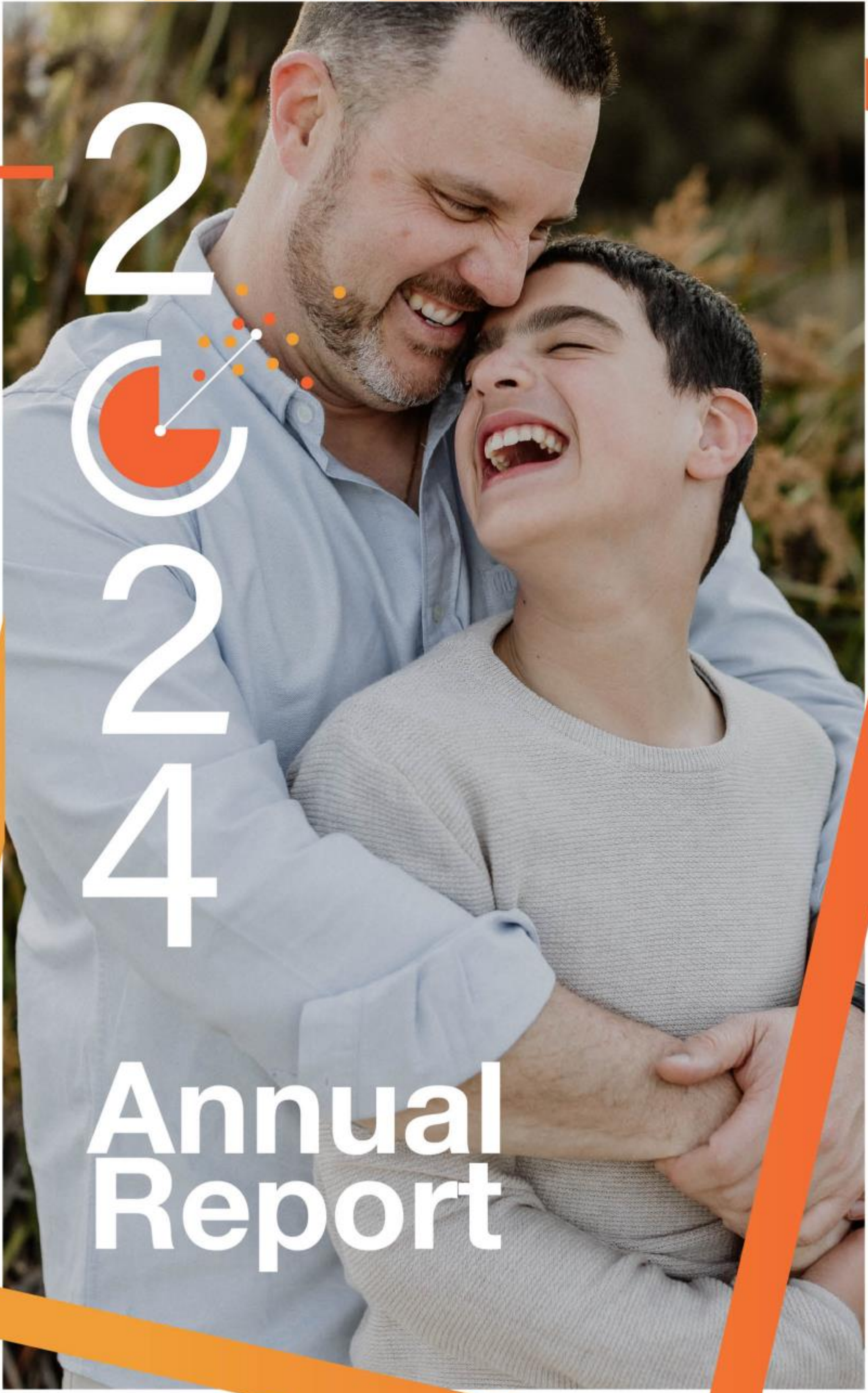
Fragile X
Association of
Australia

2023–2024 Annual Report



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30 Years Strong | Supporting | Sharing | Connecting | Informing

PRESIDENT'S REPORT

This year has been extremely productive with the FXAA Board and our small team of staff working alongside our wonderful volunteers to help ensure people with Fragile X are connected, included, understood and empowered.

- **Key highlights for 2024**

Fragile X Adults & Ageing project: the first stage of the research is complete. This included interviews with health professionals, questionnaires completed by support workers and carers of adults with Fragile X syndrome and focus groups. Thank you to everyone who contributed. We look forward to understanding the emerging trends and support needs this data identifies.

Following this we will develop learning resources for disability support and aged care teams that will better support their care of adults with Fragile X syndrome. These projects require support from many.

Thank you to the Centre for Disability Studies for working with us, and to the members of the Expert Advisory and the Lived Experience Panels, as well as **Henroth Group** for the grant which is funding this important initiative.

Reproductive genetic carrier screening: this screening provides couples with information about their chance of having a child affected by a serious genetic condition, and we have been pleased to see great uptake of the Medicare subsidy introduced in November 2023 to cover Fragile X, Cystic Fibrosis and Spinal Muscular Atrophy.

FXAA has attended several medical conferences this year to promote awareness of Fragile X. It is evident not all GPs and specialists are aware that this test should be offered to all women planning or in the early stages of pregnancy. Moreover, many GPs require further education on screening to support patients who receive a positive result of an increased chance of having a child with Fragile X syndrome. Our presence at these conferences helps us inform the medical colleges and Human Genetics Society of Australasia in relation to reporting and follow up advice which should be provided.

We continue to advocate for a comprehensive genetic counselling service to support the carrier screening processes and future expansion of genetic testing offered. We had the opportunity to speak with the assistant to the Minister for Health regarding the implementation of the carrier screening and the possibility for further improvements

FraXI: FXAA became a member of FraXI, an international alliance of FX family support groups, principally based in Europe. We've taken part in online meetings to understand the advocacy work of these groups, and shared the progress of our *Fragile X Care | Adults & Ageing* project. Pleasingly, there is the possibility of other countries undertaking similar studies in the future.

Outreach, Support and Connection: we've seen 22% growth in our membership this year and have extended our outreach to additional regional and metropolitan areas, empowering even more people living with Fragile X to live their best possible life. Our HelpLine responses, counselling service and peer connections and webinars continue to meet the needs of our community.

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- **Funding**

As a registered charity we rely on funding donations and support-in-kind which provides us with financial support for our programs. We continue to seek ongoing funding (via fundraising, grants and sponsorship) for the core services we offer our community. We encourage our members to consider making donations, conduct fundraising events, or contemplate a bequest. Our thanks and gratitude go to everyone who has made a contribution, large or small, this year.

Cecilia Kilkeary Foundation: A grant from the Foundation has continued to part-fund our Family Support Counsellor role over a three-year period, acknowledging the important impact this role has for many people in our community.

John & Margaret Cunningham: John and Margaret Cunningham have been very generous supporters over many years, and we thank them for their ongoing and extensive philanthropic support. A significant donation was received from the Cunningham family to the Endowment Fund this year. This contribution has been invested, under the advice of our Endowment Fund Committee, to provide future income to support the work we do for the FX community.

- **Volunteers**

We have many wonderful volunteers who contribute their time and expertise in attending Fragile X exhibition stands at expos and medical conferences, by fundraising, providing legal guidance, graphic design, serving on our Committees and in many other ways. Many groups have fundraised throughout the year to provide additional funds to support our operations.

- **Experts and Support Services**

We also thank the services which support our community with diagnosis including VCGS and the GOLD Service (NSW). We appreciate the commitment of the experts involved in presenting our excellent educational FX webinar series as well as the assistance of Dr Jonathan Cohen and Dr Jane Law who provide Fragile X Clinics throughout the year.

- **Board**

Our Board members are all volunteers and they ensure we continue to operate with good corporate governance. My thanks to them and, of course, our wonderful staff, Wendy Bruce and Liz Jewell. People are often surprised that we only have a staff of two, who conduct our core work of supporting the FX community, individuals and families. This includes counselling, our HelpLine, peer support & connections, and referrals. Our work extends to advocacy and awareness across a range of health & disability forums and delivery of our webinar program.

- **Other areas of advocacy**

We collaborate with several different organisations with common goals. This year these included Centre for Disability Studies, Rare Voices Australia, and Neurological Alliance Australia. We are a collaborator organisation of the National Centre of Excellence in Intellectual Disability Health. As a member of a consortium for Disability Representative Organisations, we will have input to Australia's Disability Strategy 2021-2031 and changes to the NDIS.

♦ The Future

Looking ahead, there is some exciting early-stage international research and discovery work regarding possible treatments which could reduce symptoms of Fragile X syndrome, and we continue to advocate for a stronger research focus on Fragile X Premutation Associated Conditions.

We keep up-to-date with developments via our Scientific Clinical and Research Committee (Chaired by our Vice President Prof Ted Brown) and Fragile X Roundtable meeting, together with our links with international organisations such as FRAXA Research Foundation in the United States and FraXI in Europe. We remain hopeful and confident that these will come to fruition in years to come.

We were saddened to learn of the passing of **Professor Gillian Turner AO**, in August this year.

Gillian's groundbreaking work in identifying Fragile X syndrome was crucial in advancing our understanding of its genetic basis. Gillian is remembered extremely fondly by the many families across Australia who were diagnosed by Gillian and her team, and remembered with respect and fondness by the health professionals who worked alongside her. Wendy Bruce, Liz Jewell and Board member Alison Evans represented FXAA at a memorial service for Gillian held by her family in Newcastle.

As we prepare to mark the 35th anniversary of Fragile X Association of Australia as an incorporated association in December 2024, I'm proud to share this annual report detailing our progress in support of our four key strategic focus areas:

- Connecting people living with Fragile X with the Fragile X community and providing support
- Providing information and education for people living with Fragile X and the Fragile X community
- Influencing public policy, advocating for research and building partnerships
- Developing knowledge of Fragile X amongst healthcare professionals, educators and service providers

FXAA represents all people and families living with Fragile X syndrome and Fragile X Premutation Associated Conditions, and it is an honour to support and advocate for our community.

Sincerely,

Dr Cynthia Roberts, PhD

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

Photo credits
Front cover: Luke and Logan Goss (Lana Pratt Photography) Back cover: Lindsay Family (Daniel Linnet, LinnetFoto)

OUR TEAM

BOARD 2023—2024

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 25 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 prenatal diagnosis for Fragile X. Prof Brown chairs FXAA's Scientific, Clinical & Research Advisory Committee. Prof Brown joined the Board in 2018 and is immediate past President. He is based in New York.

Adam Lawrence-Slater, Treasurer
Adam works in financial planning and data insights in the airline sector and for several years was 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 forums 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. Kate 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 lives 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 currently works part-time as a disability support worker.
Belinda is extremely passionate about raising awareness of Fragile X syndrome and she is keen to support the Fragile X 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 Fragile X, earlier diagnosis, genetic screening, and for inclusion for people living with a disability.
Mandy lives in Brisbane and joined the Board in 2021. Mandy resigned from the Board, effective on 28 June 2024.

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.

VALE

Professor Gillian Turner AO, 1930 -2024

Professor Gillian Turner AO was a distinguished physician, an internationally acclaimed geneticist and a worldwide authority on the X chromosome. Gillian contributed fifty-four years of service to the field of paediatrics and genetics before retiring in 2010. Her work led to new screening techniques for genetic disabilities.

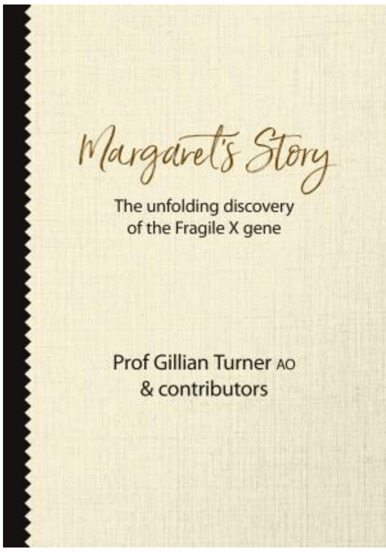
Among her most important work in the 1970s was contributing to the discovery of the gene which causes Fragile X syndrome and defining the importance of X-linked mental retardation. Gillian studied medicine at St Andrews University, Scotland, graduating in 1956. She trained in Paediatrics in Canada and London before emigrating to Australia. She became interested in developmental disability and genetics while working with her husband, Dr Brian Turner, at Johns Hopkins Hospital, Baltimore, Maryland in the US.

She was a research fellow with the Children's Medical Research Foundation in Sydney from 1970 to 1976 and the Director of the Tumbatin Clinic for Assessing Children with Disability at the Sydney Children's Hospital for a decade. As Associate Professor of Medical Genetics at the Prince of Wales Hospital, Sydney between 1986 and 1994, Gillian established a genetic outreach service for regional areas of New South Wales and ran the NSW Fragile X screening program. In 1994 she became Director of Hunter Genetics and the GOLD (Genetics of Learning Disability) service and was appointed the first Professor of Medical Genetics at the University of Newcastle.

Gillian was recognised for her outstanding contribution to the field of Medicine in being made an Officer of the Order of Australia (AO) for her services to genetics in 1990. She was an honorary member of the Human Genetics Society of Australia.

Gillian published many research articles, and her book publications include **Y the X? Unravelling intellectual disability and autism** (2012) and **Finding the Sapiens genes** (2019).

Gillian also coordinated a memoir called **Margaret's Story: The unfolding discovery of the Fragile X gene.** (2021)



Margaret's Story

The unfolding discovery
of the Fragile X gene

Prof Gillian Turner AO
& contributors

Margaret's Story was published by FXAA in 2021.
It can be read online on the ISSUU platform.

Gillian first met Margaret Cunningham in about 1970 at the Sydney Children's Hospital when Margaret took part in research which Gillian and her team were conducting to identify a cause of intellectual disability in a group of children.
Gillian later diagnosed Margaret and John's son, Sean, with Fragile X syndrome.

In the foreword to *Margaret's Story* Gillian wrote:

"Little did we know at the time how significant that meeting and her involvement in our research would be. However, my team and I weren't the only ones pursuing research in this area.

Not long after we had started, Professor Grant Sutherland began studying fragile sites on various chromosomes in Adelaide, where he was working as Head of Cytogenetics at Adelaide Children's Hospital (now the Women's and Children's Hospital, Adelaide).

A breakthrough discovery Professor Sutherland made in 1977 sparked a friendly competition between the two of us and we later collaborated, publishing a joint paper in 1985. We made a formidable team, jointly discovering the FMR1 gene mutation in 1991, a major scientific breakthrough. I am proud to say, Professor Sutherland and I led the world in both clinical and genetic aspects of X-linked intellectual disability and, most notably, Fragile X syndrome from the late 1970s until the early 1990s. The research we pioneered was continued by Professor Randi Hagerman in the United States, and several others.

Many advancements in the knowledge about Fragile X syndrome occurred over the years since I first met Margaret, and some of how this occurred is described in this booklet by a few of the key people involved, including Professor Sutherland, Professor Hagerman and myself. While we were motivated at the time by the need to find answers for families, we were also fuelled by the pure excitement of discovery."

Margaret Cunningham AM and John Cunningham AM went on to co-found Fragile X Association of Australia.

Mrs Margaret Cunningham AM and Prof Gillian Turner AO, 2019

YEAR IN REVIEW 2023-2024

FXAA's *Strategic Plan 2022-2025* sets the framework for the service and programs delivered to our member base and to the wider community of people who are living with Fragile X syndrome or are carriers of the Fragile X (FMR1) premutation. The Strategic Plan has four pillars of focus: Support & Connection, Empowerment, Advocacy and Education.

Aligned with these four pillars, FXAA's core programs involve supporting individuals and family member carers affected by a Fragile X-associated condition, HelpLine, providing information and education, referral to services, improving awareness of Fragile X in the health and disability sectors, and advocating for appropriate and early access to testing, diagnosis, treatments and supports. *[Strategic Plan, page 3]*

Highlights of 2023-2024 include:

Fragile X Care | Adults & Ageing - commencement of our grant-funded project which is the first national research to put a spotlight on the support needs and experience of adults living with Fragile X syndrome.

Reproductive genetic carrier screening for Fragile X, cystic fibrosis and spinal muscular atrophy subsidised by Medicare from 1 November 2023.

FX Webinar Series expanded to cover new topics, including the differential diagnosis of FXS and ASD and planning for the future for adults with Fragile X syndrome.

Fragile X awareness promoted through our expanded presence at Disability Expos and health professional education forums to cover each state and the ACT.

Advocacy

FXAA engages in systemic advocacy with the aim of influencing positive long-term change in public policy matters affecting individuals who live with Fragile X syndrome or the FMR1 premutation, and their family members/carers. We are actively involved in working with other organisations for advancements in testing and diagnosis, access to treatments, improved health and wellbeing, and access to disability supports.
Our Executive Director and Board members represent the Fragile X community in a range of forums.

We collaborate with organisations with whom we share areas of focus or concern, to work towards common goals. This approach amplifies the voice of the Fragile X community beyond what FXAA can deliver alone. We support the advocacy of health and disability peak bodies such as *Rare Voices Australia, Council for Intellectual Disability*, *Inclusion Australia*, and *Neurological Alliance Australia.* We are a collaborator organisation of the *National Centre of Excellence in Intellectual Disability Health.*

FXAA is a member of the Down Syndrome Australia-led government-funded Disability Representative Organisation, which is a consortium of organisations formed to conduct systemic advocacy and represent people with intellectual disability with a focus on chromosomal variations. The Consortium will be in place July 2024-October 2026, to focus on providing feedback to government on *Australia's Disability Strategy 2021-2031*, disability health and aged care, changes to the NDIS, the Foundational Supports system which will be implemented alongside the NDIS, and other issues as they emerge.

Reproductive Genetic Carrier Testing – Medicare subsidy

1 in 20 Australians are carriers for Fragile X syndrome, Cystic Fibrosis or Spinal Muscular Atrophy.

Reproductive genetic 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) covers reproductive genetic carrier testing for Cystic Fibrosis (CF), Fragile X and Spinal Muscular Atrophy (SMA) for couples planning a pregnancy or in early pregnancy. Public funding of this test has been an important 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.

FXAA worked closely for a number of years with support groups Spinal Muscular Atrophy Australia and Cystic Fibrosis Community Care together with not-for-profit Victorian Clinical Genetics Services (VCGS) and the Mackenzie's Mission carrier screening pilot study team, to advocate for government funding for this testing. Since the introduction of the new Medicare items, the takeup of this 3-gene reproductive carrier screening has been high. In the first twelve months since the introduction of the test as funded through Medicare, approximately 100,000 people have accessed the testing. (*Source: Services Australia website*)

We have identified gaps in the knowledge of some health professionals about reproductive genetic carrier screening. Such as: which patients should be offered reproductive genetic carrier screening and when, and the appropriate referral pathways for genetic counselling or additional testing for patients identified as having an increased chance of having a child with Fragile X syndrome. We encourage the professional bodies for GPs and other health professionals to make information resources on reproductive genetic carrier screening widely available and known to their members.

FXAA remains supportive of ongoing efforts advocating for increased and subsidised access to genetic counselling for individuals and couples accessing genetic testing or screening, and Medicare-subsidised access to expanded reproductive carrier screening (for 100's of genetic conditions).

Testing for Fragile X

Inconsistencies of approach by clinicians and genetic services in testing for the FMR1 premutation or Fragile X syndrome continue to be evident (as we have reported previously).
In particular, we continue to observe differences of approach across states/territories/services to parents' requests for wider family testing of children and adults (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.

Newborn bloodspot screening

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 those at risk of becoming seriously ill from a group of rare conditions.

Criteria for inclusion of a condition in the NBS testing include: availability of a specific and reliable test; health outcomes of the condition of the condition are well understood; a treatment is available and effective. Conditions screened for include certain endocrine and metabolic disorders, and conditions such as CF, and SMA. While the Commonwealth Department of Health is assessing the potential addition of more rare conditions to the program, Fragile X syndrome does not yet meet the criteria for inclusion.

However, several government-funded research studies are underway to assess the benefits of an extended NBS program. FXAA is involved as a patient advocacy group in the Epi-Genomic Newborn screening (EpiGNs) program led by A/Prof David Godler at Murdoch Children's Research Institute (MCRI). Over 5 years EpiGNs will examine whether conditions linked to intellectual disability, autism, severe obesity and seizures can be identified as part of the heel prick test performed in the first year of life of 100,000 Victorian infants. The EpiGNs program will use a new approach to identify changes in the activity of genes, to help detect developmental conditions including the Fragile X, Prader Willi, Angelman, Dup15q, Turner, XXY, XXXY and XXYY syndromes.
https://www.mcri.edu.au/research/strategic-collaborations/centres/epi-genomic-newborn-screening-program

FXAA remains hopeful that 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 children and adults with intellectual disability.

The National Centre of Excellence in Intellectual Disability Health, funded by the Commonwealth Government and led by Professor Julian Trollor, was launched in October 2023.
The Centre will play a key role in improved access to quality, timely and comprehensive healthcare for people with intellectual disability, by bringing together experts, resources and research. The work of the Centre will support the development of clinical expertise, establish a national community of practice, and develop training resources. FXAA is one of a number of organisations who act as collaborators in the work of the Centre.

NDIS

Earlier this year the Australian Parliament approved legislation to bring into effect significant wide-ranging changes to the National Disability Insurance Scheme (NDIS). The changes are intended to reduce the cost of the scheme and ensure its sustainability, and will be staged over a period of 5 years. A number of announced changes took effect from 3 October 2024, and others have been outlined, with little detail, for future introduction.

Significant changes announced at this point in time include: introduction of lists defining which NDIS Supports will be funded, and those which will not be funded; new processes for setting and managing budget amounts, rather than detailed line items; longer plans (in the future); changes to the eligibility criteria for initial and ongoing access to the NDIS; and new criteria for early intervention NDIS supports.

Further, the Federal Government has announced that it will work with State and Territory governments to implement a new system called " Foundational Supports" which is intended to provide supports and information for people with disability who don't meet the new criteria for initial or ongoing access to the NDIS. The Foundation Supports program has yet to be designed or funded; community consultation processes have commenced.

Ongoing changes to the NDIS are communicated through NDIA newsletters and the NDIA and Department of Social Services websites.

FXAA collaborates with several groups which consult with government regarding new and proposed changes to the NDIS and other public policy matters relevant to the Fragile X community. FXAA is a member of the Down Syndrome Australia -led Disability Representative Organisation which represents people with intellectual disability through chromosomal variations. FXAA is a member of a Rare Voices Australia Disability Forum and a member of advocacy group Neurological Alliance Australia. These groups and others are engaged in systemic advocacy around the impact of changes to the NDIS.

Genomics

Genomics and Disability

From 2021 FXAA represented Rare Voices Australia on an advisory panel for a University of Queensland research project investigating the implications of rapid advances in genomics for people with disabilities and their families, and creating resources for people with disability, their families and medical and health professionals regarding genomics and disability. The project, funded by the Medical Research Future Fund, and named *We Need to Talk: Genomics and Disability*, concluded its reporting in December 2023.

Genomics and Primary Care

FXAA is 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*. The project involves implementation research on strategies to improve clinical capacity to apply genomics in general practice.

The work commenced in 2024, and is led by Prof Jeffrey Braithwaite (Macquarie University). The goal of the project is to streamline pathways and resources for GPs offering, and consumers considering, screening tests.

FXAA will bring to the project our knowledge of the experiences of individuals accessing reproductive genetic carrier screening, and of the challenges some GPS have faced in offering this testing to patients.

Education

General Practitioners

Since 2015 FXAA has been supported by GP education provider *Healthed* in our goal to improve understanding of health professionals about Fragile X. Healthed provides us with an exhibition table (pro bono) at their Women's & Children's Update and Medical Update seminars which are held annually in Adelaide, Brisbane, Melbourne, Perth and Sydney.

Attended by close to 10,000 health professionals (2024 data) each year, the 7 seminars in the series enable us to have conversations with literally hundreds of GPs across Australia about conditions associated with the FMR1 premutation and about Fragile X syndrome.

As we continue to see strong interest from GPs and other primary care professionals in better understanding reproductive genetic carrier screening and the supports their patients may require following a high chance result for Fragile X, carrier screening has remained a focus of our presence at Healthed events through 2023 and 2024. Two resources we provide have been in demand at these events: 'Guidance statement for GPs on females with the Fragile X premutation', prepared by Fragile X Alliance Clinic and FXAA, and the VCGS brochure for health professionals 'Understanding fragile X carrier screening results'. We also provide the seminar attendees with a link to our webinar recording 'Carrier Screening for Fragile X', presented by A/Prof Alison Archibald (VCGS) for FXAA in 2022.

The Board extends appreciation and thanks to Dr Ramesh Manocha and his team for the opportunity to attend the Healthed seminars every year. We also thank VCGS for supporting FXAA with the presence of a VCGS genetic counsellor on the FX tables at these events through 2023 and 2024.

Genetic Counsellors

Our Family Support Counsellor, Liz Jewell, presents at the annual Fragile X Workshop for Master of Genetic Counselling and Genomics program students. Liz is an annual guest presenter at the UTS Master of Genetic Counselling "Meet the experts" series, and in May 2024 also served as an adjudicator on the UTS Research Panel for the students presenting their work.

In July 2024, FXAA was invited to co-present on Fragile X with the GOLD (Genetics of Learning Disability) Service team at the NSW Genetic Counselling Education Day, which was attended by several hundred genetic counsellors.

These forums are an invaluable way to ensure that genetic counsellors, who have a critical role to play in testing and diagnosis, develop a strong understanding of Fragile X syndrome and Fragile X Premutation Associated Conditions.

Menopause Specialists

The biennial *International Menopause Congress* attracts a large gathering of health professionals from around the world for a 3-day program of presentations and an exhibition. As an estimated 30% of FMR1 premutation carriers experience FX-associated Primary Ovarian Insufficiency (FXPOI) the Congress is a key opportunity to profile the connection between Fragile X and early menopause/POI. The 2024 event was held in Melbourne in October and was attended by close to 2,700 delegates, including over 1,600 from Australia. 34% of delegates were GPs and 28% were gynaecologists. Several presentations addressed Primary (Premature) Ovarian Insufficiency, highlighting the FMR1 premutation as a known cause. Thanks to the support of the Congress local organising committee, FXAA had a prominent table in the exhibition space, allowing FXAA's President and Executive Director to have conversations with hundreds of delegates over the 3 days.

Medical Students

The University of NSW Medical Student Expo is run every 2 years to give 1st & 2nd year medical students the opportunity to meet representatives from health-related community support organisations and patient advocacy groups. We were delighted to attend this event at UNSW in July, with a FXAA member supporting our Executive Director in having conversations about Fragile X with many of the 500 students present. The students expressed great interest in genetic testing and screening for Fragile X, and the potential for future treatments for Fragile X syndrome.

Disability Expos

Disability Expos showcase services, products and information for people with disability and continue to be an effective way for FXAA to engage on a national level with disability service providers and allied health professionals about supports for their clients with Fragile X syndrome. Expos also provide an opportunity for FXAA to learn about supports/services available in major cities and the regions, and are an important opportunity for our Counsellor, Liz Jewell, to meet our members face-to-face.

In the 12 months to 30 June 2024, FXAA attended 11 Expos in metropolitan and regional centres in the ACT, NSW, Queensland, South Australia, Tasmania and Victoria. In the second half of the 2024 calendar year, we attended 7 Expos including, for the first time, those in WA (Perth) and on the Sunshine Coast.
It's been wonderful to take part in these events.

Disability Expos have also provided an excellent platform for FXAA to engage disability support providers in our *Fragile X Care | Adults & Ageing* study through involvement in the survey for disability support teams. They also affirmed the need for learning resources about supporting adults with Fragile X syndrome.

Many thanks to *Impact Institute* for the opportunity to take a 'community' booth in their Expo series in calendar year 2024 and again in 2025. And many thanks to the annual "Bully's Campout" event in WA which raised funds for FXAA to provide for Liz to attend the Disability Expo in Perth and arrange meetups with our members in WA.

FX Webinar Series

The goal of our FX Webinar Series is to offer high value, unique and targeted content delivered by subject matter specialists across a wide range of topics relevant for the Fragile X community. Such as, understanding health or support needs of a child or adult with Fragile X syndrome, planning for the future for a child/adult with Fragile X syndrome, and understanding the Fragile X (FMR1) premutation. This is an educational series and offers presentations and a live Q&A segment.

It's always a privilege to have expert Australian and international presenters take part in the webinar program, including psychologists Dr Marcia Braden and Dr Jennifer Epstein, Katie Clapp (co-founder FRAXA Research Foundation) and Dr Jonathan Cohen MD. It has been a pleasure to co-host several of our webinars with Fragile X Society of New Zealand.

FXAA delivered 10 webinars in financial year 2024 and a further five from July-November 2024.

Topics new to the program in 2024 have included:
Fragile X syndrome and ASD (differential diagnosis),
Toileting and Fragile X syndrome, Disability Estate Planning,
Special Disability Trusts, Circles of Support, and Microboards.
The webinars on future planning aligned well with our current work on the *Fragile X Care |Adults & Ageing* project.

We convened a new 'open mic' format webinar with psychologist Dr Marcia Braden PhD and Dr Jonathan Cohen called "Ask me anything about Fragile X syndrome" which was very well attended. Our most recent webinar was an update on the FMR1 Premutation-Associated Conditions, presented by Dr Cohen.

Webinar attendance varies according to the topic presented, and may include FXAA members, the wider FX community, allied health professionals, disability support providers, educators, and genetic counsellors.

Registration to attend the webinars live varies according to topic, ranging from around 40 up to 100 (the maximum allowed for our Zoom license).

Recorded webinar presentations are made freely available on FXAA's YouTube channel and as podcasts on Spotify and Apple platforms, alongside other video and audio resources produced by FXAA. Webinar recordings are each viewed hundreds of times on our YouTube channel; the recordings have both an Australian and global audience.

In 2025 we will introduce further new topics to the series, including management of FXTAS, and supporting the Prader Willi phenotype in Fragile X syndrome, amongst others. We will also provide a further opportunity to participate in webinars on well-received topics such as Disability Estate Planning, Microboards, Medications and Fragile X syndrome, and Sensory Processing Disorders in Fragile X syndrome.

FXAA extends thanks to *Zynerba Pharmaceuticals* for educational grant funding to support a series of webinars with Dr Marcia Braden in 2024, and to the *Qantas Foundation Side by Side* grant program for supporting several webinars in 2024 and 2025.

Fundraising, Donations and Grants

The ongoing financial support from our members and the wider community is fundamental to FXAA's capacity to deliver service and support to our member base and others.

Fundraising highlights in 2023-2024:
Fundraising through charity partnerships with the annual Manly Wharf Bridge to Beach paddle race in Sydney, ongoing support from Ellinbank Football & Netball Club and the Galston Garden Club (NSW), and the FX Raffle in December 2023.
A philanthropic grant from the Henroth Group funds our 3-year Fragile X Care|Adults & Ageing project.

Fundraising

In 2023-2024, $34,535 was raised through individual and community fundraising efforts. Many thanks to everyone involved!

In 2024 FXAA celebrated the 11th year of our charity partnership with the annual *Manly Wharf Bridge to Beach* paddle race across Sydney Harbour. This event has been run for more than 20 years by elite open water sportsman Dean Gardiner and the team from *Oceanpaddler* and is sponsored by *Shaw & Partners Financial Services*. 400 paddlers take on the 11km paddle from near the base of the Harbour Bridge across to Manly Cove.
Once again, the support from the paddlers, donors and race sponsor was outstanding. Thanks to generous donation matching by *Shaw & Partners Foundation*, $29,000 was raised in February 2024 to help fund the Fragile X family counsellor role.

Team Fragile X at the *Sydney City2Surf* fun run/walk continues to grow in numbers year on year, with successful fundraising in August 2023 followed up with an incredible $18,000 raised in August 2024. Many thanks to Board members Cynthia Roberts, Belinda DÁmico, Adam Lawrence-Slater and everyone who took the event on, kitted up in special orange tutus! We look forward to fielding an even bigger team on 10 August 2025.

January 2024 marked the 6th year of our charity partnership with the annual *Ballarat Dance Awards* (BDA). The 3-day event includes masterclasses, scholarship opportunities and performance. In addition to raising funds, the BDA team works to increase understanding of Fragile X through their network.
In 2024 four BDA scholarships were presented at two large Victorian Dance events. The master of ceremonies for each event spoke about Fragile X syndrome and acknowledged BDA's support for FXAA. Many thanks to the team at *Versatility Dance College* for dedicating BDA to Fragile X, in honour of Jimmy Jones.

The *Ellinbank Football and Netball Club* in SE Victoria runs a special Fragile X awareness and fundraising event each 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 Cal Wallace, who lives with Fragile X syndrome. Many thanks to the Club for their ongoing support and enthusiasm.

In December 2023 wooden play equipment handcrafted by our member Ricky Crowe was the centrepiece of our *FX Raffle*.
The Raffle draw was held in the FX office, and was a lot of fun. The Harley Davidson bike has found a wonderful home with Jacob, who is thrilled with it. Many thanks to Ricky for an incredible effort in creating the equipment for the raffle, and his great success in selling raffle tickets. We appreciate *Chewy Charms* and *Cool Kits* donating prizes for the raffle.

Many thanks to community group *Galston & District Garden Club* (NSW) and *Masonicare* for a (matched) donation of $6,000.

Thanks to *Lion's Club Wonthaggi* and *Arabella Hair Design* in Ballarat for their donations and fundraising during the year, and to the *CBA Community Grant* program for the continued support.

Grants

Educational webinar series

A *Qantas Foundation Side by Side* program grant awarded to FXAA in December 2023 has supported several educational webinars in 2024. This grant program is open to long-term employees of Qantas who are invited to apply for a grant to support a charity which they are committed to. We thank our member who has successfully applied for this grant twice.

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, 2023 to 2025. The Counselling 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 or face to face peer support sessions; providing individual counselling sessions for FXAA members with Fragile X syndrome or FMR1 premutation, or as carers; making referrals; and advocacy.

Fragile X Care | Adults and Ageing

In early 2024 FXAA launched the first Australian research 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, and pathways for planning for their future. Further aims of the study are to develop online education resources for disability and aged care workers about Fragile X syndrome, and guidelines for care.

Fragile X Care | Adults & Ageing is a 3-year project, co-led by Centre for Disability Studies (affiliate of University of Sydney). It is funded by a grant awarded to FXAA by The Henroth Group.

FXAA is tremendously pleased to have the opportunity to undertake this important work which we know will have long term benefit. This would not have been possible without the funding support by the Henroth Group, and the Board is deeply grateful.

For more about this study, *see page 13*.

FX Awareness

Right throughout the year FXAA members and their friends and families get involved in increasing awareness and understanding of Fragile X. It's wonderful to have their support at the FX booths at Disability Expos to talk to service providers and members of the public about Fragile X. We also appreciate our members giving their time to represent FXAA at health professional educational forums, sharing posts on social media, wearing the FX logo on runs or fundraising events, and celebrating the annual "light up" for Fragile X.

This contribution makes a real difference in increasing awareness and understanding of Fragile X and is sincerely appreciated. If you'd like to help in any way, please get in touch with us.

World Fragile X Day, 22 July

A highlight in the Fragile X calendar is **22 July**. This date is designated as *World Fragile X Day* in Australia, New Zealand, the US and a growing number of other countries. On 22 July 2024 we were delighted to join with the *FRAXA Research Foundation* team in the US and FX organisations around the world to illuminate more than 400 landmarks for the shared goal of increasing awareness.

Australia's World Fragile X Day effort in 2024 was another personal best for us, with a total of just shy of 125 landmarks across each state and territory lighting up orange. It's fabulous to have such tremendous support each year from a growing number of organisations and infrastructure operators across the private and public sectors.

Special thanks to the families who went along to see their local landmarks lit up in orange and shared posts on social media.

A list of landmarks which supported World Fragile X Day in 2024 is on our website: https://www.fragilex.org.au/22-july-2024-australia-lights-up-for-world-fragile-x-day/

2025 will mark the 10th anniversary of our "light up" campaign! It was a small beginning in 2015, with Victoria Bridge and Story Bridge (Brisbane) and Launceston Town Hall lighting up and grows strongly year on year.

Special thanks to former Board member Nyleta McRae for initiating this program and her ongoing support.

Membership of FXAA

At November 2024, FXAA has 748 members. The majority of our members are individuals or family members of people who are a carrier for the FMR1 premutation or are living with Fragile X syndrome. The member base has increased 22% over November 2023, in contrast to an 8% increase in each of the two prior years. 55 new members joined FXAA over July 2023-June 2024, 34 joined July-November 2024, and a number of former members have renewed their membership and contact with FXAA.
The strong growth in new members has been driven by our face-to-face presence at metropolitan and regional events, such as Disability Expos, from engagement in our *Fragile X Care | Adults & Ageing* work and, to a lesser extent, as a result of contact made by individuals or families who have a new diagnosis of Fragile X syndrome or the FMR1 premutation through testing or reproductive genetic carrier screening.

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

Networks

FXAA values opportunities to work with organisations which are dedicated to supporting the Fragile X community or progressing research in Fragile X-associated conditions. We also value the opportunity to collaborate with organisations which share our focus on intellectual disability or rare genetic conditions. Together we work towards advances in public policy, supports and services.

We work alongside *Fragile X Society New Zealand* to host educational webinars for Australia and New Zealand.

We are a member of *FraXI (Fragile X International),* which is an international not-for-profit organization celebrating and supporting those living with Fragile X syndrome and Fragile X Premutation Associated Conditions around the world.
We have been part of several online FraXI meetings and had the chance to share our work in educating the medical community in Australia about Fragile X, and to talk about our *Fragile X Care | Adults & Ageing* project including the associated surveys for family members and support teams.

We are delighted to have *FRAXA Research Foundation* join our webinar series and the annual Australian Fragile X Roundtable for researchers & clinicians with an interest in Fragile X.
It is inspiring to hear of all of the research into potential treatments for Fragile X syndrome underway.

Our connections with the *Fragile X Alliance*, Victorian *Clinical Genetics Services (VCGS)* and the *GOLD (Genetics of Learning Disability) Service* (NSW Health) are deep and longstanding. These services have supported the Fragile X community with information, services and referrals for many years.

We value our membership of the Disability Representative Organisation led by *Down Syndrome Australia*, our membership of *Neurological Alliance Australia* and the *Intellectual Disability Peaks Group* led by Down Syndrome Queensland.

We appreciate the work of *Murdoch Children's Research Institute (MCRI)* and *VCGS* in undertaking research in testing and screening for Fragile X, and providing clinical services to children and adults. We appreciate MCRI's support of the annual *FXPAC Roundtable* for clinicians and researchers, and staff involvement in the *FXAA Scientific, Clinical and Research Committee*.

We value opportunities to work with or support initiatives of organisations focused on intellectual disability or rare genetic conditions, such as *Centre for Disability Studies*, *Rare Voices Australia and GeneEqual*. We support the initiatives of the group formerly known as *Department of Developmental Disability & Neuropsychiatry (3DN)*, which is now part of the *National Centre of Excellence Intellectual Health*.

Research

FXAA Fragile X Scientific, Clinical & Research Sub-Committee

Our Sub-Committee comprises Australian researchers and clinicians with an interest in Fragile X syndrome or Fragile X Premutation Associated Conditions. The Sub-Committee Chair is Prof W Ted Brown, Vice-President of FXAA. Vice-Chair is Dr Claudine Kraan PhD (MCRI). The role of the group is to offer the FXAA Board clinical and scientific advice on advocacy, information, research, clinical management and other matters associated with Fragile X-associated conditions and to enable a discussion forum for policy matters, knowledge sharing and collaboration. The Sub-Committee meets quarterly.
The membership of the Committee is listed on our website.

Fragile X Roundtable

FXAA co-presents the annual Fragile X Roundtable convened by Dr Claudine Kraan PhD from MCRI. Attended by researchers, clinicians and others with interest in Fragile X syndrome or Fragile X Premutation Associated Conditions, this is an important forum for profiling and discussing research developments.

At the November 2024 Roundtable, A/Prof David Godler (MCRI) and Dr David Francis (VCGS) presented an update on the impact of mosaicism on diagnosis and screening applications based on findings from their research and clinical work, with important insights into the way the genetic variability of Fragile X syndrome results in a wide variability of phenotype. Moreover, they have identified that newer DNA testing methods may not diagnose the full mutation in mosaic individuals and thus the need for Southern blot testing remains critical to accurate diagnosis for these cases.

Dr Jess Klusek from the Arnold School of Public Health in the US spoke about the findings of a study of depression symptoms in a group of women who have the FMR1 premutation. Dr Marta Ochoa (VCGS) discussed a recent qualitative study of the experiences of Australian women with reduced fertility caused by the FMR1 premutation. Dr Mike Tranfaglia, co-founder of FRAXA Foundation, spoke about some of the clinical trial developments in treatments for Fragile X syndrome – some trials underway, and some in early development phases.

International Fragile X Premutation Registry

This resource has been created to facilitate FMR1 premutation research that could positively impact quality of life for people with the FX premutation and its associated conditions.
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 FMR1 premutation carriers and their family members worldwide who are interested in contributing to future research.

Individuals joining the Registry are invited to provide basic demographic and health information so they may be approached to participate in premutation research studies relevant to their situation. The Registry's Advisory Committee members are Fragile X professionals, family members and representatives from FX groups, including FXAA Board member Karen Lipworth, and Dr Jonathan Cohen of Fragile X Alliance.
For more information about the Registry:
https://fragilex.org/opportunities-for-families/premutation-carriers-registry/

Support

People living with Fragile X-associated conditions may face a range of complexities – such as, genetic testing and screening, diagnosis, health implications, or unique psycho-social, mental health or cognitive impacts. They may also be providing for the daily living challenges and lifelong care of family members who have Fragile X syndrome or a Fragile X-associated condition. Individuals living with Fragile X syndrome may be faced with difficulties in daily living, in transitions, and support and inclusion in education, work or residential environments.

These challenges create social, physical, mental health and information needs specific to the FX community which are not met by generic supports. The need is not only at time of diagnosis, but may be ongoing throughout the life course for an individual or family.

Provision of support to the Fragile X community, in a range of forms, remains a key purpose of FXAA, representing around 40% of the time commitment of our staff.

Support Snapshot: *In FY 2024 approximately 125 HelpLine queries were responded to (260 in 2023). Our Family Support Counsellor was involved in around 370 occasions of counselling (460 in 2023) with 150 individuals, facilitated 30 small-group peer support meetings (44 in 2023), and arranged member group get togethers in 5 cities. Additional support was provided through face-to-face meetings at events, as well as delivery of online information sessions to disability support teams and educators.*

The **FXAA HelpLine** is available 5 days per week 9-5pm Eastern Time, attended by our Family Support Counsellor and Executive Director. Our Family Support Counsellor, Liz Jewell, is available 3.5 days per week (48 weeks per year).

The FXAA staff interact with our members on a daily basis in online forums, by phone or email and, to a lesser extent, in person. They also interact with the public, providing information to disability service providers, health professionals, educators and the wider FX community.

COUNSELLING

The Counselling Support role remains a major focus of the work of FXAA. This involves: providing emotional support to people living with Fragile X and their families; providing therapeutic counselling; facilitating online peer support sessions; providing individual counselling sessions for members with Fragile X syndrome / premutation, or as carers; making referrals; providing advocacy or information as required; hosting or attending FX events.

Our Counsellor, Liz Jewell, is a qualified counsellor with over 25 years' experience in counselling in the health, disability and education sectors. Employed by FXAA for over 6 years, Liz has gained specialised knowledge of the Fragile X associated-conditions enabling FXAA to provide unique and critical support to the community Australia-wide. She undertakes ongoing professional development and accesses clinical supervision.

Counselling may be ongoing or may be incidental, related to an event, diagnosis or other one-off need. The model of counselling is tailored to suit the individual's need and address the presenting issue/s. The majority of counselling takes place over Zoom or phone, to accommodate participants residing in any location in Australia. Appropriate referrals are made when necessary and beyond the scope of the counselling role.

The themes addressed by the Counsellor in the 12 months to June 2024 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: adults with Fragile X syndrome transitioning from home to independent living; future planning; transitioning through education; employment; recent diagnosis of the syndrome or a FMR1 premutation-associated condition; navigating relationships; behavioural concerns; anxiety; intimacy; mental health issues. A proportion of our members living with Fragile X syndrome continue to struggle with the ongoing impact of Covid restrictions and transitioning back into the community.

Differences in counselling provided in the prior year: greater number of counselling requests from extended family members and new members; increase in connections with families of younger age children (under 5's) with Fragile X syndrome; an increase in the number of contacts regarding the Fragile X-Associated Tremor Ataxia syndrome, particularly from women.

PEER SUPPORT

Peer support connections help alleviate the isolation experienced by many who are living remotely or experience isolation through their lived circumstances. Online peer support sessions facilitated by the Counsellor allow for people to be connected and share experiences with their peers, regardless of where they live. The Counsellor's role and presence ensures a safe and supportive environment.

While the overall number of Zoom-based peer support occasions is lower than in the previous years, the number of in-person peer support occasions has increased in line with the Counsellor's on-the-ground presence at events.

The value to our members of the peer support continues to be reflected in direct feedback to FXAA.

OUTREACH

Consistent with FXAA's intention to increase outreach to our member base and the public nationally, FXAA has become increasingly involved in participating in Disability Expos in metropolitan and regional centres. In FY 2023-2024 our Counsellor represented FXAA at Expos in Canberra, Melbourne, Brisbane, Hobart, Launceston, Adelaide, Gold Coast and Sydney.

Attending these events has been an important way for the Counsellor to learn about the supports and services in the Expo catchment area that are relevant to Fragile X and to improve local service providers' understanding of Fragile X syndrome. It's also a great opportunity to meet up with and provide peer support connection for some of the individuals and families in that location.

The opportunity to be on-the-ground in this way has been made feasible by the number of Disability Expo events which have emerged in the past couple of years in metropolitan and regional centres. Post-Covid, many FX families have been keen to attend the Expos and have some face-to-face connection.

ADVOCACY

The Counsellor is from to time involved in advocating for an individual or a family. Examples include: writing letters of support to attest to support needs of a child or adult with Fragile X syndrome or an adult with the Fragile X-Associated Tremor Ataxia in a therapeutic, educational or social context.

WEBINARS

The Counsellor hosts and moderates the Q&A in some of our FX Webinars. These events are intended to provide education and support to individuals and families, and provide an important point of connection for the community.

INFORMATION/EDUCATION DELIVERY

The Counsellor has delivered an increasing number of 'Fragile X 101' Zoom-based sessions. These are generally convened at the request of educators who have a student with Fragile X syndrome or disability or aged care service providers who have a client with Fragile X syndrome or new staff members joining their team. Liz is also involved in two genetic counselling training programs as the annual guest lecturer on Fragile X.

CLINICS

The Counsellor plays a role in arranging for or supporting members to access the occasional Fragile X syndrome-specialist clinics in Melbourne, Perth and Sydney with FX-specialist clinicians Dr Jane Law and Dr Jonathan Cohen.

TRENDS

We see an increase in: queries from parents or siblings of adults on future planning, creating life plans, accommodation options, employment supports, guardianship, or acceptance within the community; the number of members with a diagnosis of FXTAS; and a small increase in the number of women approaching FXAA after learning that they are carriers for the Fragile X premutation through reproductive genetic carrier screening or other testing. We also receive a growing number of requests from disability, aged care or education providers for online information sessions

ADULTS & AGEING WITH FRAGILE X SYNDROME

Survey for Family Members

Exploring support needs, health and wellbeing and future planning for adults with Fragile X syndrome

SURVEY OPEN
MAY 2024

NEW AUSTRALIAN RESEARCH STUDY

CDS
Centre for Disability Studies

Fragile X Association of Australia

Study approved by University of Sydney Human Research Ethics Committee

As we age, many of us worry about our health, staying connected with loved ones, and finding the support we need to live fulfilling lives. For adults living with Fragile X syndrome these challenges can be even more daunting.

As an adult living with Fragile X syndrome, ageing presents unique hurdles requiring specialised understanding and care, but an important study is underway that aims to change this for the better.

Cynthia Roberts is the proud mother of Daniel, a 30 year-old man with Fragile X syndrome and the current President of FXAA. Cynthia and Daniel's father are divorced and both remarried with both couples sharing Daniel's care. They are increasingly focused on how best to support him as they grow older and face new and different challenges.

"Daniel was diagnosed with Fragile X syndrome at 18 months. He is seriously affected, with moderate intellectual disability, epilepsy and significant anxiety and behavioural issues. He needs care in all aspects of his life, including personal care, medication, medical and therapy support, home care and out in the community," Cynthia said.

"Although his receptive language is very good, Daniel is effectively non-verbal and uses very little language for communication. This makes understanding Daniel's feelings, concerns and health issues extremely challenging. Without doubt, I understand Dan the best and have good intuition about what he needs. However, I am not the only person in Dan's life, nor am I with him all the time, to provide that interpretation so we need to continue to upskill Dan to increase his abilities to express himself.

"Fragile X syndrome isn't particularly well understood and even in professional and support services, staff may never have encountered an affected individual. This creates additional challenges for providing care, especially given individuals will have their own unique challenges. Understanding this and how this is supported is key to appropriate and compassionate care.

"As Daniel ages, I worry about his health and the support he'll receive when we're no longer able to care for him. Equally, I want him to have the very best care and outcomes possible right now. I'm committed to doing everything possible to make sure he can live his best possible life," Cynthia said.

This sentiment echoes across many families caring for adults with Fragile X syndrome.

Recognising these concerns and some of the gaps in support services, FXAA has partnered with the Centre for Disability Studies, affiliate of the University of Sydney, to undertake a first-of-its-kind Australian research study on adults with Fragile X and ageing – Fragile X Care. The three-year collaboration, funded by a philanthropic grant from the Henroth Group, will help identify the unique support, health and wellbeing needs of adults with Fragile X syndrome as they age.

Wendy Bruce, Executive Director of FXAA, believes this collaborative effort will drive significant positive change. "This is a really unique collaboration. We're focused on three important areas, that collectively, will make a huge amount of difference for adults with Fragile X syndrome," Wendy said.

"Firstly, we're conducting extensive research that is deeply informed by lived experience. We're very invested in making sure the voices of the adults with Fragile X syndrome are heard and that family members and carers have the opportunity to really share their perspective of what's needed to improve supports for their loved ones. We'll use this data to analyse both the current and future needs of adults with Fragile X syndrome so we can advocate to address the gaps in support and services. Our goal is to make sure that no aspect of care is overlooked.

In response to the findings from the survey and focus group discussions, effective education and training resources will be developed to better support disability and aged care teams in their understanding of Fragile X syndrome.

These resources are much-needed and will empower these teams with the knowledge and skills to better support those with Fragile X syndrome. Thirdly, the collaboration will enable more powerful advocacy. The data-driven approach will help FXAA advocate for better outcomes by raising awareness and influencing policy and practice in care and support settings, ensuring that adults with Fragile X syndrome receive the attention and care they deserve."

In the first phase of *Fragile X Care | Adults & Ageing*, family members of adults with Fragile X syndrome and disability support teams were invited to participate in surveys to explore the support needs, health & wellbeing and future planning for the adults. The surveys have closed and data analysis is underway.

Many thanks to our FXAA Members who are involved in our Lived Experience Expert Advisory Panel who help guide the project's design and approach.

Cynthia and Wendy look forward to sharing the results and the next steps with our members in a webinar early in 2025.
The webinar date will be advised on wwww.fragilex.org.au

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. We are also hopeful that clinical trials for treatments for FXTAS may be initiated in the future.

The **Harmony Biosciences** (Zynerba) **RECONNECT** study is underway in multiple sites across Australia (Brisbane, Sydney and Melbourne) and in the US, NZ, Ireland, and UK until the planned end sometime in 2025. The goal is to evaluate the efficacy of the product Zygel in children and adolescents with FXS. Zygel, a transdermal gel, contains pharmaceutically produced cannabidiol, a non-euphoric 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 of the product.

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 (now a Shiongi Group Company) is testing **Zatolmilast** (BPN1477) in multiple sites in the US. The trial involves males with Fragile X syndrome, aged 9-45 years. 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 patients with Fragile X syndrome. By boosting the levels, BPN14770 may help promote nerve cell connections and improve cognitive function in the patients. The results, if they're in agreement with the previous trial, will support Tetra's application for approval of BPN14770 with the FDA.

A phase 2a trial of a BK channel activator (**SPG601**) has been started at a single site in Cincinnati, US, by Dr Craig Erickson, with support from a new start-up company **Spinogenix.** Animal studies supported by FRAXA Research Foundation showed promise to increase brain functioning. If this preliminary placebo-controlled trial is successful, larger trials will be undertaken.

We are still expecting to hear the results of a trial of Metformin that Dr Randi Hagerman and Canadian colleagues had conducted and which had shown promise in earlier studies.

There are no currently active trials underway to treat FXTAS. Past preliminary trials of Allopregnanolone and Citocoline by Drs Randi Hagerman and Deborah Hall in the US have shown some positive results and larger trials may be undertaken in the future.

Future developments

Advances in understanding the genetic and molecular mechanisms of Fragile X syndrome offer hope for future treatments. Research is exploring gene therapies to reactivate the silenced FMR1 gene, restoring FMRP protein production, and targeted drugs to address symptoms like anxiety and hyperactivity. Clinical trials are testing medications that regulate mGluR5 receptors, and personalized medicine may provide more effective, individualized care. Although these treatments are experimental, ongoing research and clinical trials offer optimism for improving the quality of life for those living with Fragile X syndrome.

The FRAXA Research Foundation in the US continues to support studies exploring drugs that might help Fragile X symptoms. In 2021, a study showed that the drug Zatolmilast which is used in Alzheimers disease can improved memory, vocabulary, and reading ability in adult males with Fragile X. Larger studies began in 2022 and it is hoped that further work could lead to Zatolmilast gaining approval from the FDA in the US as a treatment for Fragile X syndrome. Results of the current trial are anticipated in 2025.

As described above, the only clinical trial enrolling participants in Australia is the RECONNECT study by Harmony Biosciences (Zynerba). Improvements in the level of irritability and social avoidance were demonstrated only in certain individuals in the first clinical trial. Consequently, the FDA has requested the current follow-up trial to obtain additional data. It is anticipated that the results of the current trial will be announced in 2025.

The process of applying for FDA and the Australian Therapeutic Goods Administration (TGA) approval for drugs is a complex and rigorous procedure that requires comprehensive regulatory submissions, including clinical trial data to demonstrate a drug's safety, efficacy, and quality. After preclinical testing, the drug sponsor submits an Investigational New Drug (IND) or Clinical Trial Application (CTA) to initiate clinical trials, which are conducted in three phases. Upon successful completion of these trials, a New Drug Application (NDA) or New Drug Submission (NDS) is filed for approval, followed by ongoing post-market surveillance to monitor the drug's long-term safety.

While the prospect of effective treatments for symptoms of Fragile X syndrome is closer than it has ever been, it will still likely be several years before they become available for use.

TREASURER'S REPORT

Fragile X Association of Australia (FXAA) continues to be well-resourced to provide support to individuals affected by Fragile X-associated conditions and their families and carers through counselling, peer connections, our educational webinar program, and facilitated access and referrals to services. FXAA also works to promote awareness of Fragile X in the health & disability arenas and advocate for advances in testing, screening and treatments.

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.

The Cunningham family maintained their very generous support and we are extremely grateful for their long-term and ongoing commitment to the operations of FXAA. The Cunningham family made a significant donation of $500,000 to the Endowment Fund, in an addition to a generous donation of $180,000 for the operations of FXAA. There is more information on the position of the Endowment Fund in the section following.

Grant funding is also increasingly important in enabling FXAA's delivery of services and programs. Grant funding of $78,500 in the 2024 financial year is to be utilised for current and future delivery of the counselling service, educational webinars and our work on the first Australian study of the support needs and experience of adults with Fragile X syndrome.

We are tremendously grateful to **Henroth Group** for supporting our 3-year *Fragile X Care | Adults and Ageing* study through a grant of $70,000 per annum for 3 years.
The project is a collaboration with *Centre for Disability Studies* and commenced in f/y 2024. Grant funding received from **Cecilia Kilkeary Foundation** ($26,000 per annum over 3 years) supports 50% of the FXAA counselling role 2023-2025, and is sincerely appreciated. A **Qantas Foundation Side by Side** grant of $8,500 has supported the production of a number of educational webinars in 2024.

This year we have had a net surplus of $499,637, though this amount is slightly negative when we consider the $500,000 Endowment Fund donation and grant funds received in advance for services and projects in FY25.

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

- **Financial resources**

At 30 June 2024, net assets of $1,682,465 largely (78%) comprised the Endowment Fund (net assets of $1,314,018). Net assets increased by 42%, largely due to the significant donation made to the Endowment Fund.

- Operating Result

Income ($893,522, up 78% 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.

Donations of $757,356, including to the Endowment Fund, increased 156% over last year.

Income from fundraising and appeals increased by 47% over the previous year, with a total of $34,535 raised.

FXAA celebrated our 11th year as charity partner for the *Manly Wharf Bridge to Beach* paddle race across Sydney Harbour, with $29,000 raised in 2024. *Shaw and Partners Foundation* once again generously matched funds raised through this event with a donation of $10,500, and we thank them for their ongoing support. Close to $170,000 has been raised from FXAA's charity partnership with the Bridge to Beach event since 2014, and we thank Dean Gardiner from Oceanpaddler for this connection.

Our end of financial year fundraising campaign raised approx. $41,500. Fundraisers through the year included Bridge to Beach, FX Raffle, Ellinbank Football Netball Club and the Sydney City2Surf event.

Donations in 2024 included those from John & Christine Kelleher, the Smith Charitable Foundation, Dr Jonathan and Rashelle Cohen, HTR Group, and Galston Garden Club (& matched funds from Masonicare). This support is sincerely appreciated.

Expenditure ($ 402,727, up 26% versus last year)

Our core fixed costs of rent and bookkeeping fees have broadly risen in line with inflation, and our salaries have had adjustments that keep them aligned with the SCHADS Award. 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. $44,284 of the *Fragile X Care | Adults & Ageing* grant funds were expended this year.

53% of expenditure relates to the provision of service to our members and the wider community, and increasing awareness of Fragile X-associated conditions in a range of forums nationally.

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

The FX Webinar Series and our online resources continue to be an efficient and effective way of providing information and education about Fragile X-associated conditions. These resources are utilised extensively by individuals and families, and allied health professionals, disability support providers and educators for professional development.

TREASURER'S REPORT

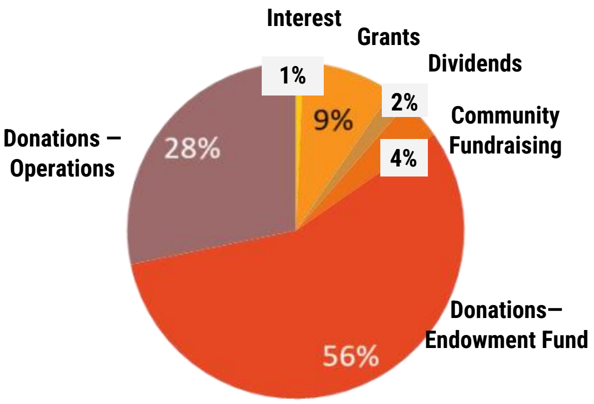
Our expenditure breakdown is 41% to support & member services, 10% to the Adults & Ageing project, 6% to education about Fragile X, 6% to awareness, 29% to organisational management and governance, 6% to rent and utilities, 2% to fundraising/merchandise.

64% of the total organisational cost comprises salary costs for our two staff members and bookkeeping fees. The cost associated with health professional and community awareness continues to reflect the leverage gained through our volunteers, supporters and partners and face-to-face health professional education forums and disability expos. Management and governance of FXAA remains critical to effective and efficient operation and ensures compliance with regulatory requirements; this cost is largely salary cost.

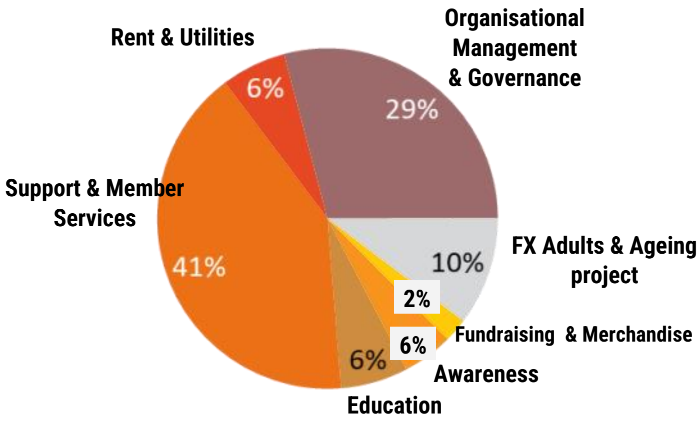
- **Outlook**

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

The accounts for FY2024 were audited by Mr Ben Hodgkinson of Manser, Tierney and Johnston (MTJ) in Turramurra, NSW.
The Board wishes to record appreciation of the audit services which provide 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 2023-2024



Expenditure 2023-2024

- **Endowment Fund - Net assets $1,314,018**
  (2023 - $785,509)

The Endowment Fund was established by resolution of the Fragile X Association of Australia Board in 2011, for the purpose of generating long-term funding for the activities of the organisation.

It is intended 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 fulfil its charitable purpose. 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.

This year the Board of FXAA wishes to thank the Cunningham family for their significant donation of $500,000, which is in addition to their past donation to the Fund of $315,974.
The Fund's growth is substantially dependent upon the continued generous support of its donors. To date the Fund has benefited in particular from the support of the Cunningham family: the *J & M Cunningham Endowment* now constitutes 63% of the total Fund as at 30 June 2024 (2023 40%).

In 2024 the Fund, like many other investments, performed better than the previous year but has continued to be impacted by poor returns on fixed interest accounts. In 2024 the Fund's interest and dividend income of $16,881 represented 4% (2023 5%) of FXAA's annual expenditure of $402,727. The market value of the Fund's investments increased by $8,842 during the period, a small net rise of 1.1%. The challenge remains to maintain reasonable investment returns in an environment of high inflation and market volatility. Additional donations of $2,786 in 2024 to the Fund are 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 2024 the Endowment Fund Committee comprised Martin Davey (chair), former FXAA President John Kelleher, FXAA President Cynthia Roberts and FXAA Treasurer Adam Lawrence-Slater.

In accordance with the guidelines established by the Board for the Endowment Fund, reviewed and updated in 2024, the funds have continued to be invested conservatively. Following the $500,000 donation from the Cunningham family, and at the request of the Board, the Endowment Fund Committee reviewed the investment strategy. The Committee recommended moving the investment strategy from "Capital Defensive" to "Conservative". The Committee's recommendations to modestly increase the mix of Equities from 31% to 42%, and lower fixed interest from 65% to 58%, were accepted by the Board and implemented in October 2024. 0.1% is currently held in cash.

OUR SUPPORTERS

Our supporters make it possible for the Board and staff of Fragile X Association of Australia 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 sincerely thank our members and the individuals, companies, philanthropic foundations, community groups and health professionals who make it possible for us to serve the Fragile X community effectively.

Fragile X Association of Australia

Cunningham Family

HENROTH Group

Cecilia Kilkeary Foundation Ltd

oceanpaddler

Zynerba Pharmaceuticals
Advancing Science | Improving Connections

Qantas sidebyside

Shaw and Partners
Financial Services

Linnet Foto

HTR

Kate Stokes | Graphic Design

Suzanne Gordon | Photography

MTJ Manser Tierney & Johnston
Chartered Accountants & Wealth Management

Healthed

BDA Ballarat Dance Awards

You can make a difference

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

Let us know if you're interested in volunteering – there are many 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.

YEAR IN REVIEW – HEALTH EDUCATION FORUMS

Taking part in education forums for health professionals helps to develop the knowledge of Fragile X-associated conditions amongst healthcare professionals. This past year our team has represented FXAA at a range of events for GPs, menopause specialists, medical students and genetic counsellors.

YEAR IN REVIEW – DISABILITY EXPOS

It's been an incredible year extending our outreach to the Fragile X community by taking part in Disability Expos in metropolitan and regional centres. From July 2023 through November 2024 our staff and volunteers have represented FXAA at Expos in Melbourne, Geelong, Brisbane, Hobart, Launceston, Adelaide, Cairns, the Gold Coast, Sunshine Coast, Sydney and Perth. It's been fantastic to meet so many of our members face to face around Australia.

SOURCE
DISABILITY
EXPO FOR KIDS, TEENS + YOUNG ADULTS

DISABILITY EXPO

RDE Regional Disability expo

YEAR IN REVIEW – FUNDRAISING

In 2024 we celebrated the 11th year of charity partnership with the Manly Wharf Bridge to Beach paddle race. Many thanks to the paddlers, Dean Gardiner (Oceanpaddler) and Shaw and Partners Financial Services for their exceptional support. We're looking forward to another great race on 23rd February 2025.

ShawandPartners
Financial Services

SHAW AND PARTNERS TO MATCH DONATIONS

Fragile X Association of Australia

SHAW AND PARTNERS WILL MATCH IT DOLLAR FOR DOLLAR!

SUPPORT OUR FUNDRAISING

ShawandPartners
FOUNDATION
Have fun. Live life. Give back.

YEAR IN REVIEW – FUNDRAISING

Team Tutu put on a fabulous show at the most recent Sydney City2Surf. A successful tutu-led effort at City2Surf in 2023 was followed up by an incredible $18,000 raised in August 2024. Thank you to everyone who joined in the fun on the day. We'd love to see more of our members join us in 2025. Tutu provided!

CITY2 SURF

YEAR IN REVIEW – FUNDRAISING

Some wonderful fundraising this past year! With thanks to Ballarat Dance Awards and Ellinbank Football and Netball Club, both based in Victoria. Thanks to the Bully's Campout team in WA, and the annual hot rod rally for raising funds. Many thanks to Galston Garden Club (NSW) & Masonicare for the support, and to Ricky Crowe for a successful raffle!

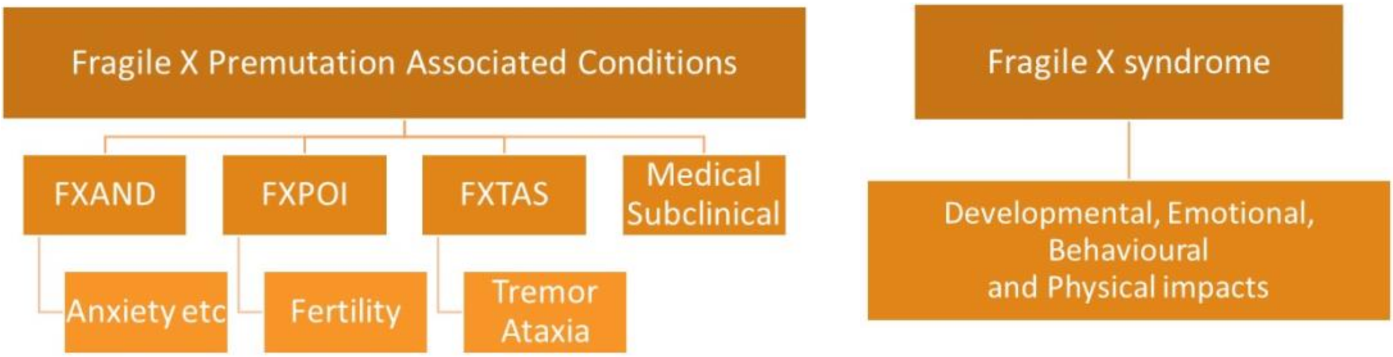
W.A.
BULLYS
BULLYS CAMPOUT

MASONICARE
Proudly helping our local communities
Date 18/03/24
Pay FRAGILE X ASSOCIATION OF AUSTRALIA INC $ 6,000.00
The sum of SIX THOUSAND DOLLARS
On behalf of Masonicare

YEAR IN REVIEW – WORLD FRAGILE X DAY, 22 JULY

Understanding Fragile X

Fragile X Association of Australia



Fragile X Premutation Associated Conditions

FXAND

Anxiety etc

FXPOI

Fertility

FXTAS

Tremor Ataxia

Medical Subclinical

Fragile X syndrome

Developmental, Emotional, Behavioural and Physical impacts

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.

Both males and females can be carriers of the Fragile X (FMR1) gene alteration, and are known as FMR1 premutation carriers.

About 1 in 250 women and 1 in 800 men are FMR1 premutation carriers.

- **Fragile X syndrome**
  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 spectrum disorder.

- **Fragile X Premutation Associated Conditions**

Several health conditions are known to be associated with the Fragile X premutation for some people, and these are covered by the universal term *Fragile X Premutation Associated Conditions*, also known as FXPAC.

Fragile X-associated Primary Ovarian Insufficiency (FXPOI)
FXPOI can lead to fertility problems and early menopause for around 30% of female FMR1 premutation carriers.

Fragile X-Associated Tremor Ataxia syndrome (FXTAS)
A late-onset neurological condition with symptoms including shaking (intention tremor), unsteadiness (ataxia) and memory problems, affecting more male than female FMR1carriers.

Fragile X-associated Neuropsychiatric Disorders (FXAND)
A term to describe a range of issues, such as 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.

To learn more, explore our website and video & audio resources

www.fragilex.org.au

30 YEARS STRONG | SUPPORTING | SHARING | CONNECTING | INFORMING

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Spotify

Listen on Apple Podcasts

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

FINANCIAL STATEMENTS
30 JUNE 2024

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 2024, 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) present a true and fair view of the financial position of the Association as at 30 June 2024 and of its financial performance for the year ended on that date.

2. There are reasonable grounds to believe that the Association will be able to pay its debts as and when they fall due and payable.

This declaration is signed in accordance with subsection 60.15(2) of the *Australian Charities and Not-for-profits Commission Regulation 2022.*

Cynthia Roberts

Dr Cynthia Roberts PhD
President

Adam

Mr Adam Lawrence-Slater
Treasurer

Dated on 14/11/2024

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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 2024, I declare that, to the best of my knowledge and belief, during the year ended 30 June 2024 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 on

MTJ AUDIT PTY LTD 15/11/2024
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Ben Hodgkinson

BEN HODGKINSON
Partner

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

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

Opinion

We have audited the financial report of Fragile X Association Australia Inc (the Association) comprising the statement of financial position as at 30 June 2024, 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 2024 and of its financial performance for the year then ended; and

b) complying with Australian Accounting Standards to the extent described in Note 1 to the Financial Statements and Division 60 of the *Australian Charities and Not-for-profits Commission Regulation 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 ACNC Act and the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110: *Code of Ethics for Professional Accountants* (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our ethical responsibilities in accordance with the Code.

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

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

The committee of the Association is responsible for the other information. The other information comprises the information included in the Association's annual report for the year ended 30 June 2024, but does not include the financial report and our auditor's report thereon.

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

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

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

Emphasis of Matter – Basis of Accounting

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

Responsibilities of the Committee for the Financial Report

The committee of the Association is responsible for the preparation of the financial report that gives a true and fair view in accordance with Australian Accounting Standards, the *Associations Incorporation Act 2009 (NSW)* and the ACNC Act and for such internal control as the committee determines is necessary to enable the preparation and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

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

Auditor's Responsibilities for the Audit of the Financial Report

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

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 on 15/11/2024

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MTJ AUDIT PTY LTD

Ben Hodgkinson

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 2024

	Note	2024	2023
CURRENT ASSETS			
Cash and cash equivalents			
At Bank		174,863	184,724
Endowment Fund	8	519,299	29,846
Petty Cash		100	100
Term Deposit		202,125	228,394
		896,387	443,064
Accounts receivable and other debtors			
Accounts Receivable		-	12,650
Franking Credits Refundable		4,857	4,642
GST Refundable		6,973	2,411
Prepayments		25,171	1,356
Rental Bond		3,416	3,416
		40,417	24,475
TOTAL CURRENT ASSETS		936,804	467,539
NON-CURRENT ASSETS			
Property, plant and equipment			
Property, Plant and Equipment - At Cost		15,250	15,250
Less: Accumulated Depreciation		(11,251)	(8,281)
		3,999	6,969
Investments			
Listed Investments at Market Value - Endowment Fund	8	231,714	243,234
Unlisted Investments at Market Value - Endowment Fund	8	558,148	507,787
		789,862	751,021
TOTAL NON-CURRENT ASSETS		793,861	757,990
TOTAL ASSETS		1,730,665	1,225,529
CURRENT LIABILITIES			
Accounts payable and other payables			
Accounts Payable		1,046	2,317
Payroll Liabilities		10,749	10,486
Other Liabilities		631	1,561
		12,426	14,364
Provisions			
Provision for Employee Entitlements		35,774	28,337
TOTAL CURRENT LIABILITIES		48,200	42,701
TOTAL LIABILITIES		48,200	42,701
NET ASSETS		$1,682,465	$1,182,828
EQUITY			
Opening Balance		1,182,828	998,294
Add: Surplus for the Year		499,637	184,534
TOTAL EQUITY		$1,682,465	$1,182,828

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 2024

	2024	2023
INCOME		
Gross Proceeds From Fundraising Appeals		
Donations - including Endowment Fund	757,356	296,361
FXAA Fundraising Events and Appeals	34,535	23,484
Merchandise Sales	501	1,054
Sponsorships	-	2,165
	792,392	323,064
Other		
Dividend Income	16,191	15,472
Grants	78,500	161,450
Interest	6,439	1,400
	101,130	178,322
Total Income (carried forward)	893,522	501,386

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 2024

	2024	2023
Total Income (brought forward)	893,522	501,386
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Other	4,839	5,481
	4,839	5,481
Total Costs Of Providing Services		
Support Services and FX Awareness	94,049	68,985
Clinics and Counselling	69,774	62,258
	163,823	131,243
Other		
Bank Fees and Charges	309	316
Board and AGM Expenses	1,151	976
Conferences and Seminars	371	1,660
Consultants and Accounting	23,285	20,440
Depreciation and Disposal of Assets	2,970	2,675
FX Adult & Ageing Project	44,284	-
General Administration - Employment Costs	84,358	77,491
Information Resource Production	20,569	16,827
Insurance	6,113	5,830
Office Expenses	6,275	6,063
Office Rent	20,137	18,885
Postage	2,540	2,681
Provision for Employee Entitlements	7,437	16,451
Stationery	310	467
Subscriptions	6,863	5,449
Sundries	465	1,252
Telephone	2,544	2,599
Website	4,084	2,984
	234,065	183,046
Total Expenditure	402,727	319,770
OPERATING SURPLUS FOR THE YEAR	490,795	181,616
Net Increase/(Decrease) in value of investments - Endowment Fund	8,842	2,918
TOTAL COMPREHENSIVE INCOME FOR THE YEAR	$499,637	$184,534

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 2024

	2024	2023
EQUITY		
Retained Earnings		
Opening Balance 1 July	1,179,910	998,294
Add: Surplus for the Year	490,795	181,616
	1,670,705	1,179,910
Less: Transfer (to)/from Asset Revaluation Reserve	-	-
Closing Balance 30 June	1,670,705	1,179,910
Asset Revaluation Reserve		
Opening Balance 1 July	2,918	-
Less: Net Transfer to/(from) Reserve	8,842	2,918
	11,760	2,918
Add: Transfer (to)/from Retained Earnings	-	-
Closing Balance 30 June	11,760	2,918
TOTAL EQUITY	$1,682,465	$1,182,828

The accompanying notes form part of these financial statements.

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 30 JUNE 2024

		2024	2023
Cash Flow from Operating Activities			
Receipts from donations, fundraising appeals and events		883,539	467,315
Interest and Dividends		22,415	17,289
Payments to suppliers and employees		(422,631)	(292,410)
Net cash provided by operating activities	10b	483,323	192,194
Cash Flows from Investing Activities			
Payment for property, plant and equipment		-	(2,290)
Net Payment for investments		(30,000)	-
Net cash used in investing activities		(30,000)	(2,290)
Net Increase/(decrease) in Cash Held		453,323	189,904
Cash on hand at the beginning of the financial year		443,064	253,160
Cash on hand at the end of the financial year	10a	$ 896,387	$443,064

The accompanying notes form part of these financial statements.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

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 association is a not-for-profit entity. 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 statements have been prepared in accordance with the *Associations Incorporation Act 2009 (NSW)*, the mandatory Australian Accounting Standards applicable to entities reporting under the ACNC Act and the basis of recognition and measurement 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

The association is first required to determine whether amounts received are accounted for as Revenue per AASB 15: Revenue from Contracts with Customers or Income per AASB 1058: Income of Not-for-Profit Entities.

Funding arrangements which are enforceable and contain sufficiently specific performance obligations are recognised as revenue under AASB 15. Otherwise, such arrangements are accounted for under AASB 1058, where upon initial recognition of an asset, the association is required to consider whether any other financial statement elements should be recognised (for example, financial liabilities representing repayable amounts), with any difference being recognised immediately in profit or loss as income.

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.

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

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.

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

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

Contributed Assets

The association receives assets from the government and other parties for nil or nominal consideration in order to further its objectives. These assets are recognised in accordance with the recognition requirements of other applicable accounting standards.

On initial recognition of an asset, the association recognises related amounts (being contributions by owners, lease liability, financial instruments, provisions).

The association recognises income immediately in profit or loss as the difference between 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.

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

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.

j) Financial Assets

Investments in financial assets are initially recognised at cost, which includes transaction costs and are subsequently measured at fair value which is equivalent to their market bid price at the end of the reporting period. Movements in fair value are recognised through an equity reserve.

k) Account Payable and Other Payables

Accounts payable and other payables represent the liability outstanding at the end of the reporting period for goods and services received by the association during the reporting period that remain unpaid. The balance is recognised as a current liability with the amounts normally paid within 30 days of recognition of the liability.

l) Member's Liability

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

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

m) Comparative Figures

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

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

n) New and Amended Accounting Policies Adopted by the Association

AASB 2021-2: Amendments to Australian Accounting Standards – Disclosure of Accounting Policies and Definition of Accounting Estimates

The entity adopted AASB 2021-2 which makes some small amendments to a number of standards including the following: AASB 7, AASB 101, AASB 108 and AASB 134.

The adoption of the amendment did not have a material impact on the financial statements.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

Note 2 - Information on Material Matters

The Association received a donation of $180,000 from the Cunningham family for the operations of the organisation, a donation of $500,000 from the Cunningham family for the FXAA Endowment Fund (J&M Cunningham Endowment), a grant of $70,000 from Henroth Group for year 2 of the *Fragile X Care | Adults and Ageing* project (f/y 2025), a donation of $10,500 from Shaw and Partners Foundation, a donation of $10,000 from John & Christine Kelleher and a grant of $8,500 from the Qantas Foundation Side by Side grant program for the production of educational webinars.

Note 3 - Application of appeal monies

During the year the Association received net income of $870,892 from fundraising appeals and $22,631 from the investment of appeal monies.

An amount of $163,824 was spent on the provision of services (including $69,773 for counselling and clinics and $94,050 for other awareness and support). We spent $139,969 on insurance, rent, administration, office expenses and IT infrastructure.

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 2024
- Ellinbank FNC fundraiser
- Sydney City2Surf 2023 & 2024
- End of financial year appeal
- Fragile X awareness events

Note 6 - Analysis of monetary figures

Ratios	$	%
Total cost of fundraising/ Gross income from fundraising	4,839/870,892	1% (1% last year)
Net surplus from fundraising/ Gross income from fundraising	866,053/870,892	99% (99% last year)
Total costs of services/ Total expenditure	163,824/427,704	38% (41% last year)
Total costs of services/ Total income received	163,824/893,523	18% (26% last year)

Note 7 – Commitments

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

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

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

	Note	2024	2023
CURRENT ASSETS			
Cash on hand			
At Bank		19,299	29,846
Term Deposits		500,000	-
		519,299	29,846
Accounts receivable and other debtors			
Franking Refund Receivable		4,857	4,642
TOTAL CURRENT ASSETS		524,156	34,488
NON-CURRENT ASSETS			
Investments			
Listed Investments - At Market Value		231,714	243,234
Unlisted Investments - At Market Value		558,148	507,787
TOTAL NON-CURRENT ASSETS		789,862	751,021
TOTAL ASSETS		1,314,018	785,509
CURRENT LIABILITIES			
Accounts payable and other creditors			
Other creditors		-	-
TOTAL CURRENT LIABILITIES		-	-
NET ASSETS		$1,314,018	$785,509
EQUITY			
Opening Balance		785,509	760,746
Add: Income for the Year	9	528,509	24,763
TOTAL EQUITY		$1,314,018	$785,509
Total Equity Comprises:			
General Fund		491,272	469,535
J & M Cunningham Endowment		822,746	315,974
		$1,314,018	$785,509

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

Note 9 - Endowment Fund

Income & Expenditure Statement - for the year ended 30 June

	2024	2023
INCOME		
Donations	502,786	5,988
Interest & Dividend Income	16,881	15,884
Increase in Market Value of Investments	8,842	2,918
	528,509	24,790
Less:		
Decrease in Market Value of Investments	-	-
Expenses	-	27
	-	27
NET INCOME FOR THE YEAR	$528,509	$ 24,763

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:

	2024	2023
Cash at bank	896,387	443,064

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

	2024	2023
Operating Surplus	490,795	181,616
Non-cash flows in Operating Surplus		
- Depreciation	2,970	2,675
Changes in assets and liabilities		
- (Increase)/decrease in receivables	12,650	(12,650)
- (Increase)/decrease in other assets	(28,591)	89
- Increase/(decrease) in payables	(1,271)	(1,593)
- Increase/(decrease) in other current liabilities	(667)	5,606
- Increase/(decrease) in provisions	7,437	16,451
Net cash provided by operating activities	$483,323	$192,194

Fragile X
Association of
Australia

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Fragile X Association of Australia is a registered charity providing support and information to people around Australia who are affected by Fragile X Syndrome and Fragile X premutation-associated conditions.

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

HELPLINE 5 DAYS PER WEEK
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