

REGISTERED COMPANY NUMBER: 06724061 (England and Wales)

REGISTERED CHARITY NUMBER: 1127861

REGISTERED SCOTTISH CHARITY NUMBER: SC047332

**Report of the Trustees and
Financial Statements for the Year Ended 28th February 2018
for
THE FRAGILE X SOCIETY**

THE FRAGILE X SOCIETY

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for the year ended 28th February 2018**

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THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 28th February 2018. The trustees have adopted the provisions of 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 2015).

OBJECTIVES AND ACTIVITIES

What is Fragile X?

"Those with Fragile X are the most extraordinary people; sheer brilliance, affection and kindness mixed with the frustration of not being understood, valued, or able to make sense of their world. Those closest to them are faced with the life-long struggle to get the appropriate support they need. This is one of the reasons why the Society is so important to families and professionals because it provides invaluable information as well as support, help, and a listening ear." - Kathryn (carrier with 3 siblings with 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 (pre-mutation) which makes it unstable when passed on. However, as well as this reproductive consideration, carriers may themselves experience effects one of two Fragile X-Associated conditions. 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 Premature 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

Both as a direct result of the condition, and due to services and society's attitudes, people living with Fragile X and their families may face wide-ranging challenges through 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 often 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 (95%) living with Fragile X feel that it is very important to have a Fragile X-specific organisation; many fed back that generic supports 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).

We are committed to engaging with those we support, in order to identify their needs and, in turn, to guide our services. Individuals and families living with Fragile X fed back to us:

- the need for a sense of community (needed by 84.5% of respondents);
- the need to access experts and the latest research (needed by 85.5%);
- the need for emotional support (needed by 83%);
- the need for awareness raising (needed by 77.5%).

We are proud that we can help to meet these needs through our aims.

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

OBJECTIVES AND ACTIVITIES (CONTINUED)

Aims of the Fragile X Society

- To provide information and practical guidance to support and empower individuals and families living with Fragile X (Fragile X Syndrome and Fragile X-Associated conditions).
- To educate and inform the public and professionals about Fragile X in order to raise awareness and understanding of the syndrome and improve support for all individuals affected by Fragile X.
- To encourage research into all aspects of Fragile X through the participation of our family members in Fragile X studies and to publicise the results.
- To raise funds to carry out our work.

Future Plans: The Charity's Main Objectives for 2018/19

- To continue to develop additional resources for individuals with Fragile X associated conditions and their families, as well as professionals.
- To develop and implement a renewed fundraising strategy to ensure sustainable income to both maintain and develop our vital services.
- Manage the challenges, but also embrace the opportunities, faced by the organisation resulting from staff succession and regulatory changes (such as GDPR).
- To develop partnership work with external organisations for the benefit of our community.
- Continue to work to meet our aims of: supporting individuals and families living with Fragile X, educating professionals, raising awareness and supporting research.

These aims are influenced by our organisational aims the feedback provided from our members, via evaluation forms and initiatives such as membership surveys and focus groups. We are developing as an organisation according to a strategy set by the Directors, 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

On 28th February 2018 the charity had a membership of 2,229 (1,805 UK full member families (many of whom have multiple members of their family living with varying effects of Fragile X), 92 overseas members, and 332 UK associate members). This represents an increase of 8% from last year.

Our National Helpline Service

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 1,035 enquiries (generating 2,917 contacts) via our helpline. Work with adults was particularly complex, involving a higher number of enquiries and greater number of contacts per enquiry when compared to children. This highlights the need of this group in particular and the need to develop support for adults.

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

"Just by knowing that there is someone on the end of the phone ready and willing to help or just listen means the world. Some days I feel quite lonely as a parent and unsure of what the future holds but now that I know there is a network of understanding folk it makes this new journey a lot easier."

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

How We Have Supported Individuals and Families Living with Fragile X

"Jane had her ear bashed by me for about an hour, and I felt she was a close family friend to talk all about my problem and not talking to a stranger"

- Helpline

"I was dreading taking my son to hospital but now feel much better prepared."

Our Families and Professionals Advisors responded to a total of 957 enquiries from individuals with, or family member of, those affected by Fragile X Syndrome or Fragile X-Associated conditions (an increase of 9% on the previous year), generating 2,801 contacts. The nature of the enquires 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 49 of these letters. In addition, our support workers created bespoke social stories and resources for individuals to help with complex situations.

"The letter was informative & perfect for our purpose.. We have taken several copies to add to the various information packs that we have had to distribute to the various boards we are now having to deal with."

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 39 enquiries (involving 117 contacts) were received from families whose children had just received a diagnosis of Fragile X. Each received a personal response from our support workers.

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 78 enquiries of this nature, which generated 116 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
- 93% of respondents felt more confident to deal with the challenge they were facing
- 99% felt better informed after contacting us

Included below is a case study of the support provided to one family during their son's school transition:

"Our son Dave was diagnosed with Fragile X Syndrome in October 2017 at the age of 10. We had been concerned about both his progress at school, and his physical/mental development for some time but hoped that things would improve with time.*

When Dave was diagnosed we had never heard of Fragile X and probably didn't fully appreciate or understand the impact this would have on both his and our lives. We were given some information at the medical centre, and advised to contact The Fragile X Society for more information and support.

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

We joined the Fragile X Society, and made contact with the Scottish Support Officer, Sandra Thoms. We can't thank Sandra enough for the help and support she has provided. Not only is she at the other end of a phone or an email, but she has also taken the time to visit our sons primary school and deliver an awareness session to his teachers and other professional which had a direct impact on their approach to teaching Dave. Sandra has also agreed to deliver a similar session at Dave's Secondary School at the appropriate time.

In her role as support officer Sandra was also instrumental in arranging an appointment with a genetic councillor to provide a detailed insight into Dave's condition and what it meant in the long term. Sandra has also made us aware and kept us informed of the various support groups and awareness conferences and has always extended a welcome for us to attend.

We are still at the early stages of Dave's diagnosis and are still coming to terms with it ourselves. It is a comfort however to know that essential support is available from The Fragile X Society and a Support Officer like Sandra as and when we need it. I honestly can't praise this service enough and don't know what we would do without it."

**pseudonym*

- **Support groups:** We also have 4 local groups run by volunteers, some with direct support from our support workers, and continue to support interested volunteer families to set up local groups.
- **Fragile X Society Newsletter:** Our quarterly newsletter is a key source of support and information to our community. We continue to commission articles on key topics and seek stories from individuals with Fragile X and their families for the newsletter.

"I love to read the Newsletter and there is always so much of interest to read, family stories, family support in other places as well as the latest news on research."

- **Family Weekend Conference:** Based upon feedback from previous events we launched an exciting new format of conference this year. Hosted at the brilliant Thomley Centre (a place for people of all abilities) the aim was to create an accessible event for individuals with Fragile X and their families to meet, play, participate in workshops and learn more about important topics. An additional benefit was that the change of format was also a more efficient use of our finances.

The event was attended by 95 adults and 54 children, which is the largest gathering of young people which we have ever held. The feedback for the event was extremely positive:

*"Well done to all involved for organising the best conference we've ever attended.
Thank you!"*

How We Have Educated Professionals and the Wider Public About Fragile X, and Raised Awareness

- **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, provided information and support in response to 254 enquiries (generating 558 contacts) from professionals, students and other organisations. Again, this is a substantial increase (32% more enquiries) compared to the previous year.

"Thank you so much for the incredible help - I really appreciate it all - I now feel confident explaining this to colleagues now and in the future. I have no doubt The Fragile X Society changes people's lives with the wonderful work you all do. Thank you so much."

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

- Training

"I now have a clearer understanding of the issues the pupil is facing and will be able to plan better for his classes." - Primary Teacher

"[the training will] certainly help modify delivery of services by multidisciplinary team to make it a smoother journey for the service users and carers as much as possible." -

Consultant Psychiatrist

- **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, 64 professionals were trained via this course.
- **Scotland Project:** Thanks to funding we have been able to conduct a substantial amount of development work in Scotland, with the aim to improve support available to those living with Fragile X through increased professional awareness and understanding. This work was conducted via various initiatives which included:
 - Clinical Psychologist Training. In collaboration with the Patrick Wild Centre, we trained the whole cohort of clinical psychology trainees at the University of Edinburgh about Fragile X. These will be a key group of professionals working with the Fragile X community in the future.
 - Awareness Sessions: 23 awareness sessions were hosted across a variety of organisations including schools; autism specialist teams; supported employment teams; learning disability teams; residential facilities; and more. Information included in the sessions was tailored to meet the needs of each service, to ensure maximum practicality and applicability. These sessions trained 443 professionals.
 - Other awareness work was conducted in collaboration with Genetic Alliance, Family Fund and Sleep Scotland.
- **Educate to Empower:** The Educate to Empower project aimed to raise awareness of Fragile X Syndrome and the importance of timely and accurate diagnosis. It was a partnership initiative between The Fragile X Society and the Patrick Wild Centre. The project involved the creation of a new information pack (including a video) for newly diagnosed families, and the training of professionals through a series of educational roadshows throughout Scotland (which reached 175 professionals). Families were involved at all stages throughout the project.

- Awareness campaigns

- **Fragile X Awareness Day.** For the second year we ran our FragileXpedition campaign to encourage our supporters to travel sponsored miles raising funds and awareness. In addition, to mark awareness day we launched the first in our new video series, which was widely viewed (45,000 video views on Facebook).
- **Other Awareness Days.** participated in digital campaigns to raise awareness to coincide with other relevant awareness days including International Autism Awareness Day and Rare Disease Day. Representatives of the Society also attended parliamentary receptions to raise awareness of Fragile X.

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

Our Information Publications

"After reading the Society's FXTAS leaflet, family member and her brother and sister were diagnosed with FXTAS"

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 a 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 reliable source of information.

At present, The Fragile X Society has over 180 information resources (some of which have been prepared in multiple languages) which include: brief leaflets, comprehensive introductory booklets, and papers which cover topics in more detail. All of these resources are available free of charge.

Thanks to funding from Jeans for Genes, we were able to produce a new introductory video series about Fragile X Syndrome, which was launched for Fragile X Awareness day in 2017. The videos involved interviews with individuals with Fragile X Syndrome, their families, and experts in the field. The series of videos cover key topics including: genetics and diagnosis, Fragile X in females, Adulthood and support available via the Fragile X Society. The videos are freely available online and the first video in the series has been viewed over 50,000 times since its launch (on Facebook and YouTube combined).

We are also passionate about creating resources that are accessible to people with a learning disability. As such, we are delighted to have launched our new Easy Read guide "I have Fragile X Syndrome" which is an accessible resource aimed at those with the condition. This resource has proved highly popular and has been translated into multiple languages and is now being used internationally.

"Helped [the individual with Fragile X] understand his mental health issues."

All families and professionals who contact the Society seeking information are offered our introductory leaflet, booklets and a selection of relevant publication papers. In addition to this a subset of our booklets and papers are available for download from our website www.fragilex.org.uk. Our website is regularly reviewed and under further development to ensure that information is easily accessible.

Our Support for 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, 1445 families (80% 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 these requests to ensure that all approaches to families for participation were 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. In addition, as a researcher, our CEO has helped to establish new research projects and act as a consultant or co-supervisor on research projects which have been noted as being of key interest in our community (such as Fragile X in adulthood).

We are proud to have supported recruitment to 13 research projects addressing key aspects of Fragile X Syndrome and Fragile X-Associated Conditions this year. We are also supporting additional on-going projects and new research proposals under review. In total, since the charity was established, we have directly supported over 90 research projects.

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

We are also passionate about accessibly disseminating the findings of research and have commissioned lay-summaries of research projects that we have supported as well as from current projects around the world. We also invite researchers to present at our annual conferences.

- **Research Workshops.** On 14th March 2017 we hosted the first "UK Fragile X Research Workshop", in collaboration with the University of Oxford. The aim was to bring together the research community interested in Fragile X (from a variety of different backgrounds) from the UK and beyond, as well as members of our community, in order to discuss current work and to discuss key topics and ways of better collaborating to address topics of key concern to our community. Over 50 researchers attended the event. The second event in this series will be being hosted in partnership with the Patrick Wild Centre, University of Edinburgh, in May 2018.

"Best conference I have ever been too. Lots of ideas about work we can do in the future."

We hope that this series will continue as part of a program of events and activities to strengthen Fragile X research and ensure that the voice of individuals and families with Fragile X is heard, and that research aligns with their concerns.

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. Of the present Directors, all of whom give freely of their time to the running of the Society, three gave the following:

- Craig McDonald (Chair) 6 hours per week
- Jennifer Keene (Treasurer) 4 hours per week
- Rachel Instone (Research) 8 hours per week

In addition, occasional volunteers (in the office or at our events) save the Society money and improve our support. We would like to thank those individuals who volunteered at our conferences, to our Specialist Advisors, and to all the others who have volunteered their time raising funds and awareness.

During the up-coming year we will be developing our work with fundraising volunteers to support our work.

Working with Others

The Society is a founding member of the European Fragile X Network, consisting of 17 Fragile X associations, representing 16 countries, and represents over 5000 families. The aim of the network is to establish and improve links between the organizations and to share information. The ninth meeting of the European Network took place in Nyon, Switzerland, in 2017.

We are also a proud member of the new International Fragile X Alliance. Through this network we have been able to share our resources, provide and receive guidance on organisational issues; and to consider future joint projects.

We are, of course, also part of the wider learning disability, autism and genetic disorder communities, and we continue to work alongside other organizations 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, and Cornerstone.

Other achievements

We achieved our primary objectives for the year of 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.

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

- **Developing a digital community and resources:** Online support and resources continue to become increasingly important to our community. This year we have continued to develop our online presence and are proud to now have a large community in our Facebook group (2337 (12% increase) members: who post daily to seek support, celebrate successes and share resources). We also have a growing following on social media including: 3273 likes (35% increase) on our Facebook Page, 2245 followers (29% increase) on Twitter and 674 followers (40% increase) on Instagram. Our website attracted over 50,000 users (14% increase upon previous year), with our most popular pages being our information pages (including the information of 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.

FINANCIAL REVIEW

Support has been given to our family members who have fund raised on our behalf. The wonderful fundraising efforts of family members have raised over £36k of the total Society income this year. This includes their support of the Society's Tea Party event, 100+ Club and Lottery which have provided vital funding for the society's programme of activities.

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.

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

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.

Governance

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

Following the Incorporation of the Society which commenced trading on 1st March 2009 the then trustees became Directors of the new company. Future Directors may be elected from outside the Society's membership. The Company Directors, who form the Board, have responsibility for the management of the Society's affairs. Directors are elected by the full membership at the Society's Annual General Meeting or by co-option by the Board. The Honorary Officers are elected by the Board at its first meeting after the AGM.

This year, our AGM preceded the speakers at our conference on 23rd September 2017. Five new directors joined the board as well as 2 who were re-elected after serving a term of 3 years on the board. During the year, 5 directors stepped down, according to a planned succession strategy, acknowledging that many of the board are approaching the end of their third three-year term (following incorporation in 2009). We are extremely grateful for their time and support during their time on the board. The board is currently full, with 15 members.

Working Structure and Management

The Board of Directors meets at least four times a year (by conference call and physical meetings) to consider management and financial issues regarding the running of the Society. The workload of the Board is spread through sub-committees, formulated to meet the organisations present needs, which operate in conjunction with the CEO 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 CEO, who provides quarterly reports to the Board, one full time Head of Fundraising and five other part-time employees: Families and Professionals Advisors (one adult- and one child-focussed, Development and Support Worker in Scotland), a Bookkeeper and an Administrative 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 and provided support and guidance around charity best practice. Directors are also required to agree and abide by the Society's policies for Confidentiality, Data Protection, Equal Opportunities, Financial Controls, Moral and Ethical Policy for Fundraising, Internet and Email Policy, and Conduct for Directors.

Notice is given to the membership informing them that elections for Directors will take place at the AGM, which in 2018 will take place on 29th September at our Family Weekend Conference. Role descriptions and adverts for Directors 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 CEO of the organisation. Interested people are also provided with a nomination form and the date (at least 28 days before the AGM) by which the nomination form should be returned to the Society.

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

STRUCTURE, GOVERNANCE AND MANAGEMENT (CONTINUED)

Staff

CEO

Becky Hardiman (part time 0.6 FTE)

Head of Fundraising

Barbara Burnett (full time)

Families and Professionals Advisors

For Children: Wendy Bowler (part time 0.6 FTE) For
Adults: Jane Oliver (part time 0.6 FTE)

Administrative Coordinator

Noel Cowley (part time 0.4 FTE)

Development and Support Worker (Scotland)

Sandra Thoms (part time 0.8 FTE)

Bookkeeper

Tim Potter (part time 0.2 FTE)

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 Angela Barnicoat, MD, FRCP

Consultant Clinical Geneticist, Great Ormond Street Hospital NHS Trust

Dr Denise Dew-Hughes, Ed.D

Teacher, researcher and author in special education

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 Sébastien Jacquemont, MD

Department of Medical Genetics, University of Lausanne

Prof Chris Oliver BSc MPhil PhD CPsychol AFBPS

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

Prof Jeremy Turk, MD, BSc(Hons), FRCPsych, FRCPCH, DCH

Consultant Child & Adolescent Psychiatrist, Southwark Child & Adolescent Mental Health Neurodevelopmental Service

Dr Iris Trender-Gerhard, MD

Consultant Neurologist, St Mary's Hospital. Clinical Scientist, University of Manchester.

Dr Hayley Crawford

Research Associate, Coventry University

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

THE FRAGILE X SOCIETY

Report of the Trustees for the year ended 28th February 2018

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number
06724061 (England and Wales)

Registered Charity number
1127861

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

Trustees

C A McDonald	Chair	
J Keene	Treasurer	- appointed 23.9.17
J Woosnam-Savage	Secretary	
R Instone	Research Officer	- appointed 23.9.17
R Dell		- appointed 23.9.17
Dr L Elghali		
Dr K Johnson		
E G Leath		
T Nothey		
Prof G Scerif		
J Shaw		
K Silk		
D A Slaney		- appointed 23.9.17
M Smith		- appointed 23.9.17
M Williams		
R Hardiman		- resigned 23.9.17
S J Harris		- resigned 23.9.17
S Hicks		- resigned 23.9.17
N M H Dewar		- resigned 23.9.17
I Stirling		- resigned 23.9.17

Auditors

Simpson Wreford & Partners
Chartered Accountants & Statutory Auditors
Suffolk House
George Street
Croydon
Surrey
CR0 0YN

Bankers

CAF Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4TA

THE FRAGILE X SOCIETY

**Report of the Trustees
for the year ended 28th February 2018**

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 auditors, Simpson Wreford & Partners, will be proposed for re-appointment at the forthcoming Annual General Meeting.

09 AUG 2018

Approved by order of the board of trustees on and signed on its behalf by:

Craig McDonald,

.....
Craig McDonald
Chairman

THE FRAGILE X SOCIETY

Statement of Trustees Responsibilities for the year ended 28th February 2018

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

Company law requires the trustees 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 trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- 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 trustees 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.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

**Report of the Independent Auditors to the Members of
The Fragile X Society**

Opinion

We have audited the financial statements of The Fragile X Society (the 'charitable company') for the year ended 28th February 2018 which comprise the Statement of Financial Activities, the Balance Sheet and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 28th February 2018 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

**Report of the Independent Auditors to the Members of
THE FRAGILE X SOCIETY**

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.

Responsibilities of trustees

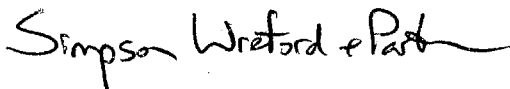
As explained more fully in the Statement of Trustees Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.



Alasdair Weaks (Senior Statutory Auditor)
Simpson Wreford & Partners
Chartered Accountants & Statutory Auditors
Suffolk House
George Street
Croydon
Surrey
CR0 0YN

Date: **09 AUG 2018**

THE FRAGILE X SOCIETY

**Statement of Financial Activities
for the year ended 28th February 2018**

		Unrestricted funds	Restricted funds	28.2.18 Total funds	28.2.17 Total funds
	Notes	£	£	£	£
INCOME AND ENDOWMENTS FROM					
Donations and legacies		58,328	53,796	112,124	211,069
Charitable activities					
DVDs		-	-	-	55
Conferences		2,280	-	2,280	2,441
Fundraising & trading activities	2	43,005	-	43,005	62,666
Investment income	3	<u>51</u>	<u>-</u>	<u>51</u>	<u>199</u>
Total		103,664	53,796	157,460	276,430
EXPENDITURE ON					
Raising funds	4	19,229	-	19,229	16,582
Charitable activities					
Conferences		1,825	-	1,825	18,872
Newsletters		15,838	-	15,838	9,909
Link		-	-	-	332
Charitable activities		122,191	53,796	175,987	150,479
Other		<u>1,840</u>	<u>-</u>	<u>1,840</u>	<u>4,907</u>
Total		160,923	53,796	214,719	201,081
NET INCOME/(EXPENDITURE)		(57,259)	-	(57,259)	75,349
RECONCILIATION OF FUNDS					
Total funds brought forward		184,330	-	184,330	108,981
TOTAL FUNDS CARRIED FORWARD		<u>127,071</u>	<u>-</u>	<u>127,071</u>	<u>184,330</u>

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

The notes form part of these financial statements

THE FRAGILE X SOCIETY

**Balance Sheet
At 28th February 2018**

		Unrestricted funds £	Restricted funds £	28.2.18 Total funds £	28.2.17 Total funds £
	Notes				
FIXED ASSETS					
Tangible assets	9	5,496	-	5,496	4,201
CURRENT ASSETS					
Stock	10	4	-	4	4
Debtors	11	357	-	357	5,606
Cash at bank and in hand		<u>136,635</u>	<u>-</u>	<u>136,635</u>	<u>208,201</u>
		136,996	-	136,996	213,811
CREDITORS					
Amounts falling due within one year	12	(15,421)	-	(15,421)	(33,682)
NET CURRENT ASSETS		<u>121,575</u>	<u>-</u>	<u>121,575</u>	<u>180,129</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>127,071</u>	<u>-</u>	<u>127,071</u>	<u>184,330</u>
NET ASSETS		<u>127,071</u>	<u>-</u>	<u>127,071</u>	<u>184,330</u>
FUNDS	13				
Unrestricted funds				127,071	184,330
Restricted funds				-	-
TOTAL FUNDS				<u>127,071</u>	<u>184,330</u>

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to charitable small companies.

09 AUG 2018

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

Craig McDonald

.....
Craig McDonald
Chairman

The notes form part of these financial statements

THE FRAGILE X SOCIETY

Notes to the Financial Statements for the year ended 28th February 2018

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 2015)', 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% on cost
Computer equipment	- 33% on cost

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.

2. FUNDRAISING & TRADING ACTIVITIES

	28.2.18	28.2.17
	£	£
Voluntary fundraising events	36,339	56,870
100+ Club	3,744	3,170
Other sales	<u>2,922</u>	<u>2,626</u>
	<u>43,005</u>	<u>62,666</u>

THE FRAGILE X SOCIETY

**Notes to the Financial Statements - continued
for the year ended 28th February 2018**

3. INVESTMENT INCOME

	28.2.18	28.2.17
	£	£
Interest received	<u>51</u>	<u>199</u>

4. RAISING FUNDS

Raising donations and legacies

	28.2.18	28.2.17
	£	£
Fundraising costs	12,193	14,425
Support costs	<u>7,036</u>	<u>2,157</u>
	<u>19,229</u>	<u>16,582</u>

5. NET INCOME/(EXPENDITURE)

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

	28.2.18	28.2.17
	£	£
Auditors' remuneration	4,528	4,334
Depreciation - owned assets	<u>484</u>	<u>684</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 28th February 2018 nor for the year ended 28th February 2017.

Trustees' expenses

	28.2.18	28.2.17
	£	£
Trustees' expenses	<u>1,717</u>	<u>573</u>

7. STAFF COSTS

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

	28.2.18	28.2.17
Directorate	1	1
Support worker	3	3
Other administration	<u>3</u>	<u>3</u>
	<u>7</u>	<u>7</u>

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

THE FRAGILE X SOCIETY

Notes to the Financial Statements - continued
for the year ended 28th February 2018

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	28.2.17 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	190,236	20,833	211,069
Charitable activities			
DVDs	55	-	55
Conferences	2,441	-	2,441
Fundraising & trading activities	62,666	-	62,666
Investment income	199	-	199
Total	255,597	20,833	276,430
 EXPENDITURE ON			
Raising funds	16,582	-	16,582
Charitable activities			
Conferences	18,872	-	18,872
Newsletters	9,909	-	9,909
Link	332	-	332
Charitable activities	128,721	21,758	150,479
Other	4,907	-	4,907
Total	179,323	21,758	201,081
 NET INCOME/(EXPENDITURE)	76,274	(925)	75,349
 RECONCILIATION OF FUNDS			
Total funds brought forward	108,056	925	108,981
 TOTAL FUNDS CARRIED FORWARD	184,330	-	184,330

THE FRAGILE X SOCIETY

**Notes to the Financial Statements - continued
for the year ended 28th February 2018**

9. TANGIBLE FIXED ASSETS

	Fixtures and fittings £	Computer equipment £	Totals £
COST			
At 1st March 2017	1,684	17,206	18,890
Additions	<u>1,779</u>	<u>-</u>	<u>1,779</u>
At 28th February 2018	<u>3,463</u>	<u>17,206</u>	<u>20,669</u>
DEPRECIATION			
At 1st March 2017	1,637	13,052	14,689
Charge for year	<u>47</u>	<u>437</u>	<u>484</u>
At 28th February 2018	<u>1,684</u>	<u>13,489</u>	<u>15,173</u>
NET BOOK VALUE			
At 28th February 2018	<u>1,779</u>	<u>3,717</u>	<u>5,496</u>
At 28th February 2017	<u>47</u>	<u>4,154</u>	<u>4,201</u>

10. STOCK

	28.2.18	28.2.17
	£	£
Stock	<u>4</u>	<u>4</u>

11. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	28.2.18	28.2.17
	£	£
Trade debtors	-	187
Prepayments and accrued income	<u>357</u>	<u>5,419</u>
	<u>357</u>	<u>5,606</u>

12. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	28.2.18	28.2.17
	£	£
Trade creditors	94	48
Social security and other taxes	5,392	2,562
Accruals and deferred income	<u>9,935</u>	<u>31,072</u>
	<u>15,421</u>	<u>33,682</u>

THE FRAGILE X SOCIETY

Notes to the Financial Statements - continued
for the year ended 28th February 2018

13. MOVEMENT IN FUNDS

	At 1.3.17 £	Net movement in funds £	At 28.2.18 £
Unrestricted funds			
General	181,595	(55,449)	126,146
Barbara Carmichael Memorial Fund	925	-	925
IT Equipment Fund	<u>1,810</u>	<u>(1,810)</u>	<u>-</u>
	184,330	(57,259)	127,071
	<u>184,330</u>	<u>(57,259)</u>	<u>127,071</u>
TOTAL FUNDS	<u>184,330</u>	<u>(57,259)</u>	<u>127,071</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General	103,664	(159,113)	(55,449)
IT Equipment Fund	<u>-</u>	<u>(1,810)</u>	<u>(1,810)</u>
	103,664	(160,923)	(57,259)
Restricted funds			
Family Support Worker (1) Fund	19,167	(19,167)	-
Family Support Worker (Scotland) Fund	20,000	(20,000)	-
Jeans for Genes Fund	4,968	(4,968)	-
Educate to Empower Project Fund	<u>9,661</u>	<u>(9,661)</u>	<u>-</u>
	53,796	(53,796)	-
	<u>157,460</u>	<u>(214,719)</u>	<u>(57,259)</u>
TOTAL FUNDS	<u>157,460</u>	<u>(214,719)</u>	<u>(57,259)</u>

THE FRAGILE X SOCIETY

Notes to the Financial Statements - continued
for the year ended 28th February 2018

13. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.3.16 £	Net movement in funds £	At 28.2.17 £
Unrestricted Funds			
General	104,246	77,349	181,595
Barbara Carmichael Memorial Fund	2,000	(1,075)	925
IT Equipment Fund	<u>1,810</u>	<u>-</u>	<u>1,810</u>
	108,056	76,274	184,330
Restricted Funds			
Production of booklet for "Carriers"	925	(925)	-
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>108,981</u>	<u>75,349</u>	<u>184,330</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General	255,597	(178,248)	77,349
Barbara Carmichael Memorial Fund	<u>-</u>	<u>(1,075)</u>	<u>(1,075)</u>
	255,597	(179,323)	76,274
Restricted funds			
Family Support Worker (1) Fund	833	(833)	-
Family Support Worker (Scotland) Fund	20,000	(20,000)	-
Production of booklet for "Carriers"	<u>-</u>	<u>(925)</u>	<u>(925)</u>
	20,833	(21,758)	(925)
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>276,430</u>	<u>(201,081)</u>	<u>75,349</u>

THE FRAGILE X SOCIETY

Notes to the Financial Statements - continued for the year ended 28th February 2018

13. MOVEMENT IN FUNDS - continued

Restricted Funds

The Family Support Worker (1) Fund is to assist the Society in running a helpline support, creating information resources and running support groups for a Family Support Worker for Children.

The Family Support Worker (Scotland) Fund provides a support and development worker who supports families, delivers professional training, raises awareness and provides development work across Scotland.

The Jeans for Genes Fund was created due to monies received in 2016/17 for the creation of an online video resource to raise awareness of the Society. This has been fully expended in the year.

The Educate to Empower Project Fund has enabled the Society to create information packs for newly diagnosed families, launch the pack through a series of educational roadshows for professionals across Scotland, and create a video on diagnosis with Scottish families, professionals and researches from the Patrick Wild Centre.

Designated Funds

The Barbara Carmichael Memorial Fund is to enable the Society to produce the booklet 'Carriers'.

14. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 28th February 2018.