Fragile X Association of Australia Inc

Notice of AGM

Fragile X Association of Australia Inc
Registered office: Suite 204 20 Dale Street Brookvale NSW 2100
Date: 13 November 2026

Notice of the Annual General Meeting of Fragile X Association of Australia Inc

Dear FXAA members,

This is to advise you of the upcoming Annual General Meeting of the members of Fragile X Association of Australia Inc (FXAA). The details of this meeting are as follows:

Date:	**Sunday 6 December 2026**
Time:	**3:00-4:15PM AEDT**
Place:	**Online via Zoom [link below]**

Documents for the meeting are:

- the **agenda** for this meeting
- the **minutes** of the last annual general meeting
- list of **members nominating** for the Board

These documents are included with this Notice AND are available on our website:
https://www.fragilex.org.au/annual-general-meeting-2026-sunday-6-december-2026-3pm-aedt-online/

At the meeting, as members you will have the opportunity to:

- hear about FXAA's operations and finances
- ask questions about FXAA's operations and finances
- speak about any items on the agenda
- vote on any resolutions proposed.

At the meeting, members will be asked to vote to:

- accept the minutes of the last annual general meeting
- accept the annual report
- accept the audited annual financial statements
- appoint an auditor
- elect directors to the Board.

To attend the meeting, please register and you will receive a Zoom link
https://us02web.zoom.us/meeting/register/v43E2VyUSC2G7R4FNtw0lg

RSVP: 4 December 2026

Regards,
Wendy Bruce
Executive Director

Fragile X Association of Australia Inc

Annual General Meeting agenda

Date:	Sunday 6 December 2026
Time:	3:00-4:15 PM AEDT
Place:	Online via Zoom

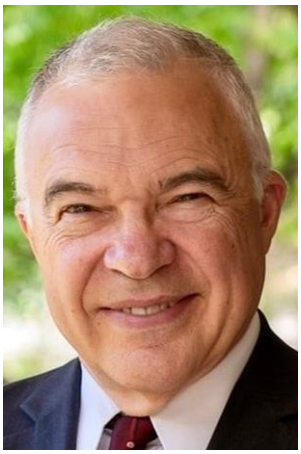
Item		
1	**Welcome**	Dr Lawrie Bott, President
2	**Apologies**	Alison Evans, Secretary
3	**Announcement of Awards** • *Achievement Awards* • *Volunteer Awards*	Liz Jewell, Rosie Donald
4	**Previous annual general meeting 23 November 2025** • Review of actions • Acceptance of minutes	Dr Lawrie Bott, President
5	**President's Report**	Dr Lawrie Bott, President
6	**Treasurer's Report**	Adam Lawrence-Slater, Treasurer
7	**Questions to directors**	Dr Lawrie Bott, President
8	**Acceptance of financial statements**	Adam Lawrence-Slater, Treasurer
9	**Appointment of auditor**	Adam Lawrence-Slater, Treasurer
10	**Annual Report 2026 and Year in Review**	Wendy Bruce, Executive Director
11	**Acceptance of Annual Report**	Dr Lawrie Bott, President
12	**Election of directors**	Wendy Bruce, Returning Officer
	Nominees for re-election: Lawrence Bott, Alison Evans, Andrew Fleming, Michael Miceli	
13.	**Other Business / Reports**	
	• Strategic Priorities 2027+ • Fragile X syndrome treatment research – the horizon • FXAA Life Membership nomination	
14	**Any Other Business**	Dr Lawrie Bott, President
15	**Meeting close**	Dr Lawrie Bott, President

Annual General Meeting, Sunday 6 December 2026

Election of Directors

Nominees Proposed for Re-election:

Dr Lawrence Bott, Alison Evans, Andrew Fleming, Michael Miceli



Dr Lawrence Bott MBBS (Hons), FRCPA, GAICD

Lawrie graduated in Medicine from the University of Sydney and specialised in Pathology. Lawrie has recently retired as Chief Medical Officer of Sonic Healthcare Australian Pathology after a long career as a Pathologist and in various senior management roles. He currently works part-time as a Pathology Consultant.
He is a Past-President of the Royal College of Pathologists of Australasia and was a long-term Board Member of RCPAQAP. Lawrie is married and has 5 children.
He has been an active sports person and is now an active artist. Through his Chief Medical Officer role and College work, Lawrie has been involved with issues relating to Genetic Pathology testing, including Fragile X, and advocacy to Government. Lawrie was first appointed to the Board at the Annual General Meeting on December 2024 and was appointed President on 24 November 2025.



Alison Evans

Alison is a corporate communication leader who helps organisations achieve strategic outcomes by aligning people behind a common purpose, inspiring behaviour change, and building stakeholder awareness and advocacy. Her deep change-communication expertise and experience as a radio news journalist have helped FXAA strengthen member communications, grow awareness, and advocate for individuals and families affected by Fragile X–associated conditions.
Following prenatal genetic screening, Alison discovered she is a Fragile X premutation carrier and experienced first-hand the gaps in clinical understanding. She is passionate about bridging these knowledge gaps in the health sector, and more broadly in the community, to ensure families receive timely, accurate, and comprehensive information and care. Alison was first appointed to the Board at the AGM in November 2022 and has served as Secretary since December 2024.



Andrew Fleming LLB

Andrew and his wife Jay live in Adelaide and have an 8 year old boy, Johannes, who was diagnosed with Fragile X syndrome at 3 years of age.
Andrew is a lawyer who currently works as a Senior Manager at the Australian Securities & Investments Commission. Andrew has prior experience working as a regulatory compliance lawyer and civil litigator at UBS Bank and, before that, as an investigator for a Financial Conduct Authority in the UK.
Andrew and his family lived in London and New York before moving back to Adelaide in 2021. Andrew has been teaching Johannes to play the drums.

Andrew was first appointed to the Board at the Annual General Meeting on 1 December 2024.



Michael Miceli

Mike is an experienced professional in enterprise and operational risk and has previously served on the board of another not-for-profit organisation in NSW. Michael is keen to contribute his professional experience in risk management and governance to the management of Fragile X Association of Australia.

Mike's brother-in-law lives with Fragile X syndrome and his wife is a premutation carrier for Fragile X. Michael says he and his Amy wife are very grateful to FXAA for their advocacy and work to help those living with Fragile X in Australia, and he is eager to contribute to the ongoing success of the organisation.

Michael was first appointed to the Board on 24 November 2025.

FRAGILE X ASSOCIATION OF AUSTRALIA INC

ANNUAL GENERAL MEETING 2025

Sunday 23 November 2025, 3:00 pm AEDT

MINUTES TO BE PRESENTED TO AGM 2026

The meeting opened at: 3:03pm

Members present (Zoom and in person):
Adam Lawrence-Slater, Alison Evans, Amy Miceli, Andrew Fleming, Belinda D'Amico, Brent Colgrave, Bronwyn Kelleher, Bruce Donald AM, Claire Colgrave, Cynthia Roberts, Daniel Fleming, Dianne Cox-Taylor, John Cox-Taylor, Donna Baatarjav, Graham Hook, James Hook, Helen Tozer, Jacqueline Mecca, Dr Lawrence Bott, Leighee Eastbury, Leonie Lewis, Liz Thomson, Megan Levy, Michael Miceli, Nick Howe, Nyleta McRae, Phil Eastbury & Hayden Eastbury, Margaret Philips, Rosie Donald, Rubyrose Campbell, Sharon Kalenjuk, Ben Kalenjuk, Shawn Wolfe, Prof W Ted Brown, Trich George.

FXAA staff present: Wendy Bruce (Executive Director), Liz Jewell (Family Support Counsellor)

The quorum for the meeting (20 members) was achieved.

1. Welcome

Chairperson: Dr. Cynthia Roberts PhD, President, welcomed attendees to the 2025 AGM.

2. Apologies

Received from:

John Cunningham AM	Sharon Davey
Margaret Cunningham AM	Kate Stokes
Robyn Iredale AM	May Mackenzie
Tim Turpin	Ross Mackenzie
Kay Cambourn and Myra	A/Prof David Godler
Chris & Lyn Roberts	Dr Claudine Kraan PhD
Mandy Barker	A/Prof Mary-Ann O'Donovan
Christine and John Kelleher	

3. Announcement of FXAA Awards 2025

Achievement Awards (Fragile X Oscars!) were presented by: Liz Jewell, and Rosie Donald

Achievement Award recipients:

- **Josiah Tozer:** incredible progress, growing independence, perseverance and great sense of humour
- **Logan George:** received his learner driver's permit and is on the way to obtaining a full licence, contributed to his hockey team's great success this season
- **Rubyrose Campbell Phillips:** great achievement at school in art, story writing, and with her dancing group

- **Tom Colgrave:** recently started a new business lawnmowing and gardening, and is gaining confidence and new skills, as well as giving back to the community where people need work done at no cost
- **Ben Kalenjuk:** participated in his first international event at the World Virtus Games (T21) – a sports event for athletes with an intellectual impairment - and holds the record for 100m and 200m. Ben achieved 5 medals.
- **Joshua Lawrence-Slater:** graduating year 12 as joint School Captain and representing the school marvellously, particularly in music and performance

Volunteer of the Year Award recipients:

- **Fragile X Care | Adults and Ageing Lived Experience Panel:** Involved since early 2023 as part of a three-year journey to help explore improved understanding and support for adults ageing with Fragile X syndrome.

Volunteer Acknowledgement: previous Achievement Award-winner **Hayden Eastbury** explained how he has been visiting various ABC news bureaus throughout a trip around Australia with his family, helping raise awareness of Fragile X syndrome and meeting many presenters, hosts and journalist in both metro and regional areas. He is currently in Streaky Bay, with many more visits still to complete on his adventure and goal to visit every ABC studio in Australia.

4. Confirmation of Minutes of Annual General Meeting Held 1 December 2024

Motion: That the minutes of the Annual General Meeting held on 1 December 2024 be accepted as a true and accurate record.

Moved by:	Graham Hook
Seconded by:	Prof W Ted Brown
Outcome:	All in favour - resolution passed

5. Matters Arising from the Minutes

Notes: Nil

6. Treasurer's Report and Appointment of Auditor

Report Presented By: Adam Lawrence-Slater, Treasurer

The Treasurer provided an update on the financial position of the Association at 30 June 2025, including an overview of income, expenditure, net assets and the performance of the Endowment Fund. FXAA remains well-resourced to provide counselling, outreach, peer connections, educational webinars, information resources and referrals, and to promote awareness and advocacy for Fragile X-associated conditions. (See below)

Donors and supporters

The Treasurer acknowledged and thanked the individuals and organisations who support FXAA through donations, fundraising and grant funding. In particular, thanks were noted to:

- **Cunningham family** (John Cunningham AM & Margaret Cunningham AM) for their long-term support and a generous $200,000 donation in FY25 to support FXAA's operations
- **Henroth Group** for a three-year grant supporting the Fragile X Care | Adults & Ageing study ($70,000p.a. x3yrs)

- **Cecilia Kilkeary Foundation** for part-funding of the Counsellor role ($78,000 for three years to 2025)
- **David Walker, John & Christine Kelleher, the Smith Charitable Foundation and HTR Group** for significant donations in FY25
- **Fundraising supporters** including Galston Gardens Open Gardens (with funds matched by Masonicare), City2Surf, Bullys Campout, Ellinbank Football Netball Club Fragile X Round, and the annual Manly Wharf Bridge to Beach paddle race (supported by Dean Gardiner OAM, Oceanpaddler and Shaw and Partners Foundation.)

Financials as at 30 June 2025

Income: $418,448
Expenditure: $400,568
Operating surplus: $17,880 (including $54,357 interest, dividends and distributions from the FXAA Endowment Fund)

At 30 June 2025, **net assets totalled $1,751,186,** of which the Endowment Fund represented $1,421,138 (81%). Income was above budget and expenditure below budget. The Treasurer noted that donations, fundraising and grant funding remain the major sources of income, and that fundraising for operational costs is a key focus for the Board in the coming year. Around 61% of expenditure relates directly to member and community services and increasing awareness of Fragile X-associated conditions, with the remainder supporting organisational management, governance, rent, utilities and fundraising.

Endowment Fund: Net assets: $1,421,138 (2024: $1,314,018)

The Treasurer reported that the Endowment Fund, established in 2011 at the direction of the FXAA Board, remains in "accumulation phase" for the purpose of generating long-term funding for the activities of FXAA. In FY25 the Fund's investment income of $54,357 represented 14% of FXAA's annual expenditure. The market value of the Fund increased by $50,841 (3.9%) over the year.

In line with the updated FXAA Endowment Fund investment guidelines approved by the Board, the Board implemented a change in strategy from "Capital Defensive" to "Conservative", modestly increasing the equity exposure and reducing fixed interest holdings while maintaining a conservative risk profile.

The Treasurer noted that the J&M Cunningham Endowment contribution represents 63% of the Fund.

The Treasurer acknowledged the contribution of the Endowment Fund Committee – Martin Davey (Chair), former FXAA President John Kelleher, FXAA President Cynthia Roberts and Treasurer Adam Lawrence-Slater – and recorded sincere thanks to Martin Davey and John Kelleher on their retirement from the Committee after 16 years of service. The earlier work and contribution of inaugural chair, David Bassingthwaighte, and Bruce Donald AM was also recognised.

Thanks and acknowledgement

The Treasurer recorded appreciation to FXAA staff, volunteers, pro bono professional advisers and supporters for their contribution of time, expertise and fundraising efforts, which significantly extend the impact of FXAA's financial resources.

Auditor re-appointment

FXAA's accounts for FY2025 were audited by Mr Ben Hodgkinson of Manser, Tierney and Johnston in Turramurra, NSW, providing important ongoing oversight of FXAA's financial affairs.

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

Moved by: Adam Lawrence Slater
Seconded by: Bruce Donald
Outcome All in favour - resolution passed

Motion: That the Treasurer's Report be accepted.

Moved by: Bruce Donald
Seconded by: Rosie Donald
Outcome All in favour - resolution passed

7. President's Report

Report Presented By: Dr. Cynthia Roberts PhD, President

The President presented her final report to members and advised that she will step down from the Board following the AGM to focus on supporting her son's transition to Supported Independent Living. In addition to the advertised Board vacancy, a casual vacancy will subsequently arise from her departure.

- **Advocacy, awareness and education** – FXAA continues to fulfil its role as a Health Promotion Charity by raising awareness of Fragile X-associated conditions, providing education and supporting individuals and families living with Fragile X. The tireless work of Executive Director Wendy Bruce and Family Support Counsellor Liz Jewell was acknowledged, supported by the Board, volunteers and donors.

- **Professional and academic engagement** – FXAA has had strong exposure at key health, genetics and disability forums. The Fragile X Care | Adults & Ageing research study, pre-pregnancy carrier screening for Fragile X, and Fragile X-associated conditions FXTAS were profiled at the International Menopause Congress, the Human Genetics Society of Australasia Annual Scientific Meeting, the Australasian Society for Intellectual Disability and PANDDA conferences, and via FXAA's presence at the Healthed Education Day series in major capital cities.

- **Outreach and connection** – Outreach has expanded across metropolitan and regional Australia through presence at Disability Expos and community events. Wendy Bruce and Liz Jewell have combined expo attendance with face-to-face visits with families, strengthening networks and deepening connection with the Fragile X community.

- **Webinar program and resources** – The webinar series continues to provide timely information and interaction with experts in Australia and internationally on Fragile X syndrome, FXTAS, the Fragile X premutation and emerging treatments and research. Recordings contribute to a growing library of enduring resources on the FXAA website, YouTube channel and podcast platforms.

- **Fragile X Adult & Ageing research project** – the study is entering its final phase, with analysis of the substantial data set continuing. A successful Validation Workshop was held in September with Centre for Disability Studies staff, the Lived Experience Panel, family members and

government and agency representatives. Work is underway with the National Centre of Excellence in Intellectual Disability Health to develop training modules for the disability and aged care workforce supporting adults with Fragile X syndrome.

- **Acknowledgements and reflections** –sincere thanks were expressed to FXAA staff Wendy Bruce and Liz Jewell for their sustained efforts, often on weekends; to the Cunningham family; to the many donors whose generosity underpins operations; and to partner organisations including Dean Gardiner OAM and the Bridge to Beach event, the Centre for Disability Studies and the National Centre of Excellence in Intellectual Disability Health.

- President Cynthia Roberts provided a short reflection on her almost 30-year involvement with FXAA, noting the Association's growth from a small parent support group to a national organisation with strong local and international connections to FRAXA Research Foundation and Fragile X International (FraXI). She emphasised the Board's commitment to maintaining strong governance while remaining firmly focused on supporting the Fragile X community.

Members present recognised Cynthia Roberts for her remarkable service to FXAA over 30+ years. A motion was moved by former Board member Bruce Donald to note the organisation's sincere thanks to Cynthia for her contribution to FXAA and the wonderful role she has played as mother to Daniel. This was seconded by former President Graham Hook.

8. Year in Review and Presentation of Annual Report 2025

Presented By: Wendy Bruce

Wendy Bruce gave a snapshot of other activities of the organisation 2024-2025 including:

- **Annual Report** – The Annual Report was commended to all attendees as it provides an excellent overview of FXAA's work in the past 12 months in supporting the Fragile X community, providing information and education to our members and the medical community, and advocating for advances in testing, screening and treatments, alongside fundraising efforts. The Annual Report will be available via the FXAA website from 24 November 2025. Wendy also noted the Built Fundraising Raffle for FXAA open to NSW residents in support of Belinda and Jason D'Amico, to raise funds for FXAA's operations.

9. Election of Members to Board Positions

Wendy Bruce (Executive Director) acted as Returning Officer. AGM Chair and President Cynthia Roberts noted her conflict of interest (as mother in law of a nominee) and noted that a casting vote (if required) would be held by Bruce Donald. It was noted that 3 members were proposed for re-nomination to the Board, and an additional two nominations had been received, for a total of 4 positions. Voting was undertaken by Zoom Poll and direct text to the returning officer.

Nominees for re-election and election to the Board were introduced:
- **Re-election**: Adam Lawrence-Slater (current Treasurer), Alison Evans (current Secretary), Belinda D'Amico
- **New Nominees**: Michael Miceli, Philip Eastbury

Outcome:

Re-appointment:	Adam Lawrence-Slater, Alison Evans, Belinda D'Amico
Appointment:	Philip Eastbury

At the next FXAA Board meeting, to be held on 24 November 2025, the Board will discuss filling the casual vacancy created by the retirement of Cynthia Roberts from the Board.

10. Other Business / Reports

1. Fragile X Care | Adults & Ageing Study—update

Members received an update on the three-year national study into the health, wellbeing and support needs of adults with Fragile X syndrome as they age, in partnership with the Centre for Disability Studies and the National Centre of Excellence in Intellectual Disability Health.

Over the past year the project has completed and analysed two national surveys, conducted interviews with Australian and international clinicians and adults with Fragile X and their families, and held a validation workshop at the University of Sydney, with early findings presented at several national conferences and the first academic paper accepted for publication.

Megan Levy, part of the lived experience panel, shared a personal perspective on her involvement and highlighted some early findings.

The next phase will deliver two free online learning modules for disability and aged care workers, to be launched mid next year.

2. Clinical Trials in Fragile X syndrome

A brief report was provided about clinical trials underway for Fragile X Syndrome and FXTAS. Professor Ted Brown spoke in more detail about some trials underway including:

- Harmony Biosciences (Zynerba) synthetic CBD transdermal gel – the study did not reach its primary endpoints, but there had been broad agreement that there were some positive results and open label availability of the product continues for now. Final results are expected in a few months.
- A study involving Dr Liz Berry-Kravis (US) based on improving cognition (young and older age trial currently in evaluation phase) is underway
- FRAXA has supported a number of small trials and early state research that appear promising
    - Metformin (Prof Randi Hagerman) – results should be known soon
    - Dr Jeannie Lee (Harvard professor) – reactivation of the silenced gene
    - Dr Joel Richter from Massachusetts University
    - Dr Ray Turner (protein and peptides – currently in mice studies)

3. Fragile X International

FraXI, of which FXAA is a member, is working on the development of guidelines for Europe and potentially the international FX community. Australian representatives form part of the group working on 3 sets of guidelines: Guideline on Fragile X Screening and Diagnosis; Guidelines on Management, Care and Support in (1) Children and Adolescents and (2) Adults with Fragile X syndrome.
FraXI also has plans for the development of an international registry for Fragile X syndrome and the Fragile X premutation.

4. FXAA Life Membership nomination

Mr Martin Davey was acknowledged for his voluntary service to FXAA over 16 years, particularly in regard to the establishment of the FXAA Endowment Fund and supporting its operation and management.

Motion: That Martin Davey be conferred Life Membership of Fragile X Association of Australia

Moved by: Cynthia Roberts
Seconded by: Graham Hook
Outcome All in favour - resolution passed

No other business was raised.

13. Close

Time Closed: 4:45pm
Minutes Prepared By: Alison Evans
Date: 23 November 2025

Action Items:
No action items noted