

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

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

**for**

**THE FRAGILE X SOCIETY**

**The Fragile X Society**

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

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

## THE FRAGILE X SOCIETY

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

The directors, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 28th February 2021. The directors have adopted the provisions of the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (the FRSSE) (effective 1 January 2015).

#### REFERENCE AND ADMINISTRATIVE DETAILS

##### Registered Company number

06724061 (England and Wales)

##### Registered Charity number (England and Wales)

1127861

##### Registered Charity number (Scotland)

SC047332

##### Registered office

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

##### Directors

Dr Kirsten Johnson (Chair)

Marie Williams (Vice Chair)

Alex Case

Tim Eccleshall (Treasurer)

Rosie Martin (Secretary)

Mark Smith

Tally Nothey

Steve Harris

Prof Gaia Scerif

Jo Woosnam-Savage

Mary Martin

Andy Clarke

Rachel Instone (Research Officer)

Dr Lucia Elghali

Craig McDonald

##### Bank

CAF Bank

25 Kings Hill Avenue

Kings Hill

West Malling

Kent

ME19 4JQ

##### Independent Examiners

Critchleys

Beaver House

23-38 Hythe Bridge Street

Oxford

OX1 2EP

#### STRUCTURE, GOVERNANCE AND MANAGEMENT

##### Governing document

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

##### Staff

###### Managing Director

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

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

###### Administrative and Communications Coordinator

Kate Williams (0.5 FTE)

##### Families and Professionals Advisors

For Children: Caroline Pringle (part time 0.6 FTE)

For Adults: Jane Oliver (part time 0.6 FTE)

\* FTE= Full-Time Equivalent

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

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

Dr Mark C Hirst, BSc (Hons), PhD  
Head of Cell and Molecular Biology, Faculty of Science, The Open University

Dr Angela Barnicoat  
Consultant Clinical Geneticist, Great Ormond Street Hospital NHS Trust

Professor Dame Kay E Davies  
Co-Director, Oxford Centre of Gene Function, University of Oxford

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

Prof Chris Oliver, BSc MPhil PhD CPsychol AFBPsS  
Professor of Neurodevelopmental Disorders, Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham

Prof Gaia Scerif, BSc, PhD  
Associate Professor and Tutorial Fellow, Department of Experimental Psychology, University of Oxford and St. Catherine's College

Dr Andrew Stanfield, MB ChB MRCPsych  
Senior Clinical Research Fellow, Patrick Wild Centre, University of Edinburgh

Dr Hayley Crawford  
Assistant Professor, University of Warwick

Dr Sundus Alusi  
Consultant Neurologist, The Walton Centre for Neurology and Neurosurgery

Prof Jonathan Herring, MA, BCL  
Professor of Law, University of Oxford and DW Wolf-Clarendon Fellow in Law, Exeter College, University of Oxford

Dr Jennifer L. Austin, Ph.D., BCBA-D  
Athro Seicoleg | Professor of Psychology  
Pennaeth Dadansoddi Ymddygiad | Head of Behaviour Analysis  
Ysgol Seicoleg | School of Psychology  
Prifysgol De Cymru | University of South Wales

Dr Becky Hardiman, Trainee Clinical Psychologist, Cardiff

## **Governance**

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

Following the Incorporation of the Society which commenced trading on 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 Annual General Meeting or by co-option by the Board. The Honorary Officers are elected by the Board at its first meeting after the AGM.

This year, our AGM took place virtually on 22 September 2020. A special resolution was agreed and confirmed at the November 7<sup>th</sup> Board meeting which updated the Fragile X Society's Memorandum and Article of Association (details are included in appendix i)

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

### **Working Structure and Management**

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

Currently, the Board of Directors is supported by a part-time Managing Director, who provides quarterly reports to the Board, and three other part-time employees: Two Families and Professionals Advisors (one adult- and one child-focussed), and an Administrative and Communications Coordinator.

### **Induction and training of Directors**

The current Directors, twelve (80%) of whom have a personal link to Fragile X, are committed to the aims of the Society and ensuring that our services are sustained or developed to meet those aims. All new directors are informed about the Society's constitution, provided with support and guidance around charity best practice and provided with an induction on the charity's key policies. In 2021-2022 we plan to have a 'self-advocate' (i.e. a person with Fragile X) joining our Board.

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

## **OBJECTIVES AND ACTIVITIES**

### **What is Fragile X?**

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

Fragile X is inherited from carriers, who have small changes to their Fragile X gene (premutation) which makes it unstable when passed on. However, as well as this reproductive consideration, carriers may themselves experience effects of Fragile X Premutation Associated Conditions. For instance, in later life, carriers may experience Fragile X Tremor Associated Ataxia (FXTAS): a late onset neurodegenerative condition which causes problems with memory, balance and tremors. In addition, women may experience Fragile X Associated Primary Ovarian Insufficiency (FXPOI), which is associated with early menopausal-like symptoms and may cause infertility. The premutation is also associated with other physical and mental health challenges. According to prevalence statistics (1 in 250 women and 1 in 800 men), approximately 160,000 people in the UK are carriers.

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

## **The Need for Our Services**

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

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

Unfortunately, despite the prevalence of Fragile X, there is still too often a lack of awareness amongst professionals and the public, which compounds these issues. In line with this, almost all families (94%)<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 2020-2021 we supported the continued employment of our Families and Professionals Advisors to run this essential unique service. People with Fragile X and associated conditions receive the tailored advice and guidance that they desperately need. Without this, many of them would fall through the increasing gaps in service provision, failing to access critical medical and social support.

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

## **Aims of the Fragile X Society**

Our aims are to:

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

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

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

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<sup>1</sup> Based upon a 2019 Membership Survey: 70 responses received.

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

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

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

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

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

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

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

## **Fundraising**

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

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

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

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

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

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

## **Grants**

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

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

## **Membership**

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

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

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

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

## **Research**

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

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

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

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

## **ACHIEVEMENTS AND PERFORMANCE**

### **Our community**

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

### **How we have supported individuals and families living with Fragile X**

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

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

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

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

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

- **Helpline**

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

The Families and Professionals Advisors provide a personal response to each enquiry, tailoring the response to the individual needs. Some enquiries require us to provide authorities input on the way that Fragile X may be influencing a person’s needs for supports or services, in which case we write in-depth support letters: this year we wrote 12 of these letters. In addition, our Advisors created bespoke social stories and resources for individuals to help with complex situations. During 2020-2021 there were a substantial number of calls asking for help and advice from members dealing with Covid related issues.

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

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

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

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

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

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

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

- **Fragile X Society Newsletter**

We send a regular email newsletter to our members, providing practical information about Fragile X (such as our Snippets of Advice blog); personal stories about life with Fragile X; updates about policy and services; news about our charity’s activities; the latest research findings and participation opportunities; as well as opportunities to support the work of our charity. We have increased the frequency of our

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<sup>2</sup> Data from 19 feedback forms returned postally or digitally

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

- **Conferences and Events**

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

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

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

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

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

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

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

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

### **Our Information Publications**

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

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

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

## **Our achievements in supporting Research**

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

Fragile X Society full members (with a direct link to Fragile X) have the option to agree to be contacted about research projects which may be relevant to them. In total, 1521 families (79% of our full members) have agreed to support research. Our unique community in the UK is a vital resource for researchers, as there is no central database of individuals diagnosed in the UK. We receive frequent requests from the UK and beyond from researchers to request support with recruiting to their projects. These projects could not take place without the support and participation of our members.

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

We are proud to have supported recruitment to 5 research projects addressing key aspects of Fragile X Syndrome and Fragile X Premutation-Associated Conditions this year. We are also supporting additional on-going projects and new research proposals under review.

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

## **Contribution of Volunteers**

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

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

## **International work and supporting other organisations**

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

As the Fragile X Society, we are of course, also part of the wider learning disability, autism and genetic disorder communities, and we will continue to work alongside other organisations with shared interests. The Fragile X Society has worked in partnership with other organisations during the year; these include but are by no means limited to: Genetic Disorders UK, Rare Disease UK, Patrick Wild Centre, the Cerebra Network, and Cornerstone. We are also proud members of the Disabled Children's Partnership and Autistica's Embracing Complexity alliance for people with neurodevelopmental conditions.

## **Measuring our impact**

We achieved our primary objectives for the year, continuing to provide support and information to families affected by Fragile X and professionals working in the field of Fragile X. Feedback on our support has continued to be extremely positive during 2020-2021.

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

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

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

## **Recognition**

The Society is acknowledged by independent agencies, such as Genetic Alliance UK, as having an important contribution to make in the consideration of genetic and disability equality issues raised by Fragile X. We have also been approached by the press to comment on relevant stories and developments. As an inherited condition, Fragile X raises serious issues for families and the Society will continue to take every opportunity to present its members' views. New grants from the Big Lottery and the Pears Foundation awarded during 2020, highlighted the increasing reach and recognition for the work of the Fragile X Society.

## **FINANCIAL REVIEW**

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

We would like to acknowledge the generous support of the Trusts and Foundations whose names are shown in the financial review. The Society is extremely grateful for their grants and donations which enabled it to continue the vital work of supporting families and spreading awareness and understanding of Fragile X Syndrome and Associated conditions.

## **STATEMENT OF DIRECTORS RESPONSIBILITIES**

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

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

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

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

## **STATEMENT AS TO DISCLOSURE OF INFORMATION TO AUDITORS**

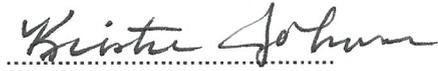
So far as the directors are aware, there is no relevant information (as defined by Section 418 of the Companies Act 2006) of which the charitable company's auditors are unaware, and each director has taken all the steps that they

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

## AUDITORS

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

### ON BEHALF OF THE BOARD:



Dr Kirsten Johnson  
Chair

Date: 6 September 2021

## Appendix i)

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

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

1.1 Insert 'and associated conditions'

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

### Suggested Changes to Articles of Association

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

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

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

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

4.2 'Membership is not transferable.' Becomes 3.6

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

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

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

8.1 [now 7.1] deleted / [21]

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

15.1.1 [now 14.1.1] Change the number of people required to nominate a person to become a director to two. "No person shall be appointed as a Director at any general meeting unless at least twenty-eight days before the date appointed for the meeting, notice is given to the Charity: 15.1.1 executed by at least two Members qualified to vote at the meeting.

15.3 [now 14.3] deleted / [21]

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

Renumber original 33.1.2 – 33.1.6 clauses as 32.1.1 – 32.1.5

Delete extra [] markings throughout document.

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

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

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

**Responsibilities and basis of report**

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

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 (the '2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

**Independent examiner's report**

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

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

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



**Name of examiner:** Robert Kirtland

**Name of firm:** Critchleys Audit LLP

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

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

**Date:** 21 September 2021

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

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

**CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

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

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

**CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

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

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

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

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

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

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



Dr Kirsten Johnson, Chairman

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

## **1 ACCOUNTING POLICIES**

### **Basis of preparing the financial statements**

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

### **Income**

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

### **Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

### **Tangible fixed assets**

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

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

### **Stocks**

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

### **Taxation**

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

### **Fund accounting**

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

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

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

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

**2 FUNDRAISING & OTHER TRADING ACTIVITIES**

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

**3 INVESTMENT INCOME**

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

**4 RAISING FUNDS**

**Raising donations and legacies**

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

**5 NET INCOME/(EXPENDITURE)**

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

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

**6 TRUSTEES' REMUNERATION AND BENEFITS**

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

**Trustees' expenses**

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

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

**7 STAFF COSTS**

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

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

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

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

**8 TANGIBLE FIXED ASSETS**

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

**9 STOCK**

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

**10 DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

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

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

**11 CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

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

**12 MOVEMENT IN FUNDS**

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

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

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

**Restricted funds**

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

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

**Movement in Funds Continued**

**Comparatives for movement in funds**

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

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

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

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

**14 RELATED PARTY DISCLOSURES**

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