



ANNUAL REPORT

2019-2020

[FRAGILEX.ORG.AU](https://fragilex.org.au)

30 Years Strong | Supporting | Sharing | Connecting | Informing

Fragile X Association of Australia



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

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, newsletter and social media
- **Referral** to services
- **Support and discussion groups** on social media
- **Educational events** providing the latest on treatments and interventions
- Opportunities for people to **connect** in person and online
- **Increasing awareness** of Fragile X conditions to promote early 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

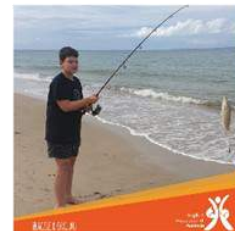
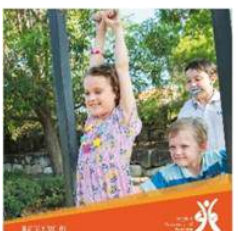
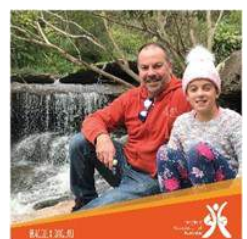
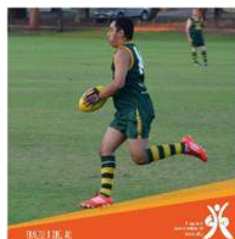
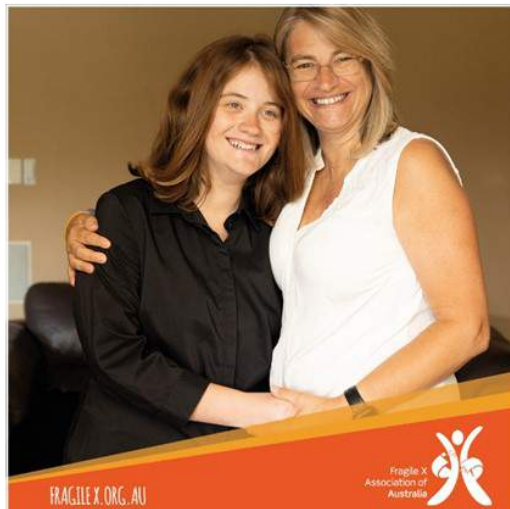
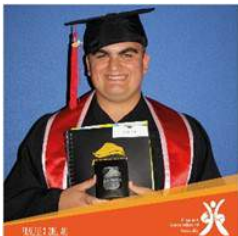


Image credits: Cover photo of the Good family by **Daniel Linnet** of Linnetfoto. Cover and poster designs by **Kate Stokes**.

President's Report

At the time of writing (October 2020) it is clear that the affects of the COVID-19 pandemic will be with us for some time.

The Association, and our member families, have all been impacted in a variety of ways. For FXAA, the pandemic has substantially reduced our fundraising opportunities for 2020, at least; and the important opportunities to engage with the medical community face to face in raising awareness of Fragile X ceased in March, and are unlikely to return in the medium term.

The pandemic has, however, led us to use new ways of providing support and connecting people; Liz has been introducing Zoom to many of our members and providing facilitated peer support and counselling in this way, and Wendy has done a great job using Zoom to coordinate activities and board meetings, as well.

The Disability Royal Commission was established in 2019 in response to community concern about widespread reports of violence against, and the neglect, abuse and exploitation, of people with disability. The work of the Commission has covered a range of key areas. In February 2020 the Commission heard the experiences of Narelle Reynolds, a Wiradjuri woman from NSW and former nurse, who has two adult sons with Fragile X syndrome. Narelle appeared before the Commission to highlight the inequities in the health system for people with disability. She called for hospitals to have trained disability workers and better access to culturally-appropriate health services for Aboriginal people. We thank Narelle sincerely for sharing her family's experience.

In March this year we were delighted to once again host Dr Marcia Braden, in conjunction with the NZ Fragile X Society. Marcia is highly sought after for her expertise in learning and behaviours in Fragile X syndrome. She presented four successful workshops on supporting adults/children with Fragile X for families and disability service providers. Many thanks to Zynerba for providing an educational grant to support costs associated with the workshops.

The Zynerba trial here and in the US has been completed with positive results and is awaiting FDA review in the US. Their open-label component is continuing. A new trial by Actinogen was recently announced to take place in Melbourne, possibly to start in autumn 2021. A number of clinical trials are underway in the US, which will be covered in my summary in the October FX newsletter and on our website.

The Light Up for Fragile X Awareness Day on 22 July this year was a great success. We saw 64 landmarks across Australia lit up orange for Fragile X: in cities large and small, from Cairns to Hobart, and Karratha to Sydney.



FXAA was pleased to continue working with several organisations to raise awareness of reproductive genetic carrier screening for Fragile X, cystic fibrosis and spinal muscular atrophy. One in 20 women are carriers of a gene alteration for one of these genetic conditions. We are delighted that a recommendation has been put to the Department of Health for public funding of this screening (via Medicare). This is an important development in making carrier screening accessible to those without a known family history of these conditions.

Many thanks to the organisations and clinicians who help us to support the Fragile X community, including Victorian Clinical Genetics Services, GOLD Service (Hunter Genetics), Murdoch Children's Research Institute, Fragile X Alliance, Council for Intellectual Disability, and Drs Jonathan Cohen, Natalie Silove, Honey Heussler, Randi Hagerman, and Marcia Braden.

It would not be possible for FXAA to achieve what we do without the dedicated commitment of our volunteers: our Board members, the experts on our Scientific, Clinical & Research Committee, the members of our Endowment Fund Committee, and the members who provide their skills and expertise in an honorary fashion.

The Board, Staff and I want to particularly acknowledge the Order of Australia award presented to former FXAA President Dr Robyn Iredale PhD this year in recognition of significant service to people with an intellectual disability and to education. Robyn served on the Board of FXAA for 13 years and has been very active in raising awareness of Fragile X through advocacy and sharing her family's story of Fragile X. We also want to thank Wayne Pointon, our retiring director from WA, for the service to the FX community over the past two years.

I would like to express sincere thanks to the Cunningham family for their generous ongoing support of Fragile X Association.

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

Best wishes,

A handwritten signature in blue ink that reads "Ted Brown".

Ted (Prof W Ted Brown)

Our Team

Board 2019–2020



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.



Wayne Pointon, Director

Wayne has held senior positions in the public sector in analytics and investigations, and in enforcement and compliance operations. He currently holds an operational leadership position within the mining industry. Wayne and his wife Lisa have three children including twin boys, one of whom has Fragile X syndrome. He is based in WA 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.

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

Advocacy

FXAA continues to be active in pursuing opportunities to represent the Fragile X community on health, disability and other areas related to Fragile X-associated conditions.

Reproductive Genetic Carrier Screening

1 in 20 people carry the gene change for Fragile X syndrome (FXS), cystic fibrosis (CF) or spinal muscular atrophy (SMA). Most people are unaware that they are carriers.

For a number of years FXAA and other organisations have been advocating for accessible reproductive carrier screening for FX, CF and SMA. In October 2020, following a submission by the Royal College of Pathologists of Australasia, the Medical Services Advisory Committee recommended to the federal Health Minister that carrier screening for the 3 conditions be funded via the Medicare Benefits Schedule, regardless of family history. It is anticipated this will be in place in mid 2021.

As a member of the Carrier Screening Reference group (with representatives from Cystic Fibrosis CommunityCare, Spinal Muscular Atrophy Australia, Victorian Clinical Genetics Services) we have been involved in the development of government-funded resources for health professionals and patients about reproductive genetic carrier screening options. The website www.carrierscreening.org.au was launched in mid 2020 by SMAA to profile carrier screening options for these three conditions.

FXAA is a member of the Reference Group for *Mackenzie's Mission*, the government-funded reproductive genetic carrier screening pilot study that will screen 10,000 couples across Australia for approximately 1300 genes responsible for more than 750 genetic conditions, including Fragile X syndrome. FXAA and the CF and SMA peak bodies provide support group and consumer feedback on the educational content, language and consumer-focussed presentation in the pilot study.

Disability Royal Commission (DRC)

The DRC was established in 2019 in response to community concern about widespread reports of violence against, and the neglect, abuse and exploitation of people with disability. The DRC is investigating a number of areas including health services, accommodation, education and employment issues. FXAA invited our members to consider making submissions to the DRC on their family's lived experience in health issues and disability. Particular thanks to Narelle Reynolds who appeared before the DRC to speak of the lack of insight and appropriate care afforded to her son, Luke, and to highlight the inequities in the health system for individuals who have a disability and are Aboriginal. (as reported in *The Guardian* newspaper and on the DRC website). FXAA continues to monitor the ongoing work of the DRC to identify areas in which FXAA and our members may provide a response.

NDIS

In October 2019 FXAA made a submission on the NDIA proposal to incorporate a Participant Service Guarantee to the NDIS scheme and responding to a call for feedback on the NDIS participant experience. The submission was based on feedback from FXAA members who are carers of NDIS participants affected by Fragile X syndrome or Fragile X-associated Tremor Ataxia Syndrome (FXTAS) .

Women's Health

In 2019 FXAA joined the Women's Health Policy Alliance convened by the not-for-profit organisation Jean Hailes for Women's Health. Our Executive Director attended the inaugural Women's Health Symposium to contribute to discussion on health issues for women who have Fragile X syndrome or the Fragile X premutation and to the discussions on reproductive genetic carrier screening.

Access to Treatments for Rare Diseases and Conditions

An upcoming Parliamentary Inquiry into approval processes for new drugs and novel medical technologies in Australia will focus on access to treatments and the establishment and conduct of clinical trials. FXAA will make a submission to the inquiry with regard to patient access to current and potential treatments for Fragile X syndrome.

Education

For much of the year FXAA continued our involvement in initiatives to provide education on Fragile X to health, education and disability professionals. The COVID-19 pandemic called a halt to face to face training and events from late March 2020 and, while some professional development events have since moved to digital platforms (through Zoom meetings, webinars, podcasts etc), we anticipate ongoing reduction in opportunities to engage in this type of awareness raising/education over the medium term.

General Practitioners and Nurses

FXAA's regular presence at the *Healthed* educational seminars for GPs in Adelaide, Brisbane, Melbourne, Perth and Sydney continued until mid March. Volunteers from the FX community and others involved in genetics helped to inform the seminar participants about Fragile X and genetic carrier screening for FX, CF and SMA. We are tremendously grateful for the support of the volunteers. We are currently working with Healthed to explore other ways to keep GPs aware of Fragile X in the absence of the face to face educational events.

The national *Maternal Child & Family Health Nurse* conference in August 2019 gave our Family Support Counsellor an opportunity to speak with participants about early diagnosis and early interventions in Fragile X syndrome.

For several years *ThinkGP*, an online education platform for health professionals, has hosted a Fragile X site with several short videos about diagnosis. The videos were produced for FXAA by ThinkGP. This presence provides exposure on Fragile X disorders to the site's 50,000+ subscriber base.

Genetic Counsellors

In 2020 FXAA accepted invitations to participate in the genetic counselling curriculum for students at University of Technology Sydney and Melbourne University. Our Family Support Counsellor gave presentations to the students via Zoom, supported by one of our members who provided a parent's perspective on receiving a Fragile X diagnosis.

Disability Service Providers

In November 2019 FXAA attended a Fragile X workshop in Victoria for disability service providers convened by the Warrnambool-based not for profit *Community Southwest*. The presentations delivered by Dr Jonathan Cohen and the team from Fragile X Alliance were filmed and made available on the FXAA youtube channel as a useful resource for disability service providers who support adults with Fragile X syndrome.

SourceKids is a parent-led organisation dedicated to providing information to parents, carers and professionals of children with special needs. The 2020 Sydney SourceKids expo for families was deferred due to the pandemic and so FXAA will have an information stall at the re-scheduled event in 2021.

In March 2020 Dr Marcia Braden's seminars in Melbourne and Sydney were geared for disability service providers, allied health professionals and family members.

Educators

FXAA was approached to provide content for a teaching resource on classroom adjustments for children who have Fragile X syndrome. Many thanks to our members Melbourne-based OT Bev Kadish and to Jimmy Jones and his mother Sarah for recording the podcast. It was produced by the Victorian Dept of Education for a national disability education series.

FXAA continues to provide an annual tutorial on Fragile X syndrome for the Disability Studies program at Australian Catholic University in Sydney. We are planning to offer this as an online option to other tertiary disability studies programs.

Workshops & Clinics

In March 2020 Dr Marcia Braden led our seminars in Melbourne and Sydney for families and disability service providers who support adults or children who have Fragile X syndrome. Dr Jonathan Cohen, Dr Jane Law and Michael Cohen also presented at these events.

The sessions were very well attended by parents, family members, disability service providers, educators and allied health professionals. 85 people attended in Melbourne and 140 attended in Sydney. Sincere thanks to the organisations which kindly provided venues at no cost to FXAA: Hireup, a disability

service provider based in Sydney; Australian Catholic University, Strathfield campus; and Royal Children's Hospital Melbourne.

FXAA continues to refer children and adults affected by Fragile X syndrome or FXTAS to specialist clinics or practitioners. We arranged for Dr Marcia Braden to provide individual clinic consultations for 14 children and adults while she was in Australia.

Fundraising

The financial support of our members and supporters, together with their friends and families, is key to our capacity to provide Fragile X-specific information and support to our members and the wider Fragile X community.

In 2019-2020 \$40,685 was raised through individual and community fundraising efforts, both in person and online.

In July 2019 the third annual Launceston High Tea raised \$4,500; the launch of craft beer FXIPA at 7th Day Brewery in Brookvale raised \$2,500. In August 2019 the Trivia Night at Manly Golf Club in Sydney raised \$28,000, supported by the generous donation of a resort holiday prize by the US-based Tomberlin family. Cynthia Roberts raised close to \$5,500 in her annual run in the Sydney to Surf.

In February 2020 Taylah Wallace and Bree Robinson raised close to \$13,000 by securing sponsorship for their run in the Murray Marathon in honour of their three young children who were recently diagnosed with Fragile X. Following the close of the 2019-20 financial year, the Ellinbank Football and Netball Club raffle in SE Victoria raised close to \$8,500, in honour of Cal Wallace. In October Mike Tozer ran the London Marathon virtually (in Sydney!) raising over \$2,500.

The annual Galston Garden Club Open Garden event in Sydney is also a regular supporter, introduced to us by Trish & Graham Piper, whose great-nephew James has Fragile X syndrome. In October 2019 the Club once again donated \$3,000 from the Open Gardens event to FXAA, matched by Masonicare.

In January 2020 the second annual Ballarat Dance Awards (BDA) competition secured regional newspaper and television coverage about Jimmy Jones, and ran a fundraiser on the final day of competition. Many thanks to BDA for choosing FXAA as their charity partner and raising \$2,500 this year.

Since 2014 FXAA has been charity partner for the annual Bridge to Beach paddle race across Sydney Harbour, which is run by Oceanpaddler as the final event in the Australian Ocean Racing Series. Oceanpaddler and FXAA were introduced to each other by the Iredale family in 2013. The 2020 Bridge to Beach raised \$12,000 in funds for the FX family support service, including \$5,000 in matched funding from race sponsor Shaw & Partners Financial Services.

Facebook fundraising by our members has increased over the past 12 months; a wonderful way to support FXAA.

Networks

FXAA works closely with a range of organisations dedicated to supporting the Fragile X community and with organisations which focus on rare genetic conditions or intellectual disability. We are a member of the *International Fragile X Alliance*, a network of representative groups from around 30 countries and a foundation member of the *International FXTAS Consortium*. We are currently working with the Fragile X Premutation Registry planning group, which has been convened by National Fragile X Foundation and the MIND Institute, UC Davis.

FXAA has worked closely with Cystic Fibrosis Community Care, SMA Australia and Victorian Clinical Genetics Services in advocating for accessible reproductive carrier screening. We greatly appreciate the support of the GOLD (Genetics of Learning Disability) Service NSW for information and referrals.

Support

The inquiries we receive through our Helpline and Family Support Counsellor are diverse and often complex, covering all of the Fragile X-associated conditions. Inquiries about support and specialised information are in areas including: behavioural supports in a range of settings for children or adults with Fragile X syndrome; educational supports for children or adults; FXTAS; FXPOI; 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 conditions; reproductive genetic carrier screening; medical or service referrals; connections with other individuals or families affected by Fragile X; and more.

Inquiries come from individuals and organisations: members of the FXAA community and their families; disability and health professionals and educators providing service or support to children or adults; students; the general public.

In 2019-2020 we attended to inquiries from around 550 people and organisations, totalling close to 1,000 interactions, a 45% increase over 2018-2019. 52 people were involved in our facilitated peer support sessions. In addition our two staff interact with our member base regularly in our online forums, by email and by phone. In comparison with previous years, we saw a noticeable decline in incoming contacts during April and May at the early stages of the COVID-19 pandemic. This was largely due, we expect, to the deferral of testing, screening and clinical appointments, as well as the closure of many schools and services.

Our members identify themselves as part of a 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 an individual or family is based on need and may span from a single contact to ongoing contact over time. Support is offered to those with a

Fragile X diagnosis but equally may also include extended family members and carers. Central to FXAA's commitment is that information and support is offered to people across the country and in a timely manner.

From the 2020 Survey: *"Knowing help and support is there if I need it and having "a family" of other Fragile X parents which means I'm not alone [is valued]."*

Counselling is delivered by the Family Support Counsellor via phone, online (email and messenger), or face to face via Zoom and 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 utilisation of the Counsellor, and by feedback provided in the recent member survey. 95% of survey respondents indicated that Family Support/ Counselling rated as Extremely or Very important to the community.

From the 2020 survey:

"You have been so helpful to many struggling families."

"At times I have felt very isolated so having this contact is of importance to me and my family".

"The longevity of the counselling support provided by FXAA is key to the quality of life our people with FXS attain."

Peer Support: This year the impact of COVID-19 has led to a decrease in opportunities for families to meet in person through social activities and events. 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 main Australian facebook discussion group currently has 900 members. Questions and responses are posted on a daily basis and comments which require additional support are flagged by the volunteer group moderators to our two staff for response or follow up.

Our Family Support Counsellor is making increasing use of Zoom to facilitate peer support connections between small groups of people for discussion on particular topics or to share experiences face to face. The opportunity to connect with people in various parts of the country via Zoom has been well received by the existing membership and our new members. These scheduled sessions provide an opportunity for participants to gain an understanding of their own experience whilst making a connection with people with a similar narrative or demographic, and to share strategies and resources peer to peer. The model has greatly increased our outreach to our community. An average of 3 facilitated peer support sessions are held each week.

From the 2020 survey:

"Connection with other families and information provision are vitally important to FX families. The support offered by FXAA in counselling is invaluable".

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. Over 2019-2020 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.

Membership: At October 2020 FXAA has 482 members, an increase of 50% in the past 2 years. Our new website, which launched in August 2019, provides an easy online membership application process and we believe this, together with the membership fee waiver from 2018, has played a part in increased membership. We also found that membership applications increased in the lead up to our workshops with Dr Marcia Braden in March.

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 service availability for FX clinics and referrals to genetic counsellors.

A number of survey respondents called for access to Fragile X specialists and clinical services outside the two largest capital cities.

Advocacy may be at an individual or community level. Individual advocacy may include supporting families who are preparing NDIS applications or attending planning meetings or reviews and liaising with educators or support workers to discuss the supports people with Fragile X syndrome need in learning environments and the workplace. Community level advocacy may include providing input to calls for feedback or submissions on policy or program matters that impact the Fragile X community.



Liz Jewell with Rosie Donald in the FXAA office

Dashboard 2019 - 2020

MEMBERS: 482 members of Fragile X Association of Australia

SUPPORT PROVIDED: 550 people assisted through our Helpline and Family Support

WEBSITE: 35,419 visitors to our website and 89,629 pages viewed

FACEBOOK PEER SUPPORT: 868 people supported through our Facebook discussion groups

SOCIAL MEDIA: facebook 3,330 instagram 950 twitter 880 followers

OUR VIDEOS: 73,000 views : Stuart X 37,000 Understanding FX 10,000 Geronimo 10,000 views

FX SEMINARS: 225 people attended the Dr Marcia Braden FX seminars

NEWSLETTERS: 3 published in print and online

EVENT PARTICIPATION: presence at 9 health and 2 education sector seminars and 1 disability expo

Financial Overview

FXAA is well positioned to provide ongoing services and support. COVID-19 and the bushfires earlier in the year have affected fundraising across the entire not-for-profit sector and we expect these challenges to continue through 2021. FXAA started the year in a solid financial position due to fundraising, the generosity of key donors such as the Cunningham family, and the hard work of the Board and Executive in recent years. In 2019-2020 FXAA has secured government stimulus, including JobKeeper, and has negotiated a reduction in the office rent.

- Financial resources

During the financial year 1 July 2019 to 30 June 2020 the net assets of FXAA increased by approximately 4%.

At 30 June 2020, net assets of \$883,454 largely (80%) comprised the Endowment Fund (see next page) net assets of \$708,421.

- Operating Result

Income (Down 17% on 2018-2019)

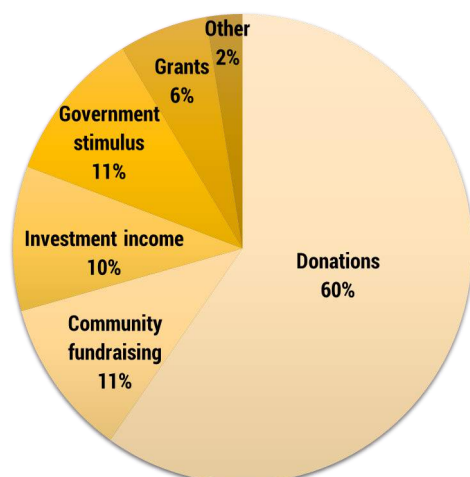
Donations and fundraising continue to form the major source of income to fund the support and services provided to our member base and the wider Fragile X community.

In 2019-2020 donations, including to the Endowment Fund, were 42% lower than in the previous year, while funds raised at live fundraising events and online increased by 74% over the previous year. In 2019-2020 the Cunningham family continued their generous support of FXAA, and we are extremely grateful for their ongoing commitment to the operation of the organisation.

In 2020 FXAA continued as charity partner for the Bridge to Beach paddle race across Sydney Harbour. Shaw and Partners Financial Services matched funds raised, and we thank them for their kind support.

FXAA received grants from the Qantas Community Foundation for the production of educational videos and from Zynerba Pharmaceuticals to support Dr Braden's workshops.

FXAA qualified for Federal Government stimulus initiatives introduced during the COVID-19 pandemic: cash boost stimulus to offset PAYG costs (capped) and JobKeeper payments for staff.



FUNDING SOURCES 2019-2020

Expenditure (Up 4% on 2018-2019)

There was a modest increase in expenditure, largely due to the four Fragile X workshops with Dr Marcia Braden. Expenditure was also incurred in the production of video resources and in costs associated with the new website launched in late 2019. The cost of providing services reduced by 12% over the previous year.

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

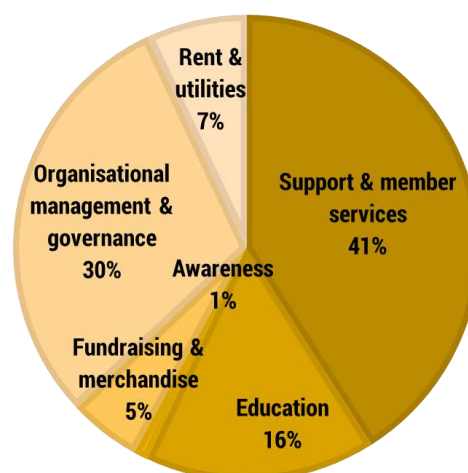
At 41 % (2019- 35%) of expenditure, the core costs of FXAA relate to the provision of service to the member base and the wider Fragile X community. This service largely comprises the Help Line, counselling and other support; 82% (2019 - 71%) of the cost comprises salary costs for our two staff members.

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 seminars with Dr Braden are included in education costs in 2019-20. 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

In late 2020 the Board undertook a review of the focus of the organisation and will develop a strategic plan for 2021-2024. The ongoing impact of the COVID-19 pandemic has seen the cancellation and deferral of a number of annual fundraising events which support Fragile X Association, and this financial impact is expected to continue throughout 2020-21.

The accounts for 2019-2020 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.



EXPENDITURE 2019-2020

Endowment Fund - Net assets \$708,421 (2019 - \$686,874)
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 be able to grow to a point where it can generate investment income sufficient to support the core infrastructure of the Association.

In 2019-2020 the Fund's interest and dividend income (before unrealised revaluation losses) represented 11% of FXAA's annual expenditure. 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 dependant 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 2020. The Fund grew by 3% in the year as a result of donations and the retention of its investment earnings.

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 2019-2020 the Endowment Fund committee comprised Martin Davey (chair), former Board member 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 2020 the Fund held investments in Australian listed shares (representing 28% of the portfolio) and fixed income securities (71%) comprising both units in unlisted unit trusts (39%) and Australian listed bank hybrid securities (32%). 1% was held in cash.

In 2019-2020 the Endowment Fund generated \$35,603 in net investment income, a net annual return of 1.75%. This compares to 4.21% for the previous year, and reflects the general decline in investment returns in the Australian market, returns which are expected to continue to be low into the 2020-2021 financial year. While, as an absolute return, this is a disappointing result, it reflects the difficult financial conditions experienced particularly towards the end of the year brought about by the financial markets' reaction to the global COVID-19 pandemic. As noted above, the Fund is invested conservatively in a mix of interest and dividend bearing investments which has sheltered it from the worst of the impact of the fall in equity markets - the ASX200 index fell by 11% in the financial year - and we can take some satisfaction in noting for example that the largest local superannuation fund, Australian Super, produced a return of only 0.52% in its "balanced" option, and 1.35% in its "conservative balanced" option over the same period.

Thanking our Supporters

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

We are deeply 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

ShawandPartners
Financial Services



Fragile X Alliance



Kate Stokes



Ballarat
Dance
Awards



Galston District Garden Club



ManserTierney&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.

FX Scientific, Clinical and Research Sub-Committee

The Fragile X Scientific, Clinical and Research Sub-Committee is made up of Australian specialists with an interest in Fragile X-associated disorders and genetics, 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 of opportunities for our members to be involved in research on Fragile X syndrome or the Fragile X pre-mutation. In 2019-2020 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

Chair

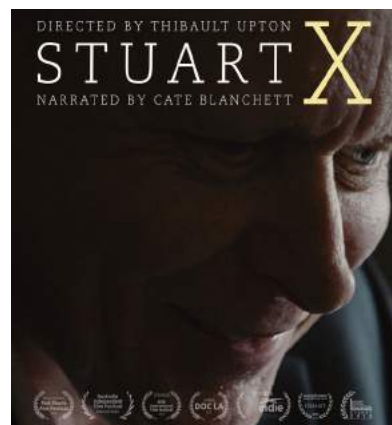
Prof W Ted Brown

FXAA representative

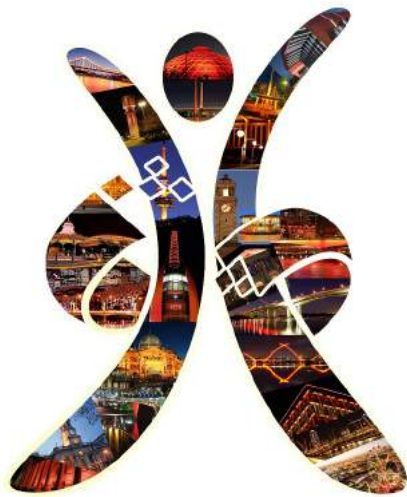
Wendy Bruce

Fundraising and Awareness 2019-2020

Highlights in 2019: Trivia Night in Manly, annual Launceston High Tea, craft brewery fundraiser and the release of our short film *Stuart X*. In 2020: Ballarat Dance Awards, Bridge to Beach paddle race, and marathon run & raffle in Ellinbank, Victoria.



Light up for Fragile X 2020



Education 2019-2020



Fragile X workshops with Dr Marcia Braden

FX and carrier screening focus at conferences





FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

FINANCIAL STATEMENTS
30 JUNE 2020

CONTENTS

- Declaration by Members of the Committee	1
- Independent Auditor's Report	2 – 4
- Statement of Financial Position	5
- Statement of Profit or Loss and Other Comprehensive Income	6 – 7
- Statement of Changes in Equity	8
- Statement of Cash Flows	9
- Notes to the Financial Statements	10 – 17

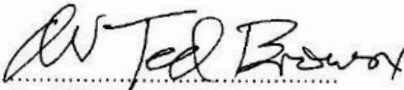
FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

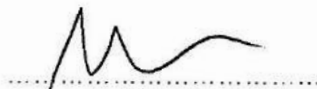
DECLARATION BY MEMBERS OF THE COMMITTEE

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 2020 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 17th day of October 2020.

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 2020, 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 2020 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 2020, 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 20th day of October 2020.

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 2020

	Note	2020	2019
CURRENT ASSETS			
Cash and cash equivalents			
At Bank		120,731	94,989
Endowment Fund	8	10,281	239,982
Petty Cash		100	100
Term Deposit		50,000	80,151
		<u>181,112</u>	<u>415,222</u>
Accounts receivable and other debtors			
Accounts Receivable		1,915	6,150
Accrued Income		17,330	-
Franking Credits Refundable		7,295	6,958
GST Refundable/(Payable)		(19)	77
Prepayments		766	2,410
Rental Bond		3,416	3,416
		<u>30,703</u>	<u>19,011</u>
TOTAL CURRENT ASSETS		<u>211,815</u>	<u>434,233</u>
NON-CURRENT ASSETS			
Property, plant and equipment			
Website - At Cost		7,556	-
<u>Less: Accumulated Depreciation</u>		<u>(1,511)</u>	<u>-</u>
		6,045	-
Investments			
Listed Investments at Market Value - Endowment Fund	8	419,809	365,910
Unlisted Investments at Market Value - Endowment Fund	8	273,360	75,848
		<u>693,169</u>	<u>441,758</u>
TOTAL NON-CURRENT ASSETS		<u>699,214</u>	<u>441,758</u>
TOTAL ASSETS		<u>911,029</u>	<u>875,991</u>
CURRENT LIABILITIES			
Accounts payable and other payables			
Accounts Payable		8,007	4,145
Payroll Liabilities		1,204	2,030
Other Liabilities		3,929	5,655
		13,140	11,830
Provisions			
Provision for Employee Entitlements		14,435	12,271
TOTAL CURRENT LIABILITIES		<u>27,575</u>	<u>24,101</u>
TOTAL LIABILITIES		<u>27,575</u>	<u>24,101</u>
NET ASSETS		<u>\$883,454</u>	<u>\$851,890</u>
EQUITY			
Opening Balance		851,890	707,311
<u>Add: Surplus for the Year</u>		<u>31,564</u>	<u>144,579</u>
TOTAL EQUITY		<u>\$883,454</u>	<u>\$851,890</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 2020

	2020	2019
INCOME		
Gross Proceeds From Fundraising Appeals		
Conference Income	6,839	2,349
Donations - including Endowment Fund	222,444	384,000
FXAA Fundraising Events and Appeals	40,685	23,357
Merchandise Sales	<u>2,652</u>	<u>389</u>
	<u>272,620</u>	<u>410,095</u>
Other		
Dividend Income	24,606	23,194
Government Stimulus	39,330	-
Grants	23,137	12,318
Interest	12,580	3,480
Subscriptions	<u>-</u>	<u>420</u>
	<u>99,653</u>	<u>39,412</u>
Total Income (carried forward)	<u>372,273</u>	<u>449,507</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 2020

	2020	2019
Total Income (brought forward)	<u>372,273</u>	<u>449,507</u>
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Other	<u>12,840</u>	<u>6,955</u>
	<u>12,840</u>	<u>6,955</u>
Total Costs Of Providing Services		
Support Services and FX Awareness	75,408	96,258
Clinics and Counselling	58,703	52,262
National Newsletter Printing	<u>3,144</u>	<u>5,967</u>
	<u>137,255</u>	<u>154,487</u>
Other		
Bank Fees and Charges	601	578
Board and AGM Expenses	1,946	2,039
Conferences and Seminars	25,309	17,956
Consultants and Accounting	24,438	-
Depreciation and Disposal of Assets	1,511	-
Donations	116	200
General Administration - Employment Costs	51,079	66,031
Information Resource Production	7,146	-
Insurance	5,175	5,938
Loss on Sale of Investments	-	664
Low Cost Assets	3,700	-
Office Expenses	6,122	9,299
Office Rent	18,959	20,807
Postage	2,967	2,958
Provision for Employee Entitlements	2,164	6,965
Stationery	1,764	2,549
Subscriptions	4,127	2,401
Sundries	450	600
Telephone	5,261	5,544
Website	<u>4,186</u>	<u>-</u>
	<u>167,021</u>	<u>144,529</u>
Total Expenditure	<u>317,116</u>	<u>305,971</u>
OPERATING SURPLUS FOR THE YEAR	55,157	143,536
Net Increase/(Decrease) in value of investments - Endowment Fund	<u>(23,593)</u>	<u>1,043</u>
TOTAL COMPREHENSIVE INCOME FOR THE YEAR	<u>\$31,564</u>	<u>\$144,579</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 2020

	2020	2019
EQUITY		
Retained Earnings		
Opening Balance 1 July	844,653	701,117
<u>Add: Surplus for the Year</u>	<u>55,157</u>	<u>143,536</u>
Closing Balance 30 June	<u>899,810</u>	<u>844,653</u>
Asset Revaluation Reserve		
Opening Balance 1 July	7,237	6,194
<u>Add: Net Transfer to/(from) Reserve</u>	<u>(23,593)</u>	<u>1,043</u>
Closing Balance 30 June	<u>(16,356)</u>	<u>7,237</u>
TOTAL EQUITY	<u><u>\$883,454</u></u>	<u><u>\$851,890</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 2020

		2020	2019
Cash Flow from Operating Activities			
Receipts from donations, fundraising appeals and events		320,366	439,682
Interest and Dividends		36,849	24,210
Payments to suppliers and employees		<u>(309,735)</u>	<u>(289,710)</u>
Net cash provided by operating activities	10b	<u>47,480</u>	<u>174,182</u>
Cash Flows from Investing Activities			
Payment for property, plant and equipment		(8,310)	-
Net Payment for investments		<u>(273,280)</u>	<u>(81,564)</u>
Net cash used in investing activities		<u>(281,590)</u>	<u>(81,564)</u>
Net Increase/(decrease) in Cash Held		(234,110)	92,618
Cash on hand at the beginning of the financial year		<u>415,222</u>	<u>322,604</u>
Cash on hand at the end of the financial year	10a	<u><u>\$181,112</u></u>	<u><u>\$415,222</u></u>

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020

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 2020

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 2020

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 2020

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.

n) New Accounting Standards

The AASB has issued new accounting standards, AASB 15: *Revenue from Contracts with Customers*, AASB 1058: *Income of Not-for-Profit Entities* and AASB 16: *Leases*. In consideration of the accounting framework of the Association the Committee has decided against the adoption of these standards.

The Committee's assessment of the impact of the new standards is that they will not have a significant material affect any of the amounts recognised in the financial statements.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020

Note 2 - Information on Material Matters

The Association received \$110,000 from the Cunningham family and \$5,000 from Philanthropic Donations from Shaw and Partners Financial Services.

Note 3 - Application of appeal monies

During the year, the Association received net income of \$272,620 from fundraising appeals, \$37,186 from the investment of appeal monies and \$23,137 from grants.

An amount of \$137,255 was spent on the provision of services (including \$58,703 for counselling and clinics, \$3,144 for newsletters, and \$75,408 for other awareness and support). We spent \$105,773 on rent, insurance, administration, office expenses. We spent \$32,455 on providing workshops for carers and disability service providers and developing video resources on Fragile X.

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 2020
- Trivia Night
- Fun runs
- Fragile X awareness events

Note 6 - Analysis of monetary figures

Ratios	\$	%
Total cost of fundraising/ Gross income from fundraising	12,840/272,620	5% (2% last year)
Net surplus from fundraising/ Gross income from fundraising	259,780/272,620	95% (98% last year)
Total costs of services/ Total expenditure	137,255/317,166	43% (50% last year)
Total costs of services/ Total income received	137,255/372,273	37% (34% 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 2020

	Note	2020	2019
Note 8 - Endowment Fund			
Balance Sheet - as at 30 June			
CURRENT ASSETS			
Cash on hand			
At Bank		10,281	4,982
Term Deposits		<u>-</u>	<u>235,000</u>
		<u>10,281</u>	<u>239,982</u>
Accounts receivable and other debtors			
Donations Receivable		-	500
Franking Refund Receivable		<u>7,295</u>	<u>6,958</u>
TOTAL CURRENT ASSETS		<u>17,576</u>	<u>247,440</u>
NON-CURRENT ASSETS			
Investments			
Listed Investments - At Market Value		419,809	365,910
Unlisted Investments - At Market Value		<u>273,360</u>	<u>75,848</u>
TOTAL NON-CURRENT ASSETS		<u>693,169</u>	<u>441,758</u>
TOTAL ASSETS		<u>710,745</u>	<u>689,198</u>
CURRENT LIABILITIES			
Accounts payable and other creditors			
Other creditors		<u>2,324</u>	<u>2,324</u>
TOTAL CURRENT LIABILITIES		<u>2,324</u>	<u>2,324</u>
NET ASSETS		<u>\$708,421</u>	<u>\$686,874</u>
EQUITY			
Opening Balance		686,874	608,731
<u>Add: Income for the Year</u>	9	<u>21,547</u>	<u>78,143</u>
TOTAL EQUITY		<u>\$708,421</u>	<u>\$686,874</u>
Total Equity Comprises:			
General Fund		429,140	412,387
J & M Cunningham Endowment		<u>279,281</u>	<u>274,487</u>
		<u>\$708,421</u>	<u>\$686,874</u>

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020

	2020	2019
Note 9 - Endowment Fund		
Income & Expenditure Statement - for the year ended 30 June		
INCOME		
Donations	9,550	52,500
Interest & Dividend Income	35,603	25,263
Increase in Market Value of Investments	-	1,044
	<u>45,153</u>	<u>78,807</u>
Less:		
Decrease in Market Value of Investments	23,593	-
Expenses	13	-
Loss on Sale of Investments	-	664
	<u>23,606</u>	<u>664</u>
NET INCOME FOR THE YEAR	<u><u>\$21,547</u></u>	<u><u>\$ 78,143</u></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>181,112</u>	<u>415,222</u>
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(b) Reconciliation of cash flow from operations with profit from ordinary activities

Operating Surplus/(Deficit)	55,157	143,536
Non-cash flows in Operating Surplus/(Deficit)		
- Depreciation	1,511	-
- (Gain)/loss on sale of investments	-	664
Changes in assets and liabilities		
- (Increase)/decrease in receivables	3,994	4,748
- (Increase)/decrease in other assets	(16,655)	20,393
- Increase/(decrease) in payables	2,135	4,160
- Increase/(decrease) in other current liabilities	(826)	(6,285)
- Increase/(decrease) in provisions	<u>2,164</u>	<u>6,966</u>
Net cash provided by operating activities	<u><u>\$47,480</u></u>	<u><u>\$174,182</u></u>

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020

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 2020 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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Find out how your organisation can partner with us in supporting the Fragile X community

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www.fragilex.org.au

HelpLine
1300 394 636 and support@fragilex.org.au

Fragile X Association of Australia Inc

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Registered Charity

