

Charity registration number 1127861 (England and Wales)

Charity registration number SC047332 (Scotland)

Company registration number 06724061 (England and Wales)

THE FRAGILE X SOCIETY
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 28 FEBRUARY 2025

THE FRAGILE X SOCIETY

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THE FRAGILE X SOCIETY

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Steve Harris (Chair)	
	Marie Williams (Vice Chair)	
	Tim Eccleshall (Treasurer)	
	Anne Eccleshall (Secretary)	
	Aiste Skegg	(Appointed 19 June 2024)
	Andrew Jaques	
	Andy Clarke	
	Jonny Cobbold	(Appointed 19 June 2024)
	Mary Martin	
	Patricia Pattison	
	Rebecca Mayers	
	Zeinab Ali	
	Michelle Flyn (Co-opted 8 February 2025)	(Appointed 8 February 2025)
Secretary	Anne Eccleshall	
Managing Director	Pete Richardson	
Charity number (England and Wales)	1127861	
Charity number (Scotland)	SC047332	
Company number	06724061 (England and Wales)	
Registered office	Suite 5 The Chestnuts Stortford Road Dunmow Essex CM6 1DA	
Independent examiner	Gravita Audit Oxford LLP First Floor, Park Central 40-41 Park End Street Oxford OX1 1JD	
Bankers	CAF Bank Ltd 25 Kings Hill Ave Kings Hill West Malling ME19 4JQ	

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 28 FEBRUARY 2025

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 29th February 2024. The Trustees have adopted the provisions of the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the provisions applicable to companies entitled to the small companies' exemption.

The financial statements have been prepared in accordance with the accounting policies set out in Note 1 to the financial statements and comply with the charity's governing document, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

Objectives and activities

What is Fragile X?

Fragile X Syndrome is the most common cause of inherited learning disability, affecting approximately 1 in 4000 males and 1 in 6000 females. Therefore, approximately 15,000 people in the UK are living with Fragile X Syndrome. Every individual with the condition is unique but common features include: a wide range of difficulties with learning and developmental delay; difficulty interacting with others and social anxiety; difficulty with attention; challenges with communication; and health-related issues. Fragile X Syndrome is associated with autistic-like behaviour and is the underlying cause of up to 1 in 20 cases of autism. Reliable genetic testing is available on the NHS, via a blood test.

Fragile X Syndrome is inherited from carriers, who have small changes to their Fragile X gene (pre-mutation) which makes it unstable when passed on. However, as well as this reproductive consideration, carriers may themselves experience effects of Fragile X Premutation Associated Conditions. For instance, in later life, carriers may experience Fragile X Tremor Associated Ataxia (FXTAS): a late onset neurodegenerative condition which causes problems with memory, balance and tremors. In addition, women may experience Fragile X Associated Primary Ovarian Insufficiency (FXPOI), which is associated with early menopausal-like symptoms and may cause infertility. The premutation is also associated with other physical and mental health challenges. According to prevalence statistics (1 in 250 women and 1 in 600 men), approximately 176,000 people in the UK are carriers.

Therefore, multiple members of families may be affected by Fragile X in different ways. Due to these wide-ranging features, in this report "Fragile X" (where not otherwise specified) is used to refer to this family of conditions.

The Need for Our Services

We are unique as the only group in the UK that specifically addresses the significantly complex and varied needs of people living with Fragile X.

The Fragile X Society plays a vital role in supporting people with Fragile X Syndrome and associated conditions, their families and supporters. Our community covers the length and breadth of the UK. We are led by people with personal experience of Fragile X on our Board of Directors (parents, premutation carriers) and our Managing Director has an extensive personal lived experience of learning disability within his family. We provide a completely free helpline (telephone and online) service to everyone and strive to ensure that we are 100% inclusive and accessible.

Both as a direct result of the condition, and due to poor services and attitudes, people living with Fragile X and their families may often face wide-ranging challenges throughout their lives. Though each individual is different, there is a constellation of features which are associated with Fragile X. Understanding these syndrome-specific issues can shed light on individual situations and may lead to issues being more effectively managed, or proactive measures may be able to be taken to reduce or prevent challenges arising in the first place. This information is frequently not provided through generic supports or diagnoses.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

Unfortunately, despite the prevalence of Fragile X, there is still too often a lack of awareness amongst professionals and the public, which compounds these issues. In line with this, almost all families (94%) living with Fragile X feel that it is very important to have a Fragile X-specific organisation; many reported that genetic support, and services did not understand their needs adequately, or that they felt lost in broader organisations (such as those relating to autism or learning disability).

Our specialist helpline is a vital resource for supporting and empowering people with evidence-based information and practical guidance. Throughout 2024/25 we supported the continued employment of our Families and Professionals Advisors to run this essential unique service. People with Fragile X and associated conditions receive the tailored advice and guidance that they need. Without this, many of them would fall through the increasing gaps in service provision, failing to access critical medical and social support.

We are proud to have maintained all our services during a difficult economic period ensuring that our members continued to be fully supported. And equally proud that support from our members remained steadfast.

Aims of the Fragile X Society

Our aims are to:

- Advance the health and well-being of individuals affected by the genetic condition known as the Fragile X Syndrome and associated conditions.
- Advance education about the condition in order to help improve the environment, conditions and services offered to people with Fragile X and associated conditions, and their families.
- Promote research into the condition and to publish the useful results thereof.
- Raise funds to carry out our work.

Our Vision is a world where people living with Fragile X and associated conditions are:

- Valued - have their individual needs met with Fragile X recognised and understood by professionals.
- Included - have access to an active community of people who understand.
- Empowered - through evidence-based knowledge about the condition.

The biggest risk to the Charity sector since Covid, has been a weak economy combined with increased inflation with a commensurate negative effect on the cost of living. This may well be reflected in a reduction in individual giving. To an extent the Fragile X Society has done very well, against this background. However, a refocus on fundraising is now a priority for 2025/26.

During the year we demonstrably improved our digital and online presence with a significant increase in Facebook and X (twitter) communications. Our monthly email newsletter to our members included practical information about Fragile X, personal stories about life with Fragile X; updates about policy and services; news about our charity's activities; the latest research findings and participation opportunities; as well as opportunities to support the work of our charity. We published a written annual newsletter which was sent to all our members.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 28 FEBRUARY 2025*

Conferences and Events

In 2024, the Fragile X Society was proud to deliver two successful UK conferences, Birmingham in the spring and Edinburgh in the autumn. Both events brought together families, professionals, and researchers for a day of connection, learning, and support. The Birmingham conference welcomed over 120 attendees and featured expert speakers covering key topics such as anxiety, behavior strategies, and early intervention. Parents shared powerful personal stories, helping others feel less alone and more empowered in their journey.

The Edinburgh conference saw a similarly strong turnout, with a particularly warm and collaborative atmosphere. Attendees praised the accessible and informative sessions, which included updates on genetic testing, education strategies, and adult services. The presence of local professionals and the Scottish Fragile X community strengthened our connections in the region and underscored the importance of regional support networks. Across both events, feedback was overwhelmingly positive—with 98% of attendees saying they would attend again and many expressing gratitude for the opportunity to meet others who truly understand. These conferences continue to play a vital role in reducing isolation and sharing practical, life-changing knowledge.

On the 16th September 2024, we held a successful online AGM and members meeting, highlighting our new Counselling services and giving members the opportunity to meet the staff team.

In 2025/26 we will continue to hold face-to-face events, with a conference in Edinburgh.

During 2025/26 there will be a focus on the following themes:

1. How Fragile X Syndrome affects women and girls throughout their life cycle.
2. Adults living with Fragile X Syndrome.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2025

Fundraising

Like all small charities, the economic downturn has had a detrimental effect on our finances over the last year. We were affected in the following ways:

Regular giving: Donations from regular supporters have declined each year since 2022. Although the actual value of the decline is modest, the effect is exacerbated by the high levels of inflation over this period. The ongoing challenge is to meet increasing costs with static regular income. We will work hard to engage our membership:

- A more active membership will help us to raise awareness of Fragile X and lobby effectively on behalf of one another.
- We will have a larger pool of active members to help support us with our fundraising activities and volunteering.

Larger donations and legacies are very welcome, but the steady income that comes from our regular supporters, is equally important as it allows the Society to plan its activities over the coming year.

It is likely that for the foreseeable future, most charity fundraising income sources, including those of the Fragile X Society, will be directly affected by the state of the UK's economy... Undoubtedly, there will be pressure on the Society, hopefully mitigated by an increase in legacies and corporate giving.

However, fundraising outcomes will also crucially result from donor and funder decision-making. Here at the Fragile X Society, we have a comprehensive Legacy programme, and are focused on growing our membership and continuing to develop income streams from wealthier donors including the corporate sector. We will focus our efforts on securing funds which cover our operating cost in the first instance and develop services after that.

Membership

Membership of the Fragile X Society has remained strong and supportive during 2024/25, with a return to fundraising activities. The charity now has a total membership of 2946 individuals or family memberships, (many of whom have multiple members of their family living with varying effects of Fragile X), 101 overseas members, and 408 UK associate members.

A priority for next year will be consolidating our existing membership and ensuring that they both feel part of, and contribute to, our community. We are increasing our work in the four nations of the UK, hoping to build our membership in Wales, Northern Ireland and Scotland. This will benefit us in three ways:

- We will be able to provide help and advice to a greater number of people affected by Fragile X Syndrome and its associated conditions.
- A larger membership will help us to raise awareness of Fragile X and lobby effectively on behalf of one another.
- We will have a larger pool of members to help support us with our fundraising activities and volunteering.

The Fragile X Society continues to support the ongoing work to set up a Fragile X Research Clinic and Charity as a Centre of Excellence for Intellectual Disability in Leicester. This ambitious member led initiative could bring potentially life changing benefits to the Fragile x Community.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

Research

Fragile X Society full members (with a direct link to Fragile X) have the option to agree to be contacted about research projects which may be relevant to them. In total, 1401 families agreed to be contacted. This figure has remained static so we will encourage more of our members to take part in research next year.

Our unique community in the UK is a vital resource for researchers, as there is no central database of individuals diagnosed in the UK. We receive frequent requests from the UK and beyond from researchers to request support with recruiting to their projects. These projects could not take place without the support and participation of our members.

Our virtual research subcommittee (predominantly consisting of people with direct family experience of Fragile X) considers all these requests to ensure that all approaches to families for participation are appropriate, useful and reasonable. In addition, they feedback on the design of the research from their personal experiences in order to identify potential issues, with the aim of facilitating participation from our members and improving the research.

We are proud to have supported recruitment to a wide range of projects addressing key aspects of Fragile X Syndrome and Fragile X Premutation-Associated Conditions this year. We are also supporting additional on-going projects and new research proposals under review.

We are passionate about accessibly disseminating the findings of research and we report back to our members with summaries of the research projects that we have supported, as well as other concluded projects from around the world. We also invite researchers to present at our annual conferences.

How we have supported individuals and families living with Fragile X

Through dedicated, specialised Families and Professionals Advisors, the Fragile X Society provides information and practical guidance to support and empower individuals and families living with Fragile X, and the professionals who support them. This service is accessible by telephone, email, social media, our website and by letter.

Our Advisors provide a personal response to each enquiry, tailoring the response to the individual needs. Some enquiries require us to provide authorities input on the way that Fragile X may be influencing a person's needs for supports or services, in which case we write in-depth support letters. In addition, our Advisors created bespoke social stories and resources for individuals to help with complex situations.

Here is some feedback we have received from our families and professionals: -

"I recently rang the society asking for suggestions to help for my son You were most helpful and sent me lots of information"

"Thanks again for all your help, I really feel blessed to be in contact with you."

Booklets received with thanks and this pdf is perfect thank you!

The staff are really happy to receive this and consider it a huge help.

I can't thank you enough for all the help you have given me so far.

I can't thank you enough for this wealth of knowledge and options we can explore.

This will aid us in the transition of the gentleman to our services in a big way.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 28 FEBRUARY 2025*

e-Learning

In collaboration with Cornerstone, and thanks to the Scottish Autism Development Fund, we offer training to professionals via our Fragile X e-Learning course

Our Information Publications

The information that we provide to our members is particularly valuable and is constantly reviewed and upgraded by our Families and Professionals Advisors and our contracted part-time information officer.

Contribution of Volunteers

The Society's fundraising, accounting, support and information work continues to be undertaken, in part, by trustees, who volunteer their time to run the charity. Their commitment to upholding the values and vision of the Society with a steadily increasing membership has been remarkable.

In addition, volunteers with a particular expertise (such as media skills, journalism, and proof reading) save the Society money and improve our support. We would like to give our thanks to these individuals, to our Specialist Advisors, and to all the others who have volunteered their time raising funds and awareness.

Supporting other organisations.

The Fragile X Society has worked in partnership with other organisations during the year; these include but are by no means limited to: Genetic Disorders UK, Rare Disease UK, the Patrick Wild Centre, the Cerebra Network, and Cornerstone. We are also proud members of the Disabled Children's Partnership and Autistica's Embracing Complexity alliance for people with neurodevelopmental conditions.

In 2024, FRaXI (Fragile X International) activity continued to grow, along with the Fragile X Society actively participating in international research and advocacy networks. FraXI contributed to global discussions on early diagnosis, supported collaborative research projects, and strengthened relationships with Fragile X organisations across Europe and beyond ensuring that the voices of UK families remain part of the international conversation.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

Measuring our impact

Our newly launched counselling service has had a powerful impact, with families sharing how it helped them process challenges and feel less alone. One parent told us, "Having someone who truly understands Fragile X has been a lifeline," while another shared, "The counselling sessions gave us the emotional tools to keep going."

We achieved our primary objectives for the year, continuing to provide support and information to families affected by Fragile X and professionals working in the field of Fragile X. Feedback on our support has continued to be extremely positive during 2024/25.

Online support and resources became increasingly important to our community. This year we have continued to develop our online presence and are proud to have a large community in our Facebook group (2946 members) which has risen by 72 members: who post daily to seek support, celebrate successes and share resources. We also have a growing following on social media including: our Facebook Page; 5068 followers and 1998 followers Instagram. The number of times our content was played or displayed was 198,400 on Facebook and 50,133 on Instagram. This is calculated by the number of times our videos were played for at least 1 minute, plus the number of times our photos and text were on screen.

Our website attracted 87,926 page views, this is counted each time a visitor loads a specific page on the website and 36,323 users with our most popular pages visited are About Fragile X, Homepage, and Information & Genetic Testing.

New Developments and Strategic Growth in 2024/25

Conferences and Engagement Events: Over the past year, the Fragile X Society successfully held both virtual and in-person events to bring together professionals, families, and researchers. These included our 2024 online members' meeting and the Birmingham event, which was kindly sponsored by Shionogi. These gatherings have allowed us to share new research, explore best practices, and strengthen our sense of community.

Board Development and Trustee Recruitment: Recruiting new trustees has brought valuable expertise, lived experience, and fresh perspectives to the Society's leadership. This has enriched our governance, boosted strategic planning, and ensured that our Board better reflects the diversity of our Fragile X community. With newly appointed trustees actively contributing across fundraising, research advocacy, and operational oversight, we are well positioned for future growth and resilience.

Fragile X Awareness Day 2024

Our Fragile X Awareness Day, held in October 2024, was a resounding success. This day gave us the opportunity to raise national awareness of Fragile X Syndrome through media coverage, school activities, fundraising challenges, and social media campaigns. The commitment of our media volunteers was instrumental in achieving a wide reach and spreading personal stories that connected deeply with the public. Their contributions helped us to bring visibility to the challenges faced by our community and the vital work of the Society.

Growing Academic Partnerships

The Fragile X Society has also been strengthening its academic partnerships. We are delighted to be developing relationships with universities including Queen's University Belfast and the University of Leeds. These partnerships are fostering collaborative research, awareness-raising opportunities, and improved student engagement with Fragile X-related topics. We look forward to working even more closely with these institutions in the future to enhance research and community support.

Recognition

The Fragile X Society is acknowledged by independent agencies, such as Genetic Alliance UK, as having an important contribution to make in the consideration of genetic and disability equality issues raised by Fragile X. As an inherited condition, Fragile X raises serious issues for families and Society will continue to take every opportunity to present its members' views.

Whilst 2024/25 was a successful year for the Fragile X Society we must continue to work hard to provide up to date quality advice and support to our members, delivered within a financially viable framework.

We are developing as an organisation according to a new 2025-2029 Strategy set by the Trustees and led by the MD, which is subject to continuous review and improvement as part of the Trustees' remit. The aim is to lead the charity forward and ensure that all living with Fragile X have the opportunity of support and the best guidance and information possible.

The Trustees believe that they comply with the Charities Act 2011 provisions and the Charity Commission's statutory guidance on public benefit in this report and when reviewing the Society's aims and objectives and planning future activities.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

Financial review

It is well documented that the UK is currently enduring an economic crisis and the consequences for the charity sector have been serious as high levels of inflation and interest rates have limited the support that many individuals or organisations, can offer to charities.

The Fragile X Society has not been immune from this trend with income received from donations, fundraising and grants reduced but nonetheless we do benefit from having a very loyal and supportive membership.

The accounts to 28 February 2025, reflect these pressures. The profit and loss account shows a loss of £22,630 (2024: Loss of £13,642). This is despite an increase in income from £131,471 in 2024 to £142,478 in 2025.

This loss has been funded from the Society's reserves. On 28 February 2025, the unrestricted reserves had reduced from £122,875 to £104,079, with the specific reserves being reduced from £26,502 to £22,669, a reduction in the total reserves of £22,630.

The unrestricted reserves can be used for any purpose, and it is probable that funds will be drawn from this reserve over the coming year to meet every day running costs. The restricted reserves are, as the name suggest restricted in their use. The Society's restricted reserves of £22,669 must be used (in accordance with the wishes of the donors) to fund expenditure in Scotland (£11,256), Northern Ireland (£6,913) and Wales (£4,500)

Although the Society will focus on fundraising, and monitoring and minimising expenditure, the challenge is a difficult one. For instance, we are faced with having to absorb the increases in expenditure without (unlike a commercial entity) being able to pass at least a proportion of those costs onto customers. We do not anticipate this pressure to ease over the current financial year and the challenge will be to manage costs whilst continuing to offer our core services to members.

We remain very grateful for the generous support of our members and those who make donations to the Society either on a regular or one-off basis thereby providing vital funding for the Society's work.

We would also like to acknowledge the generous support of the Trusts and Foundations who have made grants or donations to the Society, particularly the Chapman Family Trust, who have supported the charity for many years and significantly increased their donations during the previous year. The Society is extremely grateful for their grants and donations which enabled it to continue the vital work of supporting families and spreading awareness and understanding of Fragile X Syndrome and associated conditions.

Finally, regular donations both large and small, are a vital source of income as they allow the Society to plan its finances and future commitments. The Society operates a Friends of Fragile X scheme which provides a way of supporting the Society on a regular basis through monthly donations.

Structure, governance and management

The charity is controlled by its governing document, a memorandum, and articles, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 28 FEBRUARY 2025*

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Steve Harris (Chair)	
Marie Williams (Vice Chair)	
Tim Eccleshall (Treasurer)	
Anne Eccleshall (Secretary)	
Aiste Skegg	(Appointed 19 June 2024)
Andrew Jaques	
Andy Clarke	
Jonny Cobbold	(Appointed 19 June 2024)
Mary Martin	
Patricia Pattison	
Rebecca Mayers	
Zeinab Ali	
Christopher Jones	(Resigned 20 June 2024)
Lois Jones	(Resigned 20 June 2024)
Michelle Flyn (Co-opted 8 February 2025)	(Appointed 8 February 2025)

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

Staff

Managing Director: Peter Richardson

Administrative and Communications Coordinator: Claire Denyer (0.5 FTE)

Families and Professionals Advisors:

For Children: Alison Field (part time 0.6 FTE)

Senior FAPA (Adults): Jane Oliver (part time 0.6 FTE)

(FTE= Full-Time Equivalent)

We also engaged a contract Development Worker in Northern Ireland to strengthen our presence and outreach across the region.

In addition, in 2024/25 we were proud to deliver our dedicated counselling service, offering tailored emotional support to families and individuals affected by Fragile X.

Specialist Advisors Our specialist advisors are experts in various aspects of Fragile X from either a clinical or research background and volunteer their time to support and advise the Fragile X Society

Dr Mark C Hirst, BSc (Hons), PhD

Head of Cell and Molecular Biology, Faculty of Science, The Open University

Dr Francesca Forzano

Consultant Clinical Geneticist, Great Ormond Street Hospital NHS Trust

Professor Dame Kay E Davies

Co-Director, Oxford Centre of Gene Function, University of Oxford

Dr Angus Clarke

Professor in Clinical Genetics at Cardiff University School of Medicine and Honorary Consultant to the All-Wales Medical Genomics Service

Prof Chris Oliver BSc MPhil PhD CPsychol AFBPsS

Professor of Neurodevelopmental Disorders, Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham

Prof Gaia Scerif, BSc, PhD

Associate Professor and Tutorial Fellow, Department of Experimental Psychology, University of Oxford and St. Catherine's College

Dr Andrew Stanfield MB ChB MRCPsych

Senior Clinical Research Fellow, Patrick Wild Centre, University of Edinburgh

Dr Sundus Alusi

Consultant Neurologist, The Walton Centre for Neurology and Neurosurgery

Prof Jonathan Herring, MA, BCL

Professor of Law, University of Oxford and DW Wolf-Clarendon Fellow in Law, Exeter College, University of Oxford

Dr Jennifer L. Austin, Ph.D., BCBA-D

Athro Seicoleg

Professor of Psychology

Pennaeth Dadansoddi Ymddygiad

Head of Behaviour Analysis

Ysgol Seicoleg

School of Psychology

Prifysgol De Cymru

University of South Wales

Dr Becky Hardiman, Trainee Clinical Psychologist, Cardiff

Dr Hayley Crawford, Associate Professor, University of Warwick

Dr Carina Shey, B.Pharm. MRPharmS. PhD. Health Economist, Switzerland

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

Governance

Full (family) membership of the Society is open to individuals who have Fragile X Syndrome, or who are carriers of Fragile X, or who have a familial link to Fragile X. Associate membership of the Society is open to persons or organisations interested in learning more about Fragile X or in furthering the work of the Society.

Following the Incorporation of the Society which commenced activities on 1st March 2009, the then trustees became Trustees of the new company. Future Trustees may be elected from outside the Society's membership. The Company Trustees, who form the Board, have responsibility for the management of the Society's affairs. Directors are elected by the full membership at the Society's Annual General Meeting or by co-option by the Board. The Honorary Officers are elected by the Board at its first meeting after the AGM.

This year, our AGM took place on 16th September 2024 online.

Working Structure and Management

The Board of Trustees meets at least four times a year to consider management and financial issues regarding the running of the Society. The workload of the Board is further supported through a governance subcommittee and a panel of experts that review new research proposals. These groups operate in conjunction with the MD and staff to provide guidance on management issues and bring recommendations on growth and development to the full Board of Trustees' meetings.

Currently the Society employs a full-time Managing Director, who provides quarterly reports to the Board, and three other part-time employees: two Families and Professionals Advisors (one adult- and one child-focussed), and an Administrative and Communications Coordinator.

During 2024/25, the Fragile X Society used the services of a contract worker to undertake a specific time limited project: "Developing services in Northern Ireland".

The staff are very grateful to the Trustees for their support (given on a voluntary basis) and the 2025/26 year begins with a renewed confidence and optimism at the Society.

Induction and training of Directors

The current Trustees (twelve) ten of whom have a family link to Fragile X, are committed to the aims of the Society and ensuring that our services are sustained or developed to meet those aims. All new Trustees are informed about the Society's constitution, provided with support and guidance around charity best practice and provided with an induction on the charity's key policies.

Role descriptions and adverts for Trustee roles and required skills (according to analysis of skill gaps on the Board) are disseminated through the charity's communications as well as through other relevant organisations. Those interested in becoming a trustee are sent the Society's papers explaining the role, responsibilities, duties and commitment of the Society's Trustees, and are informally interviewed by the Chair and/or MD of the organisation. Interested people are also provided with a nomination form and the date (at least 28 days before the AGM) by which the nomination form should be returned to the Society.

Independent Examiner

The Trustees are currently reviewing the appointment of the Independent Examiners and expect to be able to make proposals at the AGM to be held in September 2024.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 28 FEBRUARY 2025*

Disclosure of independent examination information

Each of the Trustees has confirmed that there is no information of which they are aware and which is relevant to the independent examination, but of which the independent examiners are unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditor is aware of such information.

The Trustees' report was approved by the Board of Trustees.

The trustees' report was approved by the Board of Trustees.



.....
Steve Harris (Chair)
Trustee

Date: .10th July 2025

THE FRAGILE X SOCIETY

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF THE FRAGILE X SOCIETY

I report to the trustees on my examination of the financial statements of The Fragile X Society (the charity) for the year ended 28 February 2025.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Companies Act 2006 (the 2006 Act). You are satisfied that the financial statements of the charity are not required by charity or company law to be audited and have chosen instead to have an independent examination.

Having satisfied myself that the financial statements of the charity are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's financial statements carried out under section 44 (1) (c) of the 2005 Act and section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the charity is required by company law to prepare its accounts on an accruals basis and is registered as a charity in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). I confirm that I am qualified to undertake the examination because I am a member of the ICAEW, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

Gary Pready FCA
Gravita Audit Oxford LLP

First Floor, Park Central
40-41 Park End Street
Oxford
OX1 1JD
Date:

THE FRAGILE X SOCIETY

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 28 FEBRUARY 2025

		Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
	Notes						
Income and endowments from:							
Donations and legacies	3	126,516	5,983	132,499	115,401	9,000	124,401
Other trading activities	4	6,254	-	6,254	3,671	-	3,671
Investments	5	3,778	-	3,778	2,928	-	2,928
Other income	6	2,404	-	2,404	2,582	-	2,582
Total income		138,952	5,983	144,935	124,582	9,000	133,582
Expenditure on:							
Raising funds	7	8,264	-	8,264	7,834	-	7,834
Charitable activities	8	150,264	9,818	160,082	132,493	6,897	139,390
Total expenditure		158,528	9,818	168,346	140,327	6,897	147,224
Net expenditure and movement in funds		(19,576)	(3,835)	(23,411)	(15,745)	2,103	(13,642)
Reconciliation of funds:							
Fund balances at 1 March 2024		122,876	26,503	149,379	138,621	24,400	163,021
Fund balances at 28 February 2025		103,300	22,668	125,968	122,876	26,503	149,379

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

THE FRAGILE X SOCIETY

BALANCE SHEET

AS AT 28 FEBRUARY 2025

	Notes	2025 £	£	2024 £	£
Current assets					
Stocks	14	4		4	
Debtors	15	100		475	
Cash at bank and in hand		128,864		151,479	
		<u>128,968</u>		<u>151,958</u>	
Creditors: amounts falling due within one year	16	(3,000)		(2,579)	
Net current assets			<u>125,968</u>		<u>149,379</u>
The funds of the charity					
Restricted income funds	18		22,668		26,503
Unrestricted funds	19		103,300		122,876
			<u>125,968</u>		<u>149,379</u>

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 28 February 2025.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 10th July 2025



.....
Steve Harris (Chair)
Trustee

Company registration number 06724061 (England and Wales) (England and Wales)

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 28 FEBRUARY 2025

1 Accounting policies

Charity information

The Fragile X Society is a private company limited by guarantee incorporated in England and Wales. The registered office is Suite 5, The Chestnuts, Stortford Road, Dunmow, Essex, CM6 1DA.

1.1 Accounting convention

The financial statements have been prepared in accordance with Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102") and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

1.6 Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

1.7 Taxation

The charity is exempt from corporation tax on its charitable activities.

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods. These financial statements do not contain estimates or judgements that are considered critical

3 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2025 £	2025 £	2025 £	2024 £	2024 £	2024 £
Donations and legacies	126,516	5,983	132,499	115,401	9,000	124,401

4 Income from other trading activities

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Other sales	6,254	3,671

5 Income from investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Interest received	3,778	2,928

6 Other income

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
100+ Club	2,404	2,582

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

7 Expenditure on raising funds

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Fundraising and publicity		
Seeking donations, grants and legacies	852	932
Trading costs		
Support costs	7,412	6,902
Total costs	8,264	7,834

8 Expenditure on charitable activities

	Charitable activities 2025 £	Charitable activities 2024 £
Direct costs		
Staff costs	105,892	96,342
Conferences	12,897	6,210
Supporting The Fragile X Community	27,711	21,199
General expenses	10,002	11,078
	156,502	134,829
Share of support and governance costs (see note 9)		
Governance	3,580	4,561
	160,082	139,390
Analysis by fund		
Unrestricted funds	150,264	132,493
Restricted funds	9,818	6,897
	160,082	139,390

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

9 Support costs allocated to activities

	2025 £	2024 £
Support costs	7,412	6,902
Governance costs	3,580	4,561
	<u>10,992</u>	<u>11,463</u>
Analysed between:		
Fundraising	7,412	6,902
Charitable activities	3,580	4,561
	<u>10,992</u>	<u>11,463</u>

10 Net movement in funds

	2025 £	2024 £
The net movement in funds is stated after charging/(crediting):		
Fees payable for the independent examination of the charity's financial statements	<u>3,000</u>	<u>2,220</u>

11 Trustees

None of the trustees (or any persons connected with them) received any remuneration from the charity during the year.

£489 (2024: £280) was reimbursed to trustees for expenses incurred.

12 Employees

The average monthly number of employees during the year was:

	2025 Number	2024 Number
Directorate	1	1
Support worker	2	2
Administration	1	1
	<u>4</u>	<u>4</u>
Total	<u>4</u>	<u>4</u>

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

12	Employees	(Continued)	
	Employment costs	2025	2024
		£	£
	Wages and salaries	98,878	90,772
	Social security costs	3,318	2,283
	Other pension costs	3,696	3,287
		<u>105,892</u>	<u>96,342</u>
	There were no employees whose annual remuneration was more than £60,000.		
13	Taxation		
	The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.		
14	Stocks	2025	2024
		£	£
	Stock	<u>4</u>	<u>4</u>
15	Debtors	2025	2024
	Amounts falling due within one year:	£	£
	Trade debtors	<u>100</u>	<u>475</u>
16	Creditors: amounts falling due within one year	2025	2024
		£	£
	Trade creditors	-	359
	Accruals and deferred income	<u>3,000</u>	<u>2,220</u>
		<u>3,000</u>	<u>2,579</u>
17	Retirement benefit schemes	2025	2024
	Defined contribution schemes	£	£
	Charge to profit or loss in respect of defined contribution schemes	<u>3,696</u>	<u>3,287</u>

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2025

18 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 March	Incoming	Resources	At 28
	2024	resources	expended February 2025	February 2025
	£	£	£	£
The National Lottery Community Fund donation for Northern Ireland	8,019	-	(1,106)	6,913
St James Management donation for Wales	4,500	-	-	4,500
The Robertson Trust donation for Scotland	9,519	5,983	(4,247)	11,255
Shionogi B.V	4,465	-	(4,465)	-
	<u>26,503</u>	<u>5,983</u>	<u>(9,818)</u>	<u>22,668</u>
Previous year:	At 1 March	Incoming	Resources	At 29
	2023	resources	expended February 2024	February 2024
	£	£	£	£
The National Lottery Community Fund donation for Northern Ireland	9,900	-	(1,881)	8,019
St James Management donation for Wales	4,500	-	-	4,500
The Robertson Trust donation for Scotland	10,000	-	(481)	9,519
Shionogi B.V	-	9,000	(4,535)	4,465
	<u>24,400</u>	<u>9,000</u>	<u>(6,897)</u>	<u>26,503</u>

The National Lottery Community Fund Northern Ireland, St James Management Wales, and The Robertson Trust grants are all for particular projects and so they are restricted.

The grant from Shionogi B.V. was given specifically to partially fund the Society's conference in Birmingham in March 2024, at which information on the latest developments in the diagnosis & management of FXS is to be presented to an audience of Society members, clinicians, researchers, and leaders of other European FXS patient support organisations.

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2025

19 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 March 2024	Incoming resources	Resources expended	At 28 February 2025
	£	£	£	£
General funds	122,876	138,952	(158,528)	103,300

Previous year:	At 1 March 2023	Incoming resources	Resources expended	At 29 February 2024
	£	£	£	£
General funds	138,621	124,582	(140,327)	122,876

20 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2025 £	2025 £	2025 £	2024 £	2024 £	2024 £
Fund balances at 28 February 2025 are represented by:						
Current assets/(liabilities)	103,300	22,668	125,968	122,876	26,503	149,379
	103,300	22,668	125,968	122,876	26,503	149,379

21 Operating lease commitments

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

2025 £	2024 £
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THE FRAGILE X SOCIETY

Within one year

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

5,200

8,422

FOR THE YEAR ENDED 28 FEBRUARY 2025

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2025

22 Related party transactions

There were no disclosable related party transactions during the year (2024 - none) other than the transactions disclosed in note 11.