

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 29 FEBRUARY 2024

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) Andrew Jaques Andy Clarke Christopher Jones Lois Jones Mary Martin Zeinab Ali Rebecca Mayers Patricia Pattison (Co-opted)	(Appointed 30 September 2023) (Appointed 30 September 2023) (Appointed 27 January 2024)
Secretary	Anne Eccleshall	
Managing Director	Pete Richardson	
Charity number (England and Wales)	1127861	
Charity number (Scotland)	SC047332	
Company number	06724061	
Registered office	Suite 5 The Chestnuts Stortford Road Dunmow Essex CM6 1DA	
Independent examiner	Critchleys Audit LLP Beaver House 23-38 Hythe Bridge Street Oxford OX1 2EP	
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 29 FEBRUARY 2024

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 shyness or 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 800 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 Trustees (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 29 FEBRUARY 2024

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 fed back that generic 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 2023/24 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 desperately 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 public 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 and the public.
- 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 during 2022/23 was the economy faltering combined with increased inflation and with the 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 2024/25.

During the year we demonstrably improved our digital offer 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. Further, we published a written annual newsletter which was sent to all our members.

Conferences and Events

On the 30 September 2023, we held a successful online AGM and members meeting, launching our new Counselling services and giving members the opportunity to meet the staff team.

In 2024/25 we will resume face-to-face events, with conferences in Birmingham and Edinburgh.

During 2024/25 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 29 FEBRUARY 2024

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: Although, donations from regular supporters have only declined slightly over the last 3 years, the actual value of those donations has been eroded by the high levels of inflation over this period. The challenge is to meet increasing costs with static regular income.

One-off donations: These increased compared to the previous year, but we received a couple of larger donations which though very welcome, mask the fact that smaller donations have declined in this period.

As stated, 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 day-to-day activities over the coming year.

It is likely that for the foreseeable future, most charity fundraising efforts will be detrimentally affected by the state of the UK's economy. The Society is not immune to these challenges, and 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 will focus on continuing to develop our comprehensive Legacy programme, growing our membership, and seeking support from wealthier donors including the corporate sector. We will focus our efforts on securing funds which cover our operating costs in the first instance and develop services after that.

Membership

Membership of the Fragile X Society has remained strong and supportive during 2023/24, with a return to fundraising activities. The charity now has a total membership of 2471 UK individuals or family memberships, (many of whom have multiple members of their family living with varying effects of Fragile X), 101 overseas members, and 397 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.

During 2023/24 the Fragile X Society were delighted to be able 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 29 FEBRUARY 2024

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.

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.

In total this year we responded to a total of 519 enquiries (generating 2045 contacts) via our helpline.

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 29 FEBRUARY 2024

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.

International work and supporting other organisations.

The Fragile X Society continues to support the work of FraXI (Fragile X International) – “a network of country family organisations who work together to promote, support and strengthen the FX identity as an added value to society”. FraXI currently has 20 member countries including the latest members Australia and New Zealand and 6 affiliate members including several South American countries. And the number is still growing!

All the individual member organisations maintain services and support families in their countries. FraXI aims to promote social inclusion of Fragile X at all levels of society and has produced a series of bite-sized videos which have been shared through X (formerly Twitter) and Facebook, each explaining the difficulties faced by people with Fragile X Syndrome and sharing good practice in education.

Anne Eccleshall represented The Fragile X Society (UK) at FraXI's second annual conference which was held in November 2023, in Gembloux, Belgium. It gave representatives from individual member countries the opportunity to exchange ideas and share initiatives. Jorg Richstein (Vice Chair of FraXI) and Professor Frank Kooy (University of Antwerp) gave two very interesting talks explaining the current different types of research in Fragile X and the procedures for drug development and clinical trials.

Future priorities for FraXI will include work on EU Fragile X guidelines which will describe services that people with Fragile X are likely to need and developing links with other international groups such as Eurordis [Home - EURORDIS](#) and Rare Diseases International [Rare Diseases International Rare Diseases International](#)

FraXI's annual conference 2024 will be held in November in Barcelona.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 29 FEBRUARY 2024

The Fragile X Society UK is also a member of EURORDIS (Rare Diseases Europe).

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.

Measuring our impact

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 2023/24.

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 (2874 members) which has risen by 142 members: who post daily to seek support, celebrate successes and share resources. We also have a growing following on social media including: 4458 likes (2% increase) on our Facebook Page; 4949 followers (64% increase compared to the same period last year) and 1841 followers (21% increase) on Instagram.

Our website attracted 40,058 users with our most popular pages being the introductory page about Fragile X, information about genetic testing, information about the Fragile X and Autism and diagnosis.

Recognition

The 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 the Society will continue to take every opportunity to present its members' views.

Whilst 2023/24 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 2024-2029 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 29 FEBRUARY 2024

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 slightly reduced but nonetheless we do benefit from having a very loyal and supportive membership.

Although we are trying to manage this risk by refocusing on fundraising, and monitoring and minimising expenditure, 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. As the rate of inflation declines, these pressures should ease however, the challenge will be to manage costs whilst continuing to offer our core services to members will continue over the coming year.

The Society had unrestricted reserves of £ 122,876 on 29 February 2024, down from £138,621 on 28 February 2023. These can be used for any purpose, and roughly equate to 93% of our core expenditure, that is the Society's basic operating expenditure.

The Society also has restricted reserves of £26,503, which must be used for activities specified by the supporter making the donation. This figure can be broken down as follows:

Supporting families in Scotland: £9,518

Supporting families in N. Ireland: £8,020

Supporting families in Wales: £4,500

Birmingham conference: £4,465

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 us for many years and significantly increased their grant during 2023/24 with a further increase to follow in 2024/25. The Society is extremely grateful for these grants 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 29 FEBRUARY 2024*

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)

Andrew Jaques

Andy Clarke

Christopher Jones

Lois Jones

Mary Martin

Zeinab Ali

(Appointed 30 September 2023)

Rebecca Mayers

(Appointed 30 September 2023)

Patricia Pattison (Co-opted)

(Appointed 27 January 2024)

Tamara Martin

(Resigned 1 June 2023)

Dr Kirsten Johnson

(Resigned 3 August 2023)

Rosie Martin

(Resigned 9 August 2023)

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 29 FEBRUARY 2024

Staff

Managing Director: Peter Richardson (part time 0.8 FTE)

Administrative and Communications Coordinator: Claire Denyer (0.5 FTE)

Families and Professionals Advisors

For Children: Alison Field (part time 0.6 FTE)

For Adults: Jane Oliver (part time 0.6 FTE)

** FTE= Full-Time Equivalent*

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 Angela Barnicoat

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 29 FEBRUARY 2024

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 on 15 October 2008, activities commenced on 1st March 2009 and the then Trustees became Directors of the new company. Future Trustees may be elected from outside the Society's membership. The Trustees, who form the Board, have responsibility for the management of the Society's affairs. Trustees 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 30th September 2023 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 (these meetings took place both virtually and on a face-to-face basis at PPL, Unit 3 Saviours Wharf, Mill Street, London during 2023-24). 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 part-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 2023/24, the Fragile X Society used the services of an additional part-time 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 2024/25 year begins with a renewed confidence and optimism at the Society.

Induction and training of Directors

The current Trustees (twelve) eleven of whom (92%) have a personal 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 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.

Disclosure of independent examination information


Each of the trustees has confirmed that there is no information of which they are aware 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 FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 29 FEBRUARY 2024

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



Steve Harris (Chair)

Trustee

Date: 20-4-24

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 29 February 2024.

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.

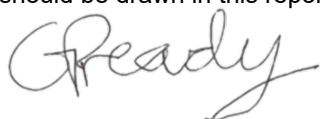
Independent examiner's statement

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 applicable to charities preparing their accounts 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
Critchleys Audit LLP

Beaver House
23-38 Hythe Bridge Street
Oxford
OX1 2EP

Dated: ..12 June 2024

THE FRAGILE X SOCIETY

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 29 FEBRUARY 2024

		Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
	Notes						
Income and endowments from:							
Donations and legacies	3	115,401	9,000	124,401	105,365	24,400	129,765
Other trading activities	4	3,671	-	3,671	4,337	-	4,337
Investments	5	2,928	-	2,928	622	-	622
Other income	6	2,582	-	2,582	2,971	-	2,971
Total income		124,582	9,000	133,582	113,295	24,400	137,695
Expenditure on:							
Raising funds	7	7,834	-	7,834	7,558	-	7,558
Charitable activities	8	132,493	6,897	139,390	150,466	4,943	155,409
Total expenditure		140,327	6,897	147,224	158,024	4,943	162,967
Net income/(expenditure) and movement in funds		(15,745)	2,103	(13,642)	(44,729)	19,457	(25,272)
Reconciliation of funds:							
Fund balances at 1 March 2023		138,621	24,400	163,021	183,350	4,943	188,293
Fund balances at 29 February 2024		122,876	26,503	149,379	138,621	24,400	163,021

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 29 FEBRUARY 2024

	Notes	2024 £	£	2023 £	£
Current assets					
Stocks	13	4		4	
Debtors	14	475		-	
Cash at bank and in hand		151,479		165,860	
		<u>151,958</u>		<u>165,864</u>	
Creditors: amounts falling due within one year	15	2,579		2,843	
		<u></u>		<u></u>	
Net current assets			149,379		163,021
			<u></u>		<u></u>
The funds of the charity					
Restricted income funds	17		26,503		24,400
Unrestricted funds			122,876		138,621
			<u>149,379</u>		<u>163,021</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 29 February 2024.

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 20-4-24



Steve Harris (Chair)

Trustee

Company registration number 06724061 (England and Wales)

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 29 FEBRUARY 2024

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.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

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 29 FEBRUARY 2024

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
	2024 £	2024 £	2024 £	2023 £	2023 £	2023 £
Donations and legacies	115,401	9,000	124,401	105,365	24,400	129,765

4 Income from other trading activities

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Other sales	3,671	4,337

5 Income from investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Interest received	2,928	622

6 Other income

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
100+ Club	2,582	2,971

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 29 FEBRUARY 2024

7 Expenditure on raising funds

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Fundraising and publicity		
Seeking donations, grants and legacies	932	808
	<hr/>	<hr/>
Trading costs		
Support costs	6,902	6,750
	<hr/>	<hr/>
Total costs	<u>7,834</u>	<u>7,558</u>

8 Expenditure on charitable activities

	Charitable activities 2024 £	Charitable activities 2023 £
Direct costs		
Staff costs	96,342	101,194
Conferences	6,210	8,500
Supporting The Fragile X Community	21,199	19,085
General expenses	11,078	13,431
	<hr/>	<hr/>
	134,829	142,210
	<hr/>	<hr/>
Share of support and governance costs (see note 9)		
Governance	4,561	13,199
	<hr/>	<hr/>
	139,390	155,409
	<hr/>	<hr/>
Analysis by fund		
Unrestricted funds	132,493	150,466
Restricted funds	6,897	4,943
	<hr/>	<hr/>
	<u>139,390</u>	<u>155,409</u>

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 29 FEBRUARY 2024

9 Support costs allocated to activities

	2024 £	2023 £
Support costs	6,902	6,750
Governance costs	4,561	13,199
	<u>11,463</u>	<u>19,949</u>
Analysed between:		
Fundraising	6,902	6,750
Charitable activities	4,561	13,199
	<u>11,463</u>	<u>19,949</u>

10 Trustees

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

£280 (2023: £1,413) was reimbursed to trustees for expenses incurred.

11 Employees

The average monthly number of employees during the year was:

	2024 Number	2023 Number
Directorate	1	1
Support worker	2	3
Administration	1	1
Total	<u>4</u>	<u>5</u>

Employment costs

	2024 £	2023 £
Wages and salaries	90,772	94,918
Social security costs	2,283	2,885
Other pension costs	3,287	3,391
	<u>96,342</u>	<u>101,194</u>

There were no employees whose annual remuneration was more than £60,000.

12 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 29 FEBRUARY 2024

13 Stocks

	2024 £	2023 £
Stock	4	4

14 Debtors

	2024 £	2023 £
Amounts falling due within one year:		
Trade debtors	475	-

15 Creditors: amounts falling due within one year

	2024 £	2023 £
Trade creditors	359	743
Accruals and deferred income	2,220	2,100
	2,579	2,843

16 Retirement benefit schemes

Defined contribution schemes

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 charge to profit or loss in respect of defined contribution schemes was £3,287 (2023 - £3,391).

17 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 2023 £	Incoming resources £	Resources expended £	At 29 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
	24,400	9,000	(6,897)	26,503

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 29 FEBRUARY 2024

17 Restricted funds

(Continued)

Previous year:	At 1 March 2022 £	Incoming resources £	Resources expended £	At 28 February 2023 £
The National Lottery Community Fund donation for Northern Ireland	4,943	9,900	(4,943)	9,900
St James Management donation for Wales	-	4,500	-	4,500
The Robertson Trust donation for Scotland	-	10,000	-	10,000
	<u>4,943</u>	<u>24,400</u>	<u>(4,943)</u>	<u>24,400</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.

18 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 2023 £	Incoming resources £	Resources expended £	At 29 February 2024 £
General funds	<u>138,621</u>	<u>124,582</u>	<u>(140,327)</u>	<u>122,876</u>
Previous year:	At 1 March 2022 £	Incoming resources £	Resources expended £	At 28 February 2023 £
General funds	<u>183,350</u>	<u>113,295</u>	<u>(158,024)</u>	<u>138,621</u>

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 29 FEBRUARY 2024

19 Analysis of net assets between funds

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Fund balances at 29 February 2024 are represented by:						
Current assets/(liabilities)	122,876	26,503	149,379	138,621	24,400	163,021
	<u>122,876</u>	<u>26,503</u>	<u>149,379</u>	<u>138,621</u>	<u>24,400</u>	<u>163,021</u>

20 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:

	2024 £	2023 £
Within one year	<u>4,686</u>	<u>7,909</u>

21 Related party transactions

There were no disclosable related party transactions during the year (2023 - none) other than the transactions disclosed in note 10.