



Fragile  Society

Annual General Meeting

Monday 16th September 2024

19:00 **Welcome and Introduction** – Steve Harris (Chair)

1. Apologies for absence
2. **Minutes** of the Annual General Meeting held on 30th September 2023
3. Overview of the year Pete Richardson – MD
4. **To receive the audited accounts** year ending 28th February 2024 & Auditors report.
5. To receive the Report of the Directors.
6. **Directors Elections**
7. **To re-appoint Critchleys** as the Fragile Society **Auditors** for 2024/25
8. Any other business (please contact us in advance of the meeting)

19.50 **Members Meeting** - New for 2025 (Pete Richardson -MD) and meet the team

20:00 Fragile X counselling service – Victoria Arthur

20:05 Research Projects – Dr Gaia Scerif

20:15 Summary and Close

Apologies for Absence

Please give apologies for absence via e-mail . Names received will be recorded in the minutes.

Papers for this meeting are found here: <https://www.fragilex.org.uk/agm>

**Please note your microphone will be muted during the meeting; please send any comments to pete@fragilex.org.uk and we'll answer in next week's newsletter.*

The Fragile X Society: 13th AGM of the Incorporated Company No. 6724061

1. Minutes of the AGM held on 18th June 2022 were formally accepted
2. Members voted via Teams poll to receive the report of Directors
3. Receipt of the independently examined accounts: Critchleys are content with the accounts.
4. The following Directors were elected by members with effect from September 30th, 2023:

Rebecca Mayers, Zeinab Ali, Andy Clarke. With Steve Harris, Tim Eccleshall, Mary Martin being re-elected and the following Directors resigned from the board:

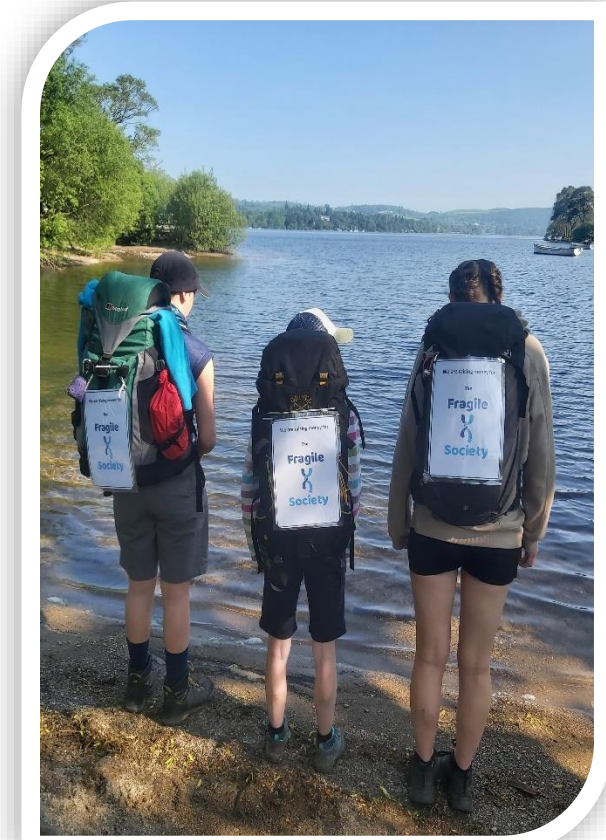
Kirsten Johnson, Tamarra Martin, John Quaye, Katherine Zwink, Mark Smith, Prof Gaia Scerif, Rosie Martin.

5. Appointment of Independent Examiners (Accounts) - Critchleys Audit LLP were reappointed

Annual Review 2023 - 2024



Our Annual Review is included in our printed Newsletter and can be found [here](#)



Key aims of the Society

- Provide information and practical guidance to support and empower individuals and families
- Educating and informing professionals about Fragile X to raise awareness and understanding of the syndrome to improve the provision of support
- Encouraging research into all aspects of Fragile X through the participation of our family members in Fragile X studies
- Raising funds to carry out our work

So...what do we do?

“We provide information and practical guidance to support and empower individuals and families living with fragile X, and the professionals who support them.”



- Part-time staff team: 1 Managing Director, 1 Office Manager, 2 specialist Families and Professionals Advisors who run helpline and support service across UK .
 - Expertise through life (adult vs children)
 - Diverse: listening ear, support with services and benefits, information about condition, practical guidance and input on specific issues.
- Conferences & Events, Professional Training, Newsletters, Information Resources, e-learning etc.

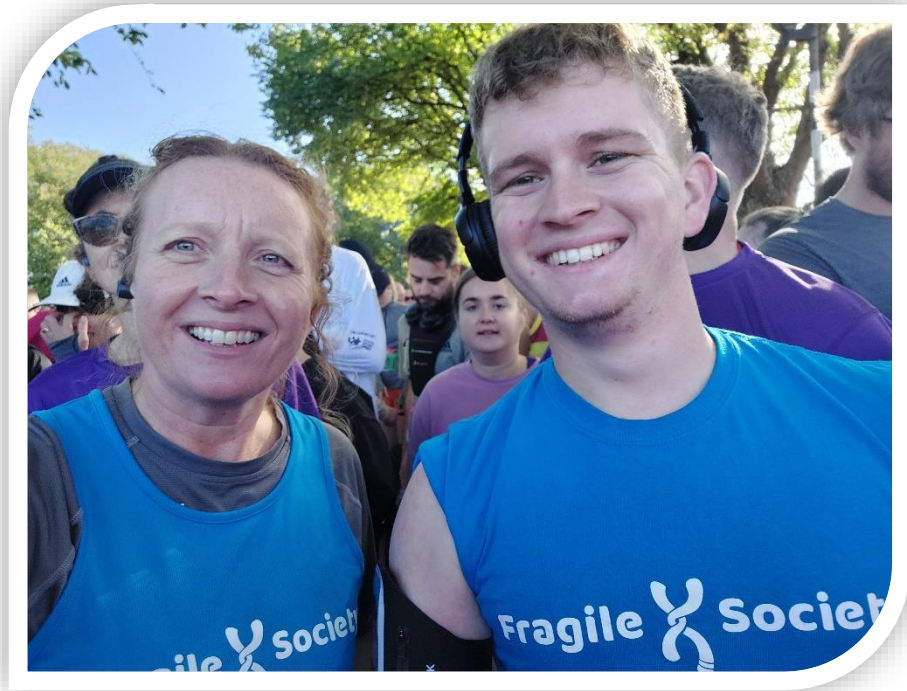
Feedback on 2023/24



The Fragile X Society continued to grow and develop during this busy year, we:

- Employed a new Families and Provisional's advisor (Children)
- Held 2 successful landmark conferences in Birmingham and Edinburgh (thank you to **Shionogi** for your sponsorship)
- Launched a new Counselling service for members.
- Strengthened our Board by recruiting new trustees.
- Volunteer Media team trained in interview techniques.
- Committed to supporting the Leicester Project.

Our membership



We now have a membership of 2471 individuals or families:-

- 1924 UK full member families (many of whom have multiple members of their family living with varying effects of Fragile X).
- 101 overseas members.
- 397 UK associate members.
- Our membership increases every year!

The impact of our support:

We responded to a total of 519 enquiries (9% increase) generating 2045 contacts via our helpline.

Enquires are frequently complex and require a considerable amount of follow up work (sometimes over months).

Feedback from members demonstrates the value of our work:

Thank you for being so helpful. It's definitely nice to know there is someone I can discuss things with when experiencing difficulties who truly understands the disability."

Moving into the digital age:

We have developed our online presence and with a large Facebook community (2874 members) who post daily to seek support, celebrate successes and share resources.

A growing following on social media including:-

- 4458 likes on our Facebook page
- 3085 X (Twitter) followers
- 4949 Instagram followers (64% increase)

Our website attracted 40,058 visitors in the last year (14% increase)



FRAXI (Fragile X International)

FraXI's mission statement says -

“Fragile X International is a network of country family organisations who will work together to promote, support and strengthen the FX identity as an added value to society...”

Here is a link to their site [Fragile X International \(fraxi.org\)](https://fraxi.org)

- FraXI currently has 20 member countries including the latest members Australia and New Zealand and 6 affiliate members including several South American countries.
- FraXI are organising a Congress for professionals in Barcelona on 7th and 8th November 2024.

Our relationship with research

We need each other!

- This year we have been proactively encouraging more participation in research (*UK has a low participation rate*) and will be piloting researcher videos.
- Research and clinical trials are essential for ensuring that Fragile X Families get the best support possible to access the best quality of life.
- Patient organisations form unique communities of people willing to **input into** and **participate in** research.
- 93% families rated research as important.



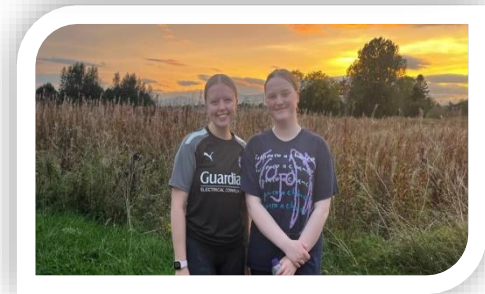
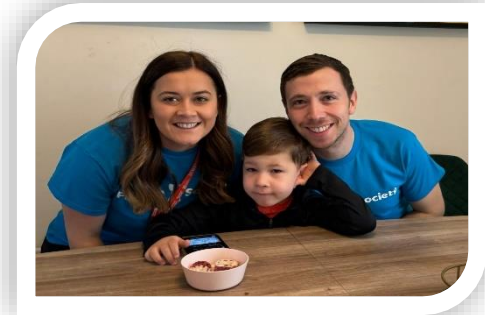
You helped to raise Funds

Like all small charities, the economic downturn has had a detrimental effect: Regular giving and donations have declined by 13%

However, our members continue to undertake valuable fundraising events. Thank you!

We will secure funds which cover our operating cost (in the first instance) developing services after that.

We welcome new corporate sponsorship and support.



How our funds are used...

We rely on the support of our amazing fundraisers, donors and grants to fund our important work. Every donation, big or small, can help to make a real difference.

Visit www.fragilex.org.uk/donate to make a donation (one-off or regular), contact us to find out more, or to request a fundraising pack.

- **£2,500** could pay for a families and professionals advisor for one month to provide specialist support and guidance to people living with Fragile X across the UK
- **£150** could provide support to a family for a whole year, including use of our helpline, conferences and free resources.
- **£50** could allow us to run our helpline service for one hour, through which we have thousands of contacts each year
- **£16** could pay for a family to receive our newsletter for 1 year, which is described as a lifeline.
- **£3** could pay for us to send our vital information to a newly-diagnosed family.



Fragile X Society

Tim Eccleshall

**Treasurer's
Report -2023/24**

Board of Directors: Elections

To elect up to 5 members to the Board of Directors:

Resignations:

Elections:

- To stand for re-election Anne Eccleshall & Andrew Jacques after reaching the end of their term.
- Patricia Patterson, Aiste Skegg and Jonny Cobbold have requested to be elected for this year

Appointment of Independent Examiners

The Trustees propose that Critchleys are re-appointed as our Independent Examiners.

Critchleys was established in 1906 to help businesses, charities and individuals. Today, they have team of over 120 staff based in Beaver House, 23-38 Hythe Bridge Street, Oxford.

They served as our Independent Examiners in 2023-2024 and the Trustees propose they be appointed for 2024-2025.

Meet the Team

- Jane Oliver –Senior Families and Professional’s Advisor (Adult)
- Claire Denyer –Office Manager
- Alison Field -Families and Professional’s Advisor (Children)



New for 2024/2025

- A new redesigned member survey.
- A family weekend.
- An Edinburgh Conference.
- A partnership with Queens University Belfast to benefit the Fragile X Community.
- A strong media campaign focussing upon FXPOI.
- Development of new services in Scotland.
- A new partnership with Leeds University.
- Building and developing Corporate relationships in line with our ethical policy.

Update on the counselling service

- We saw our first referral in August 2023
- Since then, 12 different individuals have accessed the counselling service
- Usually offer 6 sessions of remote, person-centred counselling (50 minute sessions) via zoom or telephone
- Range of individuals with fragile X, pre-mutation carriers and relatives
- Really pleased with positive feedback the service has received



Feedback for the counselling service

“I’ve been able to put my coping mechanisms in place both professionally and personally. I am so grateful that I found the service as its helped me to feel so much better and comfortable in my own skin. Thank you so much!”

“When going through difficult circumstances it is important to talk to someone to order your thoughts and feelings. The counselling service gave me the tools to work out the best way forward. I am grateful for this service available from the Fragile X Society”

Thank You for listening!



Please email pete@fragilex.org.uk