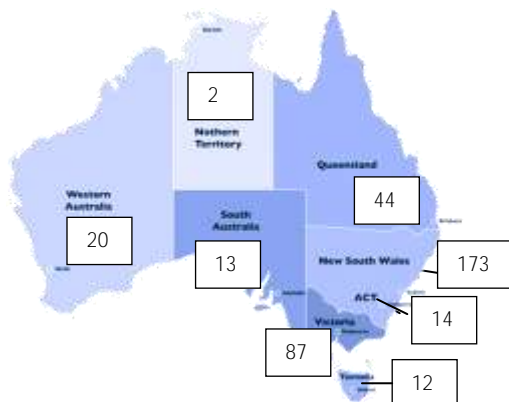
The Year Ahead

The focus for the 2015-2016 year in our approach to medical communications is to continue identifying and establishing relationships with experts and opinion leaders in the diagnosis and management of Fragile X-associated Disorders, and working with these leaders to find or create opportunities for them to deliver up-to-date information about Fragile X to various audiences. There will also be more focus on providing families affected by Fragile X with appropriate materials so that they can help us build awareness and understanding of these conditions among the health professionals in their network.



OUR COMMUNITY

OUR MEMBER BASE



At 30 June 2015, Fragile X Association had a total of 365 members. The majority of these are members of families affected by Fragile X. Other members include medical and healthcare professionals, researchers, special educators and disability service support providers.

Our contact database includes a total of around 2,000 people, ranging from individuals and families affected by Fragile X, support providers, people who have attended our workshops or clinics, our medical and healthcare network, our donors, fundraisers, and supporters.

Our quarterly newsletter is distributed by email to around 1,000 contacts, and also accessed via our website and social media.

Employment inclusion

In late 2014 FXAA was one of 21 charities in the Asia Pacific region to win a grant from French bank BNP Paribas to undertake an initiative in social inclusion. Many thanks to our member Leigh Riddell, who introduced this opportunity. Our chosen initiative was employment inclusion - looking at the challenges faces by people with Fragile X in securing work in the open employment market. A number of our member families have had very unsatisfactory experiences in their adult children seeking work through employment agencies. *The experience of many job seekers with Fragile X is that employment agencies can show little understanding of their abilities and potential.*

Tracey Learmont, who has a background in journalism and in counselling, joined us to take on this project for us, interviewing special employment providers in Sydney as a basis for understanding the situation Australia-wide. In July, as a result of this work, FXAA was well-placed to make a submission to the Department of Social Services Review of Disability Employment Services, documenting the experience of some of our members and making recommendations. A further outcome is a video profiling the challenges some of our members are facing in seeking work. We thank Zoe Friend, Marty Campbell, Rosie Donald, Hugh Rodgers and Ross Mackenzie for their contribution, together with *Jean-Marcel Guerin*, manager of Vintage Cellars, Seaforth, and *Suresh Gupta*, manager of Coffee Club, Mona Vale in Sydney. Many thanks to film maker Thibault Upton for his support.



WEBSITE AND SOCIAL MEDIA



Web traffic increased by around 10% from the previous year to 204,000 web visits, including 102,000 unique visitors



1200 likes, an increase of 30% in the 12 months to 30 June 2015



Established in mid 2015 to share our FX video content with a wide audience, including *Understanding Fragile X* and a Q&A interview with educationalist Dr Marcia Braden



Established in July 2014, with 280 followers

Scientific and research committee

The FXAA Scientific and Research Sub-Committee includes ten Australian specialists in Fragile X-associated disorders. The objective of the sub-committee is to provide a conduit between the FXAA (and members) and the technical issues and developments confronting FXAA researchers and practitioners. The sub-committee meets via teleconference four times each year. During 2014/15 the sub-committee provided:

- updates and key issues covered at international conferences (US, New Zealand and Australia);
- recent information on diagnostic tools available in Australia and overseas;
- suggestions for input to policy processes (eg, the National Bloodspot Screening Policy);
- information items and research updates for the FXAA newsletter.

The sub-committee continues to provide a valuable forum for ensuring technical terminology and FXAA information is as accurate as possible. During 2014/15, it provided input into an FXAA Fragile X screening statement, FXAA Fact Sheets and Fragile X glossary, and a FXAA research protocol statement providing guidelines for any FXAA involvement in research.

Scientific and Research Committee members through 2014/15

Dr Tim Turpin (Chair)	Consultant, Secretary, Fragile X Association
Dr Robyn Iredale	Consultant and Immigration researcher, President, Fragile X Association
<i>Co-opted Members:</i>	
A/Prof David Amor	Director, Victorian Clinical Genetics Services
Dr Alison Archibald	Associate Genetic Counsellor, Victorian Clinical Genetics Services
Dr Jonathan Cohen	Medical Director, Fragile X Alliance Clinic and Adjunct Senior Research Fellow, CDDHV, Monash University
Professor Kim Cornish	Head of School, Deputy Dean of the Sub-Faculty of Biomedical and Psychological Sciences, Monash University
Dr David Godler	Senior Research Fellow, Cyto-molecular Diagnostics Research, Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne.
Dr Honey Heussler	Medical Director Child Development Program, Childrens Health Queensland Hospital and Health Service, Associate Professor, University of Queensland
Dr Matthew Hunter	Head of Monash Genetics Unit, MonashHealth
Dr Danuta Loesch	School of Psychological Science, La Trobe University
Professor Sylvia Metcalfe	Group Leader, Genetics Education and Health Research, Murdoch Children's Research Institute and Professor in Medical Genetics, Dept of Paediatrics, University of Melbourne
Dr Tracey Williams	Macquarie University, Sydney

Endowment fund

The FXAA Endowment Fund was established in early 2012 to ensure the ongoing viability of FXAA, which receives no government funding. The Fund provides a means of generating funds to support activities, underwrite our **commitments and guard against operational deficits**. **The overall objective of the Endowment Fund's investment strategy is to provide a conservative and prudent framework within which the fund may grow its capital and earn a steady income to support the Association's core activities of raising awareness of the syndrome and supporting those families living with Fragile X.**

The Endowment Fund is maintained and accounted for separately from the Association's other funds and is managed by an Advisory Board. This Board meets at least four times a year and reports half yearly to the Association. During the year the Endowment Fund funds grew by \$67,336 to a total of \$226,469.

FXAA Endowment Fund Advisory Board 2014/2015

David Bassingthwaighte (Chair)	Self-employed financial consultant
Marion Pascoe	Deputy Parliamentary Counsel, NSW Parliamentary Counsel's Office
Martin Davey	Chartered accountant
Dr Robyn Iredale	President, Fragile X Association of Australia
Dr Tim Turpin	Secretary, Fragile X Association of Australia

Looking to the future

The Association has a strong focus on the future and our ongoing sustainability. We are currently engaged in a strategic planning process. A refreshed concentration on key areas will ensure we continue to provide essential support and a distinct voice for the Fragile X Community.

FAMILY SERVICES

Serving families in the Fragile X community is core to what we do as an Association. One key objective is to have provided a Fragile X workshop and mobile clinic in each capital city by the end of financial year 2017, building on the workshops provided during calendar year 2015. We will actively seek resources to achieve this. We will also continue to provide our core services:

Counselling Our counsellor plays a critical role in supporting members and the wider Fragile X community, and will remain available 3 days per week.

Clinics We will continue to facilitate access to FX assessment clinic services, in part through identifying and reviewing the capacity of mainstream intellectual disability services to serve individuals with Fragile X syndrome. We will also promote and facilitate access to emerging clinic facilities for Fragile X-associated disorders.

Online Our website remains an important resource for families and individuals newly diagnosed and the support it provides will be enhanced over the next 12 months. We will also continue to build video and other resources on our social media platforms.

MEDICAL AWARENESS

Actively raising awareness of Fragile X-associated Disorders in the medical and allied health community is a critical focus. Much has been achieved in the 2014-2015 year through representation at professional development events and extending our network, providing wide exposure of FX issues and a strong platform for 2015-2016 and beyond. This initiative is very generously sponsored by the Cunningham family.

RESOURCING

The future of FXAA depends on financial sustainability, and we maintain a strong focus on securing a core funding base to sustain our operations. FXAA receives no government funding, and is reliant on the generous support of private donors and fundraising, and on the input of our Board of volunteer directors. The Board will continue to actively seek financial and other resources to support the base operations of the organisation and the provision of workshops and other services. In particular, partnership potential is being actively explored. We continue to encourage our current members to support the Association financially and in other ways, through their networks of family and friends, professional acquaintances and community organisations.

MEMBERSHIP

The FXAA membership fee remains at \$25.00 per year to encourage families to join and share the information and support we provide. We will continue to work to attract new members and aspire to a membership that reflects the broader Fragile X community.

NATIONAL DISABILITY INSURANCE SCHEME

The recent announcements of the timing and stages of the NDIS allow us to plan further in this regard. As we noted in our 2013-2014 Annual Report, the next few years represent a transition phase to the NDIS and it is essential that the Association becomes active in helping people to negotiate the transition – to be “NDIS ready.” As the implementation and operation of the NDIS moves beyond the trial sites we are putting in place an approach to providing assistance our families may need in planning for and managing their transition to NDIS-funded services. Families from the trial sites are assisting greatly with this process, and we will advocate with the NDIA.

TREASURER'S REPORT

The audited accounts for the Association for 2015 confirm a well-managed small organisation living within its means and, with an appropriate administrative base, devoting its funds to four main program cost centres: Family support and counselling; Public awareness and understanding; Medical awareness and engagement; Conferences and knowledge building.

The range of all those programs is detailed in the regular newsletters which again report **an Association that 'punches above its weight', using its funds and organisational structure** to leverage a wide range of voluntary family, scientific and professional contributions adding enormous value to the investment our donors make in the Association.



As the accounts show, we work on income of only \$260k pa (with a major project grant of \$40k) to fund a well located office with just three part-time staff and a consultant. Our five main funding sources are four philanthropic and family donors and a wide range of fundraising principally by families and their networks.

While a number of donors prefer to remain private I am very happy to acknowledge the funding received during 2014-5 from Royal Bank of Canada, ICAP Charity Day 2014, BNP Paribas, Milton Corporation Foundation, Masonicare, Australian Association of Retired Pilots (Qld), the Galston Garden Club.

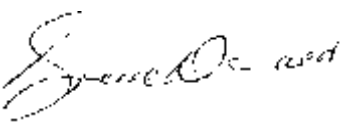
Manly business Oceanpaddler once again invited us to be their charity partner for the Bridge to Beach paddle race in March. I would also like in particular to acknowledge the fantastic efforts of Dr Cynthia Roberts and her daughter Amy, long-term members of the Association, who raised over \$7500 in sponsorship for the Sydney City2Surf run, and the Colgrave family and friends in Launceston, Tasmania, and the Jones family and friends Ballarat, Victoria, who gathered together to take part in the Fragile X Virtual Walk, raising \$3700.

It is important to note that our largest private donor has committed to continuing to support the organisation while our other sources are also likely to ensure financial predictability for that period. In addition we devote regular effort to seeking new avenues and maintaining existing relationships with those who provide value to the organisation. The notes confirm very acceptable ratios of fund raised to costs and of administration expense to service delivery.

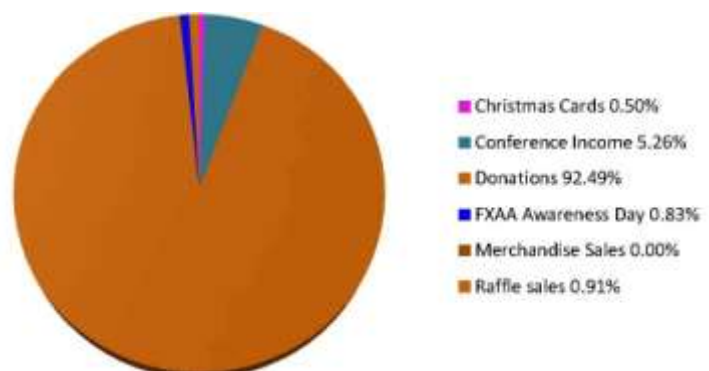
The second important financial dimension of FXAA is the Endowment Fund which has again been the beneficiary of significant donations this financial year and as at year end stands at \$225k. While our ambitions for it are far greater, in the hope that longer term it can contribute substantially to our core costs, we have nevertheless in the last year engaged constructively with the Fund Board to develop an approach to longer term investment. We do stress to members the importance of promoting the Fund throughout your networks. I thank the members of the Fund Board for their continued support.

Our competent financial management is the work of all our staff with the detail so carefully managed by our office accountant Liz Russell to whom again I extend my personal gratitude as Treasurer. The audit has again been provided on a pro bono basis by Mr Brian Tierney of ManserTierney & Johnston, a long-term supporter of the Association, to whom we extend our sincere thanks.

I commend the accounts to the Members.



Financial Overview: Total Income





ManserTierney&Johnston
Chartered Accountants

**FRAGILE X ASSOCIATION
OF AUSTRALIA INC
ABN 18 655 264 477**

**FINANCIAL STATEMENTS
30 JUNE 2015**

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477


STATEMENT BY MEMBERS OF THE BOARD

The Board has determined that the association is not a reporting entity and that these special purpose financial statements should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

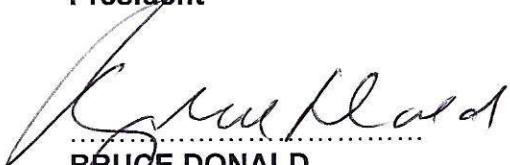
In the opinion of the Board the attached financial statements comprising the Balance Sheet, Income and Expenditure Statement and Notes to the Financial Statements:

1. present a true and fair view of the financial position of Fragile X Association of Australia Inc as at 30 June 2015 and its performance for the year ended on that date in accordance with the accounting policies described in Note 1 to the financial statements, the requirements of the Associations Incorporation Act 2009 (NSW) and the Australian Charities and Not-for-profits Commission Act 2012; and
2. at the date of this statement, there are reasonable grounds to believe that Fragile X Association of Australia Inc will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the Board and is signed for and on behalf of the Board by:



ROBYN IREDALE
President



BRUCE DONALD
Treasurer

Dated this

14th

day of

October,

2015.



ManserTierney&Johnston
Chartered Accountants

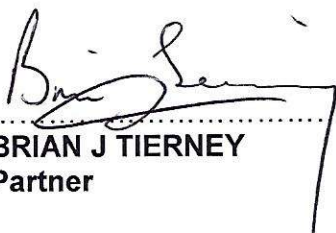
FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

AUDITOR'S DECLARATION
TO THE MEMBERS OF FRAGILE X ASSOCIATION OF AUSTRALIA INC

In accordance with Section 60-40 of the Australian Charities and Not-for-profits Commission Act 2012 (ACNC Act), I declare that, to the best of my knowledge and belief, during the year ended 30 June 2015 there have been no contraventions of any applicable code of professional conduct in relation to the audit.

Signed at Wahroonga this 20th day of October 2015.

MANSER TIERNEY & JOHNSTON
Chartered Accountants


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BRIAN J TIERNEY
Partner



ManserTierney&Johnston
Chartered Accountants

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
FRAGILE X ASSOCIATION OF AUSTRALIA INC

Report on the Financial Statements

We have audited the accompanying financial statements, being special purpose financial statements, of Fragile X Association of Australia Inc (the Association), which comprises the balance sheet as at 30 June 2015, the income and expenditure statement for the year then ended, notes comprising a summary of significant accounting policies and other explanatory information and the statement by members of the Board.

Board's Responsibility for the Financial Statements

The Board of Fragile X Association of Australia Inc is responsible for the preparation and fair presentation of the financial statements and has determined that the basis of preparation described in Note 1 is appropriate to meet the requirements of the Associations Incorporation Act 2009 (NSW), the Australian Charities and Not-for-profits Commission Act 2012 and is appropriate to meet the needs of the members. The Board's responsibility also includes such internal control as the Board determines is necessary to enable the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on the financial statements based on our audit. We have conducted our audit in accordance with Australian Auditing Standards. Those standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the association's preparation and fair presentation of the financial statements, in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the association's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the Board, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion

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ManserTierney&Johnston
Chartered Accountants

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
FRAGILE X ASSOCIATION OF AUSTRALIA INC

Opinion

In our opinion, the financial statements of Fragile X Association of Australia Inc have been prepared in accordance with the Associations Incorporation Act 2009 (NSW) and Division 60 of the Australian Charities and Not-for-profits Commission Act 2012, including:


- a) giving a true and fair view of the Association's financial position as at 30 June 2015 and of its performance for the year ended on that date, and
- b) complying with Australian Accounting Standards to the extent described in Note 1, the Associations Incorporation Act 2009 (NSW) and the Australian Charities and Not-for-profits Commission Regulation 2013.

Basis of Accounting and Restriction on Distribution

Without modifying our opinion, we draw attention to Note 1 to the financial statements, which describes the basis of accounting. The financial statements have been prepared to assist Fragile X Association of Australia Inc to meet the requirements of the Associations Incorporation Act 2009 (NSW) and the Australian Charities and Not-for-profits Commission Act 2012. As a result, the financial statements may not be suitable for another purpose.

Signed at Wahroonga this 20th day of October 2015

MANSER TIERNEY & JOHNSTON
Chartered Accountants


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BRIAN J TIERNEY
Partner

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

BALANCE SHEET
AS AT 30 JUNE 2015

	Note	2015	2014
CURRENT ASSETS			
Cash on hand			
At Bank		36,014	100,656
Bank Guarantee		6,875	6,875
Endowment Fund	8	225,919	159,133
Petty Cash		<u>102</u>	<u>52</u>
		<u>268,910</u>	<u>266,716</u>
Accounts receivable and other debtors			
Accounts Receivable		3,235	4,342
Prepayments		643	-
GST Refundable		<u>7,981</u>	<u>7,906</u>
		<u>11,859</u>	<u>12,248</u>
TOTAL CURRENT ASSETS		<u>280,769</u>	<u>278,964</u>
NON-CURRENT ASSETS			
Property, plant and equipment			
Office Equipment - At Cost		20,724	20,273
<u>Less: Accumulated Depreciation</u>		<u>(11,812)</u>	<u>(9,283)</u>
TOTAL NON-CURRENT ASSETS		<u>8,912</u>	<u>10,990</u>
TOTAL ASSETS		<u>289,681</u>	<u>289,954</u>
CURRENT LIABILITIES			
Accounts payable and other payables			
Accounts Payable		8,450	8,440
Income Received in Advance		3,640	4,125
Payroll Liabilities		1,036	1,667
Other Liabilities		<u>545</u>	<u>42</u>
TOTAL CURRENT LIABILITIES		<u>13,671</u>	<u>14,274</u>
TOTAL LIABILITIES		<u>13,671</u>	<u>14,274</u>
NET ASSETS		<u>\$276,010</u>	<u>\$275,680</u>
MEMBERS' FUNDS			
Opening Balance		275,680	320,094
<u>Add: Surplus/(Deficit) for the Year</u>		<u>330</u>	<u>(44,414)</u>
TOTAL MEMBERS' FUNDS		<u>\$276,010</u>	<u>\$275,680</u>

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

INCOME AND EXPENDITURE STATEMENT
FOR THE YEAR ENDED 30 JUNE 2015

	2015	2014
INCOME		
Gross Proceeds From Fundraising Appeals		
Bequests	-	2,345
Card Day	-	3,898
Christmas Cards	1,422	3,669
Conference Income	15,032	4,075
Donations	264,321	229,759
FXAA Awareness Day	2,383	1,646
Merchandise Sales	12	-
Raffle Sales	2,610	2,808
Sponsorships	-	9,990
	<u>285,780</u>	<u>258,190</u>
Other		
Interest	5,612	7,984
Subscriptions	6,945	4,525
	<u>12,557</u>	<u>12,509</u>
Total Income (carried forward)	<u>298,337</u>	<u>270,699</u>

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

INCOME AND EXPENDITURE STATEMENT
FOR THE YEAR ENDED 30 JUNE 2015

	2015	2014
Total Income (brought forward)	<u>298,337</u>	<u>270,699</u>
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Christmas Cards	-	3,334
Card Day	945	2,450
Other	<u>11,167</u>	<u>5,724</u>
	<u>12,112</u>	<u>11,508</u>
Total Costs Of Providing Services		
Support Services and FX Awareness	47,030	66,129
Clinics and Counselling	52,321	72,750
National Newsletter Printing	<u>5,590</u>	<u>4,185</u>
	<u>104,941</u>	<u>143,064</u>
Other		
Bank Fees and Charges	564	1,044
Board and AGM Expenses	1,583	589
Workshops and Seminars	28,300	37,419
Consultants	35,957	559
Depreciation	2,529	2,836
Gifts	50	-
General Administration - Employment Costs	56,919	55,687
Insurance	3,325	5,995
Office Expenses	9,124	4,631
Office Rent	28,818	37,041
Postage	2,796	3,341
Stationery	2,882	1,900
Subscriptions	989	923
Sundries	1,931	2,388
Telephone	<u>5,187</u>	<u>6,188</u>
	<u>180,954</u>	<u>160,541</u>
Total Expenditure	<u>298,007</u>	<u>315,113</u>
SURPLUS/(DEFICIT) FOR THE YEAR	<u>\$ 330</u>	<u>\$ (44,414)</u>

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2015

Note 1 – Summary of Significant Accounting Policies

The financial statements are special purpose financial statements prepared in order to satisfy the financial reporting requirements of the Associations Incorporation Act 2009 (NSW) and the Australian Charities and Not-for-profits Commission Act 2012 . The Board has determined that the association is not a reporting entity.

The financial statements have been prepared on an accruals basis and are based on historic costs and do not take into account changing money values, or except where specifically stated, current valuations of non-current assets.

The following significant accounting policies, which are consistent with the previous period unless otherwise stated, have been adopted in the preparation of these financial statements.

a) Income Tax

No provision for income tax has been raised, as the association is exempt from income tax.

b) Property, Plant and Equipment

Property, plant and equipment are carried at cost, independent of Boards' valuation. All assets, excluding freehold land and buildings, are depreciated over their useful lives to the association from the time the asset is held ready for use.

c) Impairment of Assets

At the end of each reporting period, the entity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have been impaired. If such an indication exists, an impairment test is carried out on the asset by comparing the recoverable amount of the asset, being the higher of the asset's fair value less costs to sell and value in use, to the asset's carrying amount. Any excess of the asset's carrying amount over its recoverable amount is recognised in the income and expenditure statement.

d) Employee Provisions

Provision is made for the association's liability for employee benefits arising from services rendered by employees to the end of the reporting period. Employee provisions have been measured at the amounts expected to be paid when the liability is settled.

e) Provisions

Provisions are recognised when the association has a legal or constructive obligation, as a result of past events, for which it is probable that an outflow of economic benefits will result and that outflow can be reliably measured. Provisions are measured at the best estimate of the amounts required to settle the obligation at the end of the reporting period.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2015

Note 1 – Summary of Significant Accounting Policies (cont'd)

f) Cash on Hand

Cash on hand includes cash on hand, deposits held at call with banks, and other short-term highly liquid investments with original maturities of three months or less.

g) Accounts Receivable and Other Debtors

Accounts receivable and other debtors include amounts due from members as well as amounts receivable from donors. Receivables expected to be collected within 12 months of the end of the reporting period are classified as current assets. All other receivables are classified as non-current assets.

h) Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable.

Interest revenue is recognised using the effective interest rate method.

Grant and donation income is recognised when the entity obtains control over the funds which is generally at the time of receipt.

All revenue is stated net of the amount of goods and services tax (GST).

i) Goods and Services Tax (GST)

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Australian Tax Office (ATO). Receivables and payables are stated inclusive of the amount of GST receivable or payable. The amount of GST recoverable from, or payable to, the ATO is included with other receivables in the Balance Sheet.

j) Financial Assets

Investments in financial assets are initially recognised at cost, which includes transaction costs and are subsequently measured at fair value which is equivalent to their market bid price at the end of the reporting period. Movements in fair value are recognised through an equity reserve.

k) Account Payable and Other Payables

Accounts payable and other payables represent the liability outstanding at the end of the reporting period for goods and services received by the association during the reporting period that remain unpaid. The balance is recognised as a current liability with the amounts normally paid within 30 days of recognition of the liability.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2015

Note 1 – Summary of Significant Accounting Policies (cont'd)

l) Member's Liability

Members are liable for the amounts each member owes the association in respect of their membership ie fees or subscriptions due to the association.

Members of the Board of the association also have limited liability for the debts of the association, as long as they have followed accepted business and community standards.

m) Comparative Figures

Where required by Accounting Standards, comparative figures have been adjusted to conform with changes in presentation for the current financial year.

Note 2 - Information on Material Matters

The Association received \$110,000 from a private benefactor family.

Note 3 - Application of appeal monies

During the year the Association received net income of \$258,634 from fundraising appeals, \$5,612 from the investment of appeal monies and \$6,945 from membership fees.

An amount of \$104,941 was spent on the provision of services (including \$52,321 for clinics and counselling, \$5,590 for newsletters and \$47,030 for other awareness and support). We spent \$98,186 on rent, insurance, administration and office expenses. We spent \$28,300 on conferences and seminars. We also spent \$35,957 on a medical marketing project to raise awareness in the medical community.

Note 4 - Information on traders

The Association did not use traders in carrying out fundraising appeals.

Note 5 - Fundraising appeals conducted during the period

Appeals conducted were:

- Soliciting of donations
- Sale of Christmas cards
- Card playing day in March 2015
- Fun runs
- Fragile X Awareness day events
- Garden open day

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2015

Note 6 - Analysis of monetary figures

Ratios	\$	%
Total cost of fundraising/ Gross income from fundraising	12,112/270,748	4.5 (4.5% last year)
Net surplus from fundraising/ Gross income from fundraising	258,634/270,748	95.5 (95.5% last year)
Total costs of services/ Total expenditure	104,941/298,007	35.2 (45.4% last year)
Total costs of services/ Total income received	104,941/298,337	35.2 (52.8% last year)

Note 7 – Commitments

No material commitments were entered into by the association during the year.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2015

	Note	2015	2014
Note 8 - Endowment Fund			
Balance Sheet - as at 30 June			
CURRENT ASSETS			
Cash and cash equivalents			
At Bank		175,919	2,156
Term Deposit - Due 16 November 2015 at 2.00%		<u>50,000</u>	<u>156,977</u>
		<u>225,919</u>	<u>159,133</u>
Accounts receivable and other debtors			
Receivable from FXAA Current Account		<u>550</u>	<u>-</u>
TOTAL CURRENT ASSETS		<u>226,469</u>	<u>159,133</u>
NET ASSETS		<u>\$226,469</u>	<u>\$159,133</u>
EQUITY			
Opening Balance		159,133	134,736
Transfer to Capital		-	19,585
<u>Add: Income for the Year</u>	9	<u>67,336</u>	<u>4,812</u>
TOTAL EQUITY		<u>\$226,469</u>	<u>\$159,133</u>
Note 9 - Endowment Fund			
Income & Expenditure Statement - for the year ended 30 June			
INCOME			
Bequest as residuary beneficiary of deceased estate		-	2,345
Donations		63,287	17,242
Interest		<u>4,059</u>	<u>4,810</u>
		67,346	24,397
Less:			
Expenses		10	-
Transfer to Capital		<u>-</u>	<u>19,585</u>
		<u>10</u>	<u>19,585</u>
INCOME FOR THE YEAR		<u>\$ 67,336</u>	<u>\$ 4,812</u>



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