

THE FRAGILE X SOCIETY

England & Wales · Charity number 1127861

Details

Status	Registered
Legal form	Charitable company
Company number	06724061
Registered	2009-02-03
Register	View on the Charity Commission register

Contact

Address	Suite 5 The Chestnuts 4 Stortford Road Great Dunmow Great Du
Phone	01371875100
Email	info@fragilex.org.uk
Website	www.fragilex.org.uk

Activities

Objects: 3.1 To advance the health and well being of individuals affected by the genetic condition known as the Fragile X Syndrome and associated conditions 3.2 To advance public education about the syndrome in order to help improve the environment, conditions and services offered to people with Fragile X and associated conditions, and their families.

Activities: Fragile X is a family of inherited genetic conditions, including Fragile X Syndrome. We provide information and practical guidance to support and empower individuals and families living with Fragile X We educate and inform public and professionals about Fragile X, to raise awareness and understanding and improve care We encourage and publicise research into Fragile X

Classification

- **How:** Provides Advocacy/advice/information
- **What:** Education/training, Disability
- **Who:** People With Disabilities

Geography

- **Area of benefit:** UNDEFINED. IN PRACTICE NATIONAL
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-02-28	£144,935	£168,346	-	-
2024-02-29	£133,582	£147,224	-	-
2023-02-28	£137,695	£162,967	-	-
2022-02-28	£205,521	£127,654	-	-
2021-02-28	£148,121	£120,841	-	-

Trustees

Name	Role	Appointed
Steve Harris	Chair	2020-09-22
Andrew Jaques		2021-09-25
Andy Clarke		2022-10-15
Anne Eccleshall		2021-09-25
Erin Williams		2026-04-25
Jonny Cobbold		2024-06-01
Lily Pattison		2026-04-25
Michelle Flynn		2025-10-12
Molly Jaques		2026-04-25
Patricia Eleanor Grace Pattison		2024-06-19
Tim Eccleshall		2020-09-22

Accounts

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

CONTENTS

	Page
Trustees' report	1 - 12
Independent examiner's report	13
Statement of financial activities	14
Balance sheet	15
Notes to the financial statements	16 - 23

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.

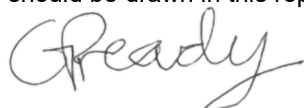
Independent examiner's statement

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 applicable to 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: 15 July 2025

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	
	£	£	£	£
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	
	£	£	£	£
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.

Accounts

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

CONTENTS

	Page
Trustees' report	1 - 11
Independent examiner's report	12
Statement of financial activities	13
Balance sheet	14
Notes to the financial statements	15 - 21

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	(Appointed 30 September 2023)
	Rebecca Mayers	(Appointed 30 September 2023)
	Patricia Pattison (Co-opted)	(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

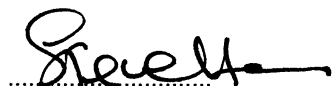
Each of the trustees has confirmed that there is no information of which they are aware which is relevant to the independent examination, but of which the independent examiners are unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to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

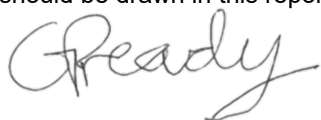
Independent examiner's statement

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
Trading costs		
Support costs	6,902	6,750
Total costs	7,834	7,558

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
	134,829	142,210
Share of support and governance costs (see note 9)		
Governance	4,561	13,199
	139,390	155,409
Analysis by fund		
Unrestricted funds	132,493	150,466
Restricted funds	6,897	4,943
	139,390	155,409

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
	<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.

Accounts

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 2023

THE FRAGILE X SOCIETY

CONTENTS

	Page
Trustees' report	1 - 11
Independent examiner's report	12
Statement of financial activities	13
Balance sheet	14
Notes to the financial statements	15 - 21

THE FRAGILE X SOCIETY

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Steve Harris (Chair from 30 March 2023) Marie Williams (Vice Chair) Tim Eccleshall (Treasurer) Rosie Martin (Secretary) Anne Eccleshall Andrew Jaques Andy Clarke Christopher Jones Dr Kirsten Johnson (Chair until 15 February 2023) Lois Jones Mary Martin Tamara Martin (Research officer from 09 January 2023)	(Appointed 15 October 2022) (Appointed 18 June 2022) (Appointed 18 June 2022) (Appointed 18 June 2022)
Secretary	Rosie Martin	
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 28 FEBRUARY 2023

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 28th February 2023. 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 everyone 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 2023

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%)¹ 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 2022-23 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 2023/24.

A membership survey held in Autumn 2022 gave us universally positive feedback and highlighted the continued need to provide members with information about Fragile X and the importance of raising awareness with health and social professionals.

We have improved our digital offer and are sending out regular email communications with our new branding. We send a regular email newsletter to our members (including a paper newsletter), providing practical information about Fragile X (such as our Snippets of Advice blog); 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.

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2023

Conferences and Events

In 2022/23 we were able to resume face-to-face conferences and events, successfully hosting a weekend at Thomley on 18th June, and a UK wide Conference on the 24th of September. These events included updates on Fragile X research studies, managing behaviours and ADHD and family workshops.

With similar in-person events taking place during 2023/24, digital will still play a large role in both events and community fundraising.

During 2023/24 there will be a focus on the following themes:

1. how Fragile X Syndrome affects women and girls throughout life cycle.
2. Older adults living with Fragile X Syndrome.

Fundraising

At the Board meeting held on 9th April 2022 the Trustees agreed to a new Legacy Programme to support the Society's fundraising objective, whilst giving members an opportunity to contribute to the long-term success of the charity. This gave Society members the chance to make their bespoke Wills online free of charge whilst being checked, vetted, and approved by an experienced practising solicitor regulated by The Solicitors Regulation Authority.

In addition, there was a significant amount of very positive fundraising activity from members including the London Marathon, the Lisbon Marathon, and competitors in the Birmingham Tough Mudder challenge.

Our fundraising across the nations was particularly successful in 2022/23 with funds brought in for Scotland and Wales, and an extension of the Lottery Grant for Northern Ireland.

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 strong and supportive during 2022/23, with a return to fundraising activities and face to face events during this year. The charity now has a membership of 2510 individuals or families which represents a 4% growth on the previous year: 2025 UK full member families (many of whom have multiple members of their family living with varying effects of Fragile X), 99 overseas members, and 385 UK associate members. This shows a growth of 8% indicating that there is an increased knowledge and awareness of Fragile X amongst health professionals.

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. Furthermore, we will continue in our efforts on increasing membership, including in under-represented groups such as BAME communities. 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

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2023

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, 1620 families agreed to be contacted. This is very encouraging as it shows a 7% increase in families wanting to be contacted compared to the previous 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 Board 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 use their personal experiences to feedback on the design of the research, 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.

Our work continued with researchers in understanding the wider ramifications of Fragile X, encouraging studies which involved girls/women as much prior research has focused on boys/men. Positive feedback was received at a successful Academic Workshop held in Oxford on April 26, 2022, and at our two conferences held at Thomley and Birmingham in June and September 2022 respectively.

In 2023/24, we aim to continue our work in raising awareness and understanding of Fragile X amongst professionals and the wider public. In August 2022, we engaged a research scientist on a consultancy basis to review and summarise new research in an accessible form for members. Further, she is reviewing and updating the Society's library of information leaflets, some of which have since been reprinted. We also have an active Communications Subcommittee whose members support policy initiatives, social media, and wider communications.

We will continue to offer information and practical support to individuals and families living with Fragile X through our helpline and literature resources.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2023

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 796 enquiries (generating 3543 contacts) via our helpline, which represents a 24% and a 26% increase respectively.

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

"Thank you so much. You guys as ever are such a lifeline for us!"

From a social worker on the helpline:

"Thank you for such amazing support and information. I know what to do now and so much more makes sense."

The nature of the enquiries was wide-ranging and included help, information and support on education, behaviour, transition from school, issues of adulthood, welfare benefits and health-related issues including epilepsy and FXTAS.

Receiving the diagnosis can be an emotional and confusing time. We are available to provide in-depth emotional and practical support at this stage, via our services. This year 13 enquiries (involving 70 contacts) were received from families who had just received a diagnosis of Fragile X Syndrome. Each received a personal response from our Advisors.

*"Thank you so much for all of your help and concern, it really did help and was much appreciated.
It was a pleasure to speak with you".*

"Thank you for your kindness, it was lovely to speak with someone who understands."

"Again, my thanks for all of your help and kindness, you will never know how much talking with you on the phone that afternoon meant to me, I had been so afraid, and you took away a lot of the fear."

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2023

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 staff and advisors.

'Thank you very much puts our mind at ease. Really appreciate your efforts is extremely helpful and helps calm the mind'.

Sadly, there is still low awareness and understanding of Fragile X amongst the professionals and the wider community. We are the key source of information on Fragile X-related issues in the UK. As an organisation we aim to be the most reliable point of contact to be able to access high quality information about Fragile X Syndrome, which is based upon the latest research. All Society publications are prepared in consultation with our expert Specialist Advisors and are currently being updated to take account of new research, meaning that we can be seen as a credible source of information.

It was a pleasure to speak with you too. Thank you for your kindness, it was lovely to speak with someone who understands. Thank you for all of the information..... Just talking with you has made me feel better, because I hadn't heard of Fragile X".

The Fragile X Society holds a wealth of information resources (some of which have been prepared in multiple languages) which include videos, brief leaflets, comprehensive introductory booklets, easy read resources and papers which cover topics in more detail. All of these resources are available free of charge, and many are available via our website www.fragilex.org.uk.

'Speaking to you today made me feel so much better, thank you so much for your time'

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 is a founding member of Fragile X International (FraXI), which became an INPO in Brussels on April 1, 2022. The Society is represented on FraXI's board and plays an active role in its international work. Fragile X International is a network of country family organisations who work together to promote social inclusion of Fragile X at all levels of society, advocating the vision that those living with Fragile X and associated conditions should not have to conform to societies' norms, but society should embrace them for who they are.

FraXI's inaugural General Meeting was held in Lyon 4-6 November 2022, at which one of the board members was elected President. This meeting covered a range of topics, including information on The Network for Neurodevelopmental Rare Diseases, and gave the opportunity for member countries to exchange ideas and share initiatives on supporting the Fragile X community.

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2023

The Fragile X Society is also a member of EURORDIS (Rare Diseases Europe). One of our board members sits on the Board of Directors for EURORDIS and plays an active role on their Newborn Screening Working Group.

As the Fragile X Society, we are also part of the wider learning disability, autism, and genetic conditions communities, and we will continue to work alongside other organisations with shared interests. The Fragile X Society has worked in partnership with other organisations during the year; these include but are by no means limited to: Gene People UK, Rare Disease UK, the Patrick Wild Centre, the Cerebra Network, and Cornerstone.

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 2022/23.

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 amounting to just under 3,000 members: who post daily to seek support, celebrate successes, and share resources. We also have a growing following on social media including: a page and profile reach of 222k, 1626 followers including an additional 510 followers that came on board. Altogether we published 680 posts across networks and had an engagement rate of 5.63% (a good social media influencer usually achieves 2-3%)

Our website attracted nearly 55,000 users (maintaining the previous year's high engagement), with our most popular pages being the introductory pages for the syndrome, information about genetic testing, information about the Fragile X premutation, and about the association between Fragile X and autism.

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.

Our proposal submission to the UK National Screening Committee (UK NSC) via the 2022 annual call for new topics was a very good example of how the Fragile X Society proactively represents the interests of our members. This proposal for including Fragile X Syndrome in newborn blood spot screening is being considered by their Annual Call Evaluation Group (this group includes the UK NSC Chair, the Chairs of the Committee's expert Foetal, Maternal and Child Health Reference Group and Adult Reference Group, Public and Patient Voice representatives, and the UK NSC secretariat team). We were delighted that this group decided that our proposal should be explored further. Now, in response to this decision, the UK NSC Secretariat will commission an evidence map to look at newborn screening for Fragile X Syndrome.

Whilst 2022/23 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 strategy set by the Trustees and led by the MD, which is subject to continuous review and improvement as part of the MD's 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 2023

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 (excluding legacies and in memoriam donations) increasing by just 2% in the year to 28 February 2023.

This would be a worrying trend on its own, but the risks and uncertainties facing the Society are increased dramatically by the consequences of inflation. Excluding a couple of large one-off items of expenditure incurred during the year, our costs increased by approximately 11% compared to the year to 28 February 2022.

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. 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.

The Society had unrestricted reserves of £138,621 at 28 February 2023. This 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.

In addition, the Society has restricted reserves of £24,400, which must be used to support work by the Society in Scotland (£10,000), Northern Ireland (£9,900) and Wales (£4,500).

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 some years. 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 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 from 30 March 2023)

Marie Williams (Vice Chair)

Tim Eccleshall (Treasurer)

Rosie Martin (Secretary)

Anne Eccleshall

Andrew Jaques

Andy Clarke

(Appointed 15 October 2022)

Christopher Jones

(Appointed 18 June 2022)

Dr Kirsten Johnson (Chair until 15 February 2023)

Lois Jones

(Appointed 18 June 2022)

Mary Martin

Tamara Martin (Research officer from 09 January 2023)

(Appointed 18 June 2022)

Dr Lucia Elghali

(Resigned 18 June 2022)

Prof Gaia Scerif

(Resigned 18 June 2022)

Katherine Zwick

(Resigned 14 November 2022)

Mark Smith

(Resigned 31 December 2022)

Tim Clarkson

(Resigned 1 January 2023)

John Quayle - Secretary

(Resigned 03 July 2022)

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2023

Staff

Managing Director

Peter Richardson MD (part time 0.8 FTE)

Administrative and Communications Coordinator

Kate Williams (0.5 FTE)

Families and Professionals Advisors

For Children: Caroline Pringle (part time 0.6 FTE)

For Adults: Jane Oliver (part time 0.6 FTE)

** FTE= Full-Time Equivalent*

Specialist Advisors

Our specialist advisors during the year ended 28 February 2023, 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 Hayley Crawford

Assistant Professor, University of Warwick

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 I Professor of Psychology

Pennaeth Dadansoddi Ymddygiad I Head of Behaviour Analysis

Ysgol Seicoleg I School of Psychology

Prifysgol De Cymru I University of South Wales

Dr Becky Hardiman, Trainee Clinical Psychologist, Cardiff

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2023

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 also became Directors of the new company, though for the purpose of this report will be referred to as Trustees. 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 at the Thomley Centre on 18th June 2022.

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 during 2022-23 both on a face-to-face basis at Jones Lang LaSalle Real Estate and Advisor's offices in London and virtually). The workload of the Board is spread through subcommittees, formulated to meet the organisation's present needs, which 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.

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 2022, 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" as well as a contracted one day per week information officer.

Winter 2022/23 saw a period of change amongst the staff at the Fragile X Society with one of our Families and Professional Advisors announcing her retirement, our Admin and Communications Manager leaving the organisation for a new role and the loss of our IT specialist Trustee. The remaining staff were very grateful to the Trustees for their additional support during a very challenging time for the organisation, and with a strong recruitment process in place there is a renewed confidence and optimism at the Society.

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 2021, the Fragile X Society brought in one additional part-time contract worker to undertake a specific time limited project: developing services in Northern Ireland.

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.

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 28 FEBRUARY 2023

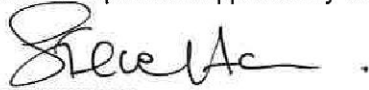
Independent Examiner

The Directors will be proposing Critchleys Audit LLP as independent examiners for the current year at the AGM to be held in September 2023.

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 trustees' report was approved by the Board of Trustees.



Steve Harris (Chair from 30 March 2023)
Trustee

Date: 1 - 7 - 2023

**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 2023.

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: 13 July 2023

THE FRAGILE X SOCIETY

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 28 FEBRUARY 2023

		Unrestricted funds 2023 £	Restricted funds 2023 £	Total Unrestricted funds 2023 £	Restricted funds 2022 £	Total 2022 £
	Notes					
<u>Income and endowments from:</u>						
Donations and legacies	3	105,365	24,400	129,765	198,202	198,202
Other trading activities	4	4,337	-	4,337	4,394	4,394
Investments	5	622	-	622	13	13
Other income	6	2,971	-	2,971	2,912	2,912
Total income		113,295	24,400	137,695	-	205,521
<u>Expenditure on:</u>						
Raising funds	7	7,558	-	7,558	-	10,381
Charitable activities	8	150,466	4,943	155,409	4,091	117,273
Total expenditure		158,024	4,943	162,967	4,091	127,654
Net (expenditure)/income for the year/						
Net movement in funds		(44,729)	19,457	(25,272)	(4,091)	77,867
Fund balances at 1 March 2022		183,350	4,943	188,293	9,034	110,426
Fund balances at 28 February 2023		138,621	24,400	163,021	4,943	188,293

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

THE FRAGILE X SOCIETY

BALANCE SHEET

AS AT 28 FEBRUARY 2023

	Notes	2023 £	£	2022 £	£
Current assets					
Stocks	12	4		4	
Cash at bank and in hand		165,860		190,125	
		165,864		190,129	
Creditors: amounts falling due within one year	13	(2,843)		(1,836)	
Net current assets			163,021		188,293
Income funds					
Restricted funds	15		24,400		4,943
Unrestricted funds			138,621		183,350
			163,021		188,293

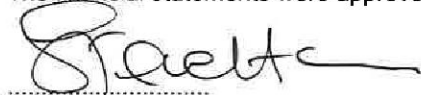
The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 28 February 2023.

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 1-7-2023



Steve Harris (Chair from 30 March 2023)
Trustee

Company registration number 06724061

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 28 FEBRUARY 2023

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 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.

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2023

1 Accounting policies

(Continued)

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	33% per annum on a straight line basis
Computers	33% per annum on a straight line basis

1.7 Stocks

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

1.8 Taxation

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

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.

3 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Unrestricted funds
	2023 £	2023 £	2023 £	2022 £
Donations and legacies	105,365	24,400	129,765	198,202

4 Other trading activities

	Unrestricted funds	Unrestricted funds
	2023 £	2022 £
Other sales	4,337	4,394

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2023

5 Investments

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
Interest received	622	13

6 Other income

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
100+ Club	2,971	2,912

7 Raising funds

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
<u>Fundraising and publicity</u>		
Seeking donations, grants and legacies	808	1,363
<u>Trading costs</u>		
Support costs	6,750	9,018
	7,558	10,381

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2023

8 Charitable activities

	Charitable activities 2023 £	Charitable activities 2022 £
Staff costs	101,194	90,774
Conferences	8,500	1,731
Bad debts written off	-	502
Supporting The Fragile X Community	19,085	15,374
General expenses	13,431	2,516
	<u>142,210</u>	<u>110,897</u>
Share of governance costs (see note 9)	13,199	6,376
	<u>155,409</u>	<u>117,273</u>
Analysis by fund		
Unrestricted funds	150,466	113,182
Restricted funds	4,943	4,091
	<u>155,409</u>	<u>117,273</u>

9 Support costs

	Support costs £	Governance costs £	2023 £	Support costs £	Governance costs £	2022 £
Support costs	6,750	-	6,750	9,018	-	9,018
Governance costs	-	13,199	13,199	-	6,376	6,376
	<u>6,750</u>	<u>13,199</u>	<u>19,949</u>	<u>9,018</u>	<u>6,376</u>	<u>15,394</u>
Analysed between						
Trading	6,750	-	6,750	9,018	-	9,018
Charitable activities	-	13,199	13,199	-	6,376	6,376
	<u>6,750</u>	<u>13,199</u>	<u>19,949</u>	<u>9,018</u>	<u>6,376</u>	<u>15,394</u>

Governance costs includes payments to the independent examiners (inclusive of VAT) of £2,100 (2022: £1,908) for independent examination fees.

10 Trustees

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

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2023

10 Trustees

(Continued)

£1,413 (2022: £174) was reimbursed to trustees for expenses incurred.

11 Employees

The average monthly number of employees during the year was:

	2023 Number	2022 Number
Directorate	1	1
Support worker	3	2
Administration	1	1
Total	5	4

Employment costs

	2023 £	2022 £
Wages and salaries	94,918	85,155
Social security costs	2,885	2,609
Other pension costs	3,391	3,010
	101,194	90,774

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

12 Stocks

	2023 £	2022 £
Stock	4	4

13 Creditors: amounts falling due within one year

	2023 £	2022 £
Trade creditors	743	246
Accruals and deferred income	2,100	1,590
	2,843	1,836

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2023

14 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 £3,391 (2022 - £3,010).

15 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Balance at 1 March 2021	Resources expended	Balance at 1 March 2022	Movement in funds		Balance at 28 February 2023
	£	£	£	Incoming resources	Resources expended	£
The National Lottery Community Fund donation for Northern Ireland	9,034	(4,091)	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>9,034</u>	<u>(4,091)</u>	<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.

16 Analysis of net assets between funds

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Fund balances at 28 February 2023 are represented by:						
Current assets/(liabilities)	138,621	24,400	163,021	183,350	4,943	188,293
	<u>138,621</u>	<u>24,400</u>	<u>163,021</u>	<u>183,350</u>	<u>4,943</u>	<u>188,293</u>

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2023

17 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:

	2023 £	2022 £
Within one year	7,909	-

18 Related party transactions

There were no disclosable related party transactions during the year (2022 - none) other than the transactions disclosed in note 10.

Accounts

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 2022

THE FRAGILE X SOCIETY

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Dr Kirsten Johnson (Chair) Marie Williams (Vice Chair) Tim Eccleshall (Treasurer) Anne Eccleshall (Research Officer) John Quaye (Secretary) Tim Clarkson Andrew Jaques Steve Harris Mary Martin Mark Smith Katherine Zwink Dr Lucia Elghali Professor Gaia Scerif Rosie Martin
Secretary	John Quaye
Charity number (England and Wales)	1127861
Charity number (Scotland)	SC047332
Company number	06724061
Registered office	Suite 5 The Chestnuts Stortford Road Dunmow England CM6 1DA
Independent examiner	Critchleys Audit LLP Beaver House 23-38 Hythe Bridge Street Oxford Oxfordshire OX1 2EP
Bankers	CAF Bank Ltd 25 Kings Hill Ave Kings Hill West Malling ME19 4JQ

THE FRAGILE X SOCIETY

CONTENTS

	Page
Trustees' report	1 - 11
Independent examiner's report	12
Statement of financial activities	13
Balance sheet	14
Notes to the financial statements	15 - 20

THE FRAGILE X SOCIETY

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 28 FEBRUARY 2022

The directors, 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 28th February 2021. The directors 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).

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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.

Trustees

The trustees who held office during the year and up to the date of approval of the financial statements were as follows:

Dr Kirsten Johnson (Chair)	
Marie Williams (Vice Chair)	
Tim Eccleshall (Treasurer)	
Anne Eccleshall (Research Officer)	(Appointed 25 September 2021)
John Quaye (Secretary)	(Appointed 25 September 2021)
Tim Clarkson	(Appointed 25 September 2021)
Andrew Jaques	(Appointed 25 September 2021)
Steve Harris	
Mary Martin	
Mark Smith	
Katherine Zwink	(Appointed 25 September 2021)
Dr Lucia Elghali	
Professor Gaia Scerif	
Rosie Martin	
Alex Case	(Resigned 13 May 2021)
Tally Nothey	(Resigned 30 June 2021)
Rachel Instone	(Retired 25 September 2021)
Craig McDonald	(Retired 25 September 2021)
Jo Woosnam-Savage	(Retired 25 September 2021)
Andy Clarke	(Resigned 7 January 2022)

Staff

Managing Director

Peter Richardson MD (part time 0.8 FT)

Administrative and Communications Coordinator

Kate Williams (0.5 FTE)

Families and Professionals Advisors

For Children: Caroline Pringle (part time 0.6 FTE)

For Adults: Jane Oliver (part time 0.6 FTE)

* FTE= Full-Time Equivalent

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

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 Hayley Crawford
Assistant Professor, University of Warwick

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

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 trading on 1st March 2009 the then trustees became Directors of the new company. Future Directors may be elected from outside the Society's membership. The Company Directors, 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

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

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 virtually on 25th September 2021.

Working Structure and Management

The Board of Directors meets at least four times a year to consider management and financial issues regarding the running of the Society (these meetings took place virtually during 2021-22 in order to comply with the UK Government Covid restrictions). The workload of the Board is spread through subcommittee, formulated to meet the organisation's present needs, which operate in conjunction with the MD and staff to provide guidance on management issues and bring recommendations on policy matters to the full Board of Directors' 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 2021, the Fragile X Society brought in one additional part-time contract worker to undertake a specific time limited project: developing services in Northern Ireland.

Induction and training of Directors

The current Directors, thirteen (93%) of whom 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 Directors 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. During 2021-2022 our first 'self-advocate' (i.e. a person with Fragile X Syndrome), Katherine Zwink, joined our Board.

Role descriptions and adverts for Director's 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 Director are sent the Society's papers explaining the role, responsibilities, duties and commitment of the Society's Directors, 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.

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

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

(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 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.

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%)¹ 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 2021-22 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.

The Covid-19 pandemic that first appeared in the UK in early 2020 and continued to varying degrees throughout 2021/22, caused significant and detrimental changes to many key services (e.g., medical care, social care, education). The impact amongst our members was compounded by the high anxiety associated with Fragile X Syndrome. We are proud to have maintained all our services during this global crisis ensuring that our members continued to be fully supported. And equally proud that support from our members remained steadfast.

¹ Based upon a 2019 Membership Survey: 70 responses received.

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

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.

During 2021/22 the significant challenges for charities of operating within a global Coronavirus Pandemic continued. Here at the Fragile X Society, we are proud to have been able to continue to deliver our vital services through a remote working arrangement set up during this unprecedented time.

We successfully upgraded our website and social media function supported by a substantial pro-bono project delivered by Costello Medical. We have improved our digital offer and are sending out regular email communications with our new branding. We send a regular email newsletter to our members, providing practical information about Fragile X (such as our Snippets of Advice blog); 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 have increased the frequency of our newsletters during the Covid-19 pandemic from quarterly to fortnightly and we have received very positive feedback (and donations!) from our members.

Conferences and Events

In 2021/22 we were unable to hold face-to-face conferences and events due to the Covid-19 pandemic and all the restrictions that followed. Instead, we have focussed on providing remote-access, online events from social coffee mornings, sessions on topics of interest, and our AGM. During period 1 March 2021 – 28 February 2022 we were able to hold the following virtual events:

- "What legal means are available to protect your loved ones?" With Richard Guy of Birketts – 9 March 2021
- Easter Virtual Coffee morning – 3 April 2021
- FXTAS workshop – 10 June 2021
- AGM and virtual conference including FXTAS with Dr Sundus Alusi and Challenging Behaviour Foundation, Ian Penfold – 25 September 2021
- Fragile X Awareness Day Quiz and social media campaign – 10 October 2021
- "Managing Transitions" with Christine Towers of Together Matters – 17 February 2022

Even with more and more in-person events taking place during 2022/23, digital will still play a large role in both events and community fundraising.

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

Fundraising

We have been fortunate to secure several legacies in 2021/22 which have helped underpin our finances. On September 9th, 2021, the Fragile X Society received the sum of £74,646.24 from the Rosalind Williams Discretionary Trust. This amount was significantly higher than expected. Legacies, combined with corporate giving, offer the Fragile X Society the opportunity to secure our future.

The Covid pandemic continued to affect our finances, with amounts received from family events and third-party fundraising continuing to be less than pre-pandemic levels. However, it is encouraging that third-party fundraising increased by £13,097 compared to 2020/21, the first year of the pandemic.

However, other "traditional" income streams held up well and member support remained very strong. One-off donations showed a slight increase over the previous year, whilst regular donations increased by £7,968.

Whilst many small Charities have struggled to survive during the pandemic, the Fragile X Society has performed remarkably well, and at the year end, we now find ourselves in the position of having reserves of approximately £190,000.

However, this success presents a short-term challenge. By holding a relatively high level of reserves the Fragile X Society was effectively 'excluded' or barred from applying for many grants and there was a reduction in grants received of £50,143 in 2021/22 compared to the previous year.

In order to mitigate against this problem, the Fragile X Society reviewed its Reserves Policy in September 2021 and agreed that we should set aside funds as designated reserves (unrestricted funds which have been set aside by trustees for an essential spend or future purpose). This will enable us to re-apply for grants during 2022/23.

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 constant and supportive during 2021/22, however engagement has fallen as families have become more insular with fewer active families taking part in our online events. The charity now has a membership of 2406 individuals or families: 1952 UK full member families (many of whom have multiple members of their family living with varying effects of Fragile X), 97 overseas members, and 357 UK associate members. This represents an increase of 1.5% from last year.

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. Furthermore, we will focus our efforts on increasing membership, including in under-represented groups such as BAME communities. This will benefit us in three ways:

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

- 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.

Research

Support for research into Fragile X is one of our key aims. In a recent survey, 95% of families in the UK felt that research was important or very important, and that our charity should support 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, 1521 families (79% of our full members) have agreed to support research. 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 Board 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.

We will continue to work with researchers in understanding the wider ramifications of Fragile X, and we are particularly keen to encourage studies which involve girls/women as much prior research has focused on boys/men. We inform our family members of research participation opportunities and feedback on research results. We will ask our members for feedback on our approach to research to help us proactively influence research studies to help ensure that their needs are understood and met. We will garner feedback at an Academic Workshop to be held in Oxford on April 26, 2022, and at our two conferences.

In 2022/23, we aim to continue our work in raising awareness and understanding of Fragile X amongst professionals and the wider public. We now have a part-time member of staff who supports our efforts in communications, as well as an active Communications Subcommittee whose members support policy initiatives, social media and wider communications. We will continue to offer information and practical support to individuals and families living with Fragile X through our helpline and literature resources. This information is being updated during 2022/23.

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

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. During 2021/2022 there were a substantial number of calls asking for help and advice from members dealing with Covid related issues.

In total this year we responded to a total of 643 enquiries (generating 2819 contacts) via our helpline.

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

"Thank you so much. You guys as ever are such a lifeline for us!"

From a social worker on the helpline:

"Thank you for such amazing support and information. I know what to do now and so much more makes sense."

The nature of the enquiries was wide-ranging and included help, information and support on education, behaviour, transition from school, issues of adulthood, welfare benefits and health-related issues including epilepsy and FXTAS.

Receiving the diagnosis can be an emotional and confusing time. We are available to provide in-depth emotional and practical support at this stage, via our services. This year 13 enquiries (involving 70 contacts) were received from families who had just received a diagnosis of Fragile X Syndrome. Each received a personal response from our Advisors.

"Just wanted to share the good news of the blue badge going through for my boy. Thank you so much for all your support. You always go out of your way for me & we appreciate all your support. Once again, thank you very much."

"I cannot tell you of the weight that has been lifted from my shoulders knowing this information now, and being able to show the school etc. Again I cannot thank you enough for this. Thank you for your time, it's much appreciated."

"Thank you ever so much. You always save the day for me! I will share it with his teachers on his review coming up next month. I sincerely appreciate all your help once again thank you ever so much from the bottom of my heart."

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

e-Learning

In collaboration with Cornerstone, and thanks to the Scottish Autism Development Fund, we are able to train professionals via our Fragile X e-Learning course. This year (1 March 2021– 28 Feb 2022), 92 professionals were trained via this course. This represents a 48% increase from the previous year.

Our Information Publications

"I was able to sit down and use the information to organise my thinking after I read your booklet and get on with the job in hand!"

Sadly, there is still low awareness and understanding of Fragile X amongst the professionals and the wider community. We are the key source of information on Fragile X-related issues in the UK. As an organisation we aim to be the most reliable point of contact to be able to access high quality information about Fragile X Syndrome, which is based upon the latest research. All Society publications are prepared in consultation with our expert Specialist Advisors and are currently being updated to take account of new research, meaning that we can be seen as a credible source of information.

The Fragile X Society holds a wealth of information resources (some of which have been prepared in multiple languages) which include videos, brief leaflets, comprehensive introductory booklets, easy read resources and papers which cover topics in more detail. All of these resources are available free of charge, and many are available via our website www.fragilex.org.uk.

Contribution of Volunteers

The Society's fundraising, accounting, support and information work continues to be undertaken, in part, by Directors, 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.

We have agreed to become founding members of the new international charity, Fragile X International (FraXI), which has been registered in Brussels, Belgium, as an INPO (International Non-Profit Organization). FraXI is an umbrella association which has country family Fragile X organisations as full members. All the individual member countries will maintain services in their countries and look after the families within their own countries. FraXI will promote social inclusion of Fragile X at all levels of society, advocating the vision that those living with Fragile X and associated conditions should not have to conform to societies' norms, but society should embrace them for who they are.

As the Fragile X Society, we are of course also part of the wider learning disability, autism and genetic disorder communities, and we will continue to work alongside other organisations with shared interests. 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

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

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 2021/22.

Online support and resources became increasingly important to our community during the Covid pandemic. This year we have continued to develop our online presence and are proud to have a large community in our Facebook group 2732 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; 3006 followers (9% increase compared to the same period last year) on Twitter; and 1510 followers (5% increase) on Instagram.

Our website attracted over 52,000 users (maintaining the previous year's high engagement), with our most popular pages being the introductory pages for the syndrome, information about genetic testing, information about the Fragile X premutation, and about the association between Fragile X and autism.

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. We have also been approached by the press to comment on relevant stories and developments. 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 2021/22 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 strategy set by the Directors and led by the MD, which is subject to continuous review and improvement as part of the Directors' 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 Directors 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.

FINANCIAL REVIEW

We are very grateful for the generous support of our members, our donors and grant givers that have helped us record a financial surplus during 2021-2022. This is an enormous achievement given the challenges we all faced within the charity sector. We are grateful for all who have supported the Society's Friends of Fragile X and 100+ Club initiatives, which have provided vital funding for the Society's work.

THE FRAGILE X SOCIETY

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

FOR THE YEAR ENDED 28 FEBRUARY 2022

We would like to acknowledge the generous support of the Trusts and Foundations whose names are shown in the financial review, these include the Rosalind Williams Discretionary Trust, the Chapman Family Trust, the National Lottery and the Pears Foundation. 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.

STATEMENT OF DIRECTORS RESPONSIBILITIES

The Directors (who are also the Directors of The Fragile X Society for the purposes of company law) are responsible for preparing the Report of the Directors and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the Directors to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the Directors are required to:

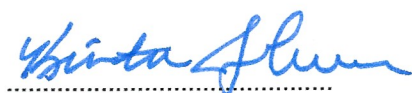
- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity Financial rules and regulations;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The Directors are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

INDEPENDENT EXAMINERS

The Directors will be proposing Critchleys Audit LLP as independent examiners for the current year at the AGM to be held in June 2022.

ON BEHALF OF THE BOARD:



Dr Kirsten Johnson
Chair

Date: 26.05.2022

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 2022.

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.



Robert Kirtland FCA
Critchleys Audit LLP

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

Dated: 27/5/2022

THE FRAGILE X SOCIETY

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 28 FEBRUARY 2022

		Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £
	Notes						
<u>Income and endowments from:</u>							
Donations and legacies	2	198,202	-	198,202	133,189	9,034	142,223
Other trading activities	3	4,394	-	4,394	2,064	-	2,064
Investments	4	13	-	13	64	-	64
Other income	5	2,912	-	2,912	3,770	-	3,770
Total income		205,521	-	205,521	139,087	9,034	148,121
<u>Expenditure on:</u>							
Raising funds	6	10,381	-	10,381	8,620	-	8,620
Charitable activities	7	113,182	4,091	117,273	112,221	-	112,221
Total expenditure		123,563	4,091	127,654	120,841	-	120,841
Net income/(expenditure) for the year/							
Net movement in funds		81,958	(4,091)	77,867	18,246	9,034	27,280
Fund balances at 1 March 2021		101,392	9,034	110,426	83,146	-	83,146
Fund balances at 28 February 2022		183,350	4,943	188,293	101,392	9,034	110,426

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

THE FRAGILE X SOCIETY

BALANCE SHEET

AS AT 28 FEBRUARY 2022

	Notes	2022 £	£	2021 £	£
Current assets					
Stocks	11	4		4	
Debtors	12	-		4,859	
Cash at bank and in hand		190,125		107,053	
		<u>190,129</u>		<u>111,916</u>	
Creditors: amounts falling due within one year	13	<u>(1,836)</u>		<u>(1,490)</u>	
Net current assets			<u>188,293</u>		<u>110,426</u>
Income funds					
Restricted funds	15		4,943		9,034
Unrestricted funds			<u>183,350</u>		<u>101,392</u>
			<u>188,293</u>		<u>110,426</u>

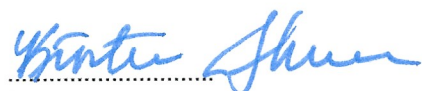
The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 28 February 2022.

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 26.05.2022



Dr Kirsten Johnson (Chair)
Trustee

Company registration number 06724061

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 28 FEBRUARY 2022

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, CM6 1DA, England.

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 has 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 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.

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2022

1 Accounting policies

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	33% per annum on a straight line basis
Computers	33% per annum on a straight line basis

1.7 Stocks

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

1.8 Taxation

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

2 Donations and legacies

	Unrestricted funds	Unrestricted funds	Restricted funds	Total
	2022 £	2021 £	2021 £	2021 £
Donations and legacies	198,202	133,189	9,034	142,223

3 Other trading activities

	Unrestricted funds	Unrestricted funds
	2022 £	2021 £
Other sales	4,394	2,064

4 Investments

	Unrestricted funds	Unrestricted funds
	2022 £	2021 £
Interest received	13	64

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2022

5 Other income

	Unrestricted funds	Unrestricted funds
	2022	2021
	£	£
Voluntary fundraising events	-	349
100+ Club	2,912	3,421
	<u>2,912</u>	<u>3,770</u>

6 Raising funds

	Unrestricted funds	Unrestricted funds
	2022	2021
	£	£
<u>Fundraising and publicity</u>		
Seeking donations, grants and legacies	1,363	1,950
	<u>1,363</u>	<u>1,950</u>
<u>Trading costs</u>		
Support costs	9,018	6,670
	<u>9,018</u>	<u>6,670</u>
	<u>10,381</u>	<u>8,620</u>

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2022

7 Charitable activities

	Charitable activities 2022 £	Charitable activities 2021 £
Staff costs	90,774	91,871
Conferences	1,731	518
Bad debts written off	502	-
Supporting The Fragile X Community	15,374	14,922
General expenses	2,516	908
	<u>110,897</u>	<u>108,219</u>
Share of governance costs (see note 8)	6,376	4,002
	<u>117,273</u>	<u>112,221</u>
Analysis by fund		
Unrestricted funds	113,182	112,221
Restricted funds	4,091	-
	<u>117,273</u>	<u>112,221</u>

8 Support costs

	Support costs £	Governance costs £	2022 Support costs £	Governance costs £	2021 £
Support costs	9,018	-	9,018	6,670	6,670
Governance costs	-	6,376	6,376	-	4,002
	<u>9,018</u>	<u>6,376</u>	<u>15,394</u>	<u>6,670</u>	<u>10,672</u>
Analysed between					
Trading	9,018	-	9,018	6,670	6,670
Charitable activities	-	6,376	6,376	-	4,002
	<u>9,018</u>	<u>6,376</u>	<u>15,394</u>	<u>6,670</u>	<u>10,672</u>

Governance costs includes payments to the independent examiners (inclusive of VAT) of £1,908 (2021: £1,950) for independent examination fees.

9 Trustees

£174 (2021: £107) was reimbursed to trustees for expenses incurred.

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2022

10 Employees

The average monthly number of employees during the year was:

	2022 Number	2021 Number
Directorate	1	1
Support worker	2	3
Administration	1	2
Total	4	6

Employment costs

	2022 £	2021 £
Wages and salaries	85,155	86,444
Social security costs	2,609	2,454
Other pension costs	3,010	2,973
	90,774	91,871

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

11 Stocks

	2022 £	2021 £
Stock	4	4

12 Debtors

	2022 £	2021 £
Amounts falling due within one year:		
Other debtors	-	4,502
Prepayments and accrued income	-	357
	-	4,859

13 Creditors: amounts falling due within one year

	2022 £	2021 £
Trade creditors	246	47
Accruals and deferred income	1,590	1,443
	1,836	1,490

THE FRAGILE X SOCIETY

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2022

14 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 £3,010 (2021 - £2,973).

15 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds			
	Incoming resources	Balance at 1 March 2021	Resources expended	Balance at 28 February 2022
	£	£	£	£
National Lottery Northern Ireland	9,034	9,034	(4,091)	4,943

The National Lottery Northern Ireland grant is for a particular project and so is restricted.

16 Analysis of net assets between funds

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £
Fund balances at 28 February 2022 are represented by:						
Current assets/(liabilities)	183,350	4,943	188,293	101,392	9,034	110,426
	<u>183,350</u>	<u>4,943</u>	<u>188,293</u>	<u>101,392</u>	<u>9,034</u>	<u>110,426</u>

17 Related party transactions

There were no disclosable related party transactions during the year (2021 - none).

Accounts

REGISTERED COMPANY NUMBER: 06724061 (England and Wales)
REGISTERED CHARITY NUMBER: 1127861
REGISTERED SCOTTISH CHARITY: SC047332

**Report of the Directors and
Financial Statements for the year ended 28th February 2021.**

for

THE FRAGILE X SOCIETY

The Fragile X Society

Contents of the Report and Financial Statements for the year ended 28th February 2021

	Page
Report of the Directors	3 to 13
Report of the Independent Examiners	14
Statement of Financial Activities	15
Comparatives for the Statement of Financial Activities	16
Balance Sheet	17
Notes to the Financial Statements	18 to 23

THE FRAGILE X SOCIETY

Report of the Directors for the year ended 28th February 2021

The directors, 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 28th February 2021. The directors have adopted the provisions of the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (the FRSSE) (effective 1 January 2015).

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

06724061 (England and Wales)

Registered Charity number (England and Wales)

1127861

Registered Charity number (Scotland)

SC047332

Registered office

Rood End House, 6 Stortford Road, Great Dunmow, Essex, CM6 1DA

Directors

Dr Kirsten Johnson (Chair)

Marie Williams (Vice Chair)

Alex Case

Tim Eccleshall (Treasurer)

Rosie Martin (Secretary)

Mark Smith

Tally Nothey

Steve Harris

Prof Gaia Scerif

Jo Woosnam-Savage

Mary Martin

Andy Clarke

Rachel Instone (Research Officer)

Dr Lucia Elghali

Craig McDonald

Bank

CAF Bank

25 Kings Hill Avenue

Kings Hill

West Malling

Kent

ME19 4JQ

Independent Examiners

Critchleys

Beaver House

23-38 Hythe Bridge Street

Oxford

OX1 2EP

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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.

Staff

Managing Director

Becky Hardiman CEO (part-time 0.6 FTE until 22 July 2020)

Peter Richardson MD (part time 0.8 FTE, from 5 May 2020)

Administrative and Communications Coordinator

Kate Williams (0.5 FTE)

Families and Professionals Advisors

For Children: Caroline Pringle (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

Charles Gibb, MA, MSc, Dip Ed, AFBPS
Principal Educational Psychologist, The Educational Psychology Practice

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 Hayley Crawford
Assistant Professor, University of Warwick

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

Governance

Full (family) membership of the Society is open to individuals who have Fragile X (this includes Fragile X Syndrome or being a carrier 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 trading on 1st March 2009 the then trustees became Directors of the new company. Future Directors may be elected from outside the Society's membership. The Company Directors, 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 virtually on 22 September 2020. A special resolution was agreed and confirmed at the November 7th Board meeting which updated the Fragile X Society's Memorandum and Article of Association (details are included in appendix i)

The Charity Commission was duly informed of these changes and gave their agreement.

Working Structure and Management

The Board of Directors meets at least four times a year to consider management and financial issues regarding the running of the Society (These meetings took place virtually during 2020-2021 in order to comply with the UK Government Covid restrictions). The workload of the Board is spread through sub-committees, formulated to meet the organisations present needs, which operate in conjunction with the MD and staff to provide guidance on management issues and bring recommendations on policy matters to the full Board of Directors' meetings.

Currently, the Board of Directors is supported by 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.

Induction and training of Directors

The current Directors, twelve (80%) of whom 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 directors 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. In 2021-2022 we plan to have a 'self-advocate' (i.e. a person with Fragile X) joining our Board.

Role descriptions and adverts for Director's 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 director are sent the Society's papers explaining the role, responsibilities, duties and commitment of the Society's Directors, 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.

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 is inherited from carriers, who have small changes to their Fragile X gene (premutation) 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 160,000 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 the only group in the UK that specifically addresses the significantly complex and varied needs of people 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.

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%)¹ 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 2020-2021 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.

The Covid-19 pandemic that first appeared in the UK during March 2020, caused rapid and detrimental changes to many key services (e.g., medical care, social care, education). The impact amongst our members was compounded by the high anxiety associated with Fragile X Syndrome. We are proud to have maintained all our services during this global crisis ensuring that our members continued to be fully supported.

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.

¹ Based upon a 2019 Membership Survey: 70 responses received.

Future Plans: The Charity's Main Objectives for 2021-2022

It is fair to say that 2020 and winter/spring 2021 was a time of exceptional circumstances and challenges, with the global Coronavirus Pandemic having a devastating effect upon the UK economy as a whole, and certain sectors like entertainment, travel and charities being particularly badly affected.

With face-to-face meetings being restricted (or prevented altogether) and many avenues of communication being rendered no longer viable for the foreseeable future, we have amended our approach, adapting and becoming more digital and social media savvy.

To help us achieve this aim, we are delighted that Costello Medical* are giving us their pro bono support to run a substantial project on our behalf to optimise our digital presence and services. Whilst we will continue to provide the helpline and all our existing services, we are also adopting this digital and social media-based strategy during 2021. This includes a complete overhaul of our website and branding.

This new project is called "Digitally Developing and Diversifying the Fragile X Society" (supported by Costello Medical and the National Lottery) and is focussed upon ensuring that we can communicate more effectively and grow our membership base through digital channels. In particular, we want to ensure we reach Black, Asian and Minority Ethnic (BAME) and other groups that may not be currently having their needs met.

There are still many families in the UK that have been affected by Fragile X and don't know about us and the services we offer. There are still many people that have not yet been diagnosed. We want to change this situation. We will ensure that as many people as possible are given the exact help and support that they need.

** Costello Medical are a healthcare consultancy with a range of clients across the healthcare sector. Their headquarters is in Cambridge, UK, but they also have offices in the US, Singapore, and China. They are committed to giving back to local communities and sharing their expertise to help improve health and healthcare globally, including dedicating time to supporting pro bono projects for charity partners, which we will benefit from here at the Fragile X Society!*

Fundraising

The results of the winter 2020-2021 Institute of Fundraising coronavirus impact survey reflected the urgent situation charities now face as small charities, like us, take steps to respond to the huge challenges we face. The initial outlook is sobering with organisations, on average, forecasting a decline in their voluntary income of 48%.

Here at the Fragile X Society, we are proud to have been able to continue to deliver our vital services through a remote working arrangement set up during this unprecedented time.

During 2021, we continue to operate in a climate where traditional fundraising activities remain either prohibited or made logistically more difficult by the longer-term effects of Covid.

We will respond by adapting a more virtual response and undertaking planned activities as agreed by the Board and detailed within our new three-year Fundraising Strategy. Our primary focus will be:

- Understanding and implementing lessons learned from other charities who have adopted similar operational models of a small, central salaried organisation connected via digital means with valuable volunteer-led support.
- Moving quickly and adeptly into the new post-pandemic world.
- Increasing our fundraising to move from a financial operating annual deficit position to a financially stable Society.

We are developing a legacy programme and have received a significant legacy already for 2021-2022. We are exploring corporate links and sponsorship, and already have one link made in 2020-2021 with Dunmow Football Club. We have valuable efforts being made by family fundraising initiatives, including obtaining a place in the London Marathon 2021. Through these, and other efforts, we aim to have a broad fundraising base which gives us the finances to achieve our aims.

Grants

We will make specific targeted approaches to Trusts based upon the potential return on investment and maximising the use of volunteer support, as well as seeking continuation funding from existing donors. We will build on the grant success of 2020-2021, using this learning to inform our applications in 2021-2022.

We will continue to develop positive relationships with existing donors using feedback and case studies to demonstrate how their continuing support and generosity benefits the Fragile X community.

Membership

Membership of the Fragile X Society has remained constant even through these challenging times, however engagement has fallen as families have become more insular.

A priority for next year will be consolidating our existing membership and ensuring that they both feel part of, and contribute to, our community. Furthermore, we will focus our efforts on increasing membership including in under-represented groups such as BAME communities. 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.

With support from Costello Medical our website will be reviewed and the information that we provide to members updated. This will include a greater focus upon, and signposting towards, donations/fundraising and legacies.

Research

We will continue to work with researchers in understanding the wider ramifications of Fragile X, and we are particularly keen to encourage studies which involve girls/women as much prior research has focused on boys/men. We inform our family members of research participation opportunities and feedback on research results. We will ask our members for feedback on our approach to research to help us proactively influence research studies to help ensure that their needs are understood and met. We will garner feedback at an Academic event to be held in June 2021 and with our members at our 25th September 2021 Conference.

In 2021-2022, we aim to continue our work in raising awareness and understanding of Fragile X amongst professionals and the wider public. We now have a part-time member of staff who supports our efforts in communications, as well as an active Communications Subcommittee whose members support policy initiatives, social media and wider communications. We will continue to offer information and practical support to individuals and families living with Fragile X through our helpline and literature resources. This information is being updated during 2021.

We are developing as an organisation according to a strategy set by the Directors and led by the MD, which is subject to continuous review and improvement as part of the Directors' 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 Directors 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.

ACHIEVEMENTS AND PERFORMANCE

Our community

The charity now has a membership of 2370 individuals or families: 1924 UK full member families (many of whom have multiple members of their family living with varying effects of Fragile X), 95 overseas members, and 351 UK associate members. This represents an increase of 1.3% from last year.

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, website and letter.

In total this year we responded to a total of 678 enquiries (generating 3168 contacts) via our helpline.

In addition, our support workers contributed to discussions on our online Facebook group, which is posted in multiple times daily by its members.

“After our recent correspondence with yourselves, we have since joined the Fragile X Society Facebook groups too. I wish we had done this years ago, it's great support and nice to be able to talk to other families who can relate to our experiences.”

“Your help and support to me and all the FX families is invaluable so thank you. And I know what a juggling act it is for the charity to manage to keep on going, especially in the current climate.”

- **Helpline**

The nature of the enquiries was wide-ranging and included help, information and support on education, behaviour, transition from school, issues of adulthood, welfare benefits and health-related issues including epilepsy and FXTAS.

The Families and Professionals 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: this year we wrote 12 of these letters. In addition, our Advisors created bespoke social stories and resources for individuals to help with complex situations. During 2020-2021 there were a substantial number of calls asking for help and advice from members dealing with Covid related issues.

“Thank you so much for your helpful and extremely kind reply- you brought tears to a very sleep deprived mum's eye!.....

Thank you again - I can only imagine how reassuring being in touch with you guys is for parents whose children are under investigation/ have been diagnosed.”

Receiving the diagnosis can be an emotional and confusing time. We are available to provide in-depth emotional and practical support at this stage, via our services. This year 17 enquiries (involving 62 contacts) were received from families whose children had just received a diagnosis of Fragile X. Each received a personal response from our Advisors.

In addition, we provide support to families who do not have a diagnosis and would like to find out more about the condition, which often includes how to get their relative tested. Via our helpline, we received 118 enquiries of this nature, which generated 464 contacts.

- **Impact of our support:** We seek feedback from our beneficiaries through physical and digital feedback forms following support from our services. The feedback demonstrates the great importance of this support:
 - All (100%) felt reassured by being in touch with our support workers.
 - 94% of respondents felt more confident to deal with the challenge they were facing.
 - All (100%) felt better informed after contacting us.²

“Once again, we thank you for your advice and time. Speaking to someone who understands has made us feel more able to deal with the situation.”

“We feel we are not the only voices speaking on behalf of our family member and this gives us hope that his needs will be met and understood.”

- **Fragile X Society Newsletter**

We send a regular email newsletter to our members, providing practical information about Fragile X (such as our Snippets of Advice blog); 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 have increased the frequency of our

² Data from 19 feedback forms returned postally or digitally

newsletters during the Covid pandemic from quarterly, to weekly during April and May 2020; now fortnightly and have received positive feedback (and donations!) from our members.

- **Conferences and Events**

We have been unable to hold face-to-face conferences and events during this year due to the Covid pandemic and all the restrictions that followed. Instead, we have focussed on providing remote-access, online events, from social coffee mornings, sessions on topics of interest, and our AGM:

- Returning Safely to School (25 August 2020)
- AGM (22 September 2020)
- Fragile X Awareness Day Q & A session with Dr Andrew Stanfield and Dr Hayley Crawford (10 October 2020)
- A Christmas Celebration (12 December 2020)
- Sibling's event (26 January 2021)

How we have educated Professionals and the wider public about Fragile X and raised awareness

"Not enough people, including GPs and other professionals, have enough information, so [we] often feel quite isolated or frustrated when outsiders are dealing with my daughter or us as a family. We cannot thank you enough."

- **Helpline:** Professionals, too, want information so that they understand the needs of children and adults with Fragile X in their care and are informed of appropriate interventions, treatment and therapy. Via our helpline service, we have provided information and support in response to 81 enquiries (generating 389 contacts) from professionals, students and other organisations.

*"Thank you so much for sending us the information, we are printing it now.
Was important to have a conversation with someone who understands what we are going through, and trying to point us in the right direction, regarding W."*

*"He is our main concern and as a family we will do everything we can to help him.
Take care and thank you again."*

- **eLearning:** In collaboration with Cornerstone, and thanks to the Scottish Autism Development Fund, we are able to train professionals via our Fragile X e-Learning course. This year (1 March 2020 – 28 Feb 2021), 48 professionals were trained via this course.

Our Information Publications

"I was able to sit down and use the information to organise my thinking after I read your booklet and get on with the job in hand!"

Sadly, there is still low awareness and understanding of Fragile X amongst the professionals and the wider community. We are the key source of information on Fragile X-related issues in the UK. As an organisation we aim to be the most reliable point of contact to be able to access high quality information about Fragile X Syndrome, which is based upon the latest research. All Society publications are prepared in consultation with our expert Specialist Advisors and are regularly updated to take account of new research, meaning that we can be seen as a credible source of information.

The Fragile X Society holds a wealth of information resources (some of which have been prepared in multiple languages) which include videos, brief leaflets, comprehensive introductory booklets, easy read resources and papers which cover topics in more detail. All of these resources are available free of charge, and many are available via our website www.fragilex.org.uk.

Our achievements in supporting Research

Support for research into Fragile X is one of our key aims. In a recent survey, 95% of families in the UK felt that research was important or very important, and that our charity should support research.³

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, 1521 families (79% of our full members) have agreed to support research. 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 Board research sub-committee (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 5 research 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.

Contribution of Volunteers

The Society's fundraising, accounting, support and information work continues to be undertaken, in part, by the Directors, 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 proofreading) 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

We have agreed to become part of the new international charity, Fragile X International, which is currently being registered through a Notary in Belgium. This will be an umbrella registered association, to include country family organisations as full members. All the individual member countries will maintain services in their countries and look after the families within their own countries. FraXI will promote social inclusion of Fragile X at all levels of society, advocating the vision that those living with Fragile X and associated conditions should not have to conform to societies' norms, but society should embrace them for who they are.

As the Fragile X Society, we are of course, also part of the wider learning disability, autism and genetic disorder communities, and we will continue to work alongside other organisations with shared interests. 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, 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 2020-2021.

³ Richstein, J., Cohen, J., & Hardiman, B. (2017). Fragile X Research from a parental perspective. In *Fragile X Syndrome* (pp. 457-470). Academic Press.

Online support and resources became increasingly important to our community during the Covid pandemic. This year we have continued to develop our online presence and are proud to now have a large community in our Facebook group 2667 (2.5% increase) members: who post daily to seek support, celebrate successes and share resources. We also have a growing following on social media including: 4379 likes (3% increase) on our Facebook Page, 2898 followers (5.5 % increase) on Twitter and 1437 followers (10% increase) on Instagram.

Our website attracted over 51,000 users (maintaining the previous year's high engagement), with our most popular pages being the introductory pages for the syndrome, information about genetic testing, information about the Fragile X premutation, and about the association between Fragile X and autism.

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. We have also been approached by the press to comment on relevant stories and developments. 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. New grants from the Big Lottery and the Pears Foundation awarded during 2020, highlighted the increasing reach and recognition for the work of the Fragile X Society.

FINANCIAL REVIEW

We are very grateful for the generous support of our members, our donors and grant givers that have helped us record a small financial surplus during 2020-2021. This is an enormous achievement given the challenges we all faced within the charity sector. We are grateful for all who have supported the Society's Friends of Fragile X and 100+ Club initiatives, which have provided vital funding for the Society's work.

We would like to acknowledge the generous support of the Trusts and Foundations whose names are shown in the financial review. 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.

STATEMENT OF DIRECTORS RESPONSIBILITIES

The directors (who are also the directors of The Fragile X Society for the purposes of company law) are responsible for preparing the Report of the Directors and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the directors to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the directors are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity Financial rules and regulations;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The directors are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

STATEMENT AS TO DISCLOSURE OF INFORMATION TO AUDITORS

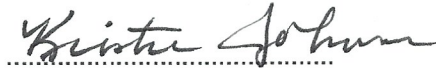
So far as the directors are aware, there is no relevant information (as defined by Section 418 of the Companies Act 2006) of which the charitable company's auditors are unaware, and each director has taken all the steps that they

ought to have taken as a director in order to make them aware of any audit information and to establish that the charitable company's auditors are aware of that information.

AUDITORS

The Directors will be proposing Critchleys as independent examiners for the current year at the AGM in September.

ON BEHALF OF THE BOARD:



Dr Kirsten Johnson

Chair

Date: 6 September 2021

Appendix i)

Fragile X Society AGM 22 September 2020 Suggested Changes to Memorandum and Articles of Association

1.1 Delete 'To preserve and protect the health' and instead change to 'To advance the health and wellbeing' of individuals affected by the genetic condition known as the Fragile X Syndrome...

1.1 Insert 'and associated conditions'

1.3 Add 'in order to help improve the environment, conditions and services offered to people with Fragile X and associated conditions, and their families.'

Suggested Changes to Articles of Association

1.1 et al. Change 'Fellows' and 'Fellowship' to 'Members' and 'Membership' throughout the document.

1.1 Under both 'Associate Member' and 'Family Member' insert 'if any' for clarification.

1.1 Original 'Member' category deleted as N/A after changing all Fellows to Members, covered in Member's definition above.

Delete 4.1 "For the purposes of the Act, the Members shall be limited to Family Fellows."

4.2 'Membership is not transferable.' Becomes 3.6

4.3 'The Charity shall maintain a register of Members.' Becomes 3.7

Original Article 5 now renumbered as Article 4, as original Article 4 has been incorporated into Article 3.

7.2.1 and 7.2.2 [now 6.2.1 and 6.2.2] In both clauses, delete 'having the right to attend and vote at general meetings.'

8.1 [now 7.1] deleted / [21]

9.3 and 9.4 [now 8.3 and 8.4] changed 'him' to 'them'.

15.1.1 [now 14.1.1] Change the number of people required to nominate a person to become a director to two.

"No person shall be appointed as a Director at any general meeting unless at least twenty-eight days before the date appointed for the meeting, notice is given to the Charity: 15.1.1 executed by at least two Members qualified to vote at the meeting.

15.3 [now 14.3] deleted / [21]

Delete '33.1.1 the rights and privileges of Fellows and the conditions of fellowship;' as the term Fellowship is no longer used.

Renumber original 33.1.2 – 33.1.6 clauses as 32.1.1 – 32.1.5

Delete extra [] markings throughout document.

**INDEPENDENT EXAMINER'S REPORT TO
THE FRAGILE X SOCIETY
FOR THE YEAR ENDED 28 FEBRUARY 2021**

Independent examiner's report to the Trustees of The Fragile X Society Charitable Company

I report to the charity trustees on my examination of the accounts of The Fragile X Charitable Company (the Company) for the year ended 28 February 2021, which are set out on pages 14 to 22.

Responsibilities and basis of report

As the charity's trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company 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 your charity's accounts as carried out under section 145 of the Charities Act 2011 (the '2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's report

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:

- 1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- 2) the accounts do not accord with those accounting records; or
- 3) the accounts 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 accounts 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 accounts to be reached.



Name of examiner: Robert Kirtland

Name of firm: Critchleys Audit LLP

Relevant professional body: Institute of Chartered Accountants in England and Wales

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

Date: 21 September 2021

**THE FRAGILE X SOCIETY
STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 28 FEBRUARY 2021**

				28.2.21	29.2.20
		Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
INCOME AND ENDOWMENTS FROM	Notes				
Donations and legacies		133,189	9,034	142,223	90,690
Charitable activities					
Conferences		-	-	-	1,834
Other		-	-	-	-
Other Trading Activities	2	2,064	-	2,064	3,978
Voluntary Fundraising	2	3,770		3,770	17,077
Investments	3	64	-	64	131
Total		139,087	9,034	148,121	113,710
EXPENDITURE ON					
Raising funds	4	8,620	-	8,620	11,936
Charitable activities					
Conferences		518	-	518	4,823
Newsletters		-	-	-	-
Supporting Fragile X Community		110,795	-	110,795	103,897
Other		908	-	908	2,855
Total		120,841	-	120,841	123,511
NET INCOME/(EXPENDITURE)		18,246	9,034	27,280	(9,801)
RECONCILIATION OF FUNDS					
Total funds brought forward		83,146	-	83,146	92,947
TOTAL FUNDS CARRIED FORWARD		101,392	9,034	110,426	83,146

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

THE FRAGILE X SOCIETY
COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 29 FEBRAURY 2020

				29.2.20	28.2.19
		Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
INCOME AND ENDOWMENTS FROM	Notes				
Donations and legacies		90,690	-	90,690	121,817
Charitable activities					
Conferences		1,834	-	1,834	2,049
Other		-	-	-	906
Other Trading Activities	2	3,978	-	3,978	4,098
Voluntary Fundraising	2	17,077		17,077	49,427
Investments	3	131	-	131	84
Total		113,710	-	113,710	178,381
EXPENDITURE ON					
Raising funds	4	11,936	-	11,936	39,433
Charitable activities					
Conferences		4,823	-	4,823	8,244
Newsletters		-	-	-	13,051
Supporting Fragile X Community		103,897	-	103,897	150,314
Other		2,855	-	2,855	1,463
Total		123,511	-	123,511	212,505
NET INCOME/(EXPENDITURE)		(9,801)	-	(9,801)	(34,124)
RECONCILIATION OF FUNDS					
Total funds brought forward		92,947	-	92,947	127,071
TOTAL FUNDS CARRIED FORWARD		83,146	-	83,146	92,947

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

THE FRAGILE X SOCIETY
BALANCE SHEET
FOR THE YEAR ENDED 28 FEBRUARY 2021
REGISTERED COMPANY NUMBER: 06724061 (England and Wales)
REGISTERED CHARITY NUMBER: 1127861

	Notes	28-Feb-21 £	£	29-Feb-20 £	£
FIXED ASSETS					
Tangible assets	8		-		604
CURRENT ASSETS					
Stock	9	4		4	
Debtors	10	4,859		859	
Cash at bank and in hand		<u>107,053</u>		<u>84,562</u>	
		111,916		85,425	
CREDITORS					
Amounts falling due within one year	11	<u>(1,490)</u>		<u>(2,883)</u>	
NET CURRENT ASSETS			<u>110,426</u>		<u>82,542</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			110,426		83,146
NET ASSETS			<u><u>110,426</u></u>		<u><u>83,146</u></u>
FUNDS	12				
Unrestricted funds			101,392		83,146
Restricted funds			<u>9,034</u>		<u>-</u>
TOTAL FUNDS			<u><u>110,426</u></u>		<u><u>83,146</u></u>

For the year ended 28 February 2021 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

The members have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.

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

The financial statements were approved by the Board of Trustees on 6 September 2021 and were signed on its behalf by:



Dr Kirsten Johnson, Chairman

**THE FRAGILE X SOCIETY
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 28 FEBRUARY 2021**

1 ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) '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)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, 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.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Fixtures and fittings	33% per annum on a straight line basis
Computer equipment	33% per annum on a straight line basis

Stocks

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

Taxation

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

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

THE FRAGILE X SOCIETY
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 28 FEBRUARY 2021

2 FUNDRAISING & OTHER TRADING ACTIVITIES

	28.2.21	29.2.20
	£	£
Voluntary fundraising events	349	13,582
100+ Club	3,421	3,495
Other sales	2,064	3,978
	<u>5,834</u>	<u>21,055</u>

3 INVESTMENT INCOME

	28.2.21	29.2.20
	£	£
Interest received	<u>64</u>	<u>131</u>

4 RAISING FUNDS

Raising donations and legacies

	28.2.21	29.2.20
	£	£
Fundraising costs	1,950	2,696
Support costs	6,670	9,240
	<u>8,620</u>	<u>11,936</u>

5 NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	28.2.21	29.2.20
	£	£
Independent auditors / examiners remuneration	1,500	1,500
Depreciation - owned assets	<u>604</u>	<u>4,257</u>

6 TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 28 February 2021 nor for the year ended 29 February 2020.

Trustees' expenses

	28.2.21	29.2.20
	£	£
Trustees' expenses	<u>107</u>	<u>397</u>

THE FRAGILE X SOCIETY
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 28 FEBRUARY 2021

7 STAFF COSTS

	28.2.21	29.2.20
Wages and Salaries	86,444	81,930
Social Security Costs	2,454	5,423
Employers Pension Contributions	2,973	2,368
	<u>91,871</u>	<u>89,721</u>

The average monthly number of employees during the year was as follows:

	28.2.21	29.2.20
Directorate	1	1
Support worker	3	3
Other administration	2	2
	<u>6</u>	<u>6</u>

No employees received emoluments in excess of £60,000.

8 TANGIBLE FIXED ASSETS

	Fixtures and fittings £	Computer equipment £	Totals £
COST			
At 1st March 2020	2,254	17,206	19,460
At 28th February 2021	<u>2,254</u>	<u>17,206</u>	<u>19,460</u>
DEPRECIATION			
At 1st March 2020	1,650	17,206	18,856
Charge for year	604	-	604
At 28th February 2021	<u>2,254</u>	<u>17,206</u>	<u>19,460</u>
NET BOOK VALUE			
At 29th February 2021	-	-	-
At 29th February 2020	<u>604</u>	<u>-</u>	<u>604</u>

9 STOCK

	28.2.2021 £	29.2.2020 £
Stock	<u>4</u>	<u>4</u>

10 DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	28.2.2021 £	29.2.2020 £
Other debtors	4,502	502
Prepayments and accrued income	357	357
	<u>4,859</u>	<u>859</u>

THE FRAGILE X SOCIETY
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 28 FEBRUARY 2021

11 CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	28.2.2021	29.2.2020
	£	£
Trade creditors	47	47
Social security and other taxes	-	1,336
Accruals and deferred income	1,443	1,500
	<u>1,490</u>	<u>2,883</u>

12 MOVEMENT IN FUNDS

	At 1.3.20	Net Movement in funds	At 28.2.21
	£	£	£
Unrestricted funds			
General	83,146	18,246	101,392
Restricted funds			
National Lottery Northern Ireland	-	9,034	9,034
Total Funds	<u>83,146</u>	<u>27,280</u>	<u>110,426</u>

Net movement in funds, included in the above are as follows:

	Incoming Resources	Resources Expended	Movement in funds
	£	£	£
Unrestricted funds			
General	139,087	(120,841)	18,246
Restricted funds			
National Lottery Northern Ireland	9,034	-	9,034
Total Funds	<u>148,121</u>	<u>(120,841)</u>	<u>27,280</u>

Restricted funds

The National Lottery Northern Ireland grant is for a particular project and so is restricted.

THE FRAGILE X SOCIETY
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 28 FEBRUARY 2021

Movement in Funds Continued

Comparatives for movement in funds

	At 1.3.19	Net Movement in funds	At 29.2.20
	£	£	£
Funds			
General	92,947	(9,801)	83,146
Total Funds	<u>92,947</u>	<u>(9,801)</u>	<u>83,146</u>

Net movement in funds, included in the above are as follows:

	Incoming Resources	Resources Expended	Movement in funds
	£	£	£
Unrestricted funds			
General	113,710	(123,511)	(9,801)
Total Funds	<u>113,710</u>	<u>(123,511)</u>	<u>(9,801)</u>

**THE FRAGILE X SOCIETY
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 28 FEBRUARY 2021**

14 RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 28 February 2021 or 29 February 2020.