Fragile X
Association of
Australia

ANNUAL REPORT
2021-2022

FRAGILE X.ORG.AU

30 Years Strong | Supporting | Sharing | Connecting | Informing

Our Vision

People living with Fragile X are connected, included, understood & empowered to live their best possible lives

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 living with a Fragile X-associated disorder such as Fragile X syndrome, Fragile X-associated Primary Ovarian Insufficiency , Fragile X-associated Tremor Ataxia syndrome, or Fragile X Premutation Associated Conditions.

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** for people living with Fragile X and their families, carers and supporters
- **Educational webinars and other events** providing the latest on support strategies and developments
- **Uptodate information** through our website, social media and email communications
- **Referral** to services, supports, information
- **Support and discussion groups** online
- Opportunities for people to **connect with peers** online and in person
- **Increasing awareness** of Fragile X to promote early and accurate diagnosis, early intervention and appropriate treatment
- **Advocacy** on health and disability policy and other matters impacting the Fragile X community

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

Service, Respect, Accountability, Evaluation, Compliance

www.fragilex.org.au

30 Years Strong - Supporting | Sharing | Connecting | Informing

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President's Report

Year in Review

The FXAA Strategic Plan continues to guide the work of FXAA in supporting people living with Fragile X through connection, education and advocacy. I am pleased to advise that the Board has renewed the Strategic Plan for 2022-2025 (see page 12).

Supporting the FX community

Despite the continued impact of COVID-19 over the past year, and the limited chance for face-to-face events, FXAA has been able to continue to extend support to the Fragile X community in many ways. For example, the use of online platforms such as Zoom has allowed us to develop peer support groups which are facilitated by our Family Support Counsellor, Liz Jewell. The FXAA HelpLine continues to take many inquiries, by phone or email, from our member base and the public. Over the past 12-18 months we have seen an increase in inquiries around Fragile X syndrome, Fragile X-associated conditions, and genetic testing. (See "Support" on page 10 of this Report)

The FX webinar/Q&A series we initiated in mid 2021 has been very successful in delivering information and strategies for parents as well as allied health, disability service providers and educators who have a child or adult with Fragile X syndrome in their care. The webinar program has also included discussions on Fragile X-associated conditions and supports for the siblings in families. We look forward to the FX webinar series continuing to develop in the coming year. I would like to acknowledge and thank the organisations which have provided grant funding to support a number of these forums, and thank the webinar presenters for sharing their insights and expertise with the Fragile X community. The recordings of these forums have ongoing value and can be accessed on the FXAA YouTube channel.

Change of name of the FMR1 gene

As we know, Fragile X syndrome and its associated conditions are caused by changes (mutations) in the FMR1 gene which is found on the X chromosome. The FMR1 gene provides instructions for making a protein called FMRP which is important for brain development. The "MR" in FMR1 previously stood for the words "mental retardation".

From April this year MR now stands for "messenger ribonucleoprotein", meaning the FMR1 gene name is now "Fragile X Messenger Ribonucleoprotein". The change was initiated by the European Fragile X Network (EFXN) and was accepted by the international HUGO Gene Nomenclature Committee, the organisation that officially decides on the naming and classification of genes. The efforts of the EFXN, which consists of seventeen national Fragile X associations in Europe, have led this important move away from stigmatising language around disability. The change of name for the FMR1 gene has been enthusiastically accepted by all that deal with Fragile X.

Important developments in testing and screening

Following years of advocacy, reproductive genetic carrier testing for the three conditions, Fragile X, Cystic Fibrosis, and Spinal Muscular Atrophy, will now be on the Medicare Benefits Schedule from November of 2023. The announcement was made in March 2022 by Hon Greg Hunt MP (Health Minister at that time). The work of the Mackenzie's Mission research program, which adds screening for some 700 other inherited conditions, has been moving towards this type of expanded reproductive carrier testing in the future. In addition, the intention of the Federal Government is to review and expand the number of conditions included in the newborn screening "heel prick" test. FXAA has been involved in the consultation processes with the aim of considering having Fragile X added to the test. FXAA has also been working with our Scientific, Clinical and Research Committee in proposing guidelines for Fragile X testing to ensure a consistency of approach.

Thanks go to FXAA's supporters

The Board and I sincerely thank the Cunningham family for their ongoing and generous support of this organisation over many years.

We also wish to thank Victorian Clinical Genetics Services and the GOLD Service (NSW Health) for their contribution to the work of FXAA and their excellent support for individuals and families affected by Fragile X. Sincere thanks to the many dedicated volunteers who provide their time, talents and enthusiasm in helping us to raise awareness of Fragile X, to advocate for change and to educate the wider community.

I also wish to personally thank the members of FXAA's Board, past and present, who dedicate time and energy to their roles, and thank our staff Wendy Bruce and Liz Jewell for their commitment.

Future developments

It is FXAA's hope and expectation that developments in testing and screening will lead to earlier diagnosis and earlier treatments for Fragile X syndrome and FX-associated conditions. It is also our hope and expectation that the current and future focus of clinical trials will yield some treatments which will be effective for symptoms of Fragile X syndrome, including anxiety, behaviour regulation and potentially cognition. I have written more about this on page 12 of this Report.

Finally, I would like to say that it has been a privilege and a pleasure to serve as President of FXAA over the past 4 years. I will continue to serve the organisation alongside my fellow Board members for a further term and look forward to the work we do together.

Best wishes,

W Ted Brown

Our Team

Board 2021—2022

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.

Cynthia Roberts PhD, Secretary
Cynthia has a background in genetic research as well as running a clinical cytogentetics 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. Cynthia lives in NSW and joined the Board in 2020

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.

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 joined the Board in 2016 and was very active in raising funds and awareness for Fragile X through elite sports events. Mike retired from the Board in March 2022.

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 represents FXAA on the International Fragile X Premutation Registry management committee and at educational events for health professionals. Karen lives in Sydney and joined the Board in 2019.

Mandy Barker, Director
Mandy is a freelance social media manager and virtual assistant. Her son and daughter have Fragile X syndrome. Mandy is a keen advocate for awareness of Fragile X and intellectual disability in the broader community, for earlier diagnosis by GPs & other medical professionals, for the availability of broader genetic screening, and inclusivity in everyday life. Mandy lives in Brisbane and joined the Board in 2021.

Belinda D'Amico, Director
Belinda is a registered Chartered Accountant (currently not practising) and has two young sons with Fragile X syndrome. Belinda has commenced an Occupational Therapy degree as she wants to help her sons and other families on the Fragile X journey. She is extremely passionate about raising awareness of Fragile X and keen to support the community. Belinda lives in Sydney, and joined the Board in 2021.

Staff

Wendy Bruce *Executive Director (fulltime)*
Wendy joined FXAA in 2013.

Liz Jewell *Family Support Counsellor (3.5 days/week)*
Liz joined FXAA in 2018.

Year in Review 2021—2022

FXAA's work in 2022 has been in line with the framework provided by **FXAA's Strategic Plan 2022-2025** and the four pillars of focus: Support & connection; Empowerment; Advocacy; Education.

Highlights of the year include the delivery of our FX Webinar Series, expansion of online counselling and peer support provided to our members, resumption of face-to-face events in the health and disability sectors, some progress in public policy, World Fragile X Day and fabulous fundraising events.

Advocacy

FXAA engages in systemic advocacy with the aim of influencing positive long-term change on health and disability matters affecting the Fragile X community at large.
For example: Fragile X testing and diagnosis, access to treatments and services, education of health and disability support professionals. Our Executive Director and Board members represent the Fragile X community in our contribution to consultation processes. FXAA positions itself alongside a range of peak bodies and other organisations with similar areas of focus and approach to achieve shared outcomes. These include Council for Intellectual Disability, 3DN (Department of Developmental Disability Neuropsychiatry) UNSW, Rare Voices Australia, Inclusion Australia, and Children and Young People with Disability Australia.

Reproductive Genetic Carrier Testing – cost reimbursement

In October 2021 the Federal Government announced that, from 1 November 2021, people will be able to claim a Medicare rebate for five new Medicare Benefits Schedule (MBS) items for new Pre-implantation Genetic Testing (PGT) services provided within the existing IVF process, where the testing covers genetic disorders including cystic fibrosis (CF), muscular dystrophy, spinal muscular atrophy (SMA), Fragile X syndrome (FXS).
This announcement was more than 10 years in the making. FXAA, through our current Board member Cynthia Roberts, was involved in the earliest stages of advocating for this change to MBS reimbursement processes – the goal was to make the cost of PGT testing more accessible to individuals who have an increased chance of having a child with one of these conditions.

For a number of years FXAA has worked alongside *SMA Australia*, *Cystic Fibrosis Community Care* and *Victorian Clinical Genetics Services* (VCGS) as a *Carrier Screening Reference Group*.
The aim of this Reference Group has been to profile reproductive genetic carrier testing as an option for people considering or in the early stages of pregnancy and to advocate for public funding of the testing. The Group welcomed the announcement in March 2022 by Hon Greg Hunt MP (Federal Health Minister at that time) that genetic carrier testing for FXS, CF and SMA will be reimbursed through the Medicare Benefits Schedule (MBS) from 1 November 2023, thereby ensuring more equitable access to this testing.
As 1 in 20 people carry the gene change for FXS, CF or SMA, this was a significant health policy announcement.

FXAA also serves as a member of the *Mackenzie's Mission Reference Group.* Mackenzie's Mission is a Federal Government-funded pilot program which over a 3-year period to 2022 tested over 9,000 couples for approximately 1300 genes responsible for over 700 conditions. Anticipated outcomes of the Mackenzie's Mission study include MBS reimbursement of (expanded) carrier screening for multiple serious conditions and access to IVF/PGT for couples at risk of having an affected child. In August 2021 and May 2022 FXAA and other representative groups engaged in a public consultation process on a proposal which, in connection with Mackenzie's Mission, had been submitted to the Medical Services Advisory Committee (MSAC) calling for MBS reimbursement of expanded reproductive carrier testing.
The proposal has been under consideration by MSAC and will be re-submitted for their further consideration.

Testing for Fragile X

FXAA continues to be aware of inconsistencies in approach by clinicians and genetic services in **testing for the Fragile X premutation or Fragile X syndrome**, where testing has been requested by an individual or a parent. FXAA's Fragile X Scientific Clinical & Research Committee will draft consensus testing guidelines for FXAA to submit to the relevant genetics and other bodies with the aim of ensuring consistency of approach to early and accurate diagnosis of Fragile X disorders.

The **newborn bloodspot screening** (NBS) test offered by state healthcare providers for all babies born in Australia identifies babies at risk of becoming seriously ill from a rare condition, such as CF, SMA and others. The screening aims to improve the health of these babies by allowing early intervention/treatments. NBS does not currently include a test for Fragile X syndrome. The Federal Government has recently committed $39.0 million over four years to expand the NBS testing to include more conditions and ensure consistency of programs across Australia. A consultation process to identify the range of issues to be considered in implementing an expansion of the program has commenced. In advocating for Fragile X syndrome to be considered for the expanded NBS testing program FXAA has had discussions with the Health Department and will engage in the public consultation processes over the coming months.

Genetic Counselling - cost reimbursement

Genetic counselling services provide critical information and support for individuals seeking/receiving a diagnosis of a genetic condition as well as those individuals who have an increased chance of having a child with a serious genetic condition.
In May 2021 FXAA supported an application to MSAC by the Genetic Counsellors Special Interest Group of the Human Genetics Society of Australasia, to open a dialogue about Medicare Provider numbers for genetic counsellors, and MBS item numbers for services provided by genetic counsellors. Since then, in July and October 2022, FXAA has contributed to both targeted and open (public) consultation processes around the proposal. The Genetic Counselling Working Group of the Medicare Benefits Schedule Review Advisory Committee will make a recommendation on these matters to government in the coming months.

Intellectual Disability Health

FXAA supports the work of Prof Julian Trollor from UNSW and Council for Intellectual Disability in advocating for improvements to healthcare for people living with intellectual disability, and we were delighted with the recent Federal Government announcement of $23.9 million in funding to establish a permanent *National Centre of Excellence in Intellectual Disability Health*. The Centre will provide for the delivery of the National Roadmap for Improving the Health of People with Intellectual Disability, bringing together experts, resources and research.

NDIS

FXAA has a Board member as representative on a Rare Voices Australia NDIS Roundtable. The group meets regularly for discussion with NDIA representatives on policy and NDIS implementation matters in relation to individuals who are living with a rare condition. This is an opportunity to provide feedback to NDIA on the experience of the Fragile X community in engaging with the NDIS.

Genomics and Disability

FXAA is very pleased to continue representing Rare Voices Australia on an advisory panel for a University of Queensland research project on social and ethical dialogue on genomics and disability. The project is named *We Need to Talk: Genomics and Disability*, is funded by the Medical Research Future Fund and will continue through 2023.

Education

Health Professional Education

The impact of COVID-19-related restrictions on face-to-face professional development opportunities continued throughout much of 2021-2022. Many health education providers transitioned to digital-only delivery of education, and some others offered hybrid options. While FXAA participated in several virtual events for health clinicians, we felt that a virtual presence offered limited capacity to engage the participants and we did not pursue that mode of event.

The face-to-face *Healthed education days* for general practitioners resumed from June 2022 and we were pleased to resume the opportunity kindly provided by Dr Manocha to have a FX presence at these events at no cost. We arranged to have FX / Carrier Screening information tables in Brisbane, Sydney, Perth, Melbourne and Adelaide from June – September 2022.
Our focus was on what GPs need to know about genetic carrier screening for FX, CF and SMA, in readiness for a new Medicare item for this testing (commencing November 2023).
Representatives on our tables at these events included our Executive Director Wendy Bruce, board members Prof Ted Brown and Karen Lipworth, FXAA members, supported by genetic counsellors from the Victorian Clinical Genetics Services team.
Many thanks to Cystic Fibrosis Community Care for sharing the costs associated with printed and other materials for our tables.
We anticipate the Healthed face-to-face education days continuing in 2023, and we're exploring opportunities for FX/carrier screening presence at other professional development events for GPs in 2023.

FXAA also had a strong presence at a major developmental and behavioural paediatrics conference in Sydney, in August 2022. A/Prof Helen (Honey) Heussler delivered a presentation on Fragile X disorders, and we had a Fragile X exhibition table attended by Prof Ted Brown and our Executive Director. It was an important opportunity to engage with paediatricians, as they are at the forefront of recognising red flags around developmental milestones, arranging testing for Fragile X syndrome, and providing care.

Our Family Support Counsellor Liz Jewell presents at the annual VCGS Fragile X workshops for Genetic Counselling/Genomics and Health students, is an annual guest presenter at the UTS Master of Genetic Counselling "Meet the experts" series and has contributed to a UNSW online learning program for medical students, doctors and health service managers on the value of patient support organisations to families.

In April 2022 Dr Amanda Vincent presented a webinar on Fragile X-associated Primary Ovarian Insufficiency. As a direct followon to the webinar, Dr Vincent prepared a FXPOI Fact Sheet for clinicians for the Australasian Menopause Society website. Dr Vincent also arranged to have a FXPOI Fact Sheet for people living with or at risk of FXPOI added to the ASK Menopause app developed by Dr Vincent and her team at Monash Health.

There is a clear need for professional development material on Fragile X syndrome for allied health professionals such as speech pathologists and occupational therapists. We are in discussion with Speech Pathology Australia about the development of an online on-demand educational module which would be available on the SPA education portal for speech pathologists on a pay-to-use basis.

Disability Expos

Disability Expos have proven to be a valuable way to engage with disability service providers and allied health professionals about supports for clients with Fragile X syndrome, and to offer resources and referrals. Expos are also an excellent way to catch up with the families in our community! Disability Expos also experienced a COVID-19 -related "pause" for much of calendar years 2020 and 2021, but most resumed late in 2021. Our Family Support Counsellor Liz Jewell has attended Disability Expos run by Social Impact Institute and SourceKids in Brisbane, Canberra, Melbourne and Sydney over the past 12 months. Many thanks to the FXAA members who assisted on our booths at these events.

Fragile X Workshop Perth

In March 2022 Dr Jonathan Cohen from the Fragile X Alliance Clinic delivered two presentations for FXAA in Perth, to an audience of family members, carers and allied health professionals. The presentations covered Fragile X syndrome and Fragile X-associated conditions. This was the first FX workshop in Perth organised by FXAA for some years. Many thanks to *ConnectGroups*, a WA not-for-profit organisation, for providing a grant to cover the venue hire for the workshop. Dr Cohen also provided clinical consultation to several FXAA member families.

Webinar Series

Since mid-2021 we have delivered regular Zoom-based webinars with a live Q&A component to our member base and the wider community. In many parts of Australia, knowledge and expertise in Fragile X is limited and difficult to access. By offering high value, unique and targeted educational content delivered by subject matter specialists to anyone who has online access, the *FX Webinar Series* has become an important component in optimal care and outcomes for people living with Fragile X disorders. Recording of these forums ensures access regardless of the time zone differences which present a barrier to cross-state/territory live delivery or connection. The recordings also form a permanent knowledge base and are captioned to promote accessibility of the content.

To date, the series has delivered 21 webinars (13 during the 2021/22 financial year) encompassing a range of topics. *Dr Marcia Braden* has presented several webinars, discussing the neurobiology of Fragile X syndrome and strategies for managing the anxiety and the behaviours associated with Fragile X syndrome. Dr Braden also presented a dedicated discussion on the challenges faced by females living with Fragile X syndrome and effective supports that help mitigate the challenges. *Dr Jonathan Cohen* has presented on health issues for adults who have Fragile X syndrome and provided an overview of medications for conditions associated with the syndrome. In December 2021 *Dr Randi Hagerman* gave a detailed presentation on the Fragile X premutation. Allied health professionals *Bev Sher* and *Bev Kadish* outlined strategies for helping children and adults with Fragile X syndrome cope with the disruptions to daily living which resulted from COVID-19, discussed sensory processing issues associated with Fragile X, and outlined strategies for supporting communication for people with high level verbals skills and those less verbal. *Prof Amanda Vincent* from Monash Health presented a detailed discussion of the causes and impact of Fragile X-associated Primary Ovarian Insufficiency and strategies for maintaining health and wellbeing. IVF specialist *Dr Mark Livingstone* gave an overview of Pre-Implantation Genetic Testing for women with pre or full mutation of Fragile X, who may be considering PGT as a reproductive option. *Kate Strohm,* the founder of Siblings Australia, presented three discussions on supporting siblings of people who are living with Fragile X syndrome.

Subscribers to the webinars include Fragile X family members, carers, allied health professionals, disability support providers, educators, genetic counsellors and other professionals. The capacity for each webinar is capped at 100, and registration numbers vary according to the topic.

To date webinar recordings have had a combined total of 10,000 views across our YouTube channel and Facebook page. While the majority of people who join the webinars live are viewing from Australia, the recordings are viewed later by people from a range of jurisdictions including the US, UK, New Zealand, Canada and India. The audio recordings of several webinars are now podcasts on Spotify and iTunes.

To date 50% of the webinars in our series have been supported by grant funding and/or a pro bono speaker. Many thanks to the *Qantas Foundation Side by Side Grant*, *Pine Property*, *Genea*, *Australasian Menopause Society* and *Zynerba Pharmaceuticals* for supporting the FX webinar series.

Having now built a core "library" of recordings on fundamental topics, on Fragile X syndrome in particular, the FX Webinar Series will continue to deliver new material and include a discussion forum approach in 2023.

Fundraising and Donations

Highlights in 2021-2022: Bridge to Beach race, FX Trivia Night, Ellinbank Football & Netball Club Raffle, Caloundra Community Walk.

The ongoing financial support from our members and the wider community is critical to FXAA's capacity to fulfil our mission to support people living with Fragile X to live their best possible lives through connection, education and advocacy. [Refer to FXAA's *Strategic Plan 2022-2025*, page 12)

In 2021-2022 $43,698 was raised through individual and community fundraising efforts, both in person and online. Many thanks are due to the individuals and organisations who make this financial contribution to FXAA.

Since 2014 FXAA has been charity partner for the annual **Bridge to Beach** ocean paddling race across Sydney Harbour. Each year around 400 paddlers tackle the 11km trek from near the base of the Harbour Bridge, across to Manly Cove. This year the support from the paddlers, and race sponsor *Shaw and Partners Financial Services,* was outstanding - close to $22,000 was raised all up. FXAA member Ross MacKenzie was thrilled to accept the "big cheque" on live TV alongside our Counsellor Liz Jewell. (see page 20). In 2023 we will celebrate the 10th anniversary of FXAA's *Bridge to Beach* charity partnership with *Oceanpaddler*, the Manly-based business operating the Australian Ocean Racing Series. Many thanks to Dean Gardiner, elite level ocean sportsman and founder of *Oceanpaddler,* and to Shaw and Partners for this longstanding support.

Once again, the **Ellinbank Football and Netball Club** in SE Victoria ran a special Fragile X awareness and fundraising event in July - with a FX raffle and dedicated football and netball games. This annual focus on Fragile X awareness is in honour of young Cal Wallace, who this year led the senior football team – all wearing orange socks! - onto the ground. The Raffle was a great success, raising $6,817 for FXAA's family support and counselling service. Many thanks to the Club for their support.

In March 2022 a **FX Trivia Night** in Sydney, organised by FXAA Board member Belinda D'Amico, raised $23,000 to help fund the support provided by FXAA to the Fragile X community. It was a well-attended event, with raffles, silent auctions, hand-made jewellery for sale, and lots of fun had by all! Many thanks to Belinda and Jason, and Jason's extremely generous workmates, for making this such a successful and awesome event.

The **Caloundra Community Walk for Fragile X** was a marvellous community event in honour of Oden White and his family. Organised by Cherie Goodwin from Caloundra City Realty, the event saw around 100 people taking part – thankful that the torrential rain had stopped for a while, and many dressed in vibrant orange! Shoutout to the wonderful supportive community in Caloundra for getting behind Fragile X.

FXAA is also charity partner for the annual **Ballarat Dance Awards** competition in Victoria. The event comprises masterclasses, scholarship opportunities and performance. The final day of competition is a fundraiser for Fragile X, in honour of Jimmy Jones. Many thanks to Anita Coutts and Versatility Dance College for their support each January.

Many thanks to community groups Lion's Club Wonthaggi, Rotary Club Galston, and Country Women's Association in Shepparton for their donations during the year. Thanks are due to the Sydney northern beaches branches of CBA for once again including FXAA in their Community Grant program.

Sydney's annual *City to Surf* fun run/walk returned in 2022 year after a COVID-19 induced break. In August, Team FX, led by our Board member Cynthia Roberts, raised around $9,000!

Grants

Educational grants to FXAA from *Zynerba Pharmaceuticals* have supported four webinars in our series. The first webinar, in July 2021, was *Fragile X syndrome: Clinical Trials in Australia*, and three webinars will be presented by Dr Marcia Braden on behaviours and learning in Fragile X before the end of calendar year 2022.
A grant from Manly-based *Pine Property*, through a real estate foundation, supported Dr Braden's webinar on Understanding Anxiety in Fragile X syndrome in November 2021.

Qantas Side by Side Grant Program funds received by FXAA in 2019 were not fully acquitted in 2020 as planned, due to COVID-19 impacts. Instead, the remainder of the Qantas Side by Side Grant funds were utilised in the 2022 financial year. The funds supported four webinars in our series, the final production of six short videos on specific topics by Dr Braden, and the publication of the recording of Dr Braden's workshops in Melbourne from the previous financial year.

A $20,000 *Social Sector Transformation Fund* grant from the NSW Department of Community and Justice, received in the 2021 financial year to "build organisational capacity for remote and flexible working", was fully expended in FY2022 to implement new FXAA office IT infrastructure, equipment, services and provide social media skills training for our staff.

A small grant from *Melbourne Disability Institute* (University of Melbourne) has provided for the time of a researcher to explore the uptake and effectiveness of our virtual support and education activities. As part of the study 16 FXAA members have been interviewed. The outcomes of the research, and a publication, will be completed in early 2023.

After the close of the 2022 financial year FXAA was privileged to receive a grant from the *Cecilia Kilkeary Foundation*. The grant will part-fund the Family Support Counsellor role for 2022-2023. Many thanks to the Foundation for this support.

FX Awareness

So many of our members and their friends and families are involved in promoting awareness of Fragile X in many arenas, and in many diverse ways. Whether it be getting involved in challenges, speaking to the media about Fragile X, meeting up with a Federal or State government representative to talk about Fragile X, giving time on FX booths at Disability Expos to talk to service providers and members of the public, giving time to speak with GPs at medical conferences about FX and carrier testing, wearing the FX logo on runs or fundraising events, appearing in our FX videos, or getting together to celebrate the annual "light up" for Fragile X… All of this contribution goes such a long way to increasing awareness and understanding of Fragile X in its various forms. So, THANK YOU to everyone!

World Fragile X Day

A highlight in the Fragile X awareness calendar every year is 22 July – designated in Australia and some other countries as World Fragile X Day. In Australia the goal of World Fragile X Day is to celebrate individuals living with Fragile X, raise awareness of Fragile X and highlight progress of research for Fragile X syndrome. We were delighted to join with the *FRAXA Research Foundation* team in the US and FX organisations around the world to illuminate close to 400 landmarks for the common goal of increasing awareness.

FRAXA organised another global webinar on 22 July, called *Fragile X syndrome: Innovative Approaches to Finding a Cure* and which had 30 distinguished speakers. FXAA was involved in the webinar through our Executive Director Wendy Bruce interviewing Prof Jeannie Lee from Harvard Medical School around her research work in a new methodology to reactivate the FMR1 gene in Fragile X syndrome and future therapies.
The webinar recording is available online: https://wxpress.wuxiapptec.com/events/fragile-x-syndrome-innovative-approaches-to-finding-a-cure/

Australia Lights up for Fragile X

The 7th "light up for Fragile X" campaign saw close to 80 significant landmarks across Australia illuminate orange to celebrate on the night of 22 July. We were thrilled to have the iconic MCG in Melbourne, the Dome of the Garvan Institute of Medical Research in Sydney, Shine Dome at the Academy of Science and the National Museum in Canberra – among others - join us for the first time!

Very much a grass roots effort, the "light up" campaign was initiated in Brisbane in 2015 by Nyleta McRae, who is a parent of children living with Fragile X syndrome.

The "light up" grows year on year, tremendously well supported by organisations and infrastructure operators across the private and public sectors.

World Fragile X Day and the illumination of buildings generated some great regional media coverage in Tasmania, WA, Victoria, Queensland and New South Wales – with Harry and Tommy Colgrave in Launceston playing a star role this year!
Board member Cynthia Roberts was interviewed on ABC Radio National in the morning prime time on 22 July and Nyleta McRae was on ABC Radio in an A-Z of the Human Body segment for the "X" chromosome instalment.

Other outcomes included increased social media reach and engagement in July, public re-posting of FXAA images, families taking photos of the light up, media contact / campaign confirmation. FXAA Facebook posts had a reach of 40,000 people (1,000% increase) and 1,300 page visits (increase 695%).
On Instagram FXAA posts reached 1,617 accounts (175% increase), with an increase in followers and a 600% increase in profile visits 725 (610% increase) to our account. We also noted a 30% increase in our website traffic through July.

Many thanks to Hon Bridget Archer MP, Liberal Member for Bass, for making a short speech in Parliament following World Fragile X Day, noting the significance of community supports for people living with Fragile X, and the value of awareness events.
Mrs Archer also acknowledged the work underway – and the work still needed - to ensure early diagnosis and treatments.

Many thanks also to Kieran "Spud" Murphy for producing a Fragile X awareness day Light up for Fragile X video, and to former Deputy Mayor of Manly Candy Bingham, and the Lindsay family for featuring in the video, which was shared widely on our social media!

Membership of FXAA

At November 2022 FXAA has a member base of 565, the majority of whom are individuals or family members impacted by Fragile X. This is an increase of 7% over November 2021.

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 years. Central to FXAA's commitment to members is that appropriate information and support is offered in a timely manner.

Networks

FXAA works closely with a range of organisations dedicated to supporting the Fragile X community as well as organisations which focus on rare genetic conditions, health 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 support the annual *World Fragile X Day* alongside FRAXA Foundation and FX family support groups in other countries.

We are an early partner of the *International Fragile X Premutation Registry.*

We greatly value the support of *Fragile X Alliance* in Melbourne, *Victorian Clinical Genetics Services* and the *GOLD Service* (Genetics of Learning Disability) NSW Health for supporting our members with information and referrals.

FXAA supports and contributes to the advocacy of a number of peak bodies and groups including *Council for Intellectual Disability*, *3DN* at UNSW, *Inclusion Australia*, *Children and Young People with Disability (CYDA)* 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 Hessl 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.

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.
We encourage everyone in the Fragile X community to consider enrolling in the Registry and we will be promoting the potential benefits and outcomes of the Registry further in 2023.

Clinical Trials

In 2021 Zynerba Pharmaceuticals initiated RECONNECT, a pivotal phase 3 trial. The RECONNECT study 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 still recruiting participants aged 3-17 years who have Fragile X syndrome and behavioural problems through sites internationally, including Australia, to the end of first quarter 2023. The current local sites are in Brisbane, Melbourne and Sydney.

While it is has been encouraging to observe interest in the establishment of additional clinical trials in Australia for potential treatments for symptoms of Fragile X syndrome, not all expressions of interest have come to fruition as a trial.
It is the case that clinical trial activity is increasing in the US and there may be some possibility of extension to Australia in time.

Support

The FX HelpLine is available 5 days per week, 9-5pm, staffed by our Family Support Counsellor and Executive Director. Our Family Support Counsellor is employed 3.5 days per week.

Initial inquiries to FXAA for information or support are served by our two staff. We aim to respond to Helpline inquiries within a 48-hour timeframe, although response is typically same-day. Inquiries are frequently multi-staged, progressing from HelpLine through to support. The flexibility of contacting FXAA via different platforms, whether that be phone, website, email or messenger, means inquires can be made outside of office hours and according to an inquirers' preferred mode of communication. Over the past 12 months we have seen a notable increase in the number of direct inquiries made by email rather than phone, which may be related to reduced phone access to the FXAA office with staff working from home during COVID-19 restrictions.

In 2021-22 approximately 200 HelpLine contacts were responded to and the staff had more than 500 occasions of contact with our members, an increase over the previous year of 25% and 33% respectively. Our Family Support Counsellor conducted 490 occasions of counselling (400 in 2021) for 95 of our members, facilitated 75 small-group peer support meetings (60 in 2021), and undertook 40 new member onboarding calls (35 in 2021). Our staff interact with FXAA members on a daily basis in our online forums, or by phone, email or messenger.

The increased number of HelpLine queries, Counselling and peer support contacts over the previous year was in part due to the resumption of testing, screening and clinical appointments, and as schools and support returned to normal practices post-COVID-19. In addition, allied health workforce shortages led to a greater number than usual inquiries from families and caregivers seeking referrals for practitioners. As COVID-19 restrictions eased, families sought support from FXAA for individuals (particularly males with Fragile X syndrome) returning to work, school or programs. Lifting of COVID-19 restrictions allowed our Family Support Counsellor to resume some face-to-face counselling or visits to families or some of our members in group home environments.

Fragile X-specific support continues to be a valued service, as indicated by the increased utilisation of the Counsellor over the past 4 years for counselling, general support and facilitated peer connections. The Counsellor is guided by any recent developments in health and disabililty and refers to the specialist knowledge available to us through experts and other organisations.

FX HELPLINE Inquiries received through the HelpLine are diverse, across multiple aspects of Fragile X-disorders, and often complex. Inquiries are made by individuals and organisations; members of the FXAA community and their families; disability service providers; educators; allied health professionals supporting children or adults; students; and the general public. The majority of inquiries centre around information on supports for individuals who have Fragile X syndrome, with a growing number of inquiries related to Fragile X premutation-associated matters.

As in previous years, inquiries around Fragile X syndrome include: behavioural and educational supports in a range of settings for children or adults; the cost and availability of testing; referrals to medical or allied health professionals with expertise; referrals to services; queries around NDIS access or funding; supports for young or adult siblings who have a brother or sister with Fragile X; access to clinical trials.

Inquiries related to Fragile X premutation continue to centre on diagnosis and support for associated health issues, ie FXTAS, FXPOI, FXPAC. Inquirers are seeking medical, allied health service or genetic testing referrals, or information about diagnosis and supports. We receive a growing number of queries about genetic carrier testing/test results or reproductive options for premutation carriers.

In 2021-22 we continued to receive enquiries about any risks which might be associated with COVID-19 vaccination for people who are Fragile X premutation or have Fragile X syndrome.

COUNSELLING is delivered by our Family Support Counsellor via phone, face-to-face via Zoom, in person or online (email and messenger). The regularity of counselling sessions has increased as FXAA's relationship with families strengthens over time and members become more aware of the opportunity to engage in conversation and of the availability of counselling. The model of counselling is tailored to suit the individual's need and address the presenting issue/s. There has been a wide range of presenting issues over the course of the year for family members, caregivers and individuals with Fragile X syndrome including: recent diagnosis, personal and workplace relationships, behavioural concerns, anxiety, intimacy, grief and loss, and mental health. Appropriate referrals are made when necessary and are beyond the scope of the counselling role.

PEER SUPPORT forums help alleviate the isolation experienced by many living remotely or through their lived experience, without having to physically leave the comfort of their home.

Peer Support group sessions via Zoom are facilitated by our Counsellor and continue to be a valuable and well-utilised forum for individuals to connect and share experiences with their peers Australia-wide. The frequency of sessions and the range of targeted groups and topics continues to grow and diversify. Existing groups continued, such as those with parents of young males or females with Fragile X syndrome. New facilitated discussion groups have formed around specific topics such as accommodation options, and transitioning to High School. There are also groups for individuals with FXTAS and for carers of individuals with FXTAS. The peer groups are intentionally small in numbers and with a short duration. The Counsellor's presence and role ensures a safe and supportive environment is maintained. The online support group established for fathers of children with Fragile X syndrome continues to convene one evening each month via Zoom and has provided a welcome forum for Dads from different parts of the country to share their experiences.

ONLINE DISCUSSION FORUMS

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 Australian Facebook discussion group currently has 1,000 members. 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.

CLINICS FXAA continues to refer member families to clinics, where available, including the Fragile X Alliance Clinic in Melbourne, which has developed a strong telehealth model and has provided consultations to individuals and families across Australia. In Sydney Dr Jane Law, a general practitioner with a special focus on intellectual disability, offers clinic appointments for adults with Fragile X syndrome twice a year at the FXAA premises. FXAA also refers people to the Movement Disorders Clinic at St Vincent's Hospital (A/Prof Stephen Tisch and Dr James Peters) in relation to FXTAS.

TRENDS

The increase in the number of new referrals from families with younger age children (under 4 years of age) continues to grow. There is an increasing focus by parents of adults who have Fragile X syndrome on future planning, creating life plans, accommodation options, employment supports, guardianship, acceptance within the community.

Support workers providing one-on-one support or residential staff in Supporting Living Accommodation facilities have actively sought out information and direction from FXAA in order to increase their knowledge and understanding of how to best support an individual with Fragile X syndrome. Similarly, educators and teaching support staff have reached out to FXAA for information resources when a student with Fragile X syndrome is in attendance. Our Family Support Counsellor has capacity to present at staff development or team meetings (live or via Zoom), and follow up with a variety of resources from our specialist library of webinars, links and videos on specific topics.

Canberra Disability Expo– *Family Support Counsellor Liz Jewell* and awesome volunteers!

Dashboard 2021 - 2022

MEMBERS: **565 members of Fragile X Association of Australia**

SUPPORT: **200 HelpLine** contacts **75 peer support** sessions **490 counselling** occasions

WEBSITE: **21,350** visitors to our **website** and **60,857 pages viewed** 62% visitors from Australia

FACEBOOK PEER SUPPORT: **1000** people belong to our **Facebook discussion groups**

SOCIAL MEDIA: **Facebook** 4,169 **Instagram** 1,380 **Twitter** 1,045 **LinkedIn** 245 followers

VIDEO VIEWS: **20,900** views **YouTube** and **2,700** views **Facebook** (top views: **Understanding FX**)

FX WEBINAR/Q & A SERIES : **13** webinars **805 attendees** registered

EVENT PARTICIPATION: presence at **2 health seminars** and **5 disability expos**

Future Developments in Clinical Trials for Fragile X syndrome

It is FXAA's hope and expectation that the current and future focus of clinical trials will yield some treatments which will be effective for symptoms of Fragile X syndrome, including anxiety, behaviour regulation and potentially cognition. The Zynerba RECONNECT study is underway in Australia and the US to evaluate the efficacy of Zygel in children and adolescents with FXS. Zygel, their transdermal gel, is the first and only pharmaceutically-produced cannabidiol, a non-euphoric cannabinoid, which is a major component of marijuana. This is a follow-up study to their previously completed CONNECT-FX, a randomized, double-blind, placebo-controlled Phase 3 trial.
That trial demonstrated significant improvements in both Social Avoidance and Irritability tests in subjects with complete methylation of their FMR1 gene. Because the observed areas of improvement found only in fully methylated subjects were not the primary outcome of that trial, the FDA requested this follow-up trial before granting approval for marketing. Zygel is a unique permeation-enhanced cannabidiol transdermal gel. Transdermal therapeutics are applied locally and absorbed through the skin directly into the systemic circulation, resulting in a lower incidence of gastrointestinal side effects, and avoidance of first-pass liver metabolism, which potentially enables lower dosage levels of active pharmaceutical ingredients and rapid, reliable absorption with increased bioavailability. Other potential benefits of transdermal delivery compared with oral administration may include fewer drug-drug interactions.

The Tetra Pharmaceutical company is testing BPN14770 in the US and is planning to expand the testing to Australia. A small pilot trial showed safety and improved cognition, which has led to this ongoing larger trial. BPN1477 inhibits the activity of an enzyme known as phosphodiesterase-4D (PDE4D), which controls the availability in the brain of cyclic adenosine monophosphate (cAMP), a molecule that is critically involved in memory formation. By inhibiting PDE4D, the drug increases the levels of cAMP in the brain. Levels of cAMP are reduced in fragile X patients.
By boosting them, BPN14770 may help promote nerve cell connections and improve cognitive function in fragile X patients. The results, if they're in agreement with the previous trial, will support Tetra's application for approval of BPN14770 with the FDA.

Planned studies from two other drug companies, Actinogen and Healx, have been put on hold for the present time but may be resumed in the future. We are expecting to soon hear the results of a trial of Metformin that Dr Randi Hagerman and Canadian colleagues have been conducting and which has shown promise in earlier studies. A drug that the Anavex company is testing in Rett syndrome, and Alzheimer's disease also has shown promise in animal preclinical studies for fragile X. Their drug ANAVEX®2-73 (blarcamesine) activates the sigma-1 receptor (SIGMAR1). Data suggests that activation of SIGMAR1 results in the restoration of homeostatic function and is pivotal to restoring neural cell balance and the promotion of neuroplasticity. Recently the FDA has granted Orphan Drug Designation (ODD) to their drug ANAVEX®2-73 for the treatment of Fragile X syndrome. So, trials in Fragile X syndrome are anticipated to begin shortly.

Strategic Plan 2022—2025

FXAA's **Strategic Plan** will take the organisation forward from 2022 through 2025 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; working towards informing health and other professionals around diagnosis and supports for Fragile X-associated disorders; and FXAA's systemic advocacy in health, disability and other areas impacting the Fragile X community. The *Strategic Plan 2022-2025* will also inform future directions.

STRATEGIC PLAN
2022 - 2025

VISION
People living with Fragile X are connected, included, understood & empowered to live their best possible lives

MISSION
Support people living with FX to live their best possible lives through connection, education and advocacy

VALUES
Supporting, sharing, connecting, informing

Support & connection	*Provide support to people living with FX and facilitate connections*	• Support the wellbeing of individuals and families • Facilitate peer support and connections • Facilitate access to services and supports
Empowerment	*Provide information and education for people living with Fragile X*	• Increase understanding and knowledge of Fragile X conditions and their impacts • Increase understanding of interventions, management and research • Increase knowledge and skills to navigate the NDIS and other services
Advocacy	*Be a strong voice for Fragile X, influence public policy and advocate for research*	• Increase awareness of Fragile X with government, professionals and the broader community • Effect public policy change and advocate for improvements in diagnosis, management and supports • Promote research and facilitate opportunities for engagement
Education	*Educate health professionals, educators and service providers*	• Increase Fragile X knowledge and expertise in health professionals • Increase educators' understanding of Fragile X and learning • Increase service providers' understanding of Fragile X

Financial Overview

FXAA continues to be well-resourced to provide support to individuals affected by Fragile X-associated conditions (including our member base) through counselling and facilitating clinics, to promote awareness and education about Fragile X, and to advocate for our community. There has been a return to face-to-face events and conferences, in addition to the excellent range of webinars.

FXAA started the year in a solid financial position due the generosity of key donors such as the Cunningham family, donations from the community, fundraising, and the efforts of the Board and Executive in prior years. This year we have had a small net profit of $12,228.

The work of FXAA is supported by the many volunteers who give their time and expertise to support our initiatives, and by the members who give their invaluable professional services and guidance pro bono, including Bruce Donald AM, Martin Davey, and John Kelleher.

- Financial resources

At 30 June 2022, net assets of $998,294 largely (76%) comprised the Endowment Fund (see next page) net assets of $760,746.
Net assets decreased by 6% due to a decline in market value of the Endowment Fund investments.

- Operating Result

Income ($331,852, down 14% 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 FY2022 the Cunningham family increased their generous support of FXAA 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 down 3% versus last year. Income from fundraising and appeals increased by 46% over the previous year, with a total of $43,698 raised. FXAA continued as charity partner for the Oceanpaddler *Bridge to Beach* paddle race across Sydney Harbour, with approx. $22,000 raised. Shaw and Partners Foundation once again matched funds raised through this event, and we thank them for their kind support. More than $120,000 has been raised from FXAA's charity partnership with the Bridge to Beach, in place since 2014. Other successful fundraisers in 2022 included a Trivia Night in Sydney ($23,000), a raffle in Ellinbank in eastern Victoria ($6,817), and a community walk in Caloundra ($5,754). FXAA received a further educational grant from Zynerba Pharmaceuticals for the production of educational webinars.

Expenditure ($319,624, up 19% versus last year)
Our core fixed costs of salaries, rent and bookkeeping fees remain consistent. The increase in expenditure over FY2021 is largely the result of the acquittal of grants and utilisation of other funds which had been received in prior years for specific projects. For example, grant funding previously received from the *Qantas Side by Side Grant* program and from *Zynerba Pharmaceuticals* for the production of educational webinars and videos was utilised in FY2022 to produce those resources. Further, a NSW government Social Sector Transformation Fund grant of $20,000 to equip FXAA for "remote and flexible working" and social media training, received in FY2021, was utilised in FY2022. The production of information resources and the webinar series combined accounted for 16% of total expenditure.
In FY2021 the cost of providing services had reduced by 15% versus the prior year, due to the COVID-19 related reduction in events.

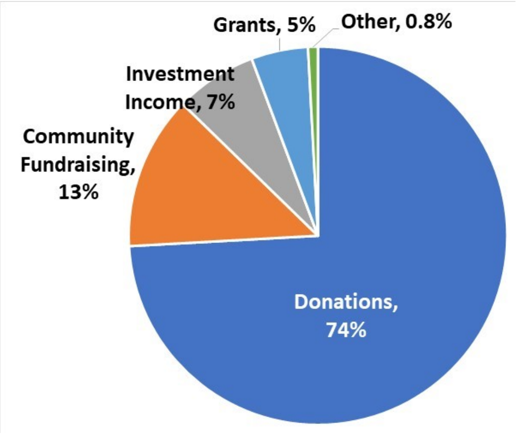
54% of expenditure relates to the provision of service to our members and the wider community, and increasing awareness of Fragile X conditions. The service to members largely comprises the HelpLine, counselling support, educational webinar series and information resource production. The FX webinar series and online resources have proven to be a cost-effective way of providing information and education, and these resources are being used by allied health professionals and disability support providers for professional development. 62% of the total organisational cost comprises salary costs for our two staff members and bookkeeping fees. The modest cost associated with health professional and community awareness continues to reflect the leverage gained through our volunteers, supporters and partners and reduction in face-to-face forums. 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

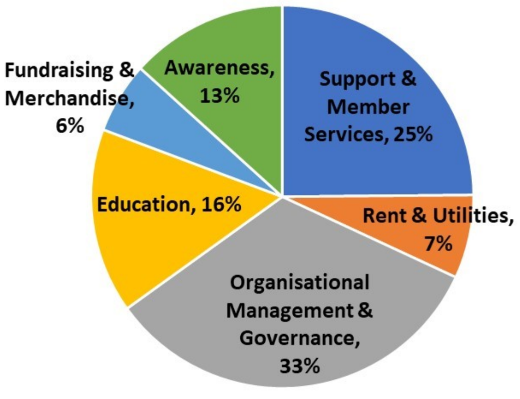
FXAA is well-resourced to deliver the *Strategic Plan 2022-2025* into the coming years with the ongoing support of our community

The accounts for FY2022 were audited by Mr Peter Vilimaa and Mr Ben Hodgkinson of Manser, Tierney and Johnston (MTJ) in Turramurra, NSW. The Board and Staff are deeply grateful to MTJ for audit services which were provided on an honorary basis for over 20 years and wish to record appreciation of their work which provides important ongoing oversight of FXAA's financial affairs.

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



INCOME 2021-2022



EXPENDITURE 2021-2022

Endowment Fund

- Endowment Fund - Net assets $760,746 (2021 - $810,457)
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 2021-2022 the Fund's interest and dividend income of $21,710 represented 6.9% (2021 12%) of the Association's annual expenditure of $319,624. 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 2022 (2021 39%).

In 2021-22 the Fund, like many other investors, suffered from the market downturn associated with the COVID-19 pandemic and global market uncertainty. The market value of the Fund's investments reduced by $75,705 during the period, a net loss of 6.1%.

This compares to a 13.12 % return for the previous year, during which time the Fund's equity portfolio in particular enjoyed significant growth. The challenge will be to maintain reasonable investment returns in an environment of high inflation and market volatility. Donations to the Fund have continued to be very modest.

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 2021-2022 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 2022 the Fund held investments in equities (Australian listed shares, representing 32% of the portfolio) and fixed interest securities (67%) comprising units in unlisted unit trusts. 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, grants, fundraising and honorary services.

Cunningham Family

Cecilia Kilkeary
Foundation Ltd

Healthed

oceanpaddler

ShawandPartners
Financial Services

Zynerba®
PHARMACEUTICALS
Advancing Science | Improving Connections

Ballarat
Dance
Awards
BDA
2019

Kate Stokes, Graphic Design

Suzanne Gordon, Photography

MTJ
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 FX premutation carriers.

Fragile X-associated Neuropsychiatric Conditions FXANC
A term to describe a range of neuropsychiatric issues some FX premutation 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 FX premutation carriers may experience.

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 and has representation from Fragile X Association of Australia.

The group provides an important conduit between FXAA and our members and developments in Fragile X research and clinical practice and other research areas. This puts FXAA in a position to inform our members of new developments and their context, to provide the Sub-Committee with our members' perspectives, and to engage in advocacy. In 2021-2022 members of the Sub-Committee kept us abreast of the progress of their work in the field of Fragile X-related research and the progress of the government-funded *Mackenzie's Mission* reproductive genetic carrier testing 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 Jonathan Cohen	Medical Director, Fragile X Alliance Clinic/Genetic Clinics Australia
Dr Rachael Cvejic	Dept of Developmental Disability Neuropsychiatry, UNSW
Dr Mike Field	NSW Health
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 staff representative	**Wendy Bruce**

Family Support 2021 - 2022

Health Education Events 2021-2022

Healthed

Disability Expos 2021-2022

CANBERRA
DISABILITY
EXPO

MELBOURNE
DISABILITY
EXPO

We love
OUR
Volunteers

National Volunteer Week 16 - 22 May 2022

SYDNEY
DISABILITY
EXPO

Raising Funds and Awareness 2021 –2022

TRIVIA NIGHT

Fundraiser

VENUE

CASABLANCA ROOM

ADDRESS

WHEN

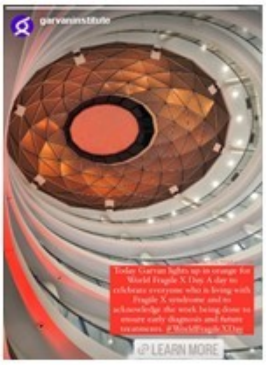
8th April 2022

AUCTION AND RAFFLE PRIZES

BALLARAT DANCE AWARDS
BDA

Raising Funds and Awareness 2021 –2022

Lighting Up for World Fragile X Day, 22 July 2022



Today Garvan lights up in orange for World Fragile X Day. A day to celebrate everyone who is living with Fragile X syndrome and to acknowledge the work being done to ensure early diagnosis and future treatments. #WorldFragileXDay

Lighting Up for World Fragile X Day, 22 July 2022

Colgrave family shines a light on disability for Fragile X Day

AFTER the birth of her first son Harry, Claire Colgrave was shocked to discover she carried the fragile X gene.

Now, with two teenage sons both with Fragile X syndrome, Claire and Brent Colgrave are advocating to spread awareness and understanding around the genetic disorder for World Fragile X Day yesterday.

Despite its uncommon name, Fragile X syndrome is the most common inherited cause of autism and intellectual disability worldwide.

Occurring more frequently in boys than girls, Fragile X syndrome can result in intellectual impairment and emotional and behavioural problems. But for the Colgraves, the support from the community has meant Harry, 18, and Tom, 17, are able to find connection and meaning as they enter adulthood.

"They're not your typical teenagers that will have their friends ringing up and heading out to do things independently," Ms Colgrave said.

The family count New Horizons Tasmania, a sporting club for people with disabilities, and Mowbray Cricket Club as examples of inclusive groups that have allowed Harry and Tom to participate socially.

The Colgraves said although support through the NDIS and Department of Education had been "amazing", they hoped more awareness around the disorder would help the community support those living with Fragile X.

"These kids and these young adults and even older adults just want the same as other people. They want to feel included and loved, they don't want to be treated differently," Ms Colgrave said.

Town Hall was last night lit up orange to help raise awareness of Fragile X.

AWARENESS: Brent and Claire Colgrave with their sons Harry and Tommy, who have Fragile X syndrome, of Kings Meadows. **Picture: Phillip Biggs**

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

FINANCIAL STATEMENTS
30 JUNE 2022

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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 2022 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*.

W Ted Brown
....
Prof W Ted Brown
President

....
Adam Lawrence-Slater
Treasurer

Dated this 9th day of November 2022.

MTJ
ManserTierney&Johnston
Chartered Accountants & Wealth Management

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 2022, 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 2022 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 (including Independence Standards)* (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our ethical responsibilities in accordance with the Code.

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

Emphasis of Matter – Basis of Accounting

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist the Association to meet the requirements of the *Associations Incorporation Act 2009 (NSW)* and for the purpose of fulfilling the 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.

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

Responsibilities of the Committee for the Financial Report

The committee is responsible for the preparation of the financial report that gives a true and fair view in accordance with the financial reporting requirements of 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 of the financial report that gives a true and fair view 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.

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.

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

- Conclude on the appropriateness of the committee' 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 Turramurra this 10th day of November 2022.

MTJ AUDIT PTY LTD

……………………………………………………

BEN HODGKINSON
Partner
Registered Company Auditor 524408

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

STATEMENT OF FINANCIAL POSITION
AS AT 30 JUNE 2022

	Note	2022	2021
CURRENT ASSETS			
Cash and cash equivalents			
At Bank		85,475	134,977
Endowment Fund	8	7,585	4,479
Petty Cash		100	100
Term Deposit		160,000	120,000
		253,160	259,556
Accounts receivable and other debtors			
Accounts Receivable		-	8,515
Franking Credits Refundable		5,059	6,197
GST Refundable/(Payable)		3,443	236
Prepayments		-	5,094
Rental Bond		3,416	3,416
		11,918	23,458
TOTAL CURRENT ASSETS		265,078	283,014
NON-CURRENT ASSETS			
Property, plant and equipment			
Property, Plant and Equipment - At Cost		12,960	8,973
Less: Accumulated Depreciation		(5,606)	(3,022)
		7,354	5,951
Investments			
Listed Investments at Market Value - Endowment Fund	8	248,894	372,687
Unlisted Investments at Market Value - Endowment Fund	8	499,208	425,621
		748,102	798,308
TOTAL NON-CURRENT ASSETS		755,456	804,259
TOTAL ASSETS		1,020,534	1,087,273
CURRENT LIABILITIES			
Accounts payable and other payables			
Accounts Payable		3,910	9,784
Payroll Liabilities		3,339	1,204
Other Liabilities		3,105	1,600
		10,354	12,588
Provisions			
Provision for Employee Entitlements		11,886	12,914
TOTAL CURRENT LIABILITIES		22,240	25,502
TOTAL LIABILITIES		22,240	25,502
NET ASSETS		$ 998,294	$1,061,771
EQUITY			
Opening Balance		1,061,771	883,454
Add: Surplus/(Deficit) for the Year		(63,477)	178,317
TOTAL EQUITY		$ 998,294	$1,061,771

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 2022

	2022	2021
INCOME		
Gross Proceeds From Fundraising Appeals		
Donations - including Endowment Fund	245,971	253,371
FXAA Fundraising Events and Appeals	43,698	29,895
Merchandise Sales	2,799	1,815
	292,468	285,081
Other		
Dividend Income	16,865	20,660
Government Stimulus	-	56,910
Grants	16,113	11,700
Interest	6,406	11,827
	39,384	101,097
Total Income (carried forward)	331,852	386,178

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 2022

	2022	2021
Total Income (brought forward)	331,852	386,178
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Other	6,225	4,037
	6,225	4,037
Total Costs Of Providing Services		
Support Services and FX Awareness	63,426	55,603
Clinics and Counselling	59,364	59,086
National Newsletter Printing	1,030	2,535
	123,820	117,224
Other		
Bank Fees and Charges	391	299
Board and AGM Expenses	1,328	838
Conferences and Seminars	13,487	379
Consultants and Accounting	20,193	20,715
Depreciation and Disposal of Assets	2,584	1,511
Donations	-	302
General Administration - Employment Costs	79,268	74,634
Information Resource Production	16,334	450
Insurance	5,679	5,606
Low Cost Assets	490	-
Office Expenses	15,049	4,436
Office Rent	18,394	17,939
Postage	2,938	3,161
Provision for Employee Entitlements	(1,028)	(1,521)
Stationery	1,947	1,730
Subscriptions	4,805	8,676
Sundries	(12)	22
Telephone	3,231	4,277
Website	4,501	3,286
	189,579	146,740
Total Expenditure	319,624	268,001
OPERATING SURPLUS FOR THE YEAR	12,228	118,177
Net Increase/(Decrease) in value of investments - Endowment Fund	(75,705)	60,140
TOTAL COMPREHENSIVE INCOME FOR THE YEAR	$(63,477)	$178,317

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 2022

	2022	2021
EQUITY		
Retained Earnings		
Opening Balance 1 July	1,017,987	899,810
Add: Surplus for the Year	12,228	118,177
	1,030,215	1,017,987
Less: Transfer (to)/from Asset Revaluation Reserve	(31,921)	-
Closing Balance 30 June	998,294	1,017,987
Asset Revaluation Reserve		
Opening Balance 1 July	43,784	(16,356)
Less: Net Transfer to/(from) Reserve	(75,705)	60,140
	(31,921)	43,784
Add: Transfer (to)/from Retained Earnings	31,921	-
Closing Balance 30 June	-	43,784
TOTAL EQUITY	$ 998,294	$1,061,771

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 2022

		2022	2021
Cash Flow from Operating Activities			
Receipts from donations, fundraising appeals and events		312,546	363,321
Interest and Dividends		24,409	33,585
Payments to suppliers and employees		(313,866)	(272,045)
Net cash provided by operating activities	10b	23,089	124,861
Cash Flows from Investing Activities			
Payment for property, plant and equipment		(3,985)	(1,417)
Net Payment for investments		(25,500)	(45,000)
Net cash used in investing activities		(29,485)	(46,417)
Net Increase/(decrease) in Cash Held		(6,396)	78,444
Cash on hand at the beginning of the financial year		259,556	181,112
Cash on hand at the end of the financial year	10a	$253,160	$259,556

The accompanying notes form part of these financial statements.

Note 1 – Summary of Significant Accounting Policies

Financial Reporting Framework

The financial statements are special purpose financial statements prepared in order to satisfy the financial reporting requirements of the *Associations Incorporation Act 2009 (NSW)* and the *Australian Charities and Not-for-Profits Commission Act 2012* (ACNC Act). The committee has determined that the Association is not a reporting entity as the users of the financial statements are able to obtain additional information to meet their needs.

Statement of Compliance

The financial report has been prepared in accordance with the *Associations Incorporation Act 2009 (NSW)* and the (ACNC Act) and the basis of accounting specified by all Australian Accounting Standards and Interpretations.

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.

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.

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

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.

h) Revenue and Other Income

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

Operating Grants, Donations and Bequests

When the Association receives operating grant revenue, donations or bequests, it assesses whether the contract is enforceable and has sufficiently specific performance obligations in accordance with AASB 15.

When both these conditions are satisfied, the Association:

- identifies each performance obligation relating to the grant;
- recognises a contract liability for its obligations under the agreement; and
- recognises revenue as it satisfies its performance obligations.

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

Where the contract is not enforceable or does not have sufficiently specific performance obligations, the Association:

- recognises the asset received in accordance with the recognition requirements of other applicable Accounting Standards (for example AASB 9, AASB 16, AASB 116 and AASB 138);
- recognises related amounts (being contributions by owners, lease liability, financial instruments, provisions, revenue or contract liability arising from a contract with a customer); and
- recognises income immediately in profit or loss as the difference between the initial carrying amount of the asset and the related amount.

If a contract liability is recognised as a related amount above, the Association recognises income in profit or loss when or as it satisfies its obligations under the contract.

Capital Grant

When the Association receives a capital grant, it recognises a liability for the excess of the initial carrying amount of the financial asset received over any related amounts (being contributions by owners, lease liability, financial instruments, provisions, revenue or contract liability arising from a contract with a customer) recognised under other Australian Accounting Standards.

The Association recognises income in profit or loss when or as the Association satisfies its obligations under terms of the grant.

Interest Income

Interest income is recognised using the effective interest method.

Dividend Income

The Association recognises dividends in profit or loss only when the Association's right to receive payment or the dividend is established.

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 OR Balance Sheet.

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

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.

m) Comparative Figures

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

Note 2 - Information on Material Matters

The Association received $182,250 in donations from the Cunningham family, $10,000 as a Philanthropic Donation from Shaw and Partners Foundation and a **$**13,575 in educational grant funding from Zynerba Pharmaceuticals.

Note 3 - Application of appeal monies

During the year the Association received net income of $308,581 from fundraising appeals and $23,271 from the investment of appeal monies.

An amount of $123,820 was spent on the provision of services (including $59,364 for counselling and clinics, $1,030 for newsletters, and $63,426 for other awareness and support). We spent $138,582 on insurance, rent, administration, office expenses and IT infrastructure for flexible and remote working.

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 2022
- FX Trivia Night, Ellinbank FNC Raffle, Caloundra Community Walk for FX
- Fragile X awareness events

Note 6 - Analysis of monetary figures

Ratios	$	%
Total cost of fundraising/ Gross income from fundraising	6,225/308,581	2% (1% last year)
Net surplus from fundraising/ Gross income from fundraising	302,356/308,581	98% (99% last year)
Total costs of services/ Total expenditure	123,820/319,624	39% (44% last year)
Total costs of services/ Total income received	123,820/331,852	37% (30% last year)

Note 7 – Commitments

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

Note 8 - Endowment Fund
Balance Sheet - as at 30 June

	Note	2022	2021
CURRENT ASSETS			
Cash on hand			
At Bank		7,585	4,479
Accounts receivable and other debtors			
Donations Receivable		-	1,473
Franking Refund Receivable		5,059	6,197
TOTAL CURRENT ASSETS		12,644	12,149
NON-CURRENT ASSETS			
Investments			
Listed Investments - At Market Value		248,894	372,687
Unlisted Investments - At Market Value		499,208	425,621
TOTAL NON-CURRENT ASSETS		748,102	798,308
TOTAL ASSETS		760,746	810,457
CURRENT LIABILITIES			
Accounts payable and other creditors			
Other creditors		-	-
TOTAL CURRENT LIABILITIES		-	-
NET ASSETS		$ 760,746	$ 810,457
EQUITY			
Opening Balance		810,457	708,421
Add: Income /(loss) for the Year	9	(49,711)	102,036
TOTAL EQUITY		$ 760,746	$ 810,457
Total Equity Comprises:			
General Fund		452,289	493,582
J & M Cunningham Endowment		308,457	316,875
		$ 760,746	$ 810,457

Note 9 - Endowment Fund

Income & Expenditure Statement - for the year ended 30 June

	2022	2021
INCOME		
Donations	4,300	9,792
Interest & Dividend Income	21,710	32,141
Increase in Market Value of Investments	-	60,140
	26,010	102,073
Less:		
Decrease in Market Value of Investments	75,705	-
Expenses	16	37
	75,721	37
NET INCOME/(LOSS) FOR THE YEAR	$ (49,711)	$102,036

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:

	2022	2021
Cash at bank	253,160	259,556

(b) Reconciliation of cash flow from operations with profit from ordinary activities

	2022	2021
Operating Surplus	12,228	118,177
Non-cash flows in Operating Surplus		
- Depreciation	2,584	1,511
Changes in assets and liabilities		
- (Increase)/decrease in receivables	8,515	(6,600)
- (Increase)/decrease in other assets	3,029	13,846
- Increase/(decrease) in payables	(5,876)	1,777
- Increase/(decrease) in other current liabilities	3,637	(2,329)
- Increase/(decrease) in provisions	(1,028)	(1,521)
Net cash provided by operating activities	$ 23,089	$124,861

Note 11 - Events After the Reporting Period

The COVID-19 pandemic continues to have an impact on the Association. The timing and extent of the impact and recovery from the COVID-19 pandemic 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 2022 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.

Fragile X
Association of
Australia

Your Support Will Make a Difference

Make a Tax-Deductible Donation

www.fragilex.org.au

Become a Member

A strong member base increases our voice and grows our network

Workplace Giving

Introduce us to your workplace giving program

Fundraise

Organise a fundraising event

Partner with Us

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

Connect with Us

www.fragilex.org.au

HelpLine

1300 394 636 and support@fragilex.org.au

Fragile X Association of Australia Inc

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