

**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

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### 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

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# THE FRAGILE X SOCIETY

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# 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

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**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 1<sup>st</sup> 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

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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 25<sup>th</sup> 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 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

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(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%)<sup>1</sup> 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.

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<sup>1</sup> 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

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#### 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

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#### **Fundraising**

We have been fortunate to secure several legacies in 2021/22 which have helped underpin our finances. On September 9<sup>th</sup>, 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

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- 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

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#### 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

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#### **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](http://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

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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

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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:

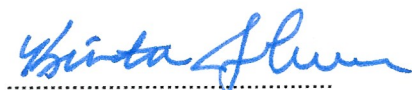
- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity Financial rules and regulations;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate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

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

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 £	£
<b>Current assets</b>					
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>	
<b>Creditors: amounts falling due within one year</b>					
	13	(1,836)		(1,490)	
Net current assets			<u>188,293</u>		<u>110,426</u>
<b>Income funds</b>					
Restricted funds	15		4,943		9,034
Unrestricted funds			183,350		101,392
			<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

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#### 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

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#### 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

	<b>Unrestricted funds</b>	Unrestricted funds	Restricted funds	Total
	<b>2022</b>	2021	2021	2021
	<b>£</b>	£	£	£
Donations and legacies	<u>198,202</u>	<u>133,189</u>	<u>9,034</u>	<u>142,223</u>

#### 3 Other trading activities

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	<b>£</b>	£
Other sales	<u>4,394</u>	<u>2,064</u>

#### 4 Investments

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	<b>£</b>	£
Interest received	<u>13</u>	<u>64</u>

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# THE FRAGILE X SOCIETY

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 28 FEBRUARY 2022

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### 5 Other income

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

### 6 Raising funds

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	<b>£</b>	£
<u>Fundraising and publicity</u>		
Seeking donations, grants and legacies	1,363	1,950
	<u>9,018</u>	<u>6,670</u>
<u>Trading costs</u>		
Support costs	9,018	6,670
	<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>
<b>Analysis by fund</b>		
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	4,002
	<u>9,018</u>	<u>6,376</u>	<u>15,394</u>	<u>6,670</u>	<u>4,002</u>	<u>10,672</u>
Analysed between						
Trading	9,018	-	9,018	6,670	-	6,670
Charitable activities	-	6,376	6,376	-	4,002	4,002
	<u>9,018</u>	<u>6,376</u>	<u>15,394</u>	<u>6,670</u>	<u>4,002</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
	<u>          </u>	<u>          </u>
Total	4	6
	<u>          </u>	<u>          </u>

#### 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
	<u>          </u>	<u>          </u>
	90,774	91,871
	<u>          </u>	<u>          </u>

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

#### 11 Stocks

	2022 £	2021 £
Stock	4	4
	<u>          </u>	<u>          </u>

#### 12 Debtors

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

#### 13 Creditors: amounts falling due within one year

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

# 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).