

ANNUAL REPORT 2016 - 2017



Who are We?

Working towards the best possible lives for Fragile X families throughout Australia



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 27 years by offering support, knowledge, and connections. At 30 June 2017 our member base was 275, including financial and honorary members, both individuals and organisations.

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

We receive no public funding and therefore donors, grants, in-kind contributions and substantial volunteer input sustain our role and the support and services we can provide.

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

The underlying principles which guide us:

Service, Respect, Accountability, Evaluation, Compliance



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Understanding Fragile X

Fragile X-associated Disorders are caused by an alteration or change to the FMR1 gene on the X chromosome. Fragile X-associated 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 Fragile X syndrome is the 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 is a neurological condition often confused with Parkinson's disease and 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, affects around 25% of women who are carriers of Fragile X.

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. An estimated 100,000 people in Australia are affected by Fragile X in some way.

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Board 2016-2017



Graham Hook President (Queensland)

Defence industry manager

Graham has an adult son, James, who is affected by Fragile X syndrome. Graham is a keen photographer, artist and cyclist. He rejoined the Board in 2016, having previously served in several roles in the early days of the Association.



Lisa Ryan Treasurer (Victoria)

Banker

Although not directly affected by Fragile X, Lisa has two young boys who have been diagnosed with Autism Spectrum Disorder which provides an understanding of the path that families need to follow, and she appreciates this opportunity to be involved with FXAA. Lisa has served on the Board since 2016.



Judith Lenart Secretary (New South Wales)

Investment consultant and community volunteer

Judith is qualified in urban valuation, natural health and school trusteeship and is trained in governance. Judith served on the Board from October 2014 until 30 April 2017.



Cathy Love Director (Victoria)

Consultant Occupational Therapist, family coach and author Cathy has worked with families affected by Fragile X for a number of years, and was a member of the BetterStart reference group. She served on the Board from October 2013

to October 2017.



Nyleta McRae Director (Queensland)

IT specialist

Nyleta is a carrier of the Fragile X premutation. She has two young children who have Fragile X syndrome, and her mother has Fragile X-associated Tremor Ataxia syndrome. Nyleta joined the Board since 2015 and is active in raising awareness of Fragile X.



Nadene Lee Director (New South Wales)

Strategy specialist

Nadene has led corporate, marketing, product and business development strategy for a range of businesses, and in the not-for-profit sector. She is passionate about increasing health literacy and outcomes. Nadene has served on the Board since 2016.



Mike Tozer Director (New South Wales)

Founder of startup Exceptional; co-founder of Fragile X Hong Kong Mike and his wife Helen have two children; their son Josiah has Fragile X syndrome. Mike is very active in raising awareness of Fragile X through participation in elite running events, fundraising events, and media. He has served on the Board since 2016.



Katherine Brown Director (South Australia)

Finance industry

Katherine has a young son who has Fragile X syndrome. Katherine is a carrier of the Fragile X premutation. Katherine is a keen runner and has raised funds for the Association through running and other events. She has served on the Board since 2015.

Our Team

In 2016-2017 our team comprised 3 staff members and one consultant, the full-time equivalent of 2 people. In September 2017 we relocated our office, which remains in Sydney, from Manly to nearby Brookvale.



Wendy Bruce Executive Officer

Wendy manages the general operations of the Association. Wendy answers our Help line, produces our quarterly newsletter and content for our website and social media channels, organises Fragile X seminars and our representation at medical conferences, and manages our compliance obligations. She also provides support to members and assists with fundraising.



Amanda Rummery-Hoy Family Support Counsellor (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 prepared the Association's budget and financial statements, processed donations and membership subscriptions, and managed the Association's financial processes and audit. Liz was with FXAA from 2012 until March 2017.



Katrina Weir Medical Communications (consultant)

Katrina has many years of experience in the communications sector, specialising in health communications. Katrina identified opportunities to increase the degree of knowledge of Fragile X-associated disorders within the medical and healthcare community, such as representation at conferences, and wrote material for our publications, website and social media. Katrina consulted to FXAA from June 2014 to September 2017.

Our Supporters

Fragile X Association is extremely grateful to a number of businesses, community groups, families and everyone who has provided support in a range of ways throughout 2016-2017. This support has been pivotal to our ability to provide services and programs to our member base, and to raise awareness of Fragile X within the medical community and beyond.





REED MEDICAL education















President's Report

2016-17 has been an interesting and eventful year for Fragile X Association. We had a significant change in the Board of Directors and have continued our involvement in raising awareness of Fragile X in the public sphere and in the medical community. The future funding of the Association presents some challenges and the Board has been developing a strategy to ensure the future sustainability of the organisation. We will be depending on our Board, our members and our networks to support our future funding initiatives.



Fragile X Awareness month in July 2016 was a highlight: including the first of what will be an ongoing light up campaign, with landmarks and buildings in Brisbane and Launceston lit in our signature colour, orange. Media coverage included the McRae family and a newborn screening study headed by Dr David Godler of MCRI on primetime national news and which flowed through to extensive coverage on social media. Mike Tozer's fabulous efforts in 2016-2017 included winning a Guinness World Record for the fastest half marathon in a suit, raising funds for the Association and generating extensive media coverage of Fragile X.

Our Medical Communications project has gone from strength to strength, resulting in Fragile X-associated disorders being profiled to thousands of GPs at medical conferences across the country. We've worked with GP education providers HealthEd and Reed Medical Education's ThinkGP platform to ensure that the complexities of diagnosis and ongoing management of Fragile X disorders are an important consideration for health professionals. We were also privileged to have the support of Dr Jane Tracy, Prof Rod Baber and Prof Graham Suthers in these endeavours. Many thanks to Katrina Weir for her work and the Cunningham family for their financial support of the initiative.

Our supporters and colleagues in the medical and research fraternity who join with us to raise awareness of FX disorders and to support our community have again been pivotal to our work in this area, and I thank them for their ongoing contributions. We are privileged to have been invited by Prof Randi Hagerman of the MIND Institute (US) to have foundation involvement in the International FXTAS Consortium. This initiative will play an important role in allowing clinicians and researchers to share expertise on treatments and studies, promoting collaboration, and assisting with diagnosis. On the local front, it's been a pleasure to have the involvement of A/Prof Steven Tisch and Dr Sam Bolitho from St Vincent's Hospital in Sydney. I would also like to acknowledge and thank the NSW GOLD Service for their work on the experiences of fathers of children who have Fragile X syndrome. I was pleased to participate in the 2017 study and encourage other fathers of children with Fragile X to become involved in the further study in early 2018.

The FXAA Endowment Fund has continued to grow. I thank the Fund's committee for their guidance in choice of investment strategy in a time of low returns. We have made gains which are appreciated.

The Board of Directors, all volunteers, has continued to support the Association and I thank them for their service throughout the year. I would like to especially thank Cathy Love who, after four years, has stepped down to focus on her business endeavours, and we wish her well.

Thank you to all members for your continued support through your annual memberships and donations. Every contribution helps us to help you and the families affected by Fragile X. I would also like to thank all of our supporters who raised funds and contributed in other ways throughout the year. In particular we were delighted to be involved with Shaw and Partners Foundation through the Oceanpaddler Bridge to Beach event, and to have the support of the ChorusCall #goodwillgiveback campaign.

I acknowledge and sincerely thank the Cunningham family for their continued financial support of FXAA throughout this financial year and over the past decade. Without their support, the Association would never have achieved so much for so many.

The coming year will be a critical time for the future direction of the Association, as we make some adjustments and continue to seek and appreciate your support in overcoming the challenges. At the forefront will be our devotion to supporting families and people affected by Fragile X.

Graham Hook



Each year Fragile X Awareness Month of July presents an ideal platform to build awareness of Fragile X-associated Disorders in the community, with July 22nd always providing a special focus.

Families, schools, and health and disability service providers were all involved this year, and we kicked off a new annual national campaign to light up landmarks in buildings in our signature colour, orange!

Media coverage of Fragile X in July 2016

The generational impact of Fragile X was highlighted through an excellent news report on Channel 7 News specifically timed for release on 22 July.

The news coverage was initiated by the McRae family, who are based in Brisbane. Nyleta and her sister Shelley are carriers of Fragile X, and they have children with Fragile X syndrome.



Their mother Rosemarie McRae, a former helicopter pilot and businesswoman, is now suffering from the affects of Fragile X-associated Tremor Ataxia syndrome. The video was shared widely through news networks and social media and was viewed several hundred thousand times in July 2016 and beyond. This report is available on youtube and via our website.

Fragile X breakthrough: World-first study to screen 100,000 Victorian babies







Dr David Godler

In July 2016, a study investigating a test for Fragile X in newborns which has the potential to provide results to parents within days was announced by Murdoch Children's Research Institute (MCRI) in Melbourne.

A team at MCRI, led by geneticist Dr David Godler, is using automation to screen blood spots from the heel prick tests of 100,000 Victorian babies. It is hoped that the results from the pilot study will result in the test being permanently incorporated into newborn screening for all babies. The study will also help determine if the incidence of Fragile X syndrome is under-estimated.

This study was covered widely in national print media, shared extensively on social media, and Dr Godler was interviewed on radio programs.

Family Support & Counselling

The current Model of Family Support and Counselling offered by FXAA is the provision of a Senior Clinical Social Worker, 16 hours a week. This service includes telephone counselling by appointment, office-based face to face appointments, home visits to families or services where practicable, informal telephone follow up and incidental phone and email contact.



In the period July 2016 to June 2017, approximately 260 counselling and family support contacts were recorded by our Family Support counsellor, **Amanda Rummery-Hoy**. Many of these contacts are a result of queries made to our Helpline 1300 phone number; others were made by email or social media messaging; and some contacts are regular scheduled appointments.

In addition to this, other family support occasions of service have included advocacy for individuals, carers and families impacted by Fragile X. For example: Individualised letters and calls to disability support agencies to highlight an individual's needs; representations to NDIS Planners/LACs highlighting the impact of Fragile X syndrome and the need for funding of particular equipment or levels/types of care; contact with schools in relation to the appropriateness of placements and supporting applications for school transport; supporting the need for Companion Cards and access to subsidized patient transport to attend specialist Fragile X clinics; and a role as support and advocate with employers and disability employment providers.

Some shared needs and concerns of individuals with Fragile X and their families:

- Support with a new diagnosis of Fragile X syndrome, FXTAS, FXPOI, or FMR1 premutation.
- Counselling, support and strategies to help manage feelings of anxiety and depression, grief and relationship issues.
- Support for siblings and other family members impacted by Fragile X syndrome
- Accessing appropriate referrals and accessing supports in the community
- Information, advocacy and support to families around the NDIS
- Education and information on supporting children and adults with Fragile X syndrome to allied health therapists, disability service providers, staff in community-based organisations, care staff in residential settings and teachers in school settings.

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 of specialists at the Fragile X Alliance Clinic in Melbourne. In 2016-2017 FXAA supported clinics for 8 of our member families.

Website and Social Media

Social media provides us with the opportunity of regular interaction and communication with the Fragile X community—through posts, likes, comments and the sharing of news, information and resources.



Traffic on our website increased by 21% over the previous year to **185,500 web visits**, although the number of unique visitors at **102,000** has remained almost the same as the previous year.



2050 followers of our main facebook page, an increase of 25% in the past year. We frequently post our own news, stories and links to our videos and events. We regularly share related posts.



20,945 views of our videos, an increase of 65%. Highlights: 17,000 views of 'Understanding Fragile X' and 1,799 views of the 6-min version of the video; 432 views of 'Q&A with Marcia Braden.'



600 followers of our Twitter account, an increase of 30% over the past 12 months. We tweet news & information resources, and follow organisations in the health, genetic and disability areas.



We established an Instagram account in July 2016 and had 150 followers by June 2017.

Focus on Healthcare Professionals

Our Medical Communications initiative commenced in July 2014, through the generous support of the Cunningham family. A key objective of the initiative is to generate greater interest in and understanding of Fragile X-associated Disorders amongst healthcare practitioners. We are achieving this through a very active presence at a range of health education and other forums across Australia, and the past 12 months was very successful on that front.

We strongly believe that through sustained and consistent effort we can reach larger and more diverse audiences 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.

GP Education and Women's and Children's Health

Over the past three years FXAA has had a strong working relationship with **HealthEd**, a major provider of education to general practitioners and other health professionals across Australia. These events give us a chance to talk face-to-face with GPs and other health professionals about Fragile X-associated disorders, including health issues impacting some women who are carriers of Fragile X.

We've had the opportunity to arrange a speaker and host an exhibition table at the 1-day **GP Education** seminars held in each capital city. Each year this opportunity allows us to reach up to 2,500 GPs.

In a huge leap forward in our relationship with HealthEd, in 2017 we were also given the opportunity to have an exhibition stand at the **Annual Women's** and **Children's Health Update events** providing us with an ideal environment to discuss Fragile X-associated Primary Ovarian Insufficiency, known as FXPOI and, to a lesser extent, FXTAS, with primary care providers. The Sydney and Melbourne events alone attracted almost 3,000 delegates. We were thrilled with the level of interest at both events.

HealthEd had also offered to produce some videos for us on topics of interest to both the primary care audience and to our members. We were fortunate to secure the support of **Professor Rod Baber**, Professor of Obstetrics and Gynaecology at Sydney Medical School, The University of Sydney and expert in primary ovarian insufficiency. Professor Baber participated in our first HealthEd video which was on the topic of FXPOI. The video was made available at the end of June 2017 and launched on our youtube channel in time for Fragile X Awareness month.



Lynn Brown at HealthEd Perth





Simone Zaia, Prof Rod Baber, Sydney



25% of women who are carriers of Fragile X will experience Fragile X-associated Primary Ovarian Insufficiency (FXPOI).

Now on our youtube channel, this 2-minute video is intended to help educate and inform GPs about the importance of testing young women with early onset menopause with undiagnosed cause for Fragile X carrier status.

The questions scripted for the video were produced by Katrina Weir of FXAA Many thanks to **HealthEd** and **Prof Baber**.



In January 2017 Reed Medical Education commenced production on two expert videos for FXAA that will form part of a dedicated Fragile X section on Reed's online medical education platform called ThinkGP.

ThinkGP provides free online education for primary care practitioners across Australia, including around 15,000 GPs, to support better health outcomes for patients.

In January, **Dr Jonathan Cohen,** GP and Medical Director of Fragile X Alliance, **Mike Tozer**, parent of a young son with Fragile X syndrome, and **Dr Cynthia Roberts**, parent of an adult son with Fragile x syndrome, together with FXAA staff, joined the ThinkGP team to film two videos for the online education platform

The videos were designed to educate GPs about the need for early and accurate diagnosis of Fragile X syndrome, and provide insights into the issues parents and carers face in managing a child with the condition, including how these issues change as children develop into adulthood.

We are incredibly grateful to Dr Cohen, Mike and Cynthia for their time and professionalism in preparing for and responding to our questions on video, and in particular to Dr Cohen for his expert medical input.



We are also indebted to

Reed Medical Education,
specifically Dr John Crimmins, for his generosity and
support of Fragile X Association.

The Fragile X section on the ThinkGP website and the videos were launched by Reed Medical Education to their database of 30,000 health professionals, for July 2017 as FX Awareness month.

The videos were accompanied by a blog post about the **importance of GPs responding to parental concerns about a child's development.**

The videos have been widely shared on our website and social media.







Fragile X Syndrome What MCaFHNs Need To Know

2nd June, 2017

Amanda Rummery-Hoy Family Support and Counsellor

Maternal Child and Family Health Nurses

In June 2017 Amanda Rummery-Hoy, our Family Support Counsellor, spoke at the conference in Melbourne which attracted 900 delegates from around Australia. Amanda spoke on the critical role of maternal and child nurses in identifying developmental delay and reminded the audience of how well placed they are to recommend an early referral for assessment. This was an important opportunity to place Fragile X syndrome front of mind with this very important group of health professionals who, for many people, are the first point of contact with the health system post birth. We'll have continued contact with this audience by sending quarterly emails on relevant information.





Better Health, Better Lives: Doctors and Developmental Disability

People with developmental disabilities suffer from poorer health outcomes than the rest of the population, and healthcare access is complicated by cognitive and communication challenges.

Many thanks to **Dr Jane Tracy**, Director of the Centre for Disability Health Victoria, for her continued support of FXAA and her interest in Fragile X syndrome. Dr Tracy presented on our behalf at the annual national Rural Medicine conference in October. Our goal was to highlight the critical role that rural and remote GPs play in patients with intellectual disability achieving optimal function and wellbeing, and to promote awareness of Fragile X syndrome. The presentation was very well received.

Raising Funds and Raising Awareness

Fundraising is an important way to generate the funds to support both our day to day work and new initiatives. Our members and supporters continue to do a wonderful job in using community events to increase awareness of Fragile X-associated disorders and to fundraise for the Association's operations.

Highlights 2016-2017

In July 2016 our fastest Board member, **Mike Tozer**, was first out of the blocks! Running in Sydney's Westlink M7 Blacktown Running Festival half marathon in a time that secured him a Guinness World Record, and extensive media coverage for Fragile X in Australia and internationally.

In the past year we raffled two fantastic prizes—both donated by members. **Ricky Crowe** handcrafted wooden outdoor play equipment, and the **Semple family** arranged the donation of a surfboard signed by their friends in the pro surfing community.

Lots of fun in the raffle processes and, by chance, both prizes were won by Queenslanders!

The Galston Garden Club and Masonicare have continued to raise funds for us, with Masonicare matching funds raised by the annual Sydney open garden event. Many thanks to Trish and Graham Piper for initiating this partnership.

The Capital & Improvement team at **GrainCorp**, and **Buzz Childcare Recruitment** became supporters.

Chorus Call win! Our members and their families and friends helped us win the 2016 Chorus Call online voting competition against stiff competition from 53 other not-for-profits. Winnings included a \$10,000 cash donation and free telecoms services for 12 months for FXAA.









SUPPORTING















We are thrilled to continue the partnership with local business Oceanpaddler. The Bridge to Beach race is an iconic 11km paddle across Sydney Harbour from Blues Point, under the Sydney Harbour Bridge, across to Manly Cove.

This year it wasn't the finest of days for a paddle, as it rained most of the morning, but that didn't deter the paddlers! Many of them supported FXAA by making donations as part of their race registration.

Shaw and Partners Foundation generously matched the funds raised, making a total of \$10,000.

Thanks are once again due to Dean Gardiner, Sherene and Yanda from Oceanpaddler, and to Luke Ratcliff who helped inspire paddlers and donors alike.

Councillor Jean Hay once again represented Northern Beaches Council at the race. Many thanks to Earl Evans, keen paddler and Co-CEO of Shaw and Partners for presenting the cheque to Graham Hook

A very special surfboard was donated to us this year, to raffle as a fundraiser in conjunction with the Bridge to Beach.

Thanks to the **Semple family**, Tim and Sonja and their boys, for arranging for **Bede Durbidge and his wife Taryn** and Bede's sponsors to donate the board signed by surf pros Mick Fanning, Joel Parkinson and Bede himself.

The winning ticket had been sold to Chanelle Avison from Brisbane, so on the afternoon after the paddle race the board was wrapped up and put on a plane, travelling back north with Graham Hook. Graham's son James later presented the board to Chanelle.







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Life Membership of Fragile X Association



Dr Jonathan Cohen

At the Annual General Meeting on 9th October 2016, **Dr Jonathan Cohen** was awarded Life Membership. In making the nomination, FXAA President Robyn Iredale said: "FXAA has developed a very strong relationship with Dr Cohen and appreciates his commitment to helping the work of the Association. Many of our members have attended his FX Alliance Clinic in Melbourne and he and his team have conducted workshops and clinics for us in many parts of Australia. All those who have attended these have spoken very highly of his sensitivity and expertise. Jonathan has been an active member of the Science and Research Sub-committee and through this means, and informally, he has provided many valuable suggestions, ongoing advice and acted as a sounding board whenever we needed an expert medical opinion. For me, personally, it has been a pleasure to work with Jonathan in many different contexts and I am delighted to nominate him for Lifetime Membership of FXAA."

Achievement Awards

The Annual Fragile X Association Achievement Awards were also announced at the 2016 AGM. From a large number of very inspiring nominations, five Award winners were selected. Each person received a certificate, and their achievements were profiled in our quarterly newsletter and on social media. Stuart Iredale was at the AGM with his carers and family members and received his Award in person.

Rebecca Jansen Participation & Achievement in Bowling Rebecca enjoys the social interaction and feeling of inclusion that participation in sport can bring, and absolutely loves bowling and her collection of trophies!

Stuart Iredale Participation in Music & Bowling Stuart has successfully made a huge adjustment from living in a mental institution for 45 years to living in a group home. His new passions are bowling and music.

Matt Bowen Independence and Social Skills Matt is a talented cricketer and footballer. His commitment to sport has resulted in Matt becoming more independent, outgoing and socially involved.

Ben Kalenjuk Participation and Resilience Ben attends mainstream school, has a group of supportive friends, and is involved in sport and a range of activities. He pushes himself, and his resilience is a credit.

Daniel Cox Growth in Confidence and Independence Volunteering at his local sports club over the past 3 years has been the key to Daniel's growing social skills and independence. Club Helper of the Year!



Rebecca Jansen



Stuart Iredale



Matt Bowen



Ben Kalenjuk



Daniel Cox

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Scientific and Research Sub-Committee

The FXAA Scientific and Research Sub-Committee includes a number of Australian specialists in Fragile X-associated disorders and genetics, with representation from the FXAA Board and staff.

The sub-committee provides an important conduit between FXAA (and members), and the developments and technical issues Fragile X researchers and practitioners are involved in. This allows FXAA to be in a position to inform our members of new developments and their context, and of opportunities for our members to be involved in research.

In 2016-2017 members of the sub-committee members also played a key role in raising awareness of testing and screening for Fragile X-associated Disorders and involving FXAA in these efforts. For example, the extensive media coverage generated in July 2016 by the newborn bloodspot screening study led by Dr David Godler and the team at the Murdoch Children's Research Institute.

The sub-committee members also ensured that the FXAA Board and staff were kept abreast of key Fragile X information and resources. They also provided important input to the opportunities and resources initiated by the FXAA staff to increase awareness of Fragile X-associated Disorders in the medical community.

Scientific and Research Committee members 2016/2017

Co-opted Members:

Prof David Amor Group Leader, Victorian Clinical Genetics Service

Dr Alison Archibald
Dr Claudine Kraan
Dr Jonathan Cohen
Dr Mike Field

Associate Genetic Counsellor, Victorian Clinical Genetics Services
Postdoctoral research fellow, Murdoch Children's Research Institute
Medical Director, Fragile X Alliance Clinic/Genetic Clinics Australia
Geneticist, Genetics of Learning Disability (GOLD) Service, NSW

Dr David Godler Group Leader, Cyto-molecular Diagnostics Research,

Murdoch Children's Research Institute

Dr Matthew HunterHead of Monash Genetics Clinic, MonashHealthDr Danuta LoeschSchool of Psychological Science, La Trobe University

Prof Sylvia Metcalfe
Dr Rachael Birch
Prof Martin Delatycki

Melbourne University and Group Leader Murdoch Children's Research Institute.
Psychologist, Dept of Developmental Disability Neuropsychiatry, UNSW Australia
Clinical Director, Victorian Clinical Genetics Service; Co-director Bruce Lefroy

Centre of Genetic Health Research, Murdoch Children's Research Institute

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 to the Association via the Board.

During the year the net growth of the Endowment Fund was \$282,844 taking the total equity to \$567,096.

FXAA Endowment Fund Advisory Committee 2016/2017

David Bassingthwaighte (Chair) Self-employed financial consultant

Marion Pascoe Former Deputy Parliamentary Counsel, NSW

Martin Davey Chartered accountant

Graham Hook President, Fragile X Association of Australia Inc Lisa Ryan Treasurer, Fragile X Association of Australia Inc

Treasurer's Report

As my first report as Treasurer, I would like to confirm to members that FXAA continued to be financially well managed and within its means. The audited accounts which combines the Association's operations with the Association's Endowment Fund, recorded a surplus for the last financial year as a result of donations to the Fund.

The main funding sources remained 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 the Ocean Paddler event and surfboard raffle which combined raised around \$13,000, and the Galston Garden Club and Masonicare which raised a combined \$6,000. We also received a \$10,000 cash donation through an online voting competition by telecommunications provider Chorus Call, together with free telephone conferencing and webinar services for 12 months. We were delighted to be involved with Shaw and Partners Foundation in their sponsorship of the Bridge to Beach 2017 and thank them for their generous matching of funds raised.

I would also like to acknowledge the active fundraising efforts of our members, their families and friends, with special mention to our new Guinness World Recordholder, Mike Tozer, for being officially accepted as the best in the world for his time in running a half marathon in a suit at last year's Blacktown Running Festival Sydney and raising funds in the leadup to this amazing achievement. We have committed a modest financial contribution from funds raised in the past year to the International FXTAS Consortium, as one of the foundation partners.

While the FXAA is currently working within budget, the Board has remained conscious that by July 2017 the Association will have received our final tranche of the three year philanthropic grant of \$100,000 from one of our key supporters and they have confirmed that we will need to find alternative funding sources after 2018. We are actively implementing our fundraising strategy and the Directors are committed to securing the income required on this in the next financial year for future operations.

The financials show a consolidated position of the Association, including the Endowment Fund, and it should be highlighted that contributions to this fund for FY17 totalled \$258,720. These funds were utilised for investment and growth purposes only. The Endowment Fund is managed by a committee including financial advisers and Directors, who ensure that the portfolio is diversified and shows a cautious investment strategy, designed for capital protection and defensive growth. This is in line with the strategy originally developed for the Endowment Fund, and can be seen by the portfolio holdings as at 30 June 2017:

Portfolio Va	luation								Issued by JBWere Limited ACN 137 978 360
Holding Descript	ion	% Of Portfolio	Quantity	Market Price	Market Value *	Estimated Income **	Estimated Yield	Est. Div / Rate	Est. Franking & Maturity Date
Cash									
JBWCT	JBWere Cash Trust	0.00%			\$ 9.78	\$ 0.12	1.26 %	1.26%	
Total Cash		0.00%			\$ 9.78	\$ 0.12	1.26 %		
Fixed Interest - D	omestic								
Banks		59.40%							
ANZPC	AUSTRALIA AND NEW ZEALAND BANKING GROUP LIMITED, CONV. PREFERENCE	18.78%	700	\$ 102.100	\$ 71,470.00	\$ 2,496.55	3.49 %	356.65¢	100.00 % 01-Sep-17
CBAPC	COMMONWEALTH BANK OF AUSTRALIA., CONV. PREFERENCE	6.59%	245	\$ 102.400	\$ 25,088.00	\$ 946.68	3.77 %	386.40 ¢	100.00 % 15-Dec-18
CBAPE	COMMONWEALTH BANK OF AUSTRALIA., CONV. PREFERENCE	8.19%	290	\$ 107.500	\$ 31,175.00	\$ 1,404.76	4.51 %	484.40 ¢	100.00 % 15-Oct-21
NABPC	NATIONAL AUSTRALIA BANK LIMITED, CONV. PREFERENCE	6.99%	260	\$ 102.240	\$ 26,582.40	\$ 949.13	3.57 %	365.05¢	100.00 % 23-Mar-20
WBCPC	WESTPAC BANKING CORPORATION, CONV. PREFERENCE	13.52%	500	\$ 102.918	\$ 51,459.00	\$ 1,835.75	3.57 %	367.15¢	100.00 % 31-Mar-18
WBCPD	WESTPAC BANKING CORPORATION, CONV. PREFERENCE	5.32%	200	\$ 101.301	\$ 20,260.20	\$ 689.50	3.40 %	344.75¢	100.00 % 08-Mar-19
Total Fixed Intere	est - Domestic	59.40%			\$ 226,034.60	\$ 8,322.37	3.68 %		
Australian Equiti	es								
Diversified Fina	ncials	40.60%							
AFI	AUSTRALIAN FOUNDATION INVESTMENT COMPANY LIMITED, ORDINARY	17.41%	11,400	\$ 5.810	\$ 66,234.00	\$ 2,736.00	4.13 %	24.00¢	100.00 %
ARG	ARGO INVESTMENTS LIMITED, ORDINARY	17.33%	8,600	\$ 7.670	\$ 65,962.00	\$ 2,623.00	3.98 %	30.50¢	100.00 %
WLE	WAM LEADERS LIMITED, ORDINARY	5.86%	20,000	\$ 1.115	\$ 22,300.00	\$ 600.00	2.69 %	3.00¢	100.00 %
Total Australian I	Equities	40.60%			\$ 154,496.00	\$ 5,959.00	3.86 %		

Our financial management is fundamentally performed by the small team in our office, and I would like to extend my thanks as Treasurer to our part-time accountant Laura Patel, and Wendy Bruce for her continued support. The audit has been provided on a pro bono basis by Mr Brian Tierney of Manser Tierney & Johnston, a long-term supporter of the Association, and Mr Peter Vilimaa to whom we extend our very sincere thanks once again.

I commend the accounts to the members.

Lisa Ryan



FINANCIAL STATEMENTS 30 JUNE 2017

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 2017 and its financial 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:

GRAHAM HOOK

President

LISA RYAN Transurar

Dated this

14th

day of NOVEMBER

2017.



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

Report on the Audit of the Financial Report

Opinion

We have audited the financial report of Fragile X Association of Australia Inc (the association), which comprises the balance sheet as at 30 June 2017, the income and expenditure statement for the year then ended, and notes to the financial statements, including a summary of significant accounting policies and the certification by members of the Board on the annual statements giving a true and fair view of the financial position and performance of the association.

In our opinion, the accompanying financial report gives a true and fair view of the financial position of the association as at 30 June 2017 and of its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements and the requirements of the Associations Incorporation Act 2009 (NSW) and Div 60 of the Australian Charities and Not-for-profits Commission Act 2012 and the Australian Charities and Not-for-profits Commission Regulation 2013.

Basis for Opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the *Auditor's Responsibilities* for the Audit of the Financial Report section of our report. We are independent of the association in accordance with the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110: Code of Ethics for Professional Accountants (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our ethical responsibilities in accordance with the Code.

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

Emphasis of Matter – Basis of Accounting

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist the association to meet the requirements of the Associations Incorporation Act 2009 (NSW) and for the purpose of fulfilling the financial reporting requirements under the *Australian Charities and Not-for-profits Commission Act* 2012. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

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

Responsibilities of the Board for the Financial Report

The Board of the association is responsible for the preparation and fair presentation of the financial report in accordance with the financial reporting requirements of the Associations Incorporation Act 2009 (NSW) and 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 and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the Board is responsible for assessing the association's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Board either intends to liquidate the association or to cease operations, or have no realistic alternative but to do so.

Auditor's Responsibilities for the Audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with Australian Auditing Standards, we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit 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.
- > Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Board.

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

- Conclude on the appropriateness of the Board' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the association's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the association to cease to continue as a going concern.
- > Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

We communicate with the Board regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Signed at Wahroonga this

2370

2017.

MTJ AUDIT PTY LTD

PETER VILIMAA

Partner

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BALANCE SHEET AS AT 30 JUNE 2017

	Note	2017	2016
CURRENT ASSETS			
Cash on hand			
At Bank		62,230	42,638
Bank Guarantee		6,875	6,875
Endowment Fund	8	251,745	38,229
Petty Cash Term Deposit		104	103
remi Deposit			5,008
Accounts receivable and other debtors		320,954	92,853
Accounts Receivable		6.750	4 400
Franking Credits Refundable		6,750 6,556	4,133
Prepayments		10,036	2,324 9,905
Rental Bond		3,416	3,303 -
		26,758	16,362
TOTAL CURRENT ASSETS		347,712	109,215
NON-CURRENT ASSETS			
Property, plant and equipment			
Office Equipment - At Cost		04.044	04 644
Less: Accumulated Depreciation		21,811	21,811
Ecos. Accumulated Depreciation		(17,321)	(15,244)
Investments		4,490	6,567
Listed Investments at Market Value - Endowment Fund	8	308,795	243,699
TOTAL NON-CURRENT ASSETS		313,285	250,266
TOTAL ASSETS		660,997	359,481
CURRENT LIABILITIES			
Accounts payable and other payables			
Accounts Payable		8,190	12,109
Income Received in Advance		1,475	3,835
Payroll Liabilities		2,673	869
Other Liabilities		865	1,425
		13,203	18,238
Provisions			
Provision for Employee Entitlements		8,027	7,771
TOTAL CURRENT LIABILITIES		21,230	26,009
TOTAL LIABILITIES		21,230	26,009
NET ASSETS		<u>\$639,767</u>	<u>\$333,472</u>
MEMBERS' FUNDS			
Opening Balance		333,472	276,010
Add: Surplus for the Year		306,295	57,462
TOTAL MEMBERS' FUNDS		\$639,767	\$333,472
The accompanying notes form part of these financia		·	

The accompanying notes form part of these financial statements.

INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2017

	2017	2016
INCOME		
Gross Proceeds From Fundraising Appeals		
Christmas Cards	644	253
Conference Income	-	3,314
Donations - including Endowment Fund	561,007	334,302
FXAA Fundraising Events and Appeals	8,174	18,079
Merchandise Sales	75	18
Raffle Sales	2,085	-
Sponsorships	-	8,500
	571,985	364,466
Other		
Dividend Income	14,108	7,883
Interest	1,517	2,229
Gain on sale of investments	-	200
Subscriptions	1 <u>,525</u>	6,180
	17,150	16,492
Total Income (carried forward)	589,135	380,958

INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2017

	2017	2016
Total Income (brought forward)	589,135	380,958
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Card Day	6	-
Other	8,333	6,883
	8,339	6,883
Total Costs Of Providing Services		
Support Services and FX Awareness	29,500	29,335
Clinics and Counselling	43,558	51,061
National Newsletter Printing	4,862	<u>7,684</u>
	77,920	88,080
Other		
Bank Fees and Charges	2,048	2,000
Board and AGM Expenses	1,167	1,962
Conferences and Seminars	6,079	25,295
Consultants	51,493	40,162
Depreciation	2,077	3,433
Donations	5,000	-
General Administration - Employment Costs	78,565	80,317
Insurance	4,406	5,277
Office Expenses	9,927	9,237
Office Rent	31,472	29,613
Postage	3,105	2,050
Provision for Employee Entitlements	256	7,771
Stationery	4,671	2,508
Subscriptions	1,229	1,266
Sundries	251	3,262
Telephone	4,463	3,831
	206,209	<u>217,984</u>
Total Expenditure	292,468	<u>312,947</u>
OPERATING SURPLUS FOR THE YEAR	296,667	68,011
Increase/(Decrease) in value of investments - Endowment Fund	9,628	(10,549)
SURPLUS FOR THE YEAR	\$306,295	<u>\$57,462</u>

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2017

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 2017

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) 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.

j) 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.

k) 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.

I) Comparative Figures

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

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2017

Note 2 - Information on Material Matters

The Association received \$305,000 from the Cunningham family.

Note 3 - Application of appeal monies

During the year the Association received income of \$571,985 from fundraising appeals, \$15,625 from the investment of appeal monies and \$1,525 from membership fees.

An amount of \$77,920 was spent on the provision of services (including \$43,558 for clinics and counselling, \$4,862 for newsletters, and \$29,500 for other awareness and support). We spent \$124,370 on rent, insurance, administration and office expenses. We spent \$6,079 on conferences and seminars. We also spent \$51,493 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
- Raffles (Toys FX awareness day, Signed surfboard Feb 2017)

Note 6 - Analysis of monetary figures

Ratios	\$	%		
Total cost of fundraising/ Gross income from fundraising	8,339/571,985	1.5 (1.9% last year)		
Net surplus from fundraising/ Gross income from fundraising	563,646/571,985	98.5 (98.1% last year)		
Total costs of services/ Total expenditure	77,920/296,667	26.3 (29.5% last year)		
Total costs of services/ Total income received	77,920/589,135	13.2 (23.5% 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 2017

	Note	2017	2016
Note 8 - Endowment Fund Balance Sheet - as at 30 June			
CURRENT ASSETS Cash on hand			
At Bank		80,005	18,229
Investments maturing within 3 months		71,740	-
Term Deposits		100,000	20,000
		251,745	38,229
Accounts receivable and other debtors			
Franking Refund Receivable		6,556	2,324
TOTAL CURRENT ASSETS		258,301	40,553
NON-CURRENT ASSETS Investments			
Listed Investments - At Market Value		308,795	243,699
TOTAL NON-CURRENT ASSETS		308,795	_243,699
NET ASSETS		<u>\$567,096</u>	<u>\$284,252</u>
EQUITY			
Opening Balance		284,252	226,469
Add: Income for the Year	9	282,844	<u>57,783</u>
TOTAL EQUITY		<u>\$567,096</u>	<u>\$284,252</u>
Note 9 - Endowment Fund Income & Expenditure Statement - for the year e	nded 3	30 June	
INCOME			
Dividend Income		14,108	7,883
Donations		258,720	59,589
Increase in Market Value of Investments Interest		9,628 388	- 660
Proceeds from sale of investment		-	200
		282,844	68,332
Less:			
Decrease in Market Value of Investments			10,549
		_	10,549
NET INCOME FOR THE YEAR		<u>\$282,844</u>	<u>\$ 57,783</u>



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