



# ANNUAL REPORT

## 2020-2021

FRAGILEX.ORG.AU

30 Years Strong | Supporting | Sharing | Connecting | Informing



## Our Mission:

Supporting people living with Fragile X to live their best possible lives through connection, education and advocacy

Since 1989 Fragile X Association of Australia has been dedicated to improving the health and wellbeing of people affected by Fragile X syndrome and other Fragile X-associated Disorders.

We are a member-based organisation and serve the Fragile X community by providing information, knowledge, connections and advocacy, and by offering support.

- **Helpline** operating 5 days per week 9:00am – 5:00pm
- **Family support and counselling** to individuals affected by Fragile X and their carers and families
- **Uptodate information** through our website, social media and email communications
- **Referral** to services
- **Support and discussion groups** on social media
- **Educational events** providing the latest on supports, interventions, and treatments
- Opportunities for people to **connect with peers** online and in person
- **Increasing awareness** of Fragile X conditions to promote early and accurate diagnosis, early intervention and appropriate treatment
- **Advocacy** on health, disability and other issues impacting the Fragile X community

The **underlying principles** which guide Fragile X Association of Australia:

*Service, Respect, Accountability, Evaluation, Compliance*

**30 Years Strong - Supporting | Sharing | Connecting | Informing**

*Image credits: Cover photo of Jayne & Albie (supplied) Cover and polaroid poster designs by Kate Stokes.*



# President's Report

At the time of writing (November) it is clear that the affects of the COVID-19 pandemic will be with us for some time.

The Association, and our member families, continue to be impacted in a variety of ways. The opportunity for face to face events, for educational or support events, and for fundraising are very much missed, but we look forward to some restoration of events and opportunities to be engaged with our members and the wider community in 2022.

As we noted in our last Annual Report one of the new opportunities presented by restricted in person connections is the increased capacity for our members and the wider community to access information, education, connections, and support through Zoom and other digital means. This gives us a powerful means of connecting people "face to face" across Australia. To illustrate, our Family Support Counsellor Liz has facilitated 60 peer support meetings on Zoom over 12 months with small groups of our members who have a common connection with Fragile X, for example a newly diagnosed young child.

We have launched a webinar program over Zoom to provide support and information to families and carers of people who have Fragile X syndrome. An early webinar in this series was a discussion of ways in which clinical trials contribute to the development of treatments for Fragile X syndrome, and I would like to acknowledge the educational grant from Zynerba which funded the production of the webinar and video. Our webinars will be available "live" and for later replay via our website and social media. These webinars are proving to be a successful and popular mechanism to deliver education to allied health professionals, educators and disability service providers about behavioural and educational supports. I would like to thank the experts who are helping to deliver the program, including allied health professionals Bev Kadish and Bev Sher, Dr Marcia Braden, Dr Randi Hagerman, Dr Jonathan Cohen.

We have been awarded a research grant through Melbourne Disability Institute to help us assess the most successful ways of delivering digital support and learning to our community, and look forward to the project helping us align digital delivery in a way that best suits the needs of our community and those involved in supporting people with Fragile X syndrome.

2021 marks the 30th anniversary of the DNA analysis of the Fragile X gene and a little over 40 years since Profs Grant Sutherland and Gillian Tuner first developed the chromosome test and described the clinical features of those affected individuals that had the fragile X chromosome. A highlight for us in 2021 was the publication of Prof Gillian Turner's latest book: *Margaret's Story: The unfolding discovery of the Fragile X gene*, which is now available to read online from our website. It gives her personal reflections on the role that Australian families and researchers played in the initial studies of the Fragile X syndrome.

It includes additional chapters by Prof Sutherland, the Hagermans and Margaret Cunningham on the early history of Fragile X.



We want to give a big thank-you to Katie Clapp and the FRAXA organization for initiating World Fragile X Day, of which we were glad to be a founding partner.

It was arranged for this to be preceded by a multi-hour webinar on recent developments aimed at finding successful therapies.

FXAA continues to work alongside SMA Australia, Cystic Fibrosis Community Care and Victorian Clinical Genetics Services in profiling reproductive genetic carrier screening as an option for people considering pregnancy through the Carrier Screening Reference Group. 1 in 20 people carry the gene change for Fragile X syndrome (FXS), cystic fibrosis (CF) and spinal muscular atrophy (SMA). While we observe increased knowledge of the risks of passing on a serious genetic condition, it remains the case that many people are unaware they carry such a risk, and the cost of pre-pregnancy or early pregnancy screening is a barrier for many.

We look forward to the Federal Government actioning the recommendation of the Medical Services Advisory Committee to reimburse the cost of carrier screening for FX, CF and SMA through the Medicare Benefits Schedule. Also, we are glad to see that Preimplantation Genetic Diagnosis is now being partially covered by Medicare subsidy for those families wishing to avail themselves of this technology.

We are glad to see that there are a number of new and promising treatment trials in preparation stages and in the works for Fragile X. These include Zynerba's RECONNECT trial and Actinogen's Xanamem trial here in Australia, as well as a half dozen or so other trials in the US and elsewhere.

The Board is delighted to present to the members FXAA's the Strategic Plan 2021-2024 and I thank them for their work on this, in particular Kate McKeand.

We also want to thank our retiring directors, Graham Hook and Katherine Brown, for their service to the Fragile X community.

I would like to express sincere thanks to the Cunningham family for their generous ongoing support of FXAA, and in particular their increased support in the past financial year in recognition of the difficult fundraising environment.

The Board and staff look forward to continuing vital support of the FX community in Australia.

Best wishes,  
W Ted Brown

# Our Team

## Board 2020–2021



### **Prof W Ted Brown MD, President**

Prof Brown is the retired director of the NY State Institute for Basic Research in Developmental Disabilities. Much of his 35-year research career has focused on Fragile X syndrome and autism. Prof Brown relocated from the US to Australia in 2017, and is based in Sydney. He joined the Board in 2018.



### **Adam Lawrence-Slater, Treasurer**

Adam is in a financial planning and data insights role with an organisation which provides an online platform that enables people with disability to find the right support workers for them. Adam and his wife Charlotte have a son, Joshua, who has Fragile X syndrome. Adam is based in Sydney and joined the Board in 2019.



### **Graham Hook, Secretary**

Graham spent the majority of his career in the Air Force and as a defence industry manager. Graham's adult son, James, is affected by Fragile X syndrome. Graham also volunteers with Special Olympics Queensland. He rejoined the Board in 2015, and has served in several roles including Vice-President and President. Graham is based in Brisbane.



### **Katherine Brown, Director**

Katherine is in the finance industry and has a young son, Andrew, who has Fragile X syndrome. She is a keen runner and has raised funds for Fragile X Association through running and other events. Originally from the UK, Katherine is now based in Adelaide. Katherine has served on the Board since 2016.



### **Mike Tozer, Director**

Mike is the founder of Xceptional, a technology services firm that employs people with autism, and co-founder of Fragile X Hong Kong. Originally from the UK, Mike and his wife Helen are based in Sydney and 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 and fundraising events, and in the media. Mike joined the Board in 2016.



### **Kate McKeand, Director**

Kate is a disability advocate and mother of two children who have Fragile X syndrome. She has been a director of a consulting organisation specialising in supporting and empowering participants in the NDIS, and has represented families of children with disabilities on a number of consumer and advocacy bodies. Kate is based in Melbourne and joined the Board in 2018.



### **Karen Lipworth, Director**

Karen is a qualified veterinarian who currently works in the pharmaceutical industry. Karen has the Fragile X premutation and is passionate about raising awareness of Fragile X amongst the medical professions. Karen lives in Sydney and joined the Board in 2019.



### **Cynthia Roberts, Director**

Cynthia has a background in genetic research as well as running a clinical cytogenetics service in NSW particularly focusing on prenatal testing. Cynthia worked at Genea as both Genetics Director and Chief Risk Officer. She has served as President of the Human Genetics Society of Australia and on the FXAA committee in its early years. Cynthia's adult son, Daniel, has Fragile X syndrome and she has two daughters.

## Staff



### **Wendy Bruce**

*Executive Director*

Wendy joined in 2013 and is employed full-time.



### **Liz Jewell**

*Family Support and Counselling*

Liz joined in 2018 and is employed 3.5 days per week.

# Year in Review 2020–2021

## Advocacy

FXAA continues to seek opportunities to represent the interests of the Fragile X community in areas relating to health and disability, such as diagnosis, treatments, access and services. FXAA is a small organization committed to the best life outcomes for individuals with Fragile X and their carers and our community's interests have been well served by leveraging our staff and Board member skills and in working with other groups who have similar areas of focus and approach. In partnering with organisations involved in rare conditions, disability, genetics and health we continue our work towards these outcomes.

### Reproductive genetic carrier screening

FXAA continues to work alongside SMA Australia, Cystic Fibrosis Community Care and Victorian Clinical Genetics Services (VCGS) as a *Carrier Screening Reference Group* to profile reproductive genetic carrier screening as an option for people considering pregnancy. 1 in 20 people carry the gene change for Fragile X syndrome (FXS), cystic fibrosis (CF) and spinal muscular atrophy (SMA). While we observe increased community knowledge of the risks of passing on a serious genetic condition, it remains the case that many people are unaware that they carry such a risk. It is also the case that the cost of pre-pregnancy or early pregnancy screening is a barrier for many.

In May 2021 the Group was delighted to launch a carrier screening education pack for GPs. The pack provides information on the prevalence of SMA, CF and FXS and, in tandem with the website [carrierscreening.org](http://carrierscreening.org), educates GPs on how to have a conversation about carrier screening with their patients. It was launched at the GPCE general practitioner conference in Sydney with a presentation by a genetic counsellor from VCGS and an information booth staffed by Julie Cini (CEO SMA Australia) and Prof Ted Brown, Karen Lipworth and Wendy Bruce from FXAA.

The Group remains optimistic that the Federal Government will action the recommendation of the Medical Services Advisory Committee (MSAC) for the cost of carrier screening for FXS, CF and SMA to be reimbursed through the Medicare Benefits Schedule.

We also note that an application for expanded carrier screening – reproductive genetic carrier screening for multiple conditions – is currently being considered by MSAC. In August 2021 the Carrier Screening Reference Group members provided input to MSAC's public consultation process on the application. The expanded carrier screening application is one of the outcomes of the Federal Government-funded pilot program known as *Mackenzie's Mission* which is screening around 8,000 couples over a 3-year period for approximately 1300 genes responsible for over 700 genetic conditions. The study will recruit couples through to the end of the first quarter of 2022, and report findings at the end of 2022. It is hoped that the outcomes of the study will include MBS reimbursement of carrier screening for serious conditions and access to IVF/PGT for couples at risk of having an affected child.

FXAA is also a member of the *Mackenzie's Mission Reference Group* providing community input to the study.

### Genetic counselling

Genetic counselling services provide critical information and support for individuals seeking or receiving a diagnosis of a genetic condition and those at risk of passing on a serious genetic condition. In May 2021 FXAA supported the application to MSAC by the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme items for services provided by genetic counsellors.

### Treatment approval processes for rare conditions

In November 2020 FXAA made a submission to the House of Representatives Standing Committee on Health, Aged Care and Sport for its consideration of approval processes for new drugs and novel medical technologies in Australia with a particular focus on those for treatment of rare diseases and conditions where there is high and unmet clinical need. FXAA made several recommendations: for increasing research to develop and commercialise new drugs and novel technologies; making Australia a more attractive location for clinical trials in these areas; and extending PBS criteria for the inclusion of off-label medication for patients who have rare conditions.

### Genomics and disability

It is a privilege for FXAA to represent Rare Voices Australia on an advisory panel for an MRFF-funded University of Queensland research project on social and ethical dialogue on genomics and disability. The research is named *We need to talk: Genomics and Disability* and will continue through 2023.

### NDIS

In February 2021 FXAA made a submission to the NDIA on its proposal to introduce "independent assessments" for access to NDIS funding. Many peak bodies and advocacy groups, including FXAA, shared concerns about the equity and efficacy of the proposed style of assessment for individuals with intellectual disability. FXAA's submission included feedback from members who had taken part in the independent assessment pilot program. This independent assessment proposal was controversial and subsequently dropped by the NDIA.

FXAA responded to the Federal Government's call for comment on the NDIA ILC program future funding beyond 2022.

(The ILC program has provided funding for support programs/services for people who have a disability but are not necessarily eligible to become an NDIS participant).

## People with disability and the justice system

On behalf of FXAA, Prof W Ted Brown was one of 70 eminent Australians who signed an open letter to the NSW Premier and Attorney General seeking funding in the NSW 2021 State budget for support of people with cognitive disability in their dealings with police and courts as victims, witnesses or people accused of crimes.

## Testing for Fragile X syndrome

FXAA has been made aware of a number of instances in which families with a history of Fragile X have not been offered testing for 'unaffected' minors (children under 18), despite a parental request for the test. This concern has been discussed in several forums, including the Fragile X Scientific, Clinical & Research Committee. A FXAA position statement will be prepared and a pathway explored to ensure genetic testing guidelines provide for Fragile X testing of minors to be offered to families with a history of Fragile X who request the testing.

## Education

### Training events

The impact of COVID-19-related restrictions on face-to-face training opportunities has increased over the past year. Many health education providers transitioned to digital-only delivery of education, while others offered hybrid options. Overall this has greatly reduced our capacity to have discussions with health care providers in a professional development setting and reduced our capacity to disseminate information about Fragile X-associated disorders. We look forward to some return of the previous opportunities, in particular our regular presence at the Health education days for general practitioners.

### Disability expos

Disability expos have proven to be a useful way to ascertain to what extent disability service providers may benefit from information about supports for clients with Fragile X syndrome, and from the resources or referrals FXAA can provide. Expos have also proven to be a good way to catch up with the Fragile X families face-to-face! We arranged a Fragile X booth at a number of disability expos in the 2021 calendar year, in particular for the Perth SourceKids expo of services and supports for children aged 0-25 and for five Disability Expos run by the Social Impact Institute. A number of these were re-scheduled as a result of COVID-19 restrictions, and we look forward to attending the Expos over the coming months.

### Videos

Earlier this year a series of short educational videos filmed for FXAA by Dr Marcia Braden were published on our website and social media. The videos cover education strategies, behaviour supports and strategies for supporting independent living for individuals who have Fragile X syndrome. The production of the videos was funded by a Qantas Foundation *Side by Side Community Grant*. The grant also supported the production of several of our webinars in the second half of 2021.

## Webinars

In late July, to close off Fragile X Awareness month, we hosted a webinar on *Clinical trials in Australia for Fragile X syndrome*. The webinar addressed the way in which clinical trials contribute to the development of treatments for Fragile X syndrome, practicalities for families involved in a clinical trial, medication approval processes in Australia, and trials on the horizon. The speakers were all exceptionally well-versed in these areas: A/Prof Honey Heussler and Michael Duhig from Children's Hospital Queensland, Prof David Amor from Royal Children's Hospital/MCRI, A/Prof Natalie Silove, from The Children's Hospital at Westmead in Sydney, and Prof Ted Brown. The production and recording of the webinar was supported by an educational grant from Zynerva Pharmaceuticals.

From mid 2021 we have been using Zoom-based webinars to provide information and education on Fragile X syndrome to our member base and allied health professionals, disability service providers and educators. The webinar program for the remainder of 2021 and through 2022 will feature a range of topics related to supporting individuals who have Fragile X, such as behaviours, communication skills, anxiety, sensory processing, and supporting daily living skills. We are very pleased to have experts including Dr Marcia Braden, Prof Randi Hagerman, Dr Jonathan Cohen, Bev Kadish and Bev Sher among the presenters in our webinar pipeline.

## Fundraising and Donations

*Highlights in 2020-2021: Ballarat Dance Awards, Ben's Shave to Raise, Bridge to Beach, Ellinbank Football & Netball Club FX raffle*

The ongoing financial support from our members and the wider community is critical to FXAA's capacity to provide service to the Fragile X community and to educate and inform the health and disability sector about Fragile X-associated conditions. In 2020-2021 \$29,895 was raised through individual and community fundraising efforts, both in person and online, in addition to donations made for the ongoing operations and services of FXAA and the FXAA Endowment Fund.

In May 2021 Ben's **Shave to Raise** was a fabulous community awareness event and fundraiser in Launceston, Tasmania. Ben is a much-loved member of the Launceston community. He works at the local Coles, volunteers at Meals on Wheels and is a regular at the local golf club. Ben decided he could brave the Tassie winter with no hair, in order to raise funds for FXAA! Ben mobilised the support of his employer and the entire community, raising over \$5500. Many thanks to Mr Clyde's Barber Shop for hosting the *Shave to Raise*, to Rosemary Armitage MLA for being a special guest, and to Ben's parents Joanne Ryan and Gary Gower for their incredible support.



FXAA is charity partner for the annual **Bridge to Beach** paddle race across Sydney Harbour. The paddle usually kicks off from under the Harbour Bridge and ends at Manly Cove. This year a big swell and inclement weather meant a rare change to the race course so that paddlers and kayakers left from and returned to Manly Cove. Close to \$25,000 was raised for FXAA's family support service and HelpLine, including a very generous donation of \$10,000 from race sponsor Shaw and Partners. This partnership with Oceanpaddler, the Manly-based business which operates the race, was initiated by the Iredale/Ratcliff family in 2014.

FXAA is also charity partner for the annual **Ballarat Dance Awards** competition in Victoria. The event comprises masterclasses, scholarships opportunities and performance. The final day of competition is a fundraiser, and is well supported by the guest instructors from the Australian Ballet School and the competition participants. This year the fundraiser was profiled on a regional TV news channel. Many thanks again to BDA for choosing Fragile X as their cause, in support of Jimmy Jones.

The **Ellinbank Football and Netball Club** in SE Victoria ran a 'festival' of Fragile X awareness in July with a **FX raffle**, a special dinner at the Club, and dedicated football and netball games. It was a pretty dark and damp day for a footy game, and the players' fluoro socks glowed in the mist! Our Family Support Counsellor Liz appeared at the Club dinner in a recorded interview with Club President Rob Pandolfo. Many thanks to Thomasine Cook for organising this community event and fundraiser in honour of young Cal Wallace and his family, raising \$8,950 for FXAA services.

## Grants

An educational grant from *Zynerba Pharmaceuticals* supported our webinar on *Fragile X syndrome: Clinical Trials in Australia*.

A grant from Manly-based *Pine Property*, through a real estate foundation, was received after the close of the financial year and has supported the production and recording of our recent webinar with Dr Marcia Braden PhD on *Understanding Anxiety in Fragile X syndrome*.

A grant from the *NSW Department of Communities and Justice* provided \$20,000 in funds for FXAA to build capacity for remote and flexible working and to develop staff skills in social media.

## FX Awareness

### World Fragile X Day

A highlight in the Fragile X awareness calendar each year is 22 July – designated in Australia and some other countries as Fragile X Awareness Day. This year we were delighted to join with the FRAXA Research Foundation team in the US as a foundation partner to bring "World Fragile X Day" to life for the first time.

FRAXA's goal was to unite efforts in multiple countries:

17 organisations across 13 countries and 6 continents worked to have more than 300 landmarks illuminated for the common goal of increasing awareness of Fragile X. The media interest, particularly in the US, was a very positive outcome.

FRAXA also organised a global webinar on 22 July, called *Fragile X: In pursuit of a Cure* to bring Fragile X experts from around the world together to canvass current research efforts and discuss what the future will bring for Fragile X treatments. Australian involvement in the webinar included Prof Ted Brown chairing a panel, and the broadcasting of two short Australian Fragile X family videos.

### Light up for Fragile X

This year our annual "lightup for Fragile X" campaign was in its 6<sup>th</sup> year. The campaign was initiated in Brisbane in 2015 by Nyleta McRae, and has grown year on year, tremendously well supported by infrastructure operators and owners in both the private and public sectors. This year we arranged for around 90 landmarks, across the length and breadth of Australia, in each state and territory, to light up orange. Despite some last minute COVID-19 restrictions and lockdowns, we secured close to 85 on the night of 22 July for a great show of support for Fragile X.

We have some outstanding photographs of landmarks lit up orange, many supporting Fragile X for the first time, thanks to the photography skills of several of our members who braved the cold to take photos for our social media. Particular thanks to photographer Suzanne Gordon in WA for the astonishing photos of Perth landmarks in both 2020 – which were featured in our roadside digital billboard campaign – and 2021. Many thanks also to Kieran "Spud" Murphy for producing a Fragile X awareness day *Light up for Fragile X* video, and to the Lindsay family and Nyleta McRae for featuring in the film. It has been watched around 10,000 times.

### Digital billboards

Through a community grant from QMS Media, and a donation arranged by a FXAA member family in Adelaide, we secured Fragile X coverage throughout July on a number of large digital roadside billboards in Melbourne, Adelaide, Sydney, Brisbane and major freeways in WA. This provided phenomenal exposure – to hundreds of thousands of drivers – for the message of Fragile X awareness and the "lightup" in July. Many thanks are due to Kate Stokes, who has provided pro bono graphic design services to FXAA for more than 5 years, and spent many hours designing the signage for each installation so the billboards displayed our own member photos. Our website showed an increase in traffic as the major roadside billboards came online.

## Fragile X gene discovery

2021 marks the 30<sup>th</sup> anniversary of the Fragile X gene. Certainly a highlight for Fragile X awareness in 2021 was the publication of Prof Gillian Turner's latest book:

*Margaret's Story: The unfolding discovery of the Fragile X gene.*

Prof Turner played a key role in Australian researchers' discoveries in relation to the gene. She coordinated contributions to the book from people who have been involved in Fragile X discovery, including Prof Grant Sutherland and Prof Randi Hagerman.

The book includes a short chapter by Margaret Cunningham, after whom the book is named, recounting the journey a Fragile X diagnosis for her son Sean, and her involvement in Prof Turner's "discovery group" of families who at that time in the 1970's had children with intellectual disability of 'no known cause'.

The book has been distributed widely to scientists, researchers and clinicians with an interest in Fragile X syndrome or genetic discoveries more broadly. The online version is available via the FXAA website. Many thanks to the Cunningham family for generously supporting the publication.

## Networks

FXAA works closely with a range of organisations dedicated to supporting the Fragile X community and other organisations which focus on rare genetic conditions or intellectual disability. We are a foundation member of the *International Fragile X Alliance*, a network of representative groups from around 30 countries, and of the *International FXTAS Consortium*. We are an early partner of the *International Fragile X Premutation Registry*. We greatly appreciate the support of Fragile X Alliance, Victorian Clinical Genetics Service and the GOLD Service (Genetics of Learning Disability, NSW Health) for supporting our members with information and referrals. FXAA supports the advocacy of peak bodies and groups including Council for Intellectual Disability, Inclusion Australia, Children and Young People with Disability (CYDA), 3DN at UNSW, and Rare Voices Australia.

## Research

### International Fragile X Premutation Registry

The purpose of the Registry is to build a database listing of a large, diverse group of Fragile X premutation carriers and their family members worldwide who are interested in contributing to future research on the Fragile X premutation. The Registry was established by clinicians, researchers and FX groups around the world who partnered with the National Fragile X Foundation (US) and the UC Davis MIND Institute in California.

The Registry is coordinated by an advisory panel led by Dr David Hessel PhD from UC Davis Health. Karen Lipworth (FXAA Board member) and Dr Jonathan Cohen (Fragile X Alliance) are the Australian representatives on the Panel and led our webinar introducing the Registry to the Australian FX community.

At November 2021, registry participants included around 70 individuals from Australia out of a total of about 700 internationally.

In 2022 we aim to grow the Australian participation in the Registry. It is hoped the Registry will facilitate research, including intervention studies of premutation-associated conditions and ultimately lead to better care and potential treatments.

### Clinical trials

It is encouraging to see increasing interest in the establishment of clinical trials in Australia for potential treatments for Fragile X symptoms.

In September 2021 *Zynerba Pharmaceuticals* initiated RECONNECT, a pivotal phase 3 trial. The RECONNECT trial is designed to evaluate the efficacy and safety of Zygel (cannabidiol formulated in a transdermal gel) in children and adolescents with Fragile X syndrome and whether it reduces behavioural symptoms such as anxiety. The study is currently recruiting participants aged 3-17 years who have Fragile X syndrome and behavioural problems through sites internationally, including Australia, to the end of 2022. The local sites are in Brisbane, Melbourne and Sydney.

*Actinogen Medical* is planning to run a Fragile X clinical trial for Xanamem, which is a novel therapeutic product specifically designed to inhibit the production of excess cortisol in the brain. Xanamem is considered a potential therapy to decrease elevated cortisol and alleviate associated symptoms such as anxiety in Fragile X syndrome. Xanamem works by inhibiting the 11 $\beta$ -HSD1 enzyme in the brain, which blocks the production of the stress hormone, cortisol. The XanaFX study will evaluate Xanamem's effect on some symptoms associated with Fragile X syndrome: behavioural problems, anxiety, and sleep.

### Virtual delivery of supports and services

FXAA has received a grant from Melbourne Disability Institute (University of Melbourne) which will provide researcher time to explore the uptake and effectiveness of our virtual support and education activities. Over the past 18 months FXAA has greatly increased our online delivery of counselling, facilitated peer support and education. This research will be undertaken in the Victorian FX community and will inform the design, delivery and evaluation of FXAA's future virtual supports and activities.



## Strategic Plan 2021–2024

The Board has developed a Strategic Plan to take the organisation forward from 2021 through 2024 with four key pillars of focus: Support & connection, Empowerment, Advocacy and Education. The Strategic Plan is an important framework for our work in supporting the Fragile X community and working towards education of health and other professionals around diagnosis and supports for Fragile X-associated disorders, and it will inform future directions.



## Support

The inquiries received through our HelpLine and Family Support Counsellor remain diverse and often complex, covering the range of Fragile X-associated conditions. Initial inquiries are served by our Family Support Counsellor and Executive Director.

Inquiries about support and specialised information include: behavioural supports in a range of settings for children or adults with Fragile X syndrome; educational supports for children or adults; FXTAS, FXPOI and other health issues experienced by carriers of the Fragile X premutation; the inheritance pattern of Fragile X; the cost and availability of Fragile X testing; diagnosis of FX-related conditions; reproductive genetic carrier screening; medical or allied health service referrals; health professionals with specific expertise in Fragile X syndrome or other conditions; and connection to other individuals or families who have a Fragile X-related diagnosis. This year we have also received inquiries about COVID-19 vaccination for people who are Fragile X premutation or full mutation.

Inquiries are made by individuals and organisations: members of the FXAA community and their families; disability service providers, educators and health professionals supporting children or adults; students; the general public.

In comparison with previous years, we saw a decline in the number of inbound contacts throughout the year, and during April and May 2021 in particular as the COVID-19 pandemic affected wider areas of Australia. The decline was largely due, we expect, to the deferral of testing, screening and clinical appointments, and the closure of many schools and clinical and support services. Our Family Support Counsellor Liz Jewell escalated the number of our outbound contacts to check in periodically with our members, to offer support, counselling or peer connections to assist individuals and families to the extent possible during times of social restriction and isolation.

Our two staff served an estimated 150 HelpLine calls, and had more than 400 occasions of contact with our members. Our Family Support Counsellor conducted 470 occasions of counselling for 80 of our members, facilitated 60 small-group peer support meetings, and undertook 35 new member onboarding calls. Our staff continued to interact with our member base on a daily basis in our online forums.

**Trends:** We have observed an increase in the number of contacts from families with a younger age of diagnosis males (between 2-4 years of age), where newly diagnosed females may be diagnosed at around 6-12 years; increased complexity of carrier pre-pregnancy testing and diagnosis queries; an increased number of queries from support workers providing one on one support or from staff supporting individuals in Supporting Living Accommodation; increased contact from educators about learning and behaviour; increase in enquiries from parents seeking accommodation for adult children; and increase in counselling for grief and loss, adjusting to change and separation.

We observed an increase in contacts from parents supporting adult children (40 plus) whose programs and work opportunities were closed or reduced due to COVID-19 restrictions; those supporting adults with FXS cope behaviourally in isolation, whilst distanced from family and routine; increased contact with parents struggling with a change in children's behaviour due to home schooling while trying to manage work or other commitments of their own.

**MEMBERSHIP** At November 2021 FXAA has a member base of 530, the great majority of whom are individuals or family members impacted by Fragile X. This is an increase of 10% over October 2020.

Our members identify themselves as part of our community served by FXAA, and have an understanding and expectation that access to support is available and provided from a place of understanding of FX conditions. FXAA's contact with a member or their family or carer is based on need and may span from a single contact to ongoing contact over many years. Central to FXAA's commitment is that appropriate information and support is offered in a timely manner.

**COUNSELLING** is delivered by the Family Support Counsellor via phone, online (email and messenger), and face-to-face via Zoom or in person. Counselling revolves around a variety of areas such as behaviour management, therapeutic intervention, diagnosis, grief and loss, relationships, anxiety, and employment. Fragile X-specific support continues to be a valued service as indicated by the increased utilisation of the Counsellor over the past 18 months for counselling, general support or facilitated peer connections. The Counsellor is guided by any recent developments in FX and refers to the specialist knowledge available to us through experts and other organisations.

## PEER SUPPORT

Whilst there has been a decline in in-person opportunities for families to connect, the number and nature of Facilitated Peer Support Sessions offered by our Counsellor have grown significantly. As a result of COVID-19 restrictions, many families have become more familiar with using online platforms for telehealth and therapy sessions as well as educational interactions with school or workplaces. This has allowed our Counsellor to escalate the number of Zoom-based facilitated peer

support sessions in this period to help alleviate some of the isolation experienced by many of our members. The nature of the peer support groups has evolved over the past year with the introduction of specific small groups. For example, to support parents with young sons with FXS, parents with daughters entering puberty, individuals diagnosed with FXTAS, an extended group of young women who have Fragile X syndrome. An online support group for fathers of children with FXS was established mid-year. The group convenes one evening each month via Zoom and has provided a welcome platform for Dads from different parts of the country to share their experiences.

The FXAA discussion groups on Facebook continue to provide a strong platform for the FX community to connect, gain and provide peer support and share resources. Our primary facebook discussion group has close to 1,000 members, an increase of around 10% over the previous year. Questions and responses are posted by group members on a daily basis. Posts which require additional support or moderation are flagged by the group moderators to FXAA staff for response or follow up.

**FX HELPLINE** The Helpline inquiries are responded to by our Family Support Counsellor and Executive Director throughout a 5 day working week. Inquiries are received via phone and online by email, messenger and our website. Initial Helpline interactions at intake may range from 10mins to an hour in length and in most cases require further provision of additional support, information, counselling, or referral. This year we have seen a general increase in the number of enquiries around testing and screening, information on premutation carrier health issues and on challenging behaviours in children and adults. There has also been a general increase in inquiries from educators and support workers seeking information and guidance around supporting individuals in their care.

**CLINICS** FXAA continues to refer member families to clinics, where available, including the Fragile X Alliance Clinic in Melbourne; this service has developed a strong telehealth model and has been able to provide service to individuals and families across Australia. We were delighted that Dr Jane Law in Sydney is offering clinic appointments for adults with Fragile X syndrome twice a year at the FXAA premises. This commenced in March 2021. Interrupted by COVID-19 restrictions in the latter part of 2021, the clinic appointments will resume in March 2022.

**REFERRAL** FXAA receives frequent inquiries from individuals seeking therapists and medical practitioners with knowledge and experience in Fragile X. The referral process may include identifying services and providers, seeking information about appointment processes or services and referrals to genetic services or genetic counsellors.

**ADVOCACY** Advocacy is delivered in a range of ways. Individual advocacy may include supporting families whose young or adult children are struggling to cope in educational, workplace or group living settings and providing resources to those who are supporting an individual, eg teachers, workplace colleagues, disability support providers. The delivery of support provided by our Counsellor to culturally and linguistically diverse communities has increased, and utilises the skills of an interpreter service and Zoom.



Liz Jewell with Andrew Sambrooke in the FXAA office





# Financial Overview

Fragile X Association of Australia (FXAA) continues to be well resourced to provide ongoing services and support to our community. COVID-19 has affected events and other fundraising activities, but we expect the impact to reduce in the coming year as lockdowns are lifted. FXAA started the year in a solid financial position due the generosity of key donors such as the Cunningham family, donations from the community, government stimulus, and the hard work of the Board and Executive in prior years. FXAA is supported by volunteers and those who give their invaluable professional services and guidance pro bono, including Bruce Donald AM, Martin Davey, and John Kelleher.

## - Financial resources

During the financial year 2020-2021 the net assets of FXAA increased by approximately \$178,000 or 20%. At 30 June 2021, net assets of \$1,061,771 largely (76%) comprised the Endowment Fund (see next page) net assets of \$810,457.

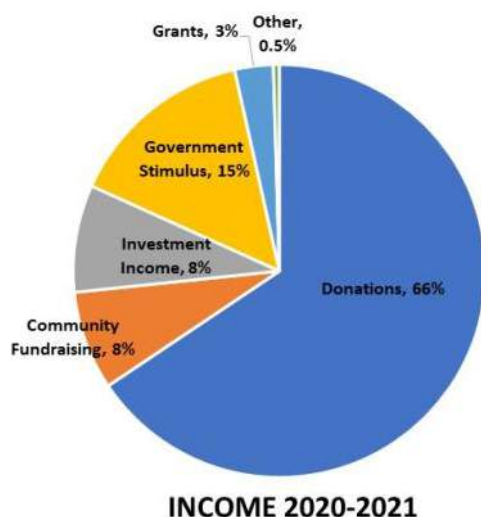
## - Operating Result

### Income (Up 4% versus last year)

Donations and fundraising continue to form the major source of income to fund the support and services provided to our member base and the wider Fragile X community. In 2020-2021 the Cunningham family increased their generous support of FXAA as a one-off to assist with the short-term funding challenges faced last year and we are extremely grateful for their ongoing commitment to the operation of the organisation.

Some specifics: Donations, including to the Endowment Fund, were up 14% versus last year. Income from fundraising events and online fell 27% versus last year. FXAA continued as charity partner for the Oceanpaddler Bridge to Beach paddle race across Sydney Harbour. Shaw and Partners Financial Services matched funds raised, and we thank them for their kind support.

Over time \$100,000 has been raised from this partnership. FXAA utilised a grant from the Qantas Community Foundation to produce educational videos, received an educational grant from Zynherba Pharmaceuticals to support a webinar, and an estimated \$300,000 in free digital billboard signage from QMS Media and additional donated signage. FXAA qualified for Federal Government's JobKeeper funding and a NSW Government Social Sector Digital Transformation Grant to accelerate our transition to online office tools for remote working.



### Expenditure (Down 15% versus last year)

There was a decrease in expenditure, largely due to the reductions in events this year. The cost of providing services reduced by 15% versus the prior year.

The fundamental purpose of the FXAA is to provide support to individuals affected by Fragile X, including our member base, through counselling and facilitating clinics. We are also charged with providing awareness and education about Fragile X to the wider community and Fragile X-related advocacy

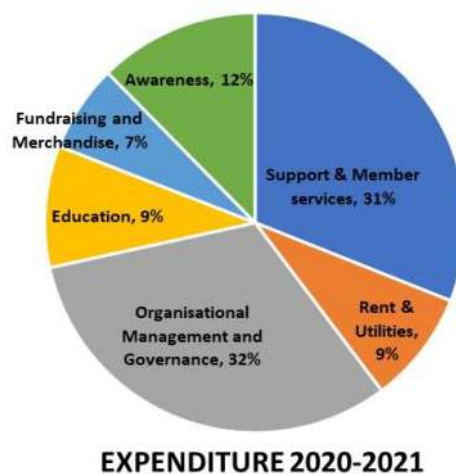
44 % of expenditure relates to the provision of service to the member base and the wider Fragile X community. This service largely comprises the Help Line, counselling and other support; 78% of the cost comprises salary costs for our two staff members and bookkeeping. The modest cost associated with health professional and community awareness and education reflects the leverage gained through our volunteers, supporters and partners and a trend to digital. The online webinars are a cost-effective way of reaching out to our broader community and can be used as training videos in the future. Management and governance of FXAA remains critical to effective and efficient operation and ensures compliance with regulatory requirements; this cost is largely salary cost.

## - Outlook

The Board undertook a review of the focus of the organisation and has developed a strategic plan for 2021-2024. FXAA is well resourced to deliver this plan into the coming years with the ongoing support of our community. The ongoing impact of the COVID-19 pandemic has seen the cancellation and deferral of a number of annual fundraising events which support FXAA but we expect this to improve in the coming year

The accounts for 2020-2021 were audited by Mr Peter Vilimaa and Mr Ben Hodgkinson of Manser, Tierney and Johnston in Turramurra, NSW. The Board and Staff are deeply grateful to Manser, Tierney and Johnston for the audit services provided on an honorary basis for over 20 years and wish to record appreciation of this valuable support which provides important oversight of FXAA's financial affairs.

The Treasurer commends to members the accounts and the re-appointment of Mr Peter Vilimaa as auditor.



### **Endowment Fund** - Net assets \$810,457 (2020 - \$708,421)

The Endowment Fund was established by resolution of the FXAA Board in 2011, for the purpose of generating long-term funding for the activities of the Association. It is hoped that over time the Fund will grow to a point where it can generate investment income sufficient to support the core infrastructure necessary for FXAA to meet its charitable purpose.

In 2020-2021 the Fund's interest and dividend income of \$32,141 represented 12% (2019-2020 11%) of the Association's annual expenditure of \$268,000. In order to try to meet the objective of self-sufficiency the Fund remains in "accumulation phase", unless future operational funding falls short to the extent that this reserve must be called upon.

The Fund's growth is substantially dependent upon the continued generous support of its donors and to date has benefited in particular from the support of the Cunningham family: the J & M Cunningham Endowment constitutes 39% of the total Fund as at 30 June 2021 (2020 39%).

In 2019-20 the Fund, like many other investors, suffered from the market downturn associated with the COVID-19 pandemic and achieved only 3% net growth. Encouragingly, in 2020/21 the Fund benefited from the market recovery and grew by 13.02% principally as a result of its investment earnings (Interest and dividend income 4.5%, and a net increase in the market value of investments 8.5%). Donations to the Fund however continued to be very modest, contributing 1.4% of the growth.

The total return on the Fund's investments in the period was \$102,036, representing a net annual return of 13.02%.

This compares to 1.75% for the previous year which was significantly impacted by the downturn in investment markets associated with the COVID-19 pandemic. In 2020-21 investment markets bounced back and the Fund's equity portfolio in particular enjoyed significant growth. The challenge will be to maintain reasonable investment returns in an environment of extremely low interest rates while the majority of the Fund's investments are in interest bearing securities.

The Fund is maintained and accounted for separately from FXAA's other funds and is managed on advice provided by a committee appointed by the Board. In 2020-2021 the Endowment Fund committee comprised Martin Davey (chair), former FXAA President John Kelleher, FXAA President Prof W Ted Brown and FXAA Treasurer Adam Lawrence-Slater.

In accordance with the guidelines established by the FXAA Board for the Endowment Fund, the funds continue to be invested conservatively. As at 30 June 2021 the Fund held investments in equities (Australian listed shares, representing 32% of the portfolio) and fixed income securities (67%) comprising both units in unlisted unit trusts (53%) and Australian listed bank hybrid securities (14%). 1% was held in cash.

## Thanking our Supporters

Our supporters are fundamental to our capacity to provide information, support and service to the Fragile X community.

We are sincerely grateful to the family members, individuals, businesses, community groups, health professionals and others who have supported us this past year through donations, fundraising and honorary services.

Cunningham Family



Kate Stokes, Graphic Design



Shaw and Partners  
Financial Services



Suzanne Gordon, Photography



Ballarat  
Dance  
Awards



Manser Tierney & Johnston  
Chartered Accountants & Wealth Management

# Understanding Fragile X

**Fragile X-associated Disorders** are a family of inherited conditions caused by alterations (expansions) in the FMR1 gene (Fragile X gene) which is located on the X chromosome. These disorders include a wide range of physical, intellectual and behavioural symptoms that can affect individuals and family members in different ways and throughout their lives. It is estimated that about 90,000 people in Australia are impacted by Fragile X in some way – with Fragile X syndrome or as carriers of the Fragile X gene alteration.

**Fragile X syndrome** is the leading cause of inherited intellectual disability, affecting about 1 in 4,000 males and about 1 in 6,000 females, and is the most common known single gene cause of autism.

## Fragile X premutation

Both males and females can be **carriers** of the Fragile X gene alteration, known as premutation carriers. About 1 in 250 women and 1 in 800 men are Fragile X premutation carriers. Several conditions are associated with the Fragile X premutation and are covered by the universal term **Fragile X Premutation Associated Conditions (FXPAC)**:

### Fragile X-associated Tremor Ataxia syndrome

FXTAS

A neurological condition with symptoms including shaking (intention tremor), unsteadiness (ataxia) and memory problems. FXTAS is often misdiagnosed as Parkinson's disease.

### Fragile X-associated Primary Ovarian Insufficiency

FXPOI

This can lead to fertility problems and early menopause in around 25% of female carriers.

### Fragile X-associated Neuropsychiatric Conditions

FXANC

A term to describe a range of neuropsychiatric issues some carriers may experience.

### Fragile X Various Associated Conditions

FXVAC

A term to describe other non-psychiatric conditions (such as auto-immune conditions etc) which some carriers may experience.

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## FX Scientific, Clinical and Research Sub-Committee

The Fragile X Scientific, Clinical and Research Sub-Committee is made up of Australian researchers and clinicians with an interest in Fragile X-associated disorders, with representation from Fragile X Association of Australia.

The group meets quarterly by video conference and provides an important conduit between FXAA and our members and developments in Fragile X research and clinical practice and other research areas relevant to the Fragile X community.

This puts us in a position to inform our members of new developments and their context and to provide the group with our members' perspectives. In 2020-2021 members of the sub-committee kept us abreast of the progress of their work in the field of Fragile X-related research and of the government-funded *Mackenzie's Mission* genetic carrier screening research study.

### Co-opted Members of the Sub-Committee:

Prof David Amor	Murdoch Children's Research Institute
Dr Alison Archibald	Victorian Clinical Genetics Services
Dr Emma Baker	Murdoch Children's Research Institute
Dr Jonathan Cohen	Medical Director, Fragile X Alliance Clinic/Genetic Clinics Australia
Dr Rachael Cvejic	Dept of Developmental Disability Neuropsychiatry, UNSW
Dr Mike Field	Genetics of Learning Disability (GOLD) Service, Hunter Genetics NSW
A/Prof David Godler	Murdoch Children's Research Institute
Dr Matthew Hunter	Head of Monash Genetics Clinic, Monash Health
Dr Claudine Kraan	Murdoch Children's Research Institute
Dr Danuta Loesch	School of Psychology and Public Health, La Trobe University
Dr Erin Turbitt	Graduate School of Health, University of Technology Sydney
Dr Cynthia Roberts	Geneticist and Board member of Fragile X Association of Australia

Chair

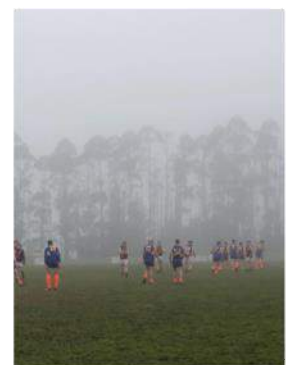
Prof W Ted Brown MD, PhD

FXAA representative

Wendy Bruce



# Fundraising and Awareness 2020-2021



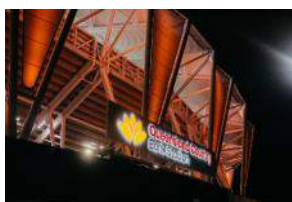


# World Fragile X Day, 22 July 2021





# Lighting up Australia for Fragile X





# Education and Awareness 2020–2021



## WEBINAR SERIES

**Saturday 13 November 2021**  
**10 - 11am AEDT**

### Understanding Anxiety

Why and how anxiety impacts people with Fragile X syndrome



**Dr Marcia Braden PhD**





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

**FINANCIAL STATEMENTS**  
**30 JUNE 2021**

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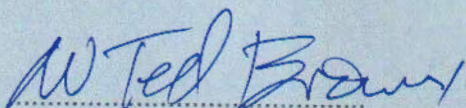
FRAGILE X ASSOCIATION OF AUSTRALIA INC  
ABN 18 655 264 477

DECLARATION BY MEMBERS OF THE COMMITTEE

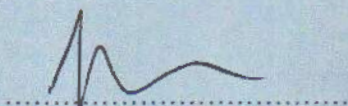
In accordance with a resolution of the committee of Fragile X Association of Australia Inc (the Association) the members of the committee declare that:

1. the attached financial statements as set out on pages 5 to 17 satisfy the requirements of the *Associations Incorporation Act 2009 (NSW)* and the *Australian Charities and Not-for-profits Commission Act 2012*; and:
  - a) comply with Australian Accounting Standards applicable to the Association; and
  - b) give a true and fair view of the financial position of the Association as at 30 June 2021 and of its financial performance for the year ended on that date.
2. There are reasonable grounds to believe that the Association will be able to pay its debts as and when they fall due and payable.

This declaration is signed in accordance with subsection 60.15(2) of the *Australian Charities and Not-for-profits Commission Regulation 2013*.



Prof W Ted Brown  
President



Adam Lawrence-Slater  
Treasurer

Dated this 17 day of November, 2021.





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

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

**Opinion**

We have audited the financial report of Fragile X Association of Australia Inc (the Association) comprising the statement of financial position as at 30 June 2021, the statement of profit or loss and other comprehensive income, statement of changes in equity and statement of cash flows for the year then ended and notes to the financial statements, including a summary of significant accounting policies and the declaration by members of the committee.

In our opinion, the accompanying financial report of the Association is in accordance with the *Associations Incorporation Act 2009 (NSW)* and Division 60 of the *Australian Charities and Not-for-profits Commission Act 2012 (ACNC Act)*, including:

- a) giving a true and fair view of the Association's financial position as at 30 June 2021 and of its financial performance for the year then ended; and
- b) complying with Australian Accounting Standards to the extent described in Note 1 to the Financial Statements and Division 60 of 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 ACNC Act and 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.

**Information Other than the Financial Report and Auditor's Report Thereon**

The committee of the Association is responsible for the other information. The other information comprises the information included in the Association's annual report for the year ended 30 June 2021, but does not include the financial report and our auditor's report thereon.

Our opinion on the financial report does not cover the other information and accordingly we do not express any form of assurance conclusion thereon.

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

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

In connection with our audit of the financial report, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial report or our knowledge obtained in the audit or otherwise appears to be materially misstated.

If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

**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 Association's financial reporting requirements under the ACNC Act. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

**Responsibilities of the Committee for the Financial Report**

The committee of the Association is responsible for the preparation of the financial report that gives a true and fair view in accordance with Australian Accounting Standards, the *Associations Incorporation Act 2009 (NSW)* and the ACNC Act and for such internal control as the committee 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 committee 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 committee 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.



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

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

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 committee.
- Conclude on the appropriateness of the committee's 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 committee 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 Turrumurra this 18th day of November 2021.

**MTJ AUDIT PTY LTD**



**PETER VILIMAA**

**Partner**

**Registered Company Auditor 312147**

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

**STATEMENT OF FINANCIAL POSITION**  
**AS AT 30 JUNE 2021**

	Note	2021	2020
<b>CURRENT ASSETS</b>			
<b>Cash and cash equivalents</b>			
At Bank		134,977	120,731
Endowment Fund	8	4,479	10,281
Petty Cash		100	100
Term Deposit		<u>120,000</u>	<u>50,000</u>
		<u>259,556</u>	<u>181,112</u>
<b>Accounts receivable and other debtors</b>			
Accounts Receivable		8,515	1,915
Accrued Income		-	17,330
Franking Credits Refundable		6,197	7,295
GST Refundable/(Payable)		236	(19)
Prepayments		5,094	766
Rental Bond		<u>3,416</u>	<u>3,416</u>
		<u>23,458</u>	<u>30,703</u>
<b>TOTAL CURRENT ASSETS</b>		<u>283,014</u>	<u>211,815</u>
<b>NON-CURRENT ASSETS</b>			
<b>Property, plant and equipment</b>			
Property, Plant and Equipment - At Cost		8,973	7,556
<u>Less: Accumulated Depreciation</u>		<u>(3,022)</u>	<u>(1,511)</u>
		5,951	6,045
<b>Investments</b>			
Listed Investments at Market Value - Endowment Fund	8	372,687	419,809
Unlisted Investments at Market Value - Endowment Fund	8	<u>425,621</u>	<u>273,360</u>
		<u>798,308</u>	<u>693,169</u>
<b>TOTAL NON-CURRENT ASSETS</b>		<u>804,259</u>	<u>699,214</u>
<b>TOTAL ASSETS</b>		<u>1,087,273</u>	<u>911,029</u>
<b>CURRENT LIABILITIES</b>			
<b>Accounts payable and other payables</b>			
Accounts Payable		9,784	8,007
Payroll Liabilities		1,204	1,204
Other Liabilities		<u>1,600</u>	<u>3,929</u>
		12,588	13,140
<b>Provisions</b>			
Provision for Employee Entitlements		<u>12,914</u>	<u>14,435</u>
<b>TOTAL CURRENT LIABILITIES</b>		<u>25,502</u>	<u>27,575</u>
<b>TOTAL LIABILITIES</b>		<u>25,502</u>	<u>27,575</u>
<b>NET ASSETS</b>		<u>\$1,061,771</u>	<u>\$883,454</u>
<b>EQUITY</b>			
Opening Balance		883,454	851,890
<u>Add: Surplus for the Year</u>		<u>178,317</u>	<u>31,564</u>
<b>TOTAL EQUITY</b>		<u>\$1,061,771</u>	<u>\$883,454</u>

The accompanying notes form part of these financial statements.

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

**STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME**  
**FOR THE YEAR ENDED 30 JUNE 2021**

	<b>2021</b>	<b>2020</b>
<b>INCOME</b>		
<b>Gross Proceeds From Fundraising Appeals</b>		
Conference Income	-	6,839
Donations - including Endowment Fund	253,371	222,444
FXAA Fundraising Events and Appeals	29,895	40,685
Merchandise Sales	<u>1,815</u>	<u>2,652</u>
	<u>285,081</u>	<u>272,620</u>
<b>Other</b>		
Dividend Income	20,660	24,606
Government Stimulus	56,910	39,330
Grants	11,700	23,137
Interest	<u>11,827</u>	<u>12,580</u>
	<u>101,097</u>	<u>99,653</u>
<b>Total Income (carried forward)</b>	<u>386,178</u>	<u>372,273</u>

The accompanying notes form part of these financial statements.



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

**STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME**  
**FOR THE YEAR ENDED 30 JUNE 2021**

	<b>2021</b>	<b>2020</b>
<b>Total Income (brought forward)</b>	<u>386,178</u>	<u>372,273</u>
<b>Less:</b>		
<b>EXPENDITURE</b>		
<b>Total Costs Of Fundraising Appeals</b>		
Other	<u>4,037</u>	<u>12,840</u>
	<u>4,037</u>	<u>12,840</u>
<b>Total Costs Of Providing Services</b>		
Support Services and FX Awareness	55,603	75,408
Clinics and Counselling	59,086	58,703
National Newsletter Printing	<u>2,535</u>	<u>3,144</u>
	<u>117,224</u>	<u>137,255</u>
<b>Other</b>		
Bank Fees and Charges	299	601
Board and AGM Expenses	838	1,946
Conferences and Seminars	379	25,309
Consultants and Accounting	20,715	24,438
Depreciation and Disposal of Assets	1,511	1,511
Donations	302	116
General Administration - Employment Costs	74,634	51,079
Information Resource Production	450	7,146
Insurance	5,606	5,175
Low Cost Assets	-	3,700
Office Expenses	4,436	6,122
Office Rent	17,939	18,959
Postage	3,161	2,967
Provision for Employee Entitlements	(1,521)	2,164
Stationery	1,730	1,764
Subscriptions	8,676	4,127
Sundries	22	450
Telephone	4,277	5,261
Website	<u>3,286</u>	<u>4,186</u>
	<u>146,740</u>	<u>167,021</u>
<b>Total Expenditure</b>	<u>268,001</u>	<u>317,116</u>
<b>OPERATING SURPLUS FOR THE YEAR</b>	118,177	55,157
Net Increase/(Decrease) in value of investments - Endowment Fund	<u>60,140</u>	<u>(23,593)</u>
<b>TOTAL COMPREHENSIVE INCOME FOR THE YEAR</b>	<u>\$178,317</u>	<u>\$31,564</u>

The accompanying notes form part of these financial statements.

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

**STATEMENT OF CHANGES IN EQUITY**  
**FOR THE YEAR ENDED 30 JUNE 2021**

	<b>2021</b>	<b>2020</b>
<b>EQUITY</b>		
<b>Retained Earnings</b>		
Opening Balance 1 July	899,810	844,653
<u>Add: Surplus for the Year</u>	<u>118,177</u>	<u>55,157</u>
Closing Balance 30 June	<u>1,017,987</u>	<u>899,810</u>
<b>Asset Revaluation Reserve</b>		
Opening Balance 1 July	(16,356)	7,237
<u>Add: Net Transfer to/(from) Reserve</u>	<u>60,140</u>	<u>(23,593)</u>
Closing Balance 30 June	<u>43,784</u>	<u>(16,356)</u>
<b>TOTAL EQUITY</b>	<u><u>\$ 1,061,771</u></u>	<u><u>\$ 883,454</u></u>

The accompanying notes form part of these financial statements.

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

**STATEMENT OF CASH FLOWS**  
**FOR THE YEAR ENDED 30 JUNE 2021**

		<b>2021</b>	<b>2020</b>
<b>Cash Flow from Operating Activities</b>			
Receipts from donations, fundraising appeals and events		363,321	320,366
Interest and Dividends		33,585	36,849
Payments to suppliers and employees		<u>(272,045)</u>	<u>(309,735)</u>
<b>Net cash provided by operating activities</b>	10b	<u>124,861</u>	<u>47,480</u>
<b>Cash Flows from Investing Activities</b>			
Payment for property, plant and equipment		(1,417)	(8,310)
Net Payment for investments		<u>(45,000)</u>	<u>(273,280)</u>
<b>Net cash used in investing activities</b>		<u>(46,417)</u>	<u>(281,590)</u>
Net Increase/(decrease) in Cash Held		78,444	(234,110)
Cash on hand at the beginning of the financial year		<u>181,112</u>	<u>415,222</u>
<b>Cash on hand at the end of the financial year</b>	10a	<u><u>\$ 259,556</u></u>	<u><u>\$ 181,112</u></u>

The accompanying notes form part of these financial statements.



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

**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2021**

**Note 1 – Summary of Significant Accounting Policies**

**Financial Reporting Framework**

The committee has prepared the financial statements on the basis that the Association is a non-reporting entity because there are no users dependent on general purpose financial statements. The financial statements are therefore special purpose financial statements that have been prepared in order to meet the requirements of the *Associations Incorporation Act 2009 (NSW)* and the *Australian Charities and Not-for-Profits Commission Act 2012 (ACNC Act)*. The Association is a not-for-profit entity for financial reporting purposes under Australian Accounting Standards.

The financial statements have been prepared in accordance with the mandatory Australian Accounting Standards applicable to entities reporting under the ACNC Act and the significant accounting policies disclosed below, which the committee has determined are appropriate to meet the needs of members. Such accounting policies are consistent with those of previous periods unless stated otherwise.

**Statement of Compliance**

The financial statements have been prepared in accordance with *Associations Incorporation Act 2009 (NSW)* and the mandatory Australian Accounting Standards applicable to entities reporting under the ACNC Act, the basis of accounting specified by all Australian Accounting Standards and Interpretations, and the disclosure requirements of Accounting Standards AASB 101: *Presentation of Financial Statements*, AASB 107: *Cash Flow Statements*, AASB 108: *Accounting Policies, Changes in Accounting Estimates and Errors*, AASB 1031: *Materiality* and AASB 1054: *Australian Additional Disclosures*.

The Association has concluded that the requirements set out in AASB 10 and AASB 128 are not applicable as the initial assessment on its interests in other entities indicated that it does not have any subsidiaries, associates or joint ventures. Hence, the financial statements comply with all the recognition and measurement requirements in Australian Accounting Standards.

**Basis of Preparation**

The financial statements, except for the cash flow information, have been prepared on an accruals basis and are based on historic costs unless otherwise stated in the notes. They 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.

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

**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2021**

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

**b) Property, Plant and Equipment**

Property, plant and equipment are carried at cost, independent or committees' 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 committee 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.

**f) Cash and Cash Equivalents**

Cash and cash equivalents 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.

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

**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2021**

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

**h) Revenue**

**Revenue recognition**

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

Revenue from the rendering of a service is recognised upon the delivery of the service to the customer.

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.

**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 statement of financial position.

**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.

**l) Member's Liability**

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

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



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

**NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 JUNE 2021**

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

**m) Comparative Figures**

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

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

**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2021**

**Note 2 - Information on Material Matters**

The Association received \$180,000 in donations from the Cunningham family, \$10,000 as a Philanthropic Donation from Shaw and Partners Foundation and a \$20,000 grant from the NSW state government's NSW Social Sector Transformation Program.

**Note 3 - Application of appeal monies**

During the year the Association received net income of \$296,781 from fundraising appeals and \$32,487 from the investment of appeal monies.

An amount of \$117,224 was spent on the provision of services (including \$59,086 for counselling and clinics, \$2,535 for newsletters, and \$55,603 for other awareness and support). We spent \$123,329 on insurance, rent, administration, office expenses.

**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
- Bridge to Beach 2021
- Ben's Shave to Raise
- Fragile X awareness events

**Note 6 - Analysis of monetary figures**

<b>Ratios</b>	<b>\$</b>	<b>%</b>
Total cost of fundraising/ Gross income from fundraising	4,037/296,781	1% (5% last year)
Net surplus from fundraising/ Gross income from fundraising	292,744/296,781	99% (95% last year)
Total costs of services/ Total expenditure	117,224/268,000	44% (42% last year)
Total costs of services/ Total income received	117,224/386,177	30% (37% last year)

**Note 7 – Commitments**

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

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

**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2021**

	Note	2021	2020
<b>Note 8 - Endowment Fund</b>			
<b>Balance Sheet - as at 30 June</b>			
<b>CURRENT ASSETS</b>			
<b>Cash on hand</b>			
At Bank		4,479	10,281
		<u>4,479</u>	<u>10,281</u>
<b>Accounts receivable and other debtors</b>			
Donations Receivable		1,473	-
Franking Refund Receivable		6,197	7,295
		<u>7,670</u>	<u>7,295</u>
<b>TOTAL CURRENT ASSETS</b>		<u>12,149</u>	<u>17,576</u>
<b>NON-CURRENT ASSETS</b>			
<b>Investments</b>			
Listed Investments - At Market Value		372,687	419,809
Unlisted Investments - At Market Value		425,621	273,360
		<u>798,308</u>	<u>693,169</u>
<b>TOTAL NON-CURRENT ASSETS</b>		<u>798,308</u>	<u>693,169</u>
<b>TOTAL ASSETS</b>		<u>810,457</u>	<u>710,745</u>
<b>CURRENT LIABILITIES</b>			
<b>Accounts payable and other creditors</b>			
Other creditors		-	2,324
		<u>-</u>	<u>2,324</u>
<b>TOTAL CURRENT LIABILITIES</b>		<u>-</u>	<u>2,324</u>
<b>NET ASSETS</b>		<u>\$ 810,457</u>	<u>\$ 708,421</u>
<b>EQUITY</b>			
Opening Balance		708,421	686,874
Add: Income for the Year	9	<u>102,036</u>	<u>21,547</u>
<b>TOTAL EQUITY</b>		<u>\$ 810,457</u>	<u>\$ 708,421</u>
Total Equity Comprises:			
General Fund		493,582	429,140
J & M Cunningham Endowment		316,875	279,281
		<u>\$ 810,457</u>	<u>\$ 708,421</u>



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

**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2021**

	<b>2021</b>	<b>2020</b>
<b>Note 9 - Endowment Fund</b>		
<b>Income &amp; Expenditure Statement - for the year ended 30 June</b>		
<b>INCOME</b>		
Donations	9,792	9,550
Interest & Dividend Income	32,141	35,603
Increase in Market Value of Investments	60,140	-
	<u>102,073</u>	<u>45,153</u>
<b>Less:</b>		
Decrease in Market Value of Investments	-	23,593
Expenses	37	13
	<u>37</u>	<u>23,606</u>
<b>NET INCOME FOR THE YEAR</b>	<u>\$102,036</u>	<u>\$21,547</u>

**Note 10 - Cash Flow Information**

(a) Reconciliation of Cash

Cash at the end of the financial year as shown in the statements of cash flows is reconciled to the related items in the statement of financial position as follows:

Cash at bank	<u>259,556</u>	<u>181,112</u>
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(b) Reconciliation of cash flow from operations with profit from ordinary activities

Operating Surplus/(Deficit)	118,177	55,157
Non-cash flows in Operating Surplus/(Deficit)		
- Depreciation	1,511	1,511
Changes in assets and liabilities		
- (Increase)/decrease in receivables	(6,600)	3,994
- (Increase)/decrease in other assets	13,846	(16,655)
- Increase/(decrease) in payables	1,777	2,135
- Increase/(decrease) in other current liabilities	(2,329)	(826)
- Increase/(decrease) in provisions	<u>(1,521)</u>	<u>2,164</u>
<b>Net cash provided by operating activities</b>	<u>\$124,861</u>	<u>\$47,480</u>

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

**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2021**

**Note 11 - Events After the Reporting Period**

The COVID-19 pandemic announced in 2020 by the World Health Organisation is impacting the Association. The timing and extent of the impact and recovery from COVID-19 is currently unknown.

Apart from the COVID-19 pandemic, the Committee are not aware of any other matters or circumstances not otherwise dealt with in the Financial Statements for the year ended 30 June 2021 that have significantly or may significantly affect the operations of the Association, the results of those operations or the state of affairs of the Association in subsequent financial years.



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**HelpLine**  
1300 394 636 and [support@fragilex.org.au](mailto:support@fragilex.org.au)

Fragile X Association of Australia Inc

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Registered Charity

