

ANNUAL REPORT 2015 - 2016





ABN 18 655 264 477







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 other Fragile X-associated Disorders. We have been serving the Fragile X community for over 25 years by offering support, knowledge, and connections.

We provide specialised information, counselling and family support, research findings, referrals, networking, advocacy, educational workshops and facilitate assessment clinics. We also work to increase awareness of Fragile X disorders in the medical and wider community, and to serve as a voice for those affected by Fragile X.

We receive no public funding and are therefore reliant on donors, grants, in-kind contributions and substantial volunteer input to sustain these activities.

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.

The underlying principles which guide us:

Service, Respect, Accountability, Evaluation, Compliance



UNDERSTANDING FRAGILE X

Fragile X-associated Disorders are caused by an alteration to the FMR1 gene on the X chromosome.

Fragile X disorders are inherited from a parent who 'carries' the altered FMR1 gene. This gene can be passed on by either parent. It is estimated that 1 in 800 males and 1 in 170 females are carriers of Fragile X, and therefore have the potential to pass this on their children.

Fragile X syndrome — most common known cause of inherited intellectual disability and the most common known single gene cause of autism spectrum disorder. An estimated 1 in 3600 males and 1 in 4000-6000 females have Fragile X syndrome.

FXTAS—Fragile X-associated Tremor Ataxia syndrome, a neurological condition often confused with Parkinson's disease, which can affect a percentage of men and women who are carriers of Fragile X.

FXPOI—Fragile X-associated Primary Ovarian Insufficiency, often leading to early menopause, which affects around 20% of women who are carriers of Fragile X.

People living with *Fragile X syndrome* (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; anxiety, hyperarousal, ADHD, depression; low muscle tone; autistic-like behaviours; aversion to touch, loud noises, bright lights & strong smells; avoidance of eye contact; mood instability. People with Fragile X syndrome 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.

Every week in Australia one child is born with Fragile X syndrome, and 20 are born who carry the FMR1 gene alteration 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 2015-2016



Robyn Iredale, PhDPresident (NSW)Migration and Human Rights ResearcherRobyn 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 Treasur

Treasurer (NSW)

Bruce is a parent of two young women with Fragile X. Seven other members of his wife's family are affected by Fragile X.



Judith LenartSecretary (NSW)Investment consultant and community volunteerJudith is qualified in urban valuation, natural health and school trusteeship and is
trained in governance



Cathy Love

Lawyer

Board member (VIC)

Consultant Occupational Therapist, Family Coach 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, PhDBoard member (VIC)PsychologistPam has substantial experience in management of professional medical

development programs and in policy development.



Nyleta McRaeBoard member (QLD)IT specialistNyleta is a carrier of Fragile X, and has two young children who have Fragile Xsyndrome. Nyleta's mother has Fragile X-associated Tremor Ataxia syndrome.



Graham HookBoard member (QLD)Defence industry managerGraham has an adult son affected by Fragile X syndrome and has previously served
on the Board.



Shane Mansfield Board m Telecommunications project manager

Board member (VIC)

Shane has a young son who has Fragile X syndrome.

OUR TEAM IN THE OFFICE

Our office remains in Sydney, at Suite 6, Level 3, 39 East Esplanade, Manly, NSW. Our small team comprises 3 members of 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. Wendy writes our newsletter, updates our website and provides content for our social media channels, organises our workshops and events, and manages our compliance obligations. Wendy also provides support to members, and assists with fundraising.



Amanda Rummery-Hoy Family Support Worker (part-time)

Amanda has a degree in Social work and a Dip ED in Adult Vocational Education, and has worked with the Association since March 2016.

Amanda's focus is on encouraging families, couples and individuals in the Fragile X community to contact her for face to face support or phone/skype based support.

In addition to counselling, Amanda also provides referral and advocacy support to families as they navigate services and government departments in an increasingly complex environment.



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 processes and compliance.



Katrina Weir

Medical Communications (consultant)

Katrina has many years of experience in the communications sector, specialising in health communications. Katrina identifies 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 writes material for Fragile X Association publications, the 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 2015-2016. This support is key to our ability to provide support and programs to our member base, and the broader Fragile X community.



PRESIDENT'S REPORT

Our Annual Report provides an excellent opportunity for review. This past year has been one of achievements in a number of areas.

We were delighted to host Fragile X experts Professor Randi Hagerman and Professor Paul Hagerman in August. They ran a number of information sessions for families and the Fragile X research community, in Melbourne, Perth and Sydney. It's always a great pleasure to see them in Australia, and we thank them for being generous with their time.



Working with Fragile X, our video focusing on employment inclusion and featuring five of our young adult members has been a great asset. I wish to particularly thank Hugh, Marty, Rosie, Ross and Zoe for being willing to talk so openly about the problems of finding and keeping employment. The video has been used in a number of forums, and viewed widely via social media.

The Medical Communications initiative has now been running for two years. Thousands of professionals have been reached with information about diagnosis of FX-associated Disorders, including Fragile X syndrome and FXTAS. The first Australian FX Carrier Family clinic was established at St Vincent's Hospital in Sydney, supported by two Sydney-based families. We have been delighted to play a role in promoting this major support to the Fragile X community, especially those at risk of developing FXTAS.

Another area where we have major contact with researchers and the health professions is through our Scientific and Research Sub-Committee, which meets to discuss current issues, research projects, the latest research findings and the possible involvement of FXAA in research and clinical trials. I wish to thank this committee for their willingness to devote time and energy to our efforts and to gaining media attention for particular Fragile X issues.

Our social media platforms have become an important means of networking, peer support and communicating information within the Fragile X community. Families can contact each other, seeking answers to questions, and to share joyous and difficult experiences. I am always impressed at this means by which the FX community support each other. Our website is updated often and we look forward to improving its accessibility later in the year thanks to a donation from Manly Rotary.

The role of the Board is crucial in determining the focus of the Association. I would like to thank each of the very committed Board members who have generously contributed their diverse skills to the Association this past year, and I would like to congratulate those who have volunteered to join the Board for the coming year. The Board has recently developed our 2020 Strategic Plan for the Association, to serve as a framework for the coming years.

Our Endowment Fund is intended to provide for the financial future of the Association, and I am delighted to see it growing over time. Thanks to Bruce Donald, our Treasurer, for his foresight in establishing the Endowment Fund.

I would also like to sincerely thank our members and supporters who have made donations, fundraised or supported our presence at conferences and events as we work to increase the visibility of Fragile X-related issues. In particular I would like to thank the Cunningham family for their continued and very generous financial support to the operations of the Association, the Medical Communications initiative and the Fragile X Premutation Carrier Clinic at St Vincent's in Sydney.

I look forward to remaining a member of the Association, and continuing my involvement in both the Scientific & Research Committee and the Association's role as charity partner for the annual Bridge to Beach ocean paddling fundraiser in Manly.

On behalf of the Board and the team in the office, it is our great pleasure to serve the membership of the Association. I wish everyone all the very best for the future.



R. R. medale

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Each year Fragile X Awareness Day on **July 22nd** presents an ideal platform to build awareness of Fragile X-associated Disorders in the general community. Families, schools, and service providers were all involved this year! A highlight for our social media was a short video made for us by renowned journalist and broadcaster, Amanda Keller, which was shared widely.







Amanda Keller made us a video ad for FX day!









Miriam featured on one of our new posters



Kids are Kids in WA celebrated the day





Kurt & his class made X chromosomes!

FAMILY SUPPORT

In the period July 2015 through to June 2016, 250 counselling sessions were recorded by our counsellors Janie Roberts and Amanda Rummery-Hoy.

The counselling sessions have ranged from regular formalised telephone appointments; office based appointments and home visits; informal telephone and email contacts, depending on need.

Counselling sessions were around supporting people with Fragile X and their families. Some of the shared needs and concerns included support with a new diagnosis of Fragile X, FXTAS and FXPOI. Counselling has also included providing support and strategies to help with managing feelings of anxiety and



Amanda Rummery-Hoy

depression, grief and relationship issues and, where necessary, referral to assist in accessing supports in the community.

Other aspects of the Family Support role included information, advocacy and support to families around the NDIS rollout, education and advice on supporting people with Fragile X to therapists and staff in community-based organisations, care staff in residential settings and teachers in school settings. The role has also involved exploring eligibility for people affected by Fragile X to access health funded transport schemes that can assist with the costs of travelling to Specialist Clinics.

The Family Support service is provided at no charge.

ASSESSMENT CLINICS

FXAA continues to support assessment clinics for children and adults who have Fragile X syndrome and attend the multidisciplinary clinics provided by Dr Jonathan Cohen and his team at the Fragile X Alliance Clinic in Melbourne. In 2015-2016 FXAA supported these clinics for 12 people. We also facilitated access to a number of clinic places for children and teenagers who have Fragile X syndrome with Professor Randi Hagerman in August.

FRAGILE X PREMUTATION CARRIER FAMILY CLINIC

Made possible by the generous support of the Cunningham family, February 2016 saw the launch of the St Vincent's Hospital *Fragile X Premutation Carrier Family Clinic.*

The clinic is facilitated by neurologists Associate Professor Stephen Tisch and Dr Sam Bolitho at St Vincent's Hospital in Darlinghurst, Sydney.

It is a dedicated service for carriers of Fragile X and their families, from anywhere in Australia, who are experiencing or at risk of developing issues related to being a carrier of Fragile X. A recent focus of the clinic has been FXTAS.

There is no cost associated with attending the clinic providing the patient has a GP referral. Janie Roberts, formerly Counsellor with Fragile X Association and with deep knowledge of Fragile X issues, is now the Counsellor for this clinic.

FXAA is working closely with Dr Tisch and Dr Bolitho to help promote the clinic to the Fragile X community and to other neurologists who may be looking for access to clinical expertise and further information about FXTAS or other issues associated with being a carrier of Fragile X.



A/Prof Stephen Tisch, Dr Sam Bolitho

FUNDRAISING

Our members and supporters continue to do a wonderful job in using community events to increase awareness of Fragile X, and to fundraise for the Association.

A couple of the inspirational fundraising moments in 2015-2016 included **Cynthia Roberts**, and her team from Genea, taking on the **Sydney Morning Herald City2Surf** (40km run!) and **Mike Tozer's** first attempt to win a Guinness World Record for running a Half Marathon—in a suit! Cynthia and Mike each raised over \$4,000 through their efforts!



Here's what Mike Tozer said before the race: One man. One suit. 21.1 kilometres. Sub 1 hour 18 goal. I'll be lining up at the start line of the Sydney Morning Herald half marathon aiming to take on a Guinness World Record: the fastest half marathon in a suit. I'm doing it to raise awareness for Fragile X syndrome. My son has this condition and I daily get to watch the joys and the challenges that come from Fragile X. This condition means having just one missing protein, which is vital for brain development. This one protein holds him and others back in a way that doesn't seem fair. In a similar but much lesser degree, my suit will hold me back and be a constant reminder throughout the race. Another record breaker spoke of the cognitive dissonance of this record; of wanting to take off the suit jacket but then reminding himself of needing to keep it on to meet the record rules. This idea of cognitive dissonance made me think of the parallels of what I've read of the neurology of Fragile X syndrome. Coupled with the fact that the record is just within my reach (2 minutes off my personal best) inspired me to give it a try.

Am excited that lots of people are getting behind this attempt, including friends, sponsors and media in Sydney and in Hong Kong. The record was broken in March in New York at 1 hr 18'40", so I'm going to need this whole team behind me to hit the goal.

And after the race he had this to say: "That race was a killer! Heat exhaustion, blisters, but so many people yelling Go Suit Guy!!! Cheered me on. Nice to see coverage of the race in the Sydney Morning Herald. As I reflect back on the amazing day, I'm grateful for all who cheered me on as well as Bonham Strand for a fantastic suit, and Brooks Running and HillySocks for their awesome lightweight gear. I can still say that on the day I beat the official world record of 1hr24. The main focus of the run was awareness raising and fundraising for the Fragile X Association of Australia. So I'm pleased we made some noise and raised \$4163."

What next? Mike's next attempt was two months later, in July – and at 1 hour 18 mins 10 seconds, he succeeded!





It was brilliant weather for the annual Bridge to Beach ocean paddling race on Sunday 22 February 2016!

This iconic race is an 11km paddle across Sydney Harbour from under the Bridge, to finish in Manly, not far from our office.

Fragile X Association was Oceanpaddler's charity partner for the 3rd year in a row, raising \$3000 from the paddlers.

Luke Ratcliff was fundraiser & paddler-in-chief, again!

Robyn Iredale, Luke Ratcliff, Mayor Jean Hay

Annual Report 2015-2016

EXPANDING THE FX KNOWLEDGE BASE OF HEALTHCARE PROFESSIONALS

Since the last report to members, there has been considerable medical communications activity including presenting and exhibiting at a number of different conferences across Australia, leveraging the visit of Professors Randi and Paul Hagerman, utilising mainstream media to raise awareness of Fragile X conditions, partnering with other organisations to host events and updating information about Fragile X on key government websites.

This year also saw the launch of the monthly Fragile X Premutation Carrier Family clinic at St Vincent's Hospital in Sydney. Combined, these activities have contributed to maintaining a higher level of 'noise' around Fragile X and a greater interest and understanding of the conditions, particularly the premutation conditions, FXPOI and FXTAS.

We have also seen the number and quality of our relationships with health professionals in the genetic, intellectual disability and related areas grow, and a greater willingness for these professionals to educate and advocate for Fragile X on our behalf. It is hoped that with further sustained and consistent effort, medical communications activities will reach an even larger audience in the coming year and that as a result, families and individuals impacted by Fragile X will have more positive experiences with their health professionals and ultimately, better health outcomes.

Maximising Conference Opportunities



HealthEd is a training organisation that hosts a range of education events for GPs and other health professionals. Each year, HealthEd runs one-day GP Education Days in each major capital city around Australia, the first one being in Sydney in August.

In 2015 HealthEd was most generous in its support of FXAA offering us a speaking opportunity, satchel insert and an exhibition stand at each of the events. We arranged for a local key opinion leader in either genetics, paediatrics or intellectual disability to deliver a 30 minute presentation to GPs at each event.



Dr Jane Tracy and Cathy Love

The topic was "What GPs need to know about intellectual disability" and had a focus on Fragile X syndrome. Numbers in the audience ranged from 650 in Sydney and Melbourne to around 200 in Adelaide and overall, this program reached close to 2000 GPs around the country. At each event, we also had an exhibition stand providing a great opportunity to have more in-depth discussions with interested delegates. FXAA staff attended the stand in Sydney, in Melbourne it was Board member Cathy Love, and in the other cities we were very grateful that a number of FXAA members were happy to volunteer their time to further our cause. Our involvement in the 2015 seminar series was the start of a strong ongoing relationship with HealthEd, and FXAA is extremely thankful to them for their generosity and ongoing support.



FXAA was also involved in the annual Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA) conference in Sydney in August 2015, and the Australian Society for Intellectual Disability (ASID) conference in Melbourne in November 2015.

Professor Randi Hagerman was a keynote speaker at the NBPSA conference and as a result, FXAA was a co-sponsor of the event. On top of the 400 delegates learning directly from Professor Hagerman's presentations, this sponsorship enabled us to provide important clinical information about Fragile X syndrome in the delegates' satchels as well as an exhibition stand for the two days of the conference which was attended by FXAA's staff, counsellor Janie Roberts and Liz Russell, and FXAA member Rosie Donald. Feedback from the delegates was excellent, many of whom provided contact details so that we could send them additional information about Fragile X syndrome once they returned to their own locations.

In November 2015, Melbourne-based psychologist Astra King kindly agreed to present to 400 delegates at the ASID conference on "Looking for ADHD in Fragile X syndrome: The parts that affect functioning". FXAA also negotiated for our brochure to be included in the delegates' satchel, providing excellent profile for Fragile X.

Leveraging Professors Randi and Paul Hagerman's Australian Visit

In August 2015, Professors Randi and Paul Hagerman visited Australia for a mixture of business and (a little) pleasure. Randi was keynote speaker at the NBPSA conference in Sydney but while they were here, FXAA was extremely fortunate to be able to involve them in a range of other activities including family events in Perth, Melbourne and Sydney, presentations and knowledge sharing with Fragile X researchers in Melbourne, filming a Q&A video on wellness issues for carriers of Fragile X and for Paul, molecular geneticist and FXTAS researcher, a number of meetings with leading neurologists in Sydney and a presentation to clinical geneticists and researchers in Perth.



Katrina Weir with Prof Randi Hagerman

FXAA also arranged a cocktail reception for the Hagermans, so that we could officially welcome them to Australia and introduce them to some of our members, donors, supporters and advocates. The reception was very well attended and generously sponsored by the Garvan Institute of Medical Research in Sydney.

As two of the world's leading Fragile X experts, it was wonderful to have Professors Randi and Paul Hagerman in Australia. They were most generous with their time and willingness to inform as many people as possible about the latest thinking in Fragile X-associated Disorders.













Fragile X Association of Australia Inc

Working with Media



In April 2016, we were delighted that after many months of negotiation, Australian Women's Weekly published a story on their website about Fragile X syndrome. It was based on the experience of FXAA member Patti, who decided to share her story about being a Fragile X carrier and the reproductive choices she made in order to have two children unaffected by Fragile X syndrome. The story was shared several hundred times by Women's Weekly readers and on social media, was an excellent awareness raising opportunity.



As 2016 marks the 25th anniversary of the discovery of the FMR1 gene, we decided to revisit the work of Professor Gillian Turner AO and Professor Grant Sutherland AC in order to reflect on the pioneering work that they did to build understanding of the impact of changes to the FMR1 gene and Fragile X syndrome around the world.



We interviewed both Professors and wrote a lengthy story that was published in the June 2016 FX quarterly newsletter and on our website.

Partnering with the Royal Hospital for Women



FXAA, together with Professor Bill Ledger, Head and Professor Obstetrics and Gynaecology at the Royal Hospital for Women (Randwick, Sydney), was fortunate to host the Grand Rounds at the hospital in April. The Grand Rounds is an information session for health care professionals about a particular area of interest.

Introduced to Professor Ledger by FXAA, Professor W Ted Brown, Director, New York State Institute for Basic Research in Developmental Disabilities and a world expert on Fragile X syndrome, addressed an audience of about 60 doctors, nurses, geneticists & counsellors on the clinical aspects of Fragile X syndrome and about

some of his recent research, including progress with the development of a new and inexpensive FMRP protein screening test. We were very fortunate to have Professor Brown share his knowledge and expertise with us and are very thankful for his passion and dedication into Fragile X syndrome research. We are also grateful to Professor Ledger for being the moderator of the event and for championing Fragile X awareness among healthcare professionals.

Improving Information on Government Websites

The Federal government and most state governments host websites providing health information to consumers, however, this can be of variable quality and currency. FXAA has been successful in reviewing and rewriting the information about Fragile X syndrome on Better Health Channel, the Victorian Department of Health and Human Services website. We have also been assessed and accepted as an Information Partner by HealthDirect, the Federal Government's website, which allows us to link our website and other resources to the site, and to benefit from original content about Fragile X that the HealthDirect website's writers will create.



Fragile X Association of Australia Inc

OUR COMMUNITY

At the 2015 Annual General Meeting, the wonderful efforts and achievements of five young people in the Fragile X community were acknowledged.

HONORARY MEMBERSHIP

Narelle Robertson from Victoria was awarded Honorary Membership of Fragile X Association in recognition and appreciation of her commitment to supporting the organisation through proactive efforts in fundraising and in raising awareness of Fragile X.

ACHIEVEMENT AWARDS



Narelle with Janie Roberts



Isaac from Adelaide - received an Award for becoming a member of Zoo Youth at Adelaide Zoo, a team of diverse peers and adults. He's been challenged on all levels and worked hard at cleaning animal enclosures, and learning a lot about caring for animals. Isaac always shows great care, empathy and passion for animals through all the work he does.

Alex from Melbourne - received an Award for working hard on self improvement and independence. Alex has had a big breakthrough as a result of working really hard at managing his anxiety, at reading and his speech therapy. Alex shows that adults with Fragile X, given motivation and help, continue to learn and develop.

Laura from Brisbane - received an Award for going above and beyond in helping her brother Luke reach his goals. Her determination to get Luke talking, and inclusion in play, has made a huge impact on Luke's progress.

Harrison from Sydney - for showing persistence and dedication in all areas of his life, with a smile on his face! He's worked hard and progressed well in literacy, and shows dedication to his karate 3 days per week.

WEBSITE AND SOCIAL MEDIA

Social media provides for regular interaction with the Fragile X community and the sharing of information and resources



Traffic on our website decreased by 9% from the previous year to 185,500 web visits, although the number of unique visitors increased slightly to **102,000 unique visitors**. 1650 likes, an increase of 37% in the 12 months to 30 June 2016. We frequently post our own news,

stories, and share related posts.



12,620 views of our videos. Highlights: 9,400 views of 'Understanding Fragile X' videos, and 1,170 views of 'Working with Fragile X' videos, and 550 views of 'Q&A with Marcia Braden.'

450 followers, and we tweet regularly!

SCIENTIFIC AND RESEARCH COMMITTEE

The FXAA Scientific and Research Sub-Committee includes ten Australian Fragile X specialists. 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 up to four times each year.

The sub-committee has met three times through 2015/16. These meetings offer opportunities for sharing information, providing FXAA with comments and advice across a range of technical issues, and updates concerning research developments in Australia and internationally. The areas of main discussion and outputs from the committee through the past year included:

- □ Inputs to the FXAA research protocol to guide the Association's response to requests for any assistance in promoting FX research;
- □ The development of a national register (at VCGS) of FX families that have agreed to participate in future FX research;
- □ Information on developments for FX screening and testing (pre-pregnancy and newborn);
- Preparation of information items and research updates for the FXAA newsletter; and
- □ A database of upcoming conferences concerning Fragile X-associated disorders.

The sub-committee continues to provide a valuable forum for ensuring technical terminology and FXAA information on Fragile X-associated disorders is as accurate as possible.

Scientific and Research Committee members 2015/2016

Dr Tim Turpin (Chair)	Consultant, Member Fragile X Association of Australia
Dr Robyn Iredale	President, Fragile X Association of Australia

Co-opted Members:	
Professor David Amor	Clinical Geneticist, Murdoch Childrens Research Institute
Dr Alison Archibald	Associate Genetic Counsellor, Victorian Clinical Genetics Services
Dr Claudine Kraan P	Postdoctoral research fellow, Murdoch Childrens Research Institute
Dr Jonathan Cohen	Medical Director, Fragile X Alliance Clinic
Dr Mike Field	Geneticist, Genetics of Learning Disability (GOLD) Service, NSW
Dr David Godler	Group Leader, Cyto-molecular Diagnostics Research, Murdoch Childrens Research Institute
Dr Matthew Hunter +	Head of Monash Genetics Clinic, MonashHealth
Dr Danuta Loesch S	School of Psychological Science, La Trobe University
Professor Sylvia Metcalfe	Group Leader, Genetics Education and Health Research, Murdoch Childrens Research Inst.
Dr Rachael Birch P	Psychologist, Department of Developmental Disability Neuropsychiatry, UNSW Australia

ENDOWMENT FUND

The FXAA Endowment Fund was established in early 2012 to ensure the ongoing viability of FXAA. 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.

The Endowment Fund is maintained and accounted for separately from the Association's other funds and is managed by an Advisory Sub-Committee. This Committee meets at least four times a year and reports half yearly to the Association. During the year the net growth of the Endowment was \$57,783 taking the total equity to \$284,252.

FXAA Endowment Fund Advisory Committee 2015/2016

David Bassingthwaighte (Chair)	Self-employed financial consultant
Marion Pascoe	Former Deputy Parliamentary Counsel, NSW
Martin Davey	Chartered accountant
Dr Robyn Iredale	President, Fragile X Association of Australia
Bruce Donald	Treasurer, Fragile X Association of Australia

FXAA 2020 — RENEWAL AND FOCUS

We are approaching the future with a strong sense of purpose and determination to serve our community by concentrating on the essentials - understanding, information and support.

As a small organisation without any public funding FXAA must identify and focus on very targeted ways to really make a difference and bring about positive change over time. We are confident of fulfilling our functions in ways that are innovative, effective and affordable.

During the past year Association staff and directors spent many hours reviewing our previous strategic plan and developing a clear achievable pathway for the organisation based on a mission devoted to: "working towards the best possible lives for FX families throughout Australia."

Priorities identified as central to this objective are summarised in the document FXAA 2020 which can be viewed in full on www.fragilex.org.au We intend this to be a living document and process that will be subject to adjustment as circumstances evolve and will be responsive to needs of our members and the wider FX community. Comments and suggestions are very welcome at any time!

The focus in the next few years will be on support and empowerment, awareness and advocacy, screening and diagnosis, partnering and sustaining the organisation. Many activities are planned within these areas, combining current programs with new initiatives. The consistent theme is delivery of what matters most to the FX community as expressed in last year's survey and in many individual interactions.

From an operational perspective the central challenge is how best to provide practical support within the parameters of available resourcing and locational factors. The FXAA history of doing a lot with little will continue, and we intend to expand future services.

"In particular, there will be more emphasis on raising the profile of FX in the medical and wider community, on providing specialised NDIS guidance, and on offering immediate assistance to newly diagnosed families. Our aim is to strengthen connections within and beyond the FX community by being an active catalyst at the heart of this process.



treasurer's Report

For my final report as Treasurer, I am pleased to confirm to members again that FXAA continues to be financially well managed within its means. The audited accounts, which combine the Association's operations with the Association's Endowment Fund, record a surplus for the last financial year made up principally of donations to the Fund but including a small cash surplus for committed operational expenses.



Our main funding sources remain our long-term supporters, the Cunningham family and a philanthropic foundation. I am also very pleased to acknowledge the funding support received this past financial year from Milton Corporation Foundation, Masonicare, the Galston District Garden Club (Sydney),

Community Living & Participation Grants (WA), Neuren Pharmaceuticals, Rotary, the Lions Club, and a member family based in Sydney.

I would like to acknowledge the active fundraising efforts of our members. Dr Cynthia Roberts again took part in the Sydney City2Surf run, and raised over \$4,000. Mike Tozer took on an extraordinary challenge, running 21.1km Sydney Half Marathon in a suit, raising over \$4,000. We're delighted to remain the charity partner for Oceanpaddler for their iconic Bridge to Beach ocean paddle race: 11km across Sydney Harbour from beneath the Sydney Harbour Bridge across to Manly. The paddlers raised \$3,000 this year. I would also like to acknowledge important in-kind support throughout the year, including Murdoch Childrens Research Institute, the Garvan Institute of Medical Research, Kids Are Kids Therapy Network (WA), Developmental Disability WA and HealthEd.

However, my farewell plea as I leave the Board is for the future. While FXAA is viable for the next two financial years, there is much to be done to raise the funding for the period after that. One of our key philanthropic supporters has advised well in advance that its financial support for the Association will conclude after many years of generous funding. The work must begin now to identify funding of the order of \$100k pa for a number of years from 2018.

The introduction of the National Disability Insurance Scheme will be of fundamental importance for many, but not all, FX families. However it will not replace the key roles FXAA identified in our 2020 Strategic Plan in family support and counselling, public awareness and understanding and engagement with the medical profession and research community. To perform those roles we will continue to need a base funding level of \$250k pa. So I call on all members and supporters to promote the value of FXAA within their families and networks.

My hope some years ago when initiating the establishment of the Endowment Fund had been that by now it would be at a level far above the nearly \$300k we have achieved and that the earnings from that Fund would have begun to be a major source of operational funding for FXAA. That has not yet been achieved despite generous additions to the Fund over the last two years. The Fund is managed by a committee including financial advisers which has diversified the portfolio to include investments as well as bank deposits. The accounts as at year's end therefore show a variation in the market value of the investments but that is not a realised variation and will change with the market until investments are actually divested. The advisers and the FXAA Board are satisfied with the status of the portfolio. Again, I urge members to promote this Fund to potential donors in their networks.

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

I commend the accounts to the Members.

Some Donald





Bruce Donald AM



ManserTierney&Johnston Chartered Accountants

FRAGILE X ASSOCIATION OF AUSTRALIA INC ABN 18 655 264 477

FINANCIAL STATEMENTS 30 JUNE 2016

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:

- present a true and fair view of the financial position of Fragile X Association of Australia Inc as at 30 June 2016 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-forprofits 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:

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ROBYN IREDALE President

BRUCE DONALD Treasurer

Dated this

5th day of October

2016



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 of Fragile X Association of Australia Inc (the Association), which comprises the balance sheet as at 30 June 2016, 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 of the financial statements that gives a true and fair view in accordance with the Associations Incorporation Act 2009 (NSW), the *Australian Charities and Not-for-profits Commission Act 2012* and for such internal control as the Board determines is necessary to enable the preparation of the financial statements that is 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 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 is 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 of the financial statements that gives a true and fair view 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 entity'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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INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF FRAGILE X ASSOCIATION OF AUSTRALIA INC

Independence

In conducting our audit, we have complied with the independence requirements of the *Australian Charities and Not-for-profits Commission Act 2012* and any applicable code of professional conduct in relation to the audit.

Opinion

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

- i) giving a true and fair view of the Association's financial position as at 30 June 2016 and of its financial performance for the year ended on that date; and
- ii) complying with Australian Accounting Standards to the extent described in Note 1, the Associations Incorporation Act 2009 (NSW) and the Australian Charities and Not-forprofits Commission Regulation 2013.

Basis of Accounting and Restriction on Distribution

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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.

dav of

October

2016.

MTJ AUDIT PTY LTD BRIAN THERNEY Partner

Signed at Wahroonga this

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BALANCE SHEET AS AT 30 JUNE 2016

	Note	2016	2015
CURRENT ASSETS			
Cash on hand			
At Bank		42,638	36,014
Bank Guarantee		6,875	6,875
Endowment Fund	8	38,229	225,919
Petty Cash		103	102
Term Deposit		5,008	
Accounts receivable and other debtors		92,853	268,910
Accounts Receivable		4,133	3,235
Franking Credits Refundable		2,324	5,255
Prepayments		-	643
GST Refundable		9,905	7,981
		16,362	11,859
TOTAL CURRENT ASSETS		109,215	280,769
NON-CURRENT ASSETS			
Property, plant and equipment			
Office Equipment - At Cost		21,811	20,724
Less: Accumulated Depreciation		(15,244)	_(11,812)
		6,567	8,912
Investments			
Listed Investments at Market Value - Endowment Fund	8	243,699	
TOTAL NON-CURRENT ASSETS		250,266	8,912
TOTAL ASSETS		359,481	289,681
CURRENT LIABILITIES			
Accounts payable and other payables			
Accounts Payable		12,109	8,450
Income Received in Advance		3,835	3,640
Payroll Liabilities		869	1,036
Other Liabilities		1,425	545
		18,238	13,671
Provisions Provision for Employee Entitlements		7,771	-
TOTAL CURRENT LIABILITIES		26,009	13,671
TOTAL LIABILITIES		26,009	13,671
NET ASSETS		\$333,472	\$276,010
MEMBERS' FUNDS			
Opening Balance		276,010	275,680
Add: Surplus for the Year		57,462	330
TOTAL MEMBERS' FUNDS		\$333,472	\$276,010

The accompanying notes form part of these financial statements.

INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2016

	2016	2015
INCOME		
Gross Proceeds From Fundraising Appeals		
Christmas Cards	253	1,422
Conference Income	3,314	15,032
Donations - including Endowment Fund	351,138	264,321
FXAA Awareness Day	1,243	2,383
Merchandise Sales	18	12
Raffle Sales	-	2,610
Sponsorships	8,500	
	364,466	285,780
Other		
Dividends	7,883	
Interest	2,229	5,612
Gain on sale of investments	200	
Subscriptions	6,180	6,945
		12,557
Total Income (carried forward)	380,958	298,337

INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2016

	2016	2015
Total Income (brought forward)	380,958	298,337
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Card Day	<u>2</u>	945
Other	6,883	11,167
	6,883	12,112
Total Costs Of Providing Services		
Support Services and FX Awareness	29,335	47,030
Clinics and Counselling	51,061	52,321
National Newsletter Printing	7,684	5,590
-	88,080	104,941
Other		
Bank Fees and Charges	2,000	564
Board and AGM Expenses	1,962	1,583
Workshops and Seminars	25,295	28,300
Consultants	40,162	35,957
Depreciation	3,433	2,529
Gifts		50
General Administration - Employment Costs	80,317	56,919
Insurance	5,277	3,325
Office Expenses	9,237	9,124
Office Rent	29,613	28,818
Postage	2,050	2,796
Provision for Employee Entitlements	7,771	=
Stationery	2,508	2,882
Subscriptions	1,266	989
Sundries	3,262	1,931
Telephone	3,831	5,187
	217,984	180,954
Total Expenditure	312,947	298,007
OPERATING SURPLUS FOR THE YEAR	68,011	330
(Decrease) in market value of listed investments - Endowment Fund	(10,549)	
SURPLUS FOR THE YEAR	\$57,462	<u>\$ 330</u>

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2016

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 or 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.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2016

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.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2016

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

I) 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 management 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 \$130,000 from the Cunningham family.

Note 3 - Application of appeal monies

During the year the Association received net income of \$345,798.53 from fundraising appeals, \$10,312 from the investment of appeal monies and \$6,180 from membership fees.

An amount of \$89,443 was spent on the provision of services (including \$52,424 for clinics and counselling, \$9,124 for newsletters and \$27,896 for other awareness and support). We spent \$122,600 on rent, insurance, administration and office expenses. We spent \$25,295 on conferences and seminars. We also spent \$40,162 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
- Fun runs
- Fragile X Awareness day events
- Garden open day

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2016

Note 6 - Analysis of monetary figures

Ratios	\$	%
Total cost of fundraising/ Gross income from fundraising	6,834/364,465	1.87 (4.5% last year)
Net surplus from fundraising/ Gross income from fundraising	357,631/364,465	98.12 (95.5% last year)
Total costs of services/ Total expenditure	89,443/303,702	29.45 (35.2% last year)
Total costs of services/ Total income received	89,443/380,956	23.479 (35.2% last year)

Note 7 – Commitments

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

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2016

	Note	2016	2015
Note 8 - Endowment Fund Balance Sheet - as at 30 June			
CURRENT ASSETS Cash on hand At Bank		18,229	175,919
Term Deposit - Due 4 December 2016 at 2.40%		<u>20,000</u> <u>38,229</u>	50,000 225,919
Accounts receivable and other debtors Receivable from FXAA Current Account Franking Refund Receivable			550
TOTAL CURRENT ASSETS		40,553	226,469
NON-CURRENT ASSETS Investments Listed Investments - At Market Value		243,699	
TOTAL NON-CURRENT ASSETS		243,699	
NET ASSETS		\$284,252	\$226,469
EQUITY			
Opening Balance Add: Income for the Year	9	226,469 <u>57,783</u>	159,133 <u>67,336</u>
TOTAL EQUITY		<u>\$284,252</u>	\$226,469

Note 9 - Endowment Fund Income & Expenditure Statement - for the year ended 30 June

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Dividend Income	7,883	· -
Donations	59,589	63,287
Interest	660	4,059
Proceeds from sale of investment	200	
	68,332	67,346
Less:		
Expenses	-	10
Decrease in Market Value of Investments	10,549	
	10,549	10
NET INCOME FOR THE YEAR	\$ 57,783	\$ 67,336



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