Fragile X
Association of
Australia

2022–2023 Annual Report

FRAGILE X.ORG.AU

30 Years Strong | Supporting | Sharing | Connecting | Informing

Understanding Fragile X

Fragile X-associated Conditions 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 conditions 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 – living 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 Associated Conditions

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 Primary Ovarian Insufficiency FXPOI
This can lead to fertility problems and early menopause in around 25% of female FX premutation carriers.

Fragile X-associated Tremor Ataxia syndrome FXTAS
A neurological condition with symptoms including shaking (intention tremor), unsteadiness (ataxia) and memory problems. FXTAS can be misdiagnosed as Parkinson's disease.

Fragile X-associated Neuropsychiatric Disorders FXAND
A term to describe a range of issues some FX premutation carriers may experience, including anxiety.

Fragile X Various Associated Conditions FXVAC
A term to describe other non-psychiatric conditions which some FX premutation carriers may experience, such as auto-immune conditions.

FX HELPLINE 1300 394 636 support@fragilex.org.au www.fragilex.org.au

Fragile X Association of Australia is a registered charity providing support and information to people around Australia who are affected by Fragile X Associated conditions, including Fragile X syndrome and Fragile X Premutation Associated Conditions.

Our vision is that people living with Fragile X are connected, included, understood and empowered to live their best possible lives.

HELPLINE 5 DAYS PER WEEK | SPECIALIST FAMILY COUNSELLOR | PEER SUPPORT | EDUCATIONAL WEBINARS | REFERRALS
ADVOCACY | INFORMATION RESOURCES FOR ALLIED HEALTH PROFESSIONALS AND EDUCATORS

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PRESIDENT'S REPORT

I am delighted to present my inaugural Annual Report as President of Fragile X Association of Australia (FXAA). I've been associated with the organisation since 1996 when my son Daniel was diagnosed with Fragile X syndrome at 18 months.

Now 29, Daniel faces challenges such as non-verbal communication, severe anxiety, and epilepsy. My involvement began with joining the management Committee post-diagnosis, where I contributed by producing newsletters, advocating for Fragile X, delivering talks, and fundraising. My professional background spans genetics, laboratory chromosome testing, and risk management in a fertility clinic. During my career, I successfully lobbied for the inclusion of a Medical Benefits Scheme (MBS) item number for Preimplantation Genetic Diagnosis (PGD). I joined the Board in 2020.

◆ Key highlights for FXAA in 2023

Mrs Margaret Cunningham AM was honoured in the Australia Day 2023 Honours list for notable service to the community via charitable organisations, including FXAA. Her involvement in the Fragile X discovery group, led by Prof Gillian Turner AO, not only provided answers to disability affecting her son but also contributed to a noteworthy academic paper. This study eventually led Australian researchers to discover the Fragile X gene in 1991. Margaret and her husband John later co-founded FXAA.

Implementation of an MBS item number to subsidise reproductive genetic carrier screening for Fragile X syndrome, cystic fibrosis and spinal muscular atrophy. After well over a decade of advocacy and research, including the Federal Government's carrier screening pilot initiative (*MacKenzie's Mission*), and the involvement of so many organisations including ours this is an important change to public health policy. The Board is pleased with the government supporting equitable access to this testing. We are monitoring the increase in community need from women who are identified as carriers for Fragile X.

Fragile X Adults & Ageing. We are delighted to have been awarded a 3-year grant by the Henroth Group for our groundbreaking study on adults and ageing and Fragile X syndrome, which has garnered interest from Fragile X communities globally. Co-led by FXAA and the Centre for Disability Studies (research affiliate of Sydney University), this important work will look at the supports needed, and those in place, for adults with Fragile X syndrome to age well. It will also address disability and aged care workforce capacity to appropriately support adults with Fragile X syndrome.

Support for our counselling role. A grant was awarded to FXAA by the Cecilia Kilkeary Foundation to part-fund the Family Support Counsellor role, which serves as an acknowledgement of the important impact this role has for many people in our community.

◆ We owe gratitude to:

FXAA could not continue to support our community or advocate for change and improved outcomes without generous donations of funds and support–in–kind.

The Board, staff and I especially thank the Cunningham family for their generous support over many years.

We also wish to thank the philanthropic donors and organisations which provide support. We sincerely thank our many volunteers who contribute time, expertise, and skills in various forms. Such as, attending Fragile X exhibition stands at events, serving on the FXAA Endowment Fund committee, providing graphic design, legal guidance, fundraising, and much more.

We also thank the services which support the community with diagnosis and treatment: including Victorian Clinical Genetics Services, GOLD Service (NSW), Dr Jonathan Cohen and Dr Jane Law, among others. We also appreciate the commitment of the experts involved in presenting this year's educational FX webinar series.

I personally acknowledge the commitment of our Board members, who are all volunteers and ensure that we continue to operate with good corporate governance.

We thank our wonderful staff, Wendy Bruce and Liz Jewell, who conduct our core work of supporting the FX community – individuals and families. This includes counselling, HelpLine, peer support & connections, and facilitating access to clinics. It also extends to advocacy and awareness across a range of health and disability forums as well as organising and hosting our very successful webinar program.

◆ Other areas of advocacy

The widely adopted term used as an 'umbrella' for conditions which can impact some carriers for Fragile X is now FXPAC—Fragile X Premutation Associated Conditions. This key change to language originated from the FX community in Europe and is internationally endorsed, including at the recent International FX Premutation Conference in New Zealand. This shift is crucial for concentrating research, treatment, and understanding efforts. While knowledge is expanding, there's still much to learn about the impact of FX premutation and potential treatments.

◆ Funding

We continue to need to secure ongoing funding for the core services we offer our community. We will be looking for corporate sponsorship as well as applying for further grant opportunities as they arise. We also encourage our members to consider making donations, conducting fundraising events, and to consider bequests.

◆ What's ahead?

We remain hopeful and confident that clinical trials using repurposed existing drugs to ameliorate symptoms will lead to treatments for symptoms of Fragile X syndrome. Other longer term research projects in the United States and other countries can target components in the brain that are misregulated in Fragile X syndrome. There are also exciting research efforts in the United States and other countries which may provide a cure for Fragile X by turning back on the FMR1 protein which is lacking in affected individuals. While some years away these are exciting prospects.

Sincerely,

Cynthia Roberts

Dr Cynthia Roberts, PhD

OUR TEAM

BOARD 2022—2023

Dr Cynthia Roberts PhD, President
Cynthia is a trained geneticist and ran a clinical cytogentetics service in NSW particularly focusing on prenatal testing. Cynthia worked at Genea as both Genetics Director and Chief Risk Officer. She served as President of the Human Genetics Society of Australasia and has been involved with FXAA for over 20 years, since the time her now-adult son, Daniel, was diagnosed with Fragile X syndrome. Cynthia lives in Kiama, NSW, and joined the Board in 2020.

Prof W Ted Brown MD PhD, Vice-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 was the first to describe a relationship between autism and the Fragile X syndrome. His team was the first to demonstrate the feasibility of pre-natal diagnosis for Fragile X. Prof Brown chairs FXAA's Fragile X Scientific, Clinical and Advisory Committee. Prof Brown joined the Board in 2018 and is immediate past President. Prof Brown relocated from the US to Sydney in 2017.

Adam Lawrence-Slater, Treasurer
Adam has a background in financial planning and data insights in the airline sector and 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 lives in Sydney and joined the Board in 2019.

Karen Lipworth, Secretary
Karen is a qualified veterinarian who is currently on maternity leave from a role in the pharmaceutical industry.
Karen 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.

Kate McKeand
Kate is a parent of two children who have Fragile X syndrome. She currently works as an engineer in energy and sustainability policy. Previously she was a director of a consulting organisation specialising in supporting and empowering participants in the NDIS, and has also 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.

Belinda DÁmico
Belinda is a registered Chartered Accountant, although not currently practising since the diagnosis of Fragile X syndrome for her two young boys. Belinda has an online skincare business. Belinda is extremely passionate about raising awareness of Fragile X syndrome and she is keen to support the FX community. Belinda lives in Sydney and joined the Board in 2021.

Mandy Barker
Mandy works in social media marketing and business development, specialising in the disability and aged care sectors. Mandy's son and daughter live with Fragile X syndrome. Mandy is a keen advocate for raised awareness of FX, earlier diagnosis, genetic screening, and for inclusion for people living with a disability. Mandy lives in Brisbane and joined the Board in 2021.

Alison Evans
Alison is a corporate communication professional with experience in journalism, media and public relations.
After finding her health support providers to be lacking knowledge about Fragile X following the discovery of her premutation carrier status, Alison is passionate about increasing awareness of Fragile X within the general public and medical communities alike. Alison lives in Newcastle, NSW and joined the Board in 2022.

STAFF

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

Liz Jewell, Family Support Counsellor (part-time)
Liz joined FXAA in 2018.

YEAR IN REVIEW 2022-2023

The FXAA *Strategic Plan 2022-2025* provides a framework for the service and programs FXAA delivers to our member base and to the wider Fragile X community. The Plan has four pillars of focus: Support & connection; Empowerment; Advocacy; Education.

FXAA's core programs remain: counselling support, HelpLine, information/education, referrals, facilitating access to clinics, increasing awareness of Fragile X in the health and disability sectors for improved supports, and advocating for appropriate and early access to diagnosis and treatments.

Highlights of 2023 include the expansion of our FX Webinar Series to cover more areas related to Fragile X, the opportunity for our Family Support Counsellor to engage with members in different states alongside attendance at Disability Expos, and our engagement in World Fragile X Day on 22 July with FX groups in a growing number of countries. Our collaboration throughout the year with Cystic Fibrosis Community Care (CFCC), SMA Australia (SMAA) and Victorian Clinical Genetics Services (VCGS) provided a key base for our engagement with GPs at face-to-face education forums in advance of the listing of 3-gene genetic carrier screening on the Medicare Schedule on 1 November 2023.

Advocacy

FXAA engages in systemic advocacy with the aim of influencing positive long-term change in matters of health and intellectual disability affecting individuals living with Fragile X syndrome, and individuals who are premutation carriers for Fragile X, and family members/carers.

We are invited or arrange to collaborate with organisations with whom we share areas of focus or concern, and to work towards common goals. This allows us to advocate effectively despite our own limited base of human resources, and amplifies the voice of our members.

Our Executive Director and Board members represent the Fragile X community in a range of forums, and are involved as required in government or sector-led consultation processes. We continue to focus on key areas: advances in testing and diagnosis of Fragile X -associated conditions, reproductive genetic carrier screening, access to treatments and services, and informing health professionals about Fragile X. We collaborate with peak groups such as *Council for Intellectual Disability*, *Rare Voices Australia*, *Inclusion Australia*, *Neurological Alliance Australia*, and organisations including *Centre for Disability Studies* (research affiliate of University of Sydney) and the newly established *National Centre of Excellence in Intellectual Disability Health.*

Reproductive Genetic Carrier Testing – Medicare subsidy

1 in 20 Australians are carriers for Fragile X syndrome, Cystic Fibrosis (CF) and Spinal Muscular Atrophy (SMA).

From 1 November 2023, a Medicare rebate applies to reproductive genetic carrier testing for CF, FXS and SMA for eligible couples considering pregnancy or in the early stages of pregnancy. Prior to 1 November 2023, the cost of this testing was around $400. Public funding of genetic carrier screening for these 3 conditions is a key step towards equity of access to this testing, allowing all eligible couples to have the opportunity to learn if they are at risk of having a child with FXS, CF or SMA. For many years FXAA has advocated for subsidised carrier screening testing, working closely with support groups SMAA and CFCC and not-for-profit genetics service VCGS, together with the *Mackenzie's Mission* carrier screening pilot study team, and other groups. We anticipate an increase in contacts via our HelpLine from women in the general population who have learned of their Fragile X carrier status through this testing. FXAA's staff will monitor the volume and type of contacts made, and we plan to expand the coverage on our website of the Fragile X premutation and associated conditions.

FXAA remains supportive of ongoing efforts advocating for expanded carrier screening (for 100's of genetic conditions) to be more accessible to couples through a Medicare subsidy.

Testing for Fragile X

Inconsistencies of approach by clinicians and genetic services in **testing for the Fragile X premutation or Fragile X syndrome** continue to be evident. In particular, we observe differences of approach across states/territories/services to parents' requests to test their female children and wider family (cascade testing) where there is a family history of Fragile X. Consistency of approach to early and accurate diagnosis of Fragile X syndrome and Fragile X-associated conditions is essential for the best outcomes for any individual or family and their understanding of the potential health and generational effects of Fragile X.

The **newborn bloodspot screening** (NBS) test, also known as the heel prick test, is offered by state and territory governments for all babies born in Australia to identify babies at risk of becoming seriously ill from a group of rare diseases, such as SMA. Diagnosis shortly after birth allows for early interventions/ treatments to improve the health of the baby. The Federal Government has recently taken steps to ensure the newborn testing program has a consistent national approach. The Health Department is currently assessing the potential addition of more rare conditions to the program. FXAA continues to advocate for the addition of Fragile X syndrome to the NBS test, has been involved in consultation processes initiated by the Health Department, and is following developments closely.

Several government-funded research studies are underway to assess the benefits of an extended NBS program. FXAA is involved in the patient advocacy group for one such study led by A/Prof David Godler from Murdoch Children's Research Institute.

FXAA remains hopeful that over time advances in technology, treatments and reduced costs of testing will result in the addition of Fragile X syndrome to the national NBS program.

Intellectual Disability Health

FXAA is deeply concerned to see improved healthcare supports and outcomes for people with intellectual disability.

The launch of the *National Centre of Excellence in Intellectual Disability Health* in October 2023 has been a critical step towards improved access to quality, timely and comprehensive healthcare for people with intellectual disability. The Centre will support the delivery of the Australian government's *National Roadmap for Improving the Health of People with Intellectual Disability*, which was launched in 2021.

The Centre has been funded by the Federal Government and will be led by a consortium including *UNSW, Council for Intellectual Disability, Centre for Disability Studies, Inclusion Australia*, and *MIDAS.*

UNSW Professor Julian Trollor, acting head of the Centre, said: " core functions of the National Centre would include providing leadership in intellectual disability health, driving innovation and collaboration, and lifting the capability of health services to meet the needs of people with intellectual disability through training and development of best practice models of care."
FXAA is one of a group of small bodies which aim to support the work of the Centre as collaborator organisations.

Another initiative under the Federal Government's *National Roadmap* is the development of an intellectual disability health curriculum for medical students. The aim is to "prepare graduates with the required capabilities to provide the highest quality care to people with intellectual disability throughout their future health professional careers." FXAA has provided feedback on the draft framework and core capabilities to be addressed by the curriculum.

NDIS

The Minister for the National Disability Insurance Scheme, the Hon Bill Shorten MP, announced a review of the National Disability Insurance Scheme (NDIS) in October 2022. The NDIS Review was established to review the design, operations and sustainability of the NDIS and look at ways to make the market and workforce more responsive, supportive and sustainable.

The Review involved extensive consultation across the disability sector, and it received 2,500 submissions.

FXAA engaged with the NDIS Review team and made two submissions specific to Fragile X syndrome and FXTAS.

The NDIS Review report was presented to the Federal Government in October 2023 and will be made public after State and Federal Government consideration.

We look forward to the Federal Government's response to the NDIS Review Report and will monitor recommendations that may impact the Fragile X community.

Genomics

Genomics and Disability

Since 2021 FXAA has represented *Rare Voices Australia* on an advisory panel for a University of Queensland research project about social and ethical dialogue on genomics and disability. The project, funded by the Medical Research Future Fund, is named *We Need to Talk: Genomics and Disability*, and will report its findings in December 2023.

Genomics and Primary Care

FXAA will be a consumer advocacy partner for a 3-year research project called *Embedding genomics in primary care: using implementation science to design a robust national approach.*
It involves implementation research on strategies to improve clinical capacity to apply genomics in general practice. The work, set to commence in 2024, will be led by Prof Braithwaite from Macquarie University, and will streamline pathways and resources for GPs offering, and consumers considering, screening tests.

Education

Health Professionals

The full resumption of face-to-face professional development events for general practitioners gave FXAA the opportunity to profile reproductive carrier screening for Fragile X, CF and SMA nationally at seven events in f/y 2023 and a further four later in 2023. FXAA was present at *Healthed* 1-day events for GPs in Adelaide, Brisbane, Melbourne, Sydney and Perth, and at another larger 3-day *GPCE* conference in Sydney.

FXAA's team of representatives included Executive Director Wendy Bruce, Board members (Prof Ted Brown, Dr Cynthia Roberts, Karen Lipworth, Kate McKeand) and other FXAA members, supported by genetic counsellors from VCGS and representatives from CFCC.

The support of the FX community and the groups we collaborate with is key to FXAA achieving a national presence in this way.

Combined, our team had conversations with hundreds of GPs about carrier testing, any concerns the GPs had about discussing carrier screening with their patients, about the inheritance pattern of Fragile X, and about conditions associated with the Fragile X premutation.

With the listing of carrier screening for FX, CF and SMA on the Medicare Benefits schedule on 1 November 2023, we expect ongoing interest from GPs in better understanding the screening and the supports their patients may require.

Many thanks are due to Dr Ramesh Manocha, the founder of *Healthed*, for the opportunity for FXAA to be present at many of Healthed's professional development events for GPs since 2015, at no cost to FXAA. We also acknowledge that CFCC shares the costs associated with FXAA providing materials to GPs in these forums.

In August 2022 FXAA was represented at a major regional conference for developmental and behavioural paediatricians. A/Prof Honey Heussler presented on Fragile X disorders, including an overview of diagnosis of Fragile X syndrome and appropriate supports.

Genetic Counsellor Education Programs

Our Family Support Counsellor presents at the annual VCGS Fragile X workshops for Genetic Counselling/Genomics and Health students, and is an annual guest presenter at the UTS Master of Genetic Counselling "Meet the experts" series.

These are key platforms for FXAA to build knowledge in the genetic counselling cohort about Fragile X syndrome and Fragile X Premutation Associated Conditions.

Disability Expos

Disability Expos continue to be an important and effective way to engage on a national level with disability service providers and allied health professionals about supports for their clients with Fragile X syndrome, and for FXAA to learn about supports and services available in major cities and regions. Expos are also an excellent way to catch up with the people in our community!

In the 12 months to 20 June 2023, our Family Support Counsellor Liz Jewell represented FXAA at Disability Expos run by *Social Impact Institute* or *SourceKids* in Adelaide, Canberra and Western Sydney. From July – October 2023, FXAA was present at Expos in Brisbane, Canberra, Melbourne and, for the first time, Tasmania.

While in Hobart and Launceston, Liz had the chance to catch up with several of our members. The FXAA face-to-face presence in Tasmania was made possible by the students from Fraser House at Launceston Church Grammar School fundraising for FXAA in honour of their former classmate Harry Colgrave.

FX Webinar Series

Knowledge and expertise in Fragile X continues to be quite limited and difficult to access. Our *FX Webinar* series offers high value, unique and targeted content delivered by Australian and international subject matter specialists. The series also offers the audience the chance to ask questions directly during a live Q&A segment. We are glad to co-host some of these events with Fragile X Society of New Zealand.

We believe that the educational content of this series plays a role in optimal care and outcomes for people living with Fragile X syndrome. Over the next year we hope to increase the focus on FX premutation health issues. The webinars are attended by FXAA members, the wider FX community, carers, allied health professionals, disability support providers, educators, and genetic counsellors. The presentations are recorded to form a library of excellent educational resources, freely available as videos on FXAA's YouTube channel and as podcasts on Spotify and Apple.

FXAA ran 11 webinars in financial year 2023, and a further six after 1 July 2023. The webinars generally covered topics related to Fragile X syndrome – behaviours, learning, sensory processing, sleep disorders, medications, health issues for adults with FX, and toileting issues. Other webinars focussed on IVF/PGD for FX premutation carriers, sibling support, and opportunities for participation in Fragile X-related research studies and clinical trials. Speakers included US-based psychologists Dr Marcia Braden PhD and Dr Jennifer Epstein, Dr Jonathan Cohen, Dr Honey Heussler, occupational therapist Bev Kadish, fertility specialist Dr Mark Livingstone, and Katie Clapp co-founder of FRAXA Research Foundation.

To date, webinar recordings have had a combined total of close to 13,000 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 by people from a range of jurisdictions – principally the US, but also , UK, New Zealand, Canada and India.

FXAA extends thanks to Zynerba Pharmaceuticals for educational grant funding to support a series of webinars with Dr Marcia Braden in 2023 and 2024, and to Genea for supporting the webinar on PGD/IVF in late 2022.

Fundraising, Donations and Grants

Highlights in 2022-2023: Fundraising through charity partnerships with the Bridge to Beach paddle race and Ellinbank Football & Netball Club, a philanthropic grant in memory of Mr Greg Mosbey, and grant funding to support programs.

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.

Fundraising

In 2022-2023, $23,484 was raised through individual and community fundraising efforts, both in person and online. Many thanks to the individuals and organisations involved in supporting FXAA in this way.

In 2023 FXAA celebrated the 10th anniversary of our charity partnership with the annual **Bridge to Beach** paddle race across Sydney Harbour. This event is part of the Australian Ocean Racing Series and has been run for more than 20 years by elite open water sportsman Dean Gardiner and the team from *Oceanpaddler*. The race is sponsored by Shaw & Partners Financial Services. Every year about 400 paddlers take on the 11km paddle from near the base of the Harbour Bridge, around the Harbour and across to Manly Cove. Once again, the support from the paddlers and donors was outstanding. Thanks to generous donation matching by *Shaw & Partners Foundation*, $22,000 was raised to help fund FXAA's family support role.

Once again, the **Ellinbank Football and Netball Club** in SE Victoria ran a special Fragile X awareness and fundraising event in July - with fundraising and a dedicated Fragile X Round for the Club's football and netball teams. The Fragile X Round is in honour of young Cal Wallace, who lives with Fragile X syndrome. Cal led the senior football team - all wearing orange socks! - onto the ground, an annual tradition. Many thanks to the Club for their ongoing support.

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

Many thanks to community group **Galston & District Garden Club** (NSW) and **Masonicare** for a matched donation of $3,000. Thanks to **Lion's Club Wonthaggi**, **Country Women's Association** in Shepparton, and **Arabella Hair Design** in Ballarat for their donations and fundraising during the year, and to the **CBA Community Grant** program for their support.

FXAA was represented at Sydney's annual **City to Surf** fun run/ walk in August 2023, with Team FX led by FXAA members Belinda DÁmico, Monique Smith and our Family Support Counsellor Liz Jewell in orange tutus. Successful fundraising once again by FXAA President Cynthia Roberts, with $3,165 raised in total.

We would particularly like to acknowledge a significant philanthropic grant and donation made to FXAA in memory of **Mr Greg Mosbey**. Greg was a member of FXAA for a number of years. He had developed the Fragile X-associated Tremor Ataxia condition. We are tremendously grateful to Greg's wife Debbie and their family for securing this funding which is to be used for our base operations/staffing in support of other people affected by Fragile X in some way.

Grants

Educational webinar series

Zynerba Pharmaceuticals has awarded FXAA a further educational grant to support our FX webinar series The funding will support 5 webinars with psychologist and Fragile X specialist Dr Marcia Braden PhD in late 2023 and through 2024. These webinars will focus on Anxiety and Behaviours, Females and Fragile X syndrome, and topics which will be new to our program.
The recordings form a valuable library of insights and strategies for supporting children or adults with Fragile X syndrome, and are available on the FXAA YouTube channel and as podcasts.
The educational grants from Zynerba have been very important to the development of our webinar program, and FXAA is very thankful for this continued support.

Family Support Counselling role

FXAA is privileged to have been awarded grant funding by the *Cecilia Kilkeary Foundation* to help support the FX Family Counselling role over 3 years, to 2025. This role provides important support to our members and their family members/carers. The role involves: providing emotional support to people living with Fragile X and their families; taking inbound HelpLine calls; providing therapeutic counselling; facilitating online peer support sessions; providing individual counselling sessions for members with Fragile X syndrome / premutation, or as carers; making referrals; and providing advocacy as required.

Fragile X Care | Adults and Ageing

In early 2024 FXAA will launch the first Australian study to focus on what life is like for adults with Fragile X syndrome and seek to understand the adults' support needs and gaps in support. Further aims of the project are to develop online education resources for disability and aged care workers about Fragile X syndrome, and guidelines for care. This 3-year project, co-led by FXAA and Centre for Disability Studies (research affiliate of University of Sydney), will be funded by a 3-year grant awarded to FXAA by the *Henroth Group*. FXAA is tremendously excited to have the opportunity to undertake such an important study, made possible by this grant, and sincerely thanks the Henroth Group.

FX Awareness

FXAA members and their friends and families get involved in increasing understanding of Fragile X in many ways.
Whether that be 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, sharing their stories with the media, 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 makes a real difference in increasing awareness and understanding of Fragile X in its various forms, amplifying the efforts of FXAA and is sincerely appreciated.

World Fragile X Day

A highlight in the Fragile X calendar every year is 22 July. This date is designated in the US, Australia and a growing number of other countries as World Fragile X Day. In Australia the aim of World Fragile X Day is to celebrate individuals living with Fragile X-associated conditions and promote understanding and inclusion. We were delighted to join with the *FRAXA Research Foundation* team in the US and FX organisations around the world to illuminate a total of 545 landmarks for the common goal of increasing awareness.

Australia's World Fragile X Day effort in 2023 was a personal best, with 109 landmarks illuminated in orange, across each state and territory in regional and metropolitan locations! Many landmarks joined the lightup for the first time, such as the Tasman Bridge in Hobart, 101 Collins Street in Melbourne, Port Adelaide Lighthouse, the WA Parliament Fountains, the Big Banana in Coffs Harbour and more – too many to name....
Photos and a list of landmarks supporting Fragile X in 2023 are on our website: www.fragilex.org.au/22-july-australia-lights-up-for-world-fragile-x-day/

Very much a grassroots effort, the "light up" campaign was initiated in Brisbane in 2015 by former FXAA Board member Nyleta McRae, who is a parent of two children living with Fragile X syndrome. The "light up" in Australia grows year on year, tremendously well supported by organisations and infrastructure operators across the private and public sectors.

Membership of FXAA

At November 2023 FXAA has a member base of 610. The majority of members are individuals or family members of people who have Fragile X syndrome or are a carrier for the Fragile X premutation. Consistent with last year, this is an annual increase in members of 8%.

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 Fragile X-associated conditions and the premutation. 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 organisations dedicated to supporting the Fragile X community or progressing Fragile X research.

We are a foundation member of the *International FXTAS Consortium* and an early partner of the *International Fragile X Premutation Registry.* We work alongside *Fragile X Society New Zealand* to host educational webinars for Australia and New Zealand.

We are a foundation partner of the annual *World Fragile X Day* initiative of *FRAXA Research Foundation* and support this campaign alongside FX organisations in other countries.
We have applied for membership of *FraXI,* an international not-for-profit celebrating and supporting those living with Fragile X Syndrome and Fragile X Premutation Associated Conditions around the world.

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, services and referrals.

We greatly value opportunities to work with or support initiatives of organisations focused on intellectual disability or rare conditions, such as *Rare Voices Australia*, *Council for Intellectual Disability*, *Centre for Disability Studies*, and *National Centre of Excellence in Intellectual Disability Health.* Together we work towards advances in public policy, supports and services.

Research

Adults and Ageing with Fragile X syndrome

We are thrilled that in 2024 FXAA will launch the first Australian study to focus on what life is like for adults with Fragile X syndrome and seek to understand the adults' support needs and gaps in support. This 3-year project, co-led by FXAA and Centre for Disability Studies (research affiliate of University of Sydney) will be funded by a 3-year grant awarded to FXAA by the Henroth Group.

The study team includes an Expert Steering Committee, consisting of four eminent clinicians, and a Lived Experience Expert Advisory Panel, consisting of five FXAA members.
This mixed methods study will include surveys, interviews and focus groups, involving our member base and the Fragile X community more broadly, as well as Fragile X specialists, and disability and aged care service providers. Further aims of the project are to develop online education resources for disability and aged care workers about Fragile X syndrome, and guidelines for care. The online education modules are to be developed by the team at UNSW Department of Developmental Disability Neuropsychiatry (3DN).

Fragile X Roundtable

FXAA participates in the annual Fragile X Roundtable convened by Dr Claudine Kraan PhD at Murdoch Children's Research Institute. The Roundtable is attended by researchers, clinicians and others with interest in Fragile X syndrome or Fragile X Premutation Associated Conditions.

FXAA Fragile X Scientific, Clinical & Research Sub-Committee

This Sub-Committee is made up of Australian researchers and clinicians with an interest in Fragile X, and has representation from FXAA. The Chair is Prof W Ted Brown, Vice-President of FXAA, and Vice-Chair is Dr Claudine Kraan PhD, from Murdoch Children's Research Institute.

International Fragile X Premutation Registry

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 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 Advisory Panel for the Registry includes FXAA Board member Karen Lipworth and Dr Jonathan Cohen , a member of the FXAA Scientific, Clinical & Research Committee.

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, Liz Jewell is available 3.5 days per week.

Our staff interact with FXAA members on a daily basis in our online forums, by phone, email or messenger, and interact with the wider Fragile X community, service providers, and the general public.

Support snapshot: *In 2022-23 approximately 260 HelpLine contacts were responded to, an increase over the previous year of 30%. Our Family Support Counsellor conducted 460 occasions of counselling (490 in 2022) for around 175 of our members, and facilitated 44 small-group peer support meetings (75 in 2022).*

Fragile X-specific support continues to be a valued service, as indicated by the increased number of HelpLine calls and increased utilisation of the Family Support Counsellor for counselling, general support, facilitated peer connections, referrals and Fragile X '101' Zoom sessions for some schools or disability service providers.

Inquiries made to FXAA are frequently multi-staged, often progressing from HelpLine through to support. The flexibility of contacting FXAA via different platforms (phone, website, email, social media, messenger) means inquiries can be made outside of office hours and according to an inquirer's preferred mode of communication. We aim to respond to Helpline inquiries within a 48-hour timeframe, although response is typically same-day.

FX HELPLINE

The increased number of HelpLine queries over the previous year is likely to be partly due to the full resumption of testing, screening and clinical appointments as the timing of many medical and diagnostic practices returned to more typical patterns following cessation of service or backlogs experienced during-COVID-19. Ongoing allied health workforce shortages in many areas continue to generate inquiries from families and caregivers seeking referrals for practitioners.

Inquiries received through the HelpLine continue to be diverse, across multiple aspects of Fragile X-associated conditions, and often complex. The great majority of inquiries are made by individuals - members of the FXAA community and their families/carers or members of the public. Other inquiries are from disability service providers, educators, allied health professionals supporting children or adults, genetic counsellors, other health professionals, and students.

The majority of inquiries centre around information on supports for individuals who have Fragile X syndrome, while the number of inquiries related to FXTAS and other Fragile X PremutationAssociated Conditions continues to increase.

Inquiries made around *Fragile X syndrome* commonly centre on core areas: behavioural and educational supports in a range of settings for children or adults; the availability of testing for Fragile X syndrome; referrals to medical or allied health professionals with expertise; referrals to health or disability services; queries around NDIS access or funding; supports for young or adult siblings who have a brother or sister with Fragile X; advocacy in a range of settings; future treatments for Fragile X syndrome.

Inquiries related to *Fragile X premutation* centre on testing, diagnosis and support for associated health issues, ie FXTAS, FXPOI, and other health concerns. Inquirers are seeking medical, allied health service or genetic testing referrals, or information about diagnosis and supports which they can pass on to their relevant health practitioner or utilize themselves.

OUTREACH

Counselling

The Counselling Support role involves: providing emotional support to people living with Fragile X and their families; taking inbound HelpLine calls; providing therapeutic counselling; facilitating online peer support sessions; providing individual counselling sessions for members with Fragile X syndrome / premutation, or as carers; making referrals; and providing advocacy or information as required.

Counselling support is delivered via phone, face-to-face via Zoom, in person or online. The volume of counselling sessions has increased in the past few years as FXAA's relationship with families strengthens over time and members become more aware of the opportunity to engage in conversation and of the value and availability of counselling. The model of counselling is tailored to suit the individual's need and address the presenting issue/s.

The themes addressed by the FX Family Support Counsellor in the 12 months July 2022 – June 2023 reflect the ongoing challenges faced by individuals, families and carers in navigating life with Fragile X. These themes are consistent with those arising in counselling occasions in previous years: 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.

Points of difference over the prior year: greater number of counselling requests and contacts; growing number of counsellees from states other than NSW and Victoria (eg WA); fewer contacts around diagnosis of a young child with Fragile X syndrome; increased number of contacts regarding the Fragile X-associated Tremor Ataxia syndrome.

Travelling interstate to facilitate the FX Tables at Disability Expos has provided a key opportunity for the Family Support Counsellor to meet members in person and provide face-to-face counselling and support. Being able meet face-to-face with members only met online previously has really improved connections and understanding. Attending the Expos in different cities and regions has also given the Counsellor the opportunity to introduce families to one another,and for informal group get togethers.

Peer support

Peer support connections via Zoom help alleviate the isolation experienced by many who are living remotely or experience isolation through their lived circumstances, without having to physically leave the comfort of their home. Over the past 12 months, there has been a significant increase in connections made with families from WA and from regional areas in this way.

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 Counsellor's presence and role ensures a safe and supportive environment is maintained.
Existing groups continued in 2023, 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 supporting adult children with Fragile X syndrome. There has been a marked increase in the number of participants joining the FXTAS carers Peer Support group as well as individuals with a FXTAS diagnosis.

The online support group established for fathers of children with Fragile X syndrome has continued to convene one evening a month via Zoom and has provided a welcome forum for Dads from different parts of the country to share their experiences.

The value of online peer support groups facilitated by the Family Support Counsellor is reflected in direct feedback received from the participants. The impact is also reflected in a report published by Melbourne Disability Institute called:
Exploring Experiences with Online Peer Support for the Fragile X Community.

This report, published in March 2023, was an outcome of a qualitative research study conducted for FXAA through a Melbourne Disability Institute grant which funded research time. The report is available online:
https://healthsciences.unimelb.edu.au/departments/physiotherapy/chesm/research-overview/exploring-experiences-with-online-peer-support-programs-for-the-fragile-x-community

Overall Findings (extracts from the report)

"Uncertainty, and value of shared experiences
The opportunity to participate in online support programs was highly valued. The support and information that participants received helped address feelings of uncertainty about the future- for themselves and/or their child/relative with a Fragile X disorder. In addition, the ability to share experiences with others in similar situations was invaluable.
"For doctors, it's easy to say, "This is how it is," but when you live it it's different…. I didn't know anything, and it was amazing to feel connected, and I got a lot of valuable information and resources."

Support to navigate healthcare
Participants found it difficult to access care. Participating in online support programs enhanced their confidence and knowledge, particularly regarding how to navigate healthcare services. Participants used this knowledge to identify and connect with clinicians who have expertise in managing Fragile X disorders.
"It gave me a great framework to try and see what's happening, so it made me actually sit down and think about behaviours or communication strategies or what I might need to do differently."

"*What was the key take away message?*
Online peer support programs have numerous benefits for the Fragile X community, allowing people to readily access information and emotional support. Using online delivery modes has enabled a small organisation like Fragile X Association of Australia to support people in the community nation-wide."

[See page 11]

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 1,100 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 a telehealth model for consultations with individuals and families nationally. In Sydney Dr Jane Law, a general practitioner with a specialist intellectual disability practice, offers clinic appointments several times a year at the FXAA premises for adults with Fragile X syndrome. 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.

From July 2022 – June 2023 FXAA organised appointments for 4 days of clinics with Dr Law in the FXAA office, and 1 day of clinics for Dr Cohen in Perth. In November 2023, Dr Cohen saw FXAA members in clinic appointments across two further days in Perth, arranged by FXAA.

TRENDS

We observe an increased focus by parents or siblings of adults who have Fragile X syndrome on future planning, creating life plans, accommodation options, employment supports, guardianship, acceptance within the community. There has been an increase in the number of members with a diagnosis of FXTAS.

Support workers providing one-on-one support or residential staff in Supporting Living Accommodation facilities and educators 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. The Counsellor has presented a number of Fragile X 101 (overview) sessions during staff development or team meetings (live or via Zoom). The presentations have been followed up with a variety of resources from our specialist library of webinar recordings, links and videos on specific topics.

Exploring experiences with online peer support programs for the Fragile X Community

What did we do?

Interviewed **16 people** from the Fragile X community (75% parents/carers of adult/child, 25% adult carriers for Fragile X)

Asked about their experiences with **3 online peer support programs**:
- Educational webinars
- Facebook discussion group
- Zoom group peer support sessions

What did we find?

Overall themes:

Feelings of uncertainty addressed and opportunity to share experiences valued	Enhanced confidence and knowledge in services and supports	Advantages being online, but still a place for in-person events
Experiences with educational webinars	**Experiences with Facebook discussion group**	**Experiences with Zoom group peer support sessions**
Highly valuable source of information	Valuable way to connect and network with other families	Very positive experience and participants well matched
Enhanced learning to a wide audience	Opportunity to share tips on health and support	Helpful to share personal experience whilst learning from others
Content did not always meet individual needs	Different needs and preferences	Consistency and clear organisation is important

What was the key take away message?

Online peer support programs have numerous benefits for the Fragile X community, allowing people to readily access information and emotional support. Using online delivery modes has enabled a small organisation like the Fragile X Association of Australia to support people in the community nation-wide.

Centre for Health, Exercise and Sports Medicine
Department of Physiotherapy, University of Melbourne
More information: Dr Belinda Lawford, belinda.lawford@unimelb.edu.au
Study conducted for the Fragile X Association of Australia and funded by the Melbourne Disability Institute
@CHESM_unimelb
/CHESMunimelb
/company/chesm

"IT'S ESPECIALLY GOOD JUST TO KNOW THAT YOU'RE NOT THE ONLY ONE"

CENTRE FOR HEALTH, EXERCISE AND SPORTS MEDICINE,
THE UNIVERSITY OF MELBOURNE

This research was designed and developed by researchers (Dr Belinda Lawford, Travis Haber, Luke Davies, Prof Kim Bennell, Prof Rana Hinman, and Prof Ann Borda) at the University of Melbourne, for Fragile X Association of Australia.

This project was funded by the National Health and Medical Research Council.

FXAA sincerely thanks Dr Lawford and team for their work on this study, and Melbourne Disability Institute for awarding the grant.

DEVELOPMENTS

Clinical Trials

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 (potentially until the end of 2023) 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 Zynerba's 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 US Federal Drug Administration (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.

Tetra Therapeutics 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.

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.

Future developments

Current treatments for Fragile X treat symptoms are using repurposed drugs which have already been developed for other purposes.

New research in the United States is focused on ways that may provide a cure by enabling cells to produce the FMR protein.

Briefly there are 3 different techniques:

- Delivering the FRAX mRNA using the same technology that was used in some COVID vaccines.
- Reactivating the gene by reducing the CGG repeats using gene shears (CRISPR) or a small molecule drug that shrinks the CGG repeat. Both of these techniques then turn the FMR gene back on.
- Another study found that the Fragile X gene actually does produce a message (RNA) for protein, but that it is abnormal. The researchers found that by blocking this abnormal message, cells were able to produce the correct protein.

These research projects are in their very early stage, using cells grown in culture in the laboratory. Further work would require testing in animal models, then clinical trials in humans and then an approval as a medical device through government agencies like the FDA and TGA in Australia. This will take many years, but the glimmer of hope for a cure is there!

Being a carrier may not impact that person's own health, but there is a chance that their future children may have the condition.

Carrier screening is a genetic test that can tell people if they have an increased chance of having children with an inherited genetic condition.

From 1st November 2023, a new Medicare item number (Item 73451) will cover reproductive genetic carrier testing for Cystic Fibosis, Fragile X syndrome and Spinal Muscular Atrophy for people planning a pregnancy or in early pregnancy.

This important development will make carrier testing more accessible, enabling people to find out at no direct cost whether they have an increased chance of having children with any of these conditions.

The testing may be bulk billed or provided with a gap payment – this will depend on the pathology service providing the testing.

FXAA encourages people interested in this testing to speak with their medical practitioner.

It is important for people to understand how the testing works and the information that it can provide.

People who find out through screening that they have an increased chance of having children with CF, FXS or SMA should be referred to a genetic counselling service.

TREASURER'S REPORT

FXAA continues to be well-resourced to provide support to individuals affected by Fragile X-associated conditions and their families through counselling, peer connections, our educational webinar program, facilitated access to clinics, and promoting awareness of Fragile X in the health & disability arenas.

FXAA started the year in a solid financial position due the generosity of the Cunningham family and other committed donors, donations from the community, fundraising, grants and the efforts of the Board in prior years.

Grant funding is increasingly important in enabling FXAA's delivery of services and programs. Grant funding received this year increased to $161,450 year for current and future delivery of the counselling service, educational webinars and the first national study of the experience of adults and ageing with Fragile X in Australia.

We thank the Cecilia Kilkeary Foundation for supporting 50% of the FX counselling role over 3 years, with grant funding of $78,000 received. FXAA is very appreciative of additional educational grant funding from Zynerba Pharmaceuticals to support further webinars with Dr Marcia Braden in 2023 and 2024. We thank Henroth Group for their support of our 3-year *Fragile X Care | Adults and Ageing* study which will commence in f/y 2024, with a grant of $70,000 per annum for 3 years.

This year we have had a net surplus of $184,534, though this amount is $49,884 when we take into account the grant funds received in advance for the execution of services and projects in f/y 2024 and 2025.

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

- Financial resources

At 30 June 2023, net assets of $1,182,828 largely (66%) comprised the Endowment Fund (see next page) net assets of $785,509.

Net assets increased by 18%, largely due to receiving grant funding in advance of the expenses in the coming years.

- Operating Result

Income ($501,386, up 51% versus last year)

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

In FY2023 the Cunningham family maintained their very generous support and we are extremely grateful for their long-term and on-going commitment to the operations of FXAA.

Donations of $296,361, including to the Endowment Fund, were up 20% versus last year.

Income from fundraising and appeals was down by 41% over the previous year, with a total of $25,649 raised.

FXAA celebrated our 10th year as charity partner for the Oceanpaddler Manly Wharf Bridge to Beach paddle race across Sydney Harbour, with $22,000 raised in 2023. Shaw and Partners Foundation once again generously matched funds raised through this event, and we thank them for their kind and ongoing support. More than $140,000 has been raised from FXAA's charity partnership with the Bridge to Beach, in place since 2014, and we thank Dean Gardiner from Oceanpaddler for this connection.

Other significant donations and fundraisers in 2023 included: Donation and philanthropic grant totalling $40,000 in honour of Mr Greg Mosbey. Donations from John & Christine Kelleher, Smith Charitable Foundation, Dr Jonathan & Rashelle Cohen, and HTR Group. Fundraisers: Sydney City to Surf fundraiser $8,363, Ellinbank Football Netball Club (SE Victoria) $3,120, Galston Garden Club & matching Masonicare funding $3,000, Launceston Church Grammar School $2,800.

Expenditure ($ 319,770, up 1% versus last year)

Our core fixed costs of salaries, rent and bookkeeping fees remain consistent. We have made a provision for long service leave. The FXAA has renewed the office lease for 3 years, with an option for another 3 years.

The service to members largely comprises the HelpLine, counselling support, peer connections, facilitation of clinics, educational webinar series and information resources.

The FX webinar series and online resources have proven to be an efficient and effective way of providing information and education. These resources are being used by families, and by allied health professionals and disability support providers for professional development.

51% of expenditure relates to the provision of service to our members and the wider community, and increasing awareness of Fragile X-associated conditions.

Our expenditure breakdown is 25% to support & member services, 13% to education about Fragile X, 13% to awareness, 36% to organisational management and governance, 7% to rent and utilities, 6% to fundraising/merchandise.

64% 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 the gradual return to face-to-face GP and disability forums in 2023. Management and governance of FXAA remains critical to effective and efficient operation and ensures compliance with regulatory requirements; this cost is largely salary cost.

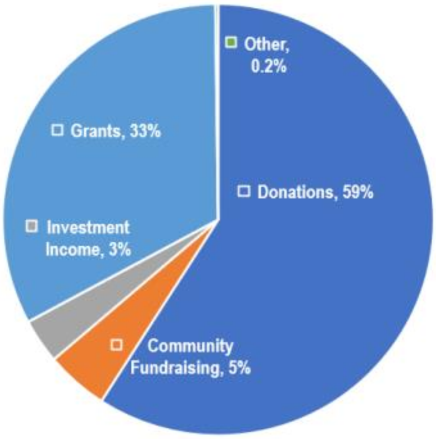
TREASURER’S REPORT—ENDOWMENT FUND

- 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 FY2023 were audited by 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 2022—2023

Expenditure 2022—2023

Endowment Fund

- Endowment Fund - Net assets $785,509
(2022 - $760,747, up 3% versus last year)

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 2023 the Fund's interest and dividend income of $15,884 represented 5% (2022 6.9%) of the Association's annual expenditure of $319,770. 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 40% of the total Fund as at 30 June 2023 (2022 39%).

In 2023 the Fund, like many other investments, performed better than last year but was impacted by poor returns on fixed interest accounts. The market value of the Fund’s investments increased by $2,918 during the period, a small net gain of 0.4%. The challenge will be to maintain reasonable investment returns in an environment of high inflation and market volatility. Donations of $5,988 in 2023 to the Fund remain modest but appreciated.

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 2023 the Endowment Fund Committee comprised Martin Davey (chair), former FXAA President John Kelleher, FXAA Presidents Prof W Ted Brown / Cynthia Roberts and FXAA Treasurer Adam Lawrence-Slater.

In accordance with the guidelines established by the FXAA Board for the Endowment Fund, reviewed and updated in 2023, the funds continue to be invested conservatively.

As at 30 June 2023 the Fund held investments in equities (Australian listed shares, representing 31% of the portfolio) and fixed interest securities (65%) comprising units in unlisted unit trusts. 4% was held in cash which has since been transferred to fixed interest funds.

STRATEGIC PLAN 2022—2025

In 2023 the FXAA Board has renewed its commitment to the **Strategic Plan 2022—2025** as the framework for the service and programs delivered by FXAA to our member base and to the wider Fragile X community.

Fragile X Association of Australia

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

THANKING OUR SUPPORTERS

Our supporters make it possible for the Board and staff of FXAA to continue working towards our vision that people living with Fragile X are connected, included, understood and empowered to live their best possible lives. We are sincerely grateful to the families, individuals, companies, philanthropic foundations, community groups, health professionals and everyone who has supported FXAA this past year.

Cunningham Family

HENROTH Group

Cecilia Kilkeary Foundation Ltd

oceanpaddler

Zynerba Pharmaceuticals
Advancing Science | Improving Connections

ShawandPartners
Financial Services

LINNET FOTO

HTR

Kate Stokes | Graphic Design

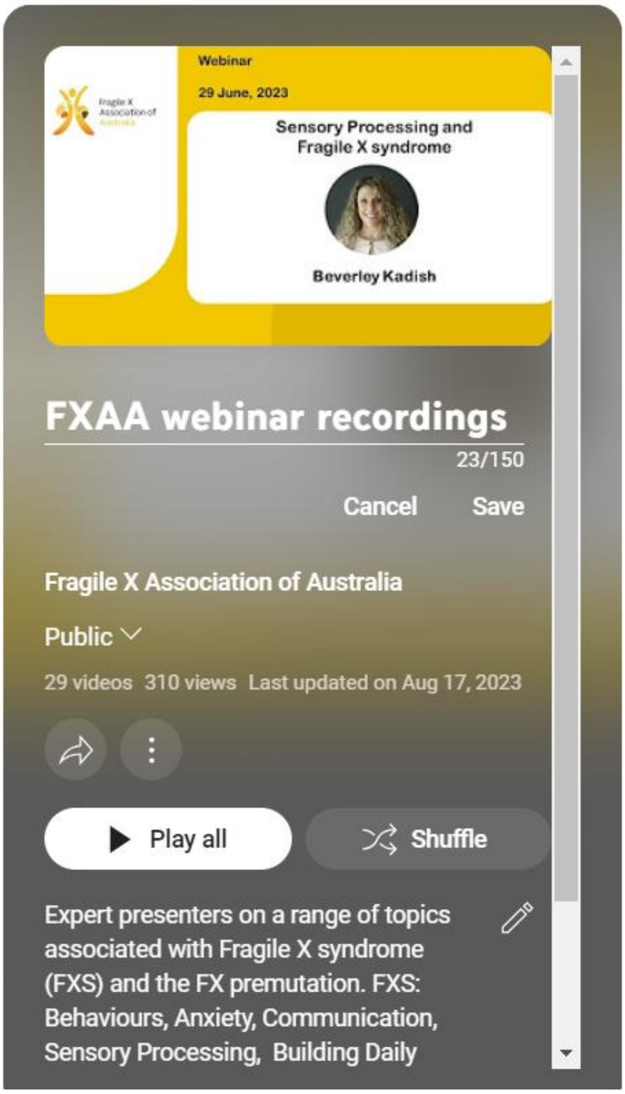
Suzanne Gordon | Photography

MTJ ManserTierney&Johnston
Chartered Accountants & Wealth Management

Healthed

BDA Ballarat Dance Awards

YEAR IN REVIEW — EDUCATIONAL WEBINARS



FXAA webinar recordings

Fragile X Association of Australia

29 videos 310 views Last updated on Aug 17, 2023

Expert presenters on a range of topics associated with Fragile X syndrome (FXS) and the FX premutation. FXS: Behaviours, Anxiety, Communication, Sensory Processing, Building Daily

YouTube

Fragile X Association of Australia

fragileXnewzealand
supporting families living with fragile X syndrome

Webinars with Dr Marcia Braden supported by an educational grant: Zynerba PHARMACEUTICALS

FX Webinar podcasts

Fragile X Association of Australia

Listen on Apple Podcasts

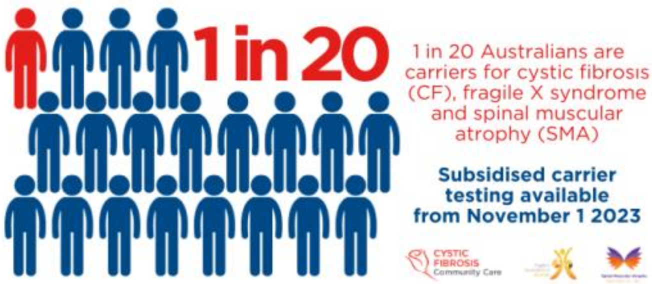
Spotify

The Sunflower Conversations

Fragile X Syndrome with Monique Mitchell and Liz Jewell, Fragile X Australia

AUGUST 06, 2023 HIDDEN DISABILITIES SUNFLOWER

YEAR IN REVIEW – AT HEALTH PROFESSIONAL FORUMS



1 in 20 Australians are carriers for cystic fibrosis (CF), fragile X syndrome and spinal muscular atrophy (SMA)

Subsidised carrier testing available from November 1 2023

YEAR IN REVIEW – AT HEALTH PROFESSIONAL FORUMS

YEAR IN REVIEW – AT DISABILITY EXPOS

DISABILITY EXPO

YEAR IN REVIEW – AT DISABILITY EXPOS

DISABILITY EXPO Gearing Up for Choice & Control

HOBART | **Thursday, 21 September 2023**
Princes Wharf No 1 • 9.30am – 3.30pm

LAUNCESTON | **Thursday, 5 October 2023**
Hotel Grand Chancellor • 9.30am – 3.30pm

DEVONPORT | **Tuesday, 10 October 2023**
paranaple centre • 9.30am – 3.30pm

/disabilityexpostas @disabilityexpostas

FREE ENTRY
www.disabilityexpotas.org

PRESENTED BY SPEAKOUT ADVOCACY

YEAR IN REVIEW – FUNDRAISING

10th year of charity partnership with Oceanpaddler and Manly Wharf *Bridge to Beach* , sponsored by Shaw & Partners

YEAR IN REVIEW – FUNDRAISING

CITY2
SURF

Galston District Garden Club
Friendship Through Gardens

BALLARAT DANCE AWARDS

RM
RUNMELBOURNE

YEAR IN REVIEW – FUNDRAISING

ELLINBANK EAGLES

FOOTBALL & NETBALL CLUB

FRAGILE X
AFTERNOON TEA

JOIN US TO HELP RAISE AWARENESS OF FRAGILE X SYNDROME

Sunday
July 16th
2:00 - 4:00 pm

Cost
$25.00 *

KARRAMOMUS HALL & REC RESE
1005 Karramomus Road
Kialla East

YEAR IN REVIEW – WORLD FRAGILE X DAY

World
FRAGILE X
Day
Global Initiative of FRAXA

OFFICIAL 2023 PARTNER
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YEAR IN REVIEW – WORLD FRAGILE X DAY

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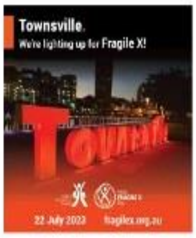

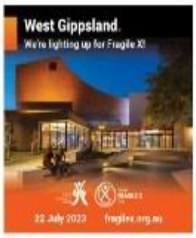

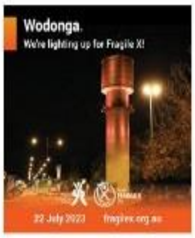

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

FINANCIAL STATEMENTS
30 JUNE 2023

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 comprising the statement of financial position as at 30 June 2023, 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 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 2023 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 Regulations 2022.*

Cynthia Roberts
....
Committee Member Dr Cynthia Roberts PhD, President

....
Committee Member Adam Lawrence-Slater, Treasurer

Dated this 13th day of November 2023.

MTJ
ManserTierney&Johnston
Chartered Accountants & Wealth Management

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

AUDITOR'S INDEPENDENCE DECLARATION UNDER ACNC ACT SECTION 60-40 TO THE COMMITTEE OF FRAGILE X ASSOCIATION OF AUSTRALIA INC

In accordance with Subdivision 60-C of the *Australian Charities and Not-for-profits Commission Act 2012*, I am pleased to provide the following declaration of independence to the committee of Fragile X Association of Australia Inc.

As the lead audit partner for the audit of the financial report of Fragile X Association of Australia Inc for the year ended 30 June 2023, I declare that, to the best of my knowledge and belief, during the year ended 30 June 2023 there have been no contraventions of:

a) the auditor independence requirements as set out in the *Australian Charities and Not-for-profits Commission Act 2012* in relation to the audit; and

b) any applicable code of professional conduct in relation to the audit.

Signed at Turramurra this 14th day of November 2023.

MTJ AUDIT PTY LTD

BEN HODGKINSON
Partner

MTJ
ManserTierney&Johnston
Chartered Accountants & Wealth Management

INDEPENDENT AUDITOR'S REPORT
TO THE MEMBERS OF
FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

REPORT ON THE AUDIT OF THE FINANCIAL REPORT

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 2023, 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 2023 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 Regulations 2022*.

Basis for Opinion

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

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 and have determined that the basis of preparation described in Note 1 to the financial report is appropriate to meet the requirements of the *Associations Incorporation Act 2009 (NSW)* and the ACNC Act and the needs of the members. The committee's responsibility also includes such internal control as the committee determines is necessary to enable the preparation of a financial report that gives a true and fair view and 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 relating to going concern and using the going concern basis of accounting unless the responsible entities either intend to liquidate the registered entity or to cease operations, or have no realistic alternative but to do so.

The committee is responsible for overseeing the Association's financial reporting process.

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.

- 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 14th day of November 2023.

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 2023

	Note	2023	2022
CURRENT ASSETS			
Cash and cash equivalents			
At Bank		184,724	85,475
Endowment Fund	8	29,846	7,585
Petty Cash		100	100
Term Deposit		228,394	160,000
		443,064	253,160
Accounts receivable and other debtors			
Accounts Receivable		12,650	-
Franking Credits Refundable		4,642	5,059
GST Refundable		2,411	3,443
Prepayments		1,356	-
Rental Bond		3,416	3,416
		24,475	11,918
TOTAL CURRENT ASSETS		467,539	265,078
NON-CURRENT ASSETS			
Property, plant and equipment			
Property, Plant and Equipment - At Cost		15,250	12,960
Less: Accumulated Depreciation		(8,281)	(5,606)
		6,969	7,354
Investments			
Listed Investments at Market Value - Endowment Fund	8	243,234	248,894
Unlisted Investments at Market Value - Endowment Fund	8	507,787	499,208
		751,021	748,102
TOTAL NON-CURRENT ASSETS		757,990	755,456
TOTAL ASSETS		1,225,529	1,020,534
CURRENT LIABILITIES			
Accounts payable and other payables			
Accounts Payable		2,317	3,910
Payroll Liabilities		10,486	3,339
Other Liabilities		1,561	3,105
		14,364	10,354
Provisions			
Provision for Employee Entitlements		28,337	11,886
TOTAL CURRENT LIABILITIES		42,701	22,240
TOTAL LIABILITIES		42,701	22,240
NET ASSETS		$1,182,828	$ 998,294
EQUITY			
Opening Balance		998,294	1,061,771
Add: Surplus/(Deficit) for the Year		184,534	(63,477)
TOTAL EQUITY		$1,182,828	$ 998,294

The accompanying notes form part of these financial statements.

STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME
FOR THE YEAR ENDED 30 JUNE 2023

	2023	2022
INCOME		
Gross Proceeds From Fundraising Appeals		
Donations - including Endowment Fund	296,361	245,971
FXAA Fundraising Events and Appeals	23,484	43,698
Merchandise Sales	1,054	2,799
Sponsorships	2,165	-
	323,064	292,468
Other		
Dividend Income	15,472	16,865
Grants	161,450	16,113
Interest	1,400	6,406
	178,322	39,384
Total Income (carried forward)	501,386	331,852

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 2023

	2023	2022
Total Income (brought forward)	501,386	331,852
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Other	5,481	6,225
	5,481	6,225
Total Costs Of Providing Services		
Support Services and FX Awareness	68,985	63,426
Clinics and Counselling	62,258	59,364
National Newsletter Printing	-	1,030
	131,243	123,820
Other		
Bank Fees and Charges	316	391
Board and AGM Expenses	976	1,328
Conferences and Seminars	1,660	13,487
Consultants and Accounting	20,440	20,193
Depreciation and Disposal of Assets	2,675	2,584
General Administration - Employment Costs	77,491	79,268
Information Resource Production	16,827	16,334
Insurance	5,830	5,679
Low Cost Assets	-	490
Office Expenses	6,063	15,049
Office Rent	18,885	18,394
Postage	2,681	2,938
Provision for Employee Entitlements	16,451	(1,028)
Stationery	467	1,947
Subscriptions	5,449	4,805
Sundries	1,252	(12)
Telephone	2,599	3,231
Website	2,984	4,501
	183,046	189,579
Total Expenditure	319,770	319,624
OPERATING SURPLUS FOR THE YEAR	181,616	12,228
Net Increase/(Decrease) in value of investments - Endowment Fund	2,918	(75,705)
TOTAL COMPREHENSIVE INCOME FOR THE YEAR	$184,534	$(63,477)

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 2023

	2023	2022
EQUITY		
Retained Earnings		
Opening Balance 1 July	998,294	1,017,987
Add: Surplus for the Year	181,616	12,228
	1,179,910	1,030,215
Less: Transfer (to)/from Asset Revaluation Reserve	-	(31,921)
Closing Balance 30 June	1,179,910	998,294
Asset Revaluation Reserve		
Opening Balance 1 July	-	43,784
Less: Net Transfer to/(from) Reserve	2,918	(75,705)
	2,918	(31,921)
Add: Transfer (to)/from Retained Earnings	-	31,921
Closing Balance 30 June	2,918	-
TOTAL EQUITY	$1,182,828	$ 998,294

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 2023

		2023	2022
Cash Flow from Operating Activities			
Receipts from donations, fundraising appeals and events		467,315	312,546
Interest and Dividends		17,289	24,409
Payments to suppliers and employees		(292,410)	(313,866)
Net cash provided by operating activities	10b	192,194	23,089
Cash Flows from Investing Activities			
Payment for property, plant and equipment		(2,290)	(3,985)
Net Payment for investments		-	(25,500)
Net cash used in investing activities		(2,290)	(29,485)
Net Increase/(decrease) in Cash Held		189,904	(6,396)
Cash on hand at the beginning of the financial year		253,160	259,556
Cash on hand at the end of the financial year	10a	$ 443,064	$253,160

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;
- 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.

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.

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.

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

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.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023

Note 2 - Information on Material Matters

The Association received a donation of $180,000 from the Cunningham family, a philanthropic donation of $37,471, a donation of $10,000 from Shaw and Partners Foundation, a grant of $70,000 from Henroth Investments Pty Ltd for year 1 of the *Fragile X Care | Adults and Ageing* project (f/y 2024), and a grant of $71,000 from Cecilia Kilkeary Foundation in support of the FX Family Counselling role in f/y 2023 – 2025.

Note 3 - Application of appeal monies

During the year the Association received net income of $484,514 from fundraising appeals and $16,872 from the investment of appeal monies.

An amount of $131,243 was spent on the provision of services (including $62,258 for counselling and clinics and $68,985 for other awareness and support). We spent $131,000 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 2023
- Ellinbank FNC fundraiser
- Fragile X awareness events

Note 6 - Analysis of monetary figures

Ratios	$	%
Total cost of fundraising/ Gross income from fundraising	5,481/484,514	1% (2% last year)
Net surplus from fundraising/ Gross income from fundraising	479,033/484,514	99% (98% last year)
Total costs of services/ Total expenditure	131,243/319,770	41% (39% last year)
Total costs of services/ Total income received	131,243/501,386	26% (37% 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	2023	2022
CURRENT ASSETS			
Cash on hand			
At Bank		29,846	7,585
Accounts receivable and other debtors			
Franking Refund Receivable		4,642	5,059
TOTAL CURRENT ASSETS		34,488	12,644
NON-CURRENT ASSETS			
Investments			
Listed Investments - At Market Value		243,234	248,894
Unlisted Investments - At Market Value		507,787	499,208
TOTAL NON-CURRENT ASSETS		751,021	748,102
TOTAL ASSETS		785,509	760,746
CURRENT LIABILITIES			
Accounts payable and other creditors			
Other creditors		-	-
TOTAL CURRENT LIABILITIES		-	-
NET ASSETS		$785,509	$760,746
EQUITY			
Opening Balance		760,746	810,457
Add: Income /(loss) for the Year	9	24,763	(49,711)
TOTAL EQUITY		$785,509	$760,746
Total Equity Comprises:			
General Fund		469,535	452,289
J & M Cunningham Endowment		315,974	308,457
		$785,509	$760,746

Note 9 - Endowment Fund

Income & Expenditure Statement - for the year ended 30 June

	2023	2022
INCOME		
Donations	5,988	4,300
Interest & Dividend Income	15,884	21,710
Increase in Market Value of Investments	2,918	-
	24,790	26,010
Less:		
Decrease in Market Value of Investments	-	75,705
Expenses	27	16
	27	75,721
NET INCOME/(LOSS) FOR THE YEAR	$ 24,763	$(49,711)

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:

	2023	2022
Cash at bank	443,064	253,160

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

	2023	2022
Operating Surplus	181,616	12,228
Non-cash flows in Operating Surplus		
- Depreciation	2,675	2,584
Changes in assets and liabilities		
- (Increase)/decrease in receivables	(12,650)	8,515
- (Increase)/decrease in other assets	89	3,029
- Increase/(decrease) in payables	(1,593)	(5,876)
- Increase/(decrease) in other current liabilities	5,606	3,637
- Increase/(decrease) in provisions	16,451	(1,028)
Net cash provided by operating activities	$192,194	$ 23,089

Fragile X
Association of
Australia

You can make a difference in the lives of those affected by Fragile X

Become a Member

Membership is free and open to anyone in Australia impacted by Fragile X syndrome or Fragile X-associated conditions

Donate

Now or at any point throughout the year. Your donation will help us to provide support to the Fragile X community, and to increase awareness of Fragile X-associated disorders.

Volunteer

Register your interest to volunteer, there are endless ways to get involved and show your support in a way that suits you

Fundraise

Ask us how we can support and promote your fundraising efforts

Connect

Keep up to date via our website and social media updates

Bequest

A very special way of making a positive difference beyond your lifetime.

Fragile X Association of Australia Inc

Registered office: Suite 204, 20 Dale Street, Brookvale NSW 2100
02 9907 2366   1300 394 636
ABN 18 655 264 477   ARBN 626 478 966
Registered Charity