

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

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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 | 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

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

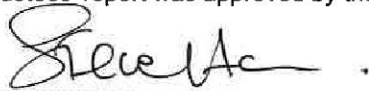
Independent Examiner

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

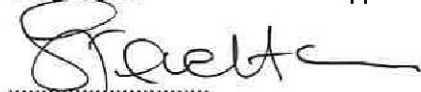
The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 28 February 2023.

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.