

**REGISTERED COMPANY NUMBER: 06724061 (England and Wales)**

**REGISTERED CHARITY NUMBER: 1127861**

**Report of the Trustees and  
Financial Statements for the Year Ended 29th February 2016  
for  
THE FRAGILE X SOCIETY**

Simpson Wreford & Partners  
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**THE FRAGILE X SOCIETY**

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for the year ended 29th February 2016**

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## **THE FRAGILE X SOCIETY**

### **Report of the Trustees for the year ended 29th February 2016**

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 29th February 2016. 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 for Smaller Entities (the FRSE) (effective 1 January 2015).

#### **OBJECTIVES AND ACTIVITIES**

##### **Objectives of the charity for delivering public benefit**

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

Fragile X Syndrome is the most common cause of inherited learning disability, affecting approximately 1 in 4,000 males and 1 in 6,000 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.

##### **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. Though each individual is different, there is a constellation of features which are associated with fragile X. Understanding these 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, such as learning disability or autism.

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%).

These statistics are based upon a recent external survey of our membership (via BlueTree). Full report available via the CEO.

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 29th February 2016

#### 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.

#### ACHIEVEMENT AND PERFORMANCE

##### Our Community

On 28th February 2016 the charity had a membership of 1,963 (1,678 UK full member families (many of whom have multiple members of their family living with varying effects of fragile X), 79 overseas members, and 206 UK associate members). This represents an increase of 6% from last year.

##### Our National Helpline Service

Through dedicated, specialised support workers, 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, from 9am-5pm, Monday to Friday.

In total this year we responded to a total of 933 enquiries (generating 2,905 contacts) via our helpline, in addition to contributing to discussions on our online Facebook group, which is posted in multiple times daily by its members.

A recent survey of the Fragile X Society members highlighted that 70% of respondents said that the support workers had made a difference to them; 58% said that they had made "a big difference", demonstrating the value of this service.

*"All my questions are answered without being made to feel silly. The Society gets us as parents, they are helpful and friendly. It seems like nothing is too much trouble....without you I'd be a heap on the floor"*

##### How We Have Supported Individuals and Families Living with Fragile X

*"When I had a crisis, I rang. I called every time there was a battle. I knew I could ring up and someone would talk to me."*

*"It's almost like a counsellor. Especially when you're newly diagnosed. Wendy has been my support. She has put me in contact with other families in the same situation. That has been wonderful. And backing it up with all those free, printed materials -it has been so useful."*

Quotes taken from feedback forms and comments on survey of our membership.

## THE FRAGILE X SOCIETY

### Report of the Trustees for the year ended 29th February 2016

#### ACHIEVEMENTS AND PERFORMANCE

##### Our Community

###### - Helpline

Our support workers responded to a total of 867 enquiries (37% increase upon last year) from individuals with, or family member of, those affected by fragile X syndrome or fragile X-associated conditions, generating 2,799 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. The support workers 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.

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 41 enquiries (involving 97 contacts) were received from families whose children had just received a diagnosis of fragile X. Each received an immediate 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 66 enquiries of this nature, which generated 106 contacts.

###### - 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

*"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."*

Our newsletter continues to be a key source of support and information to our community. As aimed, this year we updated the style of our newsletter to a new, easier to read A4 format, which we are now publishing quarterly. We continue to commission articles on key topics and seek stories from individuals with fragile X and their families for the newsletter.

###### - Fragile X Society Conferences

The Society held two conferences during the year which, as well as providing the opportunity to learn about fragile X and the latest findings from fragile X research, also gave time for families to meet and share their experiences. Our conferences are primarily aimed at families, though are open to professionals.

Our annual Scottish Conference, was held at Stirling Management Centre on Saturday 16th May. The event was a great success and was attended by 58 people, as well as 9 young people in the crèche. The talks focussed on the key topics of sleep and behaviour. All attendees who responded rated the event as good or very good on the feedback form.

*"Best yet. Most relevant and practical conference attended so far"*

Our annual National Conference was held on Saturday 26th September in Birmingham (Holiday Inn, Birmingham City Centre) with a theme of translating research into practice. The day involved talks on the latest research from internationally renowned researchers and clinicians, followed by workshops on the application of this information. The conference was one of our largest ever with 193 adults in attendance (predominantly people with a direct personal link to fragile X, but also researchers), and 23 young people. 95% of attendees (who completed the feedback forms) agreed that the event had provided useful information that they would be able to put into practice.

*"A really informative day; presented very professionally yet in a friendly way"*

## THE FRAGILE X SOCIETY

### Report of the Trustees for the year ended 29th February 2016

#### ACHIEVEMENT AND PERFORMANCE

##### Our Community

We held a half-day event at the University of Edinburgh on the key topics of adulthood and carrier issues, in partnership with the Patrick Wild Centre. Talks were given by Dr Jonathan Cohen (medical Director, Fragile X Alliance, Australia), Rashelle Cohen (Behavioural Optometrist) and Michael Cohen (who lives with fragile X Syndrome). The event was attended by 27 individuals in total but was watched live from across the world by a further 53, and is available to catch-up recorded on our website and YouTube.

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

*"If the Fragile X Society wasn't there, we wouldn't be able to deliver anything specific on fragile X, any behaviour strategies; we wouldn't be able to provide advice to schools on how to adapt the environment in order to support young people who need it. We don't have that expertise. We would be giving advice about autism, which might not meet the needs of young people with fragile X."-Autism professional*

##### - 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 160 contacts (generating 327 enquiries) from professionals, students and other organisations.

##### - Training

- o **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, 74 professionals were trained via this course.
- o **School Awareness:** In collaboration with the Patrick Wild Centre, we conducted awareness sessions for 114 pupils across 2 mainstream secondary schools in Edinburgh.
- o **Scotland Project:** Thanks to funding we have been able to conduct a substantial amount of development work in Scotland, which has led to 428 professionals receiving training about fragile X. 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 (29) at the University of Edinburgh about fragile X. These will be a key group of professionals working with the fragile X community.
  - **Lunch and Learn.** We educated 62 social care professionals from Cornerstone Community Care about fragile X syndrome through Lunch and learn sessions for European fragile X day (10th October).
  - **One Stop Shops:** 8 fragile X awareness sessions were run through the year at Autism One Stop Shops Across Scotland, which are attended by parents and professional from various backgrounds.

## THE FRAGILE X SOCIETY

### Report of the Trustees for the year ended 29th February 2016

#### ACHIEVEMENT AND PERFORMANCE

##### - Awareness Day

October 10th (XX) is European Fragile X Awareness Day. We encouraged individuals with fragile X, their families and loved ones to share photographs and stories about achievements and the ways that people have faced or overcome challenges of living with fragile X, on social media, using the hashtag #fragileXtraordinary. The aim was to create a positive awareness message.

*"Josh went to Wembley with his siblings for the England game last night. This is such a huge step that josh has made over the years as crowds of people he found very difficult to deal with. He really is very special and always finds a place in people's hearts that he meets, so proud of him xx #fragileXtraordinary"*

Over 700 photos and stories were shared as part of this campaign, which was also shared by large organisations such as Mencap and Rare Diseases. Our key awareness message was seen by over 70,000 people on Facebook.

In addition, three flash mobs were held across the country in London (Farringdon Tube Station), Cardiff (Capitol Shopping Centre, supported by Rubicon Dance: a learning disability dance group) and Aberdeen (at the Bon Accord Shopping Centre, supported by KaSt Dance Company, Fusion Youth Dance Company and Flux Dance Festival). A billboard campaign was also featured in central Cardiff, thanks to Maxx Media.

Finally, in collaboration with Cornerstone (a charity providing services for people with a learning disability in Scotland) we trained 62 professionals about fragile X through lunch and learn sessions.

##### - Tweet chats

In partnership with WeLDNs online learning disability community, and #PBSchat (an initiative run by volunteers allowing learning disability professionals to meet virtually to discuss relevant issues) we hosted two chats on Twitter. Aimed predominantly at professionals, though also open to families, in these chats we focussed on topics including health and behaviour in individuals with fragile X syndrome. Families and two of our specialist advisors (professor Jeremy Turk and Professor Gaia Scerif) volunteered to input on the discussions. Across both chats, approximately 70 users participated (including professionals from different medical and educational backgrounds).

*"@fragilexuk I've learnt a lot tonight, & have a lot of bedtime reading to do!  
Thanks for a super interesting chat #WeLDNs"*

##### - Other awareness campaigns

We 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.

##### - Other outreach

This included but was not limited to:

- o Fragile X was front page news in the July/August edition of Learning Disability Today, thanks to an article written by our CEO.
- o We represented the UK Fragile X community at Strasbourg Fragile X Research Conference
- o Our support workers represented us at a Rare Disease Day event at the Royal Holloway.

## THE FRAGILE X SOCIETY

### Report of the Trustees for the year ended 29th February 2016

#### ACHIEVEMENT AND PERFORMANCE

##### Our Information Publications

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.

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. In addition to these resources, we have an award winning DVD and a book "Educating Children with fragile X Syndrome". Our resources include easy-read material, and we are working to expand our range further.

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.

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](http://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, 1,344 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.

We are proud to have supported the following projects over the past year:

- Arousal and Escape Behaviour. Becky Hardiman and colleagues, Tizard Centre, University of Kent.
- Decreasing the Incidence of Temper Outbursts triggered by change in boys and girls aged 7 - 16. Kate Woodcock and colleagues, Queen's University Belfast
- Fragile X Imaging Study. Andrew MacKechanie and colleagues, The Patrick Wild Centre, University of Edinburgh
- Social Cognition in Fragile X Syndrome. Chris Oliver and colleagues, Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham
- Sleep in Infants and Toddlers with Fragile X. Dean D'Souza and colleagues, Centre for Brain and Cognitive Development, Birbeck.
- Study of Male Fragile X Premutation Carriers. Andrew Stanfield and colleagues, Patrick Wild Centre, University of Edinburgh
- Identifying Barriers to Research Participation in Families with Fragile X. Andrew Stanfield and colleagues, Patrick Wild Centre, University of Edinburgh
- Memory Training and Fragile X. Sonya Campbell and colleagues, Patrick Wild Centre, University of Edinburgh
- Parents views on Fragile X Research. Collaboration between the European Fragile X Network and the National Fragile X Foundation.

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 70 research projects.



## THE FRAGILE X SOCIETY

### Report of the Trustees for the year ended 29th February 2016

#### ACHIEVEMENT AND PERFORMANCE

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

#### 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, five gave the following:

Craig McDonald (Chair):	6 hours per week
Steve Harris (Vice Chair):	5 hours per week
Isabel Stirling (Treasurer):	4 hours per week
Dorcas Slaney (Family Fundraising):	3 hours per week
Sally Hicks (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, to the dance groups who supported our Flash Mobs, to the therapists who volunteered their skills to provide free therapies to families at the Holistic Evening at the Glasgow Support group, and to all the others who have volunteered their time raising funds and awareness.

#### 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 5,000 families. The aim of the network is to establish and improve links between the organisations and to share information. The sixth meeting of the European Network took place in Lisbon in November 2015.

A new **International Fragile X Alliance** is also under development which we will be proud to be a part of. We hope that this new network will act as a valuable resource for existing organisations (through sharing resources and ideas) but will also encourage and facilitate the development of new organisations worldwide.

We are, of course, also part of the wider learning disability, autism and genetic disorder communities, and we continue to work alongside other organisations with shared interests. As mentioned above, 2015/6 has also seen a joint awareness and education initiative for fragile X with the Patrick Wild Centre. In addition, 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, AnnaKennedyOnline 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.

##### - **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 (1,784 members: who post daily to seek support, celebrate successes and share resources). We also have a growing following on social media including: 1,843 likes on our Facebook page, 1,244 followers on Twitter and 222 followers on Instagram. Our website attracted over 33,000 users, with our most popular pages being our information pages (including the information of fragile X and autism).

## **THE FRAGILE X SOCIETY**

### **Report of the Trustees for the year ended 29th February 2016**

#### **ACHIEVEMENT AND PERFORMANCE**

##### **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**

##### **Financial position**

This has been a difficult year for the Fragile X Society. Overall a deficit of £63,838 was generated, compared to a surplus in the prior year of £90,365. It should be noted that last year the Society benefitted from an anonymous donation of £100,000.

In total, income fell from £311,945 to £127,665. Family fundraising was halved this year and stood at £23,143 (2015 - £46,767). Fundraising continues to be a significant source of income and we are grateful for all of the effort and dedication that goes into each of these events, which not only support us financially but also help raise awareness of fragile X syndrome and the Society.

Appeals to Companies and Trusts and grant income totalled £40,000 and we thank:

- The Robertson Trust
- The Chapman Charitable Trust
- The Martin Laing Foundation
- The Leathersellers' Charity
- The Scottish Government
- NEXT plc
- Essex Community Fund

We are pleased to announce that we have secured a 3 year grant from the Robertson Trust of £45,000. The first instalment of £15,000 was received during the year.

NEXT plc and The Leathersellers Company have both provided support towards our Family Support Worker salaries by way of grants in annual instalments over the past 3 and 4 years respectively. The final instalment of each grant was received during the year and we express our thanks for your generous support.

General donations totalled £52,248 (2015 - £144,500) and included donations large and small from both individuals and organisations. We are grateful to those who Gift Aid donations which last year brought a tax reclaim of over £3,000 to the Society.

Total expenditure has reduced to £191,503 (2015 - £221,580). This is due to the reduced paid hours that some of our staff are now working, namely Tim Potter (Bookkeeper) and Sandra Thoms (Support Worker).

##### **Going concern**

Whilst the Society has some confirmed funding arrangements for the next two or three years, we still require additional donated income to be able to maintain service levels. Fundraising and other donation income have previously been forthcoming, although it cannot be guaranteed that the derived income will be sufficient to cover ongoing costs.

The trustees continue to explore various funding opportunities and are optimistic that grants will be secured to support the Society's work. Budgets and forecasts have been prepared to monitor cash flow and expenditure is reviewed regularly to identify potential savings.

The Board therefore considers it appropriate to prepare the accounts on the going concern basis given the nature of charitable operations and current projections.

## **THE FRAGILE X SOCIETY**

### **Report of the Trustees for the year ended 29th February 2016**

#### **FINANCIAL REVIEW**

##### **Reserves Policy**

The Directors have adopted a reserve policy whereby free reserves (that is general funds in excess of the amounts invested in fixed assets held for charity use) should be maintained at a level which at least amounts to three months direct charitable expenditure not covered by restricted and designated funds. As income does not arise evenly through the year, these reserves will provide working capital to help manage cash flow. At £103,171, free reserves currently exceed this target, but with minimal confirmed ongoing funding, the trustees feel that these extra funds are appropriate.

#### **FUTURE PLANS - THE SOCIETY'S MAIN OBJECTIVES FOR 2016/17**

- To review our information resources and begin the process of updating where necessary, to ensure that they answer people's key questions, that they are clear and easy to use and that they are available in a variety of formats including: easy-read, online and video. Based on feedback received from our members, we will develop our resources and information about fragile X carriers, in particular.
- To consult our members living with fragile X syndrome about how we may be able to provide more direct support for them and ensure that their voice is heard, and respond to their feedback, aiming to develop our services where needed.
- To develop our case for support and improve the evaluation and communication of the impact of our work, in order to develop fundraising to maintain and grow our services.
- Continue to develop our website and digital resources.
- 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 and the feedback provided from our members, via evaluation forms and initiatives such as our membership survey. We are developing as an organisation according to a 5 year-plan 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 affected by fragile X have the opportunity of support and the best guidance and information possible.

The Directors confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Society's aims and objectives and planning future activities.

## THE FRAGILE X SOCIETY

### Report of the Trustees for the year ended 29th February 2016

#### 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

###### CEO

Becky Hardiman (part time 0.5 FTE\*)

###### Information & Communications Officer

Sophie Kashi (part time 0.6 FTE)

###### Support Workers

Wendy Bowler (part time 0.8 FTE)

Jane Oliver (part time 0.6 FTE)

Sandra Thoms (part time 0.8 FTE)

###### Clerical Assistant

Susan Layton (part time 0.4 FTE)

###### Bookkeeper

Tim Potter (part time 0.2 FTE)

\* FTE = Full-Time Equivalent

##### Specialist Advisors

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

Dr Angela Barnicoat, MD, FRCP

Consultant Clinical Geneticist, Great Ormond Street Hospital NHS Trust

Prof Kay E Davies, CBE, F Med Sci, FRS

Department of Human Anatomy & Genetics, University of Oxford

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, University of Edinburgh

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

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

##### 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.

## **THE FRAGILE X SOCIETY**

### **Report of the Trustees for the year ended 29th February 2016**

#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **Governing document**

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 26th September 2015. One new director joined the board as well as 5 who were re-elected after serving a term of 3 years on the board. During the year, 3 directors stepped down. With one member co-opted since the AGM, there are currently 14 members on the board, leaving 1 vacancy.

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

The current Directors, nearly all of whom are elected from the family membership, know well the aims of the Society and how, through its activities, the charity endeavours to meet its aims. All new directors are informed about the Society's constitution and Charity Commission for England and Wales publications including Responsibilities of Trustees and Hallmarks of a Well Run Charity. Trustees 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 family membership informing them that elections for Directors will take place at the AGM, which in 2015 will take place on 26th September at our Birmingham Conference. Family members are encouraged to come forward for election to the Board of Directors. Those interested in becoming a Director are sent the Society's paper explaining the role, responsibilities, duties and commitment of the Society's directors and the executive committee, and an indication of the particular skills and experience that are needed on the Society's executive committee. This information is sent to all interested family members together 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.

##### **Working structure and management**

The Board of Directors meets four times a year 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 part-time Development and Support Worker in Scotland and five part-time employees (Information and Communications Officer, Support Workers (one adult- and one child-focussed), a Book-keeper and a Clerical Assistant).

##### **Risk management**

The trustees have a risk management strategy which comprises:

- an annual review of the principal risks and uncertainties that the Society faces;  
the establishment of policies, systems and procedures to mitigate those risks identified in the annual review;
- and  
the implementation of procedures designed to minimise or manage any potential impact on the charity should
- those risks materialise.

This work has identified that financial sustainability is the major financial risk for the Society. A key element in the management of financial risk is a regular review of available liquid funds to settle debts as they fall due to ensure sufficient working capital. Attention has also been focussed on non-financial risks arising from fire and health and safety of staff. These risks are managed by regular awareness training for our staff team and maintaining appropriate insurance.

## THE FRAGILE X SOCIETY

### Report of the Trustees for the year ended 29th February 2016

#### 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**

Mrs Z Carroll		
Mrs N M Dewar	Secretary	- re-elected 26.9.15
Dr L Elghali		
Ms A Evans		
Ms R Hardiman		- re-elected 26.9.15
Mrs E Harris		- resigned 26.9.15
Mr Mr S J Harris	Vice Chair	- re-elected 26.9.15
Mrs S Hicks		
Mr Mr E J McDonald-Scott		- resigned 26.9.15
Mr Mr C A McDonald	Chair	
Prof G Scerif		
Ms K Silk		- appointed 25.9.15
Mrs D A Slaney		- re-elected 26.9.15
Mrs I Stirling	Treasurer	
Mrs R Waines		- re-elected 26.9.15
Mrs M Williams		- resigned 26.9.15
Ms J Woosnam-Savage		- co-opted 5.12.15

**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

**STATEMENT OF TRUSTEES RESPONSIBILITIES**

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 Generally Accepted Accounting Practice.

## **THE FRAGILE X SOCIETY**

### **Report of the Trustees for the year ended 29th February 2016**

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.

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

So far as the trustees 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 trustee has taken all the steps that they ought to have taken as a trustee 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.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

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

.....  
Mr C A McDonald - Chairman

## **Report of the Independent Auditors to the Trustees of The Fragile X Society**

We have audited the financial statements of The Fragile X Society for the year ended 29th February 2016 on pages sixteen to twenty seven. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard for Smaller Entities (effective January 2015) (United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities).

This report is made solely to the charitable company's trustees, as a body, in accordance with Section 144 of the Charities Act 2011 and regulations made under Section 154 of that Act. Our audit work has been undertaken so that we might state to the charitable company's trustees 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 trustees as a body, for our audit work, for this report, or for the opinions we have formed.

### **Respective responsibilities of trustees and auditors**

As explained more fully in the Statement of Trustees Responsibilities set out on page thirteen, 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.

The trustees have elected for the financial statements to be audited in accordance with the Charities Act 2011 rather than the Companies Act 2006. Accordingly we have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with regulations made under Section 154 of that Act.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors, including APB Ethical Standard - Provisions Available for Small Entities (Revised), in the circumstances set out in note 20 to the financial statements

### **Scope of the audit of the financial statements**

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Report of the Trustees to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

### **Opinion on financial statements**

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 29th February 2016 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 applicable to Smaller Entities; and
- have been prepared in accordance with the requirements of the Companies Act 2006.



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

**Matters on which we are required to report by exception**

We have nothing to report in respect of the following matters where the Charities Act 2011 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements ; or
- the charitable company has not kept adequate accounting records; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Simpson Wreford & Partners  
Chartered Accountants & Statutory Auditors  
Eligible to act as an auditor in terms of Section 1212 of the Companies Act 2006  
Suffolk House  
George Street  
Croydon  
Surrey  
CR0 0YN

Date: .....

**THE FRAGILE X SOCIETY**

**Statement of Financial Activities  
(Incorporating an Income and Expenditure Account)  
for the year ended 29th February 2016**

		Unrestricted funds £	Restricted funds £	29.2.16 Total funds £	28.2.15 Total funds £
	Notes				
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	2	64,248	28,000	92,248	252,300
<b>Charitable activities</b>	5				
DVDs		81	-	81	135
Members' subscriptions		45	-	45	45
Conferences		2,400	-	2,400	987
Other trading activities	3	32,512	-	32,512	58,253
Investment income	4	<u>379</u>	<u>-</u>	<u>379</u>	<u>225</u>
<b>Total</b>		99,665	28,000	127,665	311,945
<b>EXPENDITURE ON</b>					
Raising funds	6	13,253	-	13,253	18,133
<b>Charitable activities</b>	7				
Conferences		15,569	-	15,569	23,170
Newsletters		11,989	-	11,989	9,807
Link		293	-	293	375
Charitable activities		109,983	31,777	141,760	161,564
Other		<u>8,639</u>	<u>-</u>	<u>8,639</u>	<u>8,531</u>
<b>Total</b>		159,726	31,777	191,503	221,580
<b>NET INCOME/(EXPENDITURE)</b>		(60,061)	(3,777)	(63,838)	90,365
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		168,117	4,702	172,819	82,454
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u>108,056</u>	<u>925</u>	<u>108,981</u>	<u>172,819</u>

The notes form part of these financial statements

THE FRAGILE X SOCIETY

Balance Sheet  
At 29th February 2016

	Notes	29.2.16 £	28.2.15 £
<b>FIXED ASSETS</b>			
Tangible assets	13	4,885	5,152
<b>CURRENT ASSETS</b>			
Stocks		57	156
Debtors	14	4,003	1,256
Cash at bank and in hand		<u>107,589</u>	<u>177,784</u>
		111,649	179,196
<b>CREDITORS</b>			
Amounts falling due within one year	15	(7,553)	(11,529)
<b>NET CURRENT ASSETS</b>		<u>104,096</u>	<u>167,667</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		108,981	172,819
<b>NET ASSETS</b>		<u>108,981</u>	<u>172,819</u>
<b>FUNDS</b>	18		
Unrestricted funds		108,056	168,117
Restricted funds		<u>925</u>	<u>4,702</u>
<b>TOTAL FUNDS</b>		<u>108,981</u>	<u>172,819</u>

The notes form part of these financial statements

**THE FRAGILE X SOCIETY**

**Balance Sheet - continued  
At 29th February 2016**

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 29th February 2016.

The members have not deposited notice, pursuant to Section 476 of the Companies Act 2006 requiring an audit of these financial statements.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been audited under the requirements of Section 144 of the Charities Act 2011.

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies and with the Financial Reporting Standard for Smaller Entities (effective January 2015).

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

.....  
Mr C A McDonald - Chairman

## THE FRAGILE X SOCIETY

### notes to the financial statements for the year ended 29th February 2016

#### 1. ACCOUNTING POLICIES

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

The financial statements of the charitable company have been prepared in accordance with the Charities SORP (FRSSE) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (the FRSSE) (effective 1st January 2015)', the Financial Reporting Standard for Smaller Entities (effective January 2015) and the Companies Act 2006. The financial statements have been prepared under the historical cost convention and in accordance with applicable charity and company law.

Whilst the Society has some confirmed future funding arrangements in place, additional donated income is required to maintain service levels. Fundraising and other donation income have previously been forthcoming, although it cannot be guaranteed that the derived income will be sufficient to cover ongoing costs. The trustees continue to explore various funding opportunities and are optimistic that further grants will be secured to support the Society's work. Budgets and forecasts have been prepared to monitor cash flow and expenditure is reviewed regularly to identify potential savings.

Taking account of the uncertainties of ongoing funding the Board still considers it appropriate to prepare the accounts on the going concern basis.

##### **Exemption from preparing a cash flow statement**

Exemption has been taken from preparing a cash flow statement in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015).

##### **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.

##### **Allocation and apportionment of costs**

Support costs are incurred in support of expenditure on these activities, but do not in themselves, constitute an activity. They are therefore allocated to the activities on a basis consistent with the use of time and resources of the charity. Governance costs are incurred in connection with the administration of the charity and statutory compliance.

##### **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.

# THE FRAGILE X SOCIETY

## Notes to the Financial Statements - continued for the year ended 29th February 2016

### 1. ACCOUNTING POLICIES - continued

#### Fund accounting

##### (i) Designated funds

Designated funds are unrestricted funds earmarked by the trustees for particular purposes.

##### (ii) General fund

The general fund consists of those funds which the charity may use in furtherance of its charitable objectives at the discretion of the trustees.

##### (iii) Restricted funds

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.

#### Video production costs and income

The full cost of producing information videos is charged as an expense in the accounts in the year it is incurred. Receipts from subsequent sales of copies are included in income in the accounts in the period they are received.

#### Leases

Operating lease commitments are provided for in the balance sheet at the time rental payments fall due. Such rental costs are charged to the income and expenditure account as incurred.

### 2. DONATIONS AND LEGACIES

	29.2.16	28.2.15
	£	£
Donations	52,248	144,500
Grants	<u>40,000</u>	<u>107,800</u>
	<u>92,248</u>	<u>252,300</u>

### 3. OTHER TRADING ACTIVITIES

	29.2.16	28.2.15
	£	£
Voluntary fundraising events	23,143	46,767
100+ Club	3,500	2,398
Other sales	<u>5,869</u>	<u>9,088</u>
	<u>32,512</u>	<u>58,253</u>

### 4. INVESTMENT INCOME

	29.2.16	28.2.15
	£	£
Interest received	<u>379</u>	<u>225</u>

**THE FRAGILE X SOCIETY**

**Notes to the Financial Statements - continued  
for the year ended 29th February 2016**

**5. INCOME FROM CHARITABLE ACTIVITIES**

	Activity	29.2.16 £	28.2.15 £
Sale of DVDs	DVDs	81	135
Subscriptions	Members' subscriptions	45	45
Scottish conference	Conferences	290	295
AGM and National Family Conference	Conferences	<u>2,110</u>	<u>692</u>
		<u>2,526</u>	<u>1,167</u>

**6. RAISING FUNDS**

**Other trading activities**

	29.2.16 £	28.2.15 £
Fundraising costs	11,153	8,050
Support costs	<u>2,100</u>	<u>10,083</u>
	<u>13,253</u>	<u>18,133</u>

**7. CHARITABLE ACTIVITIES COSTS**

	Direct costs £	Support costs (See note 8) £	Totals £
Conferences	15,569	-	15,569
Newsletters	11,989	-	11,989
Link	293	-	293
Charitable activities	<u>112,998</u>	<u>28,762</u>	<u>141,760</u>
	<u>140,849</u>	<u>28,762</u>	<u>169,611</u>

**8. SUPPORT COSTS**

	Management £	Other £	Governance costs £	Totals £
Fundraising trading: cost of goods sold and other costs	-	2,100	-	2,100
Other resources expended	830	-	7,809	8,639
Charitable activities	<u>9,198</u>	<u>19,564</u>	<u>-</u>	<u>28,762</u>
	<u>10,028</u>	<u>21,664</u>	<u>7,809</u>	<u>39,501</u>

Support costs, included in the above, are as follows:

THE FRAGILE X SOCIETY

Notes to the Financial Statements - continued  
for the year ended 29th February 2016

8. SUPPORT COSTS - continued

Management

			29.2.16	28.2.15
	Other resources expended	Charitable activities	Total activities	Total activities
	£	£	£	£
Rent	380	3,421	3,801	3,798
Insurance	128	1,160	1,288	1,247
Light and heat	192	1,721	1,913	2,438
Health and safety	48	432	480	456
Office maintenance	-	1,724	1,724	826
Depreciation of tangible and heritage assets	<u>82</u>	<u>740</u>	<u>822</u>	<u>2,433</u>
	<u>830</u>	<u>9,198</u>	<u>10,028</u>	<u>11,198</u>

Other

			29.2.16	28.2.15
	Fundraising trading: cost of goods sold and other costs	Charitable activities	Total activities	Total activities
	£	£	£	£
Salaries	<u>2,100</u>	<u>19,564</u>	<u>21,664</u>	<u>56,555</u>

Governance costs

	29.2.16	28.2.15
	£	£
Trustees' expenses	3,249	3,387
Auditors' remuneration	<u>4,560</u>	<u>4,200</u>
	<u>7,809</u>	<u>7,587</u>

9. NET INCOME/(EXPENDITURE)

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

	29.2.16	28.2.15
	£	£
Auditors' remuneration	4,560	4,200
Depreciation - owned assets	822	2,433
Other operating lease	<u>4,902</u>	<u>3,600</u>



# THE FRAGILE X SOCIETY

## Notes to the Financial Statements - continued for the year ended 29th February 2016

### 10. TRUSTEES' REMUNERATION AND BENEFITS

During the year a salary of £15,000 (Employment commenced November 2015. Salary for 2014/15 November-March employment period - £5,289) was paid to Ms R Hardiman for her services as Chief Executive Officer (2.5 days per week) of the charity and travel expenses of £5,080 (November-March 2015 - £1,735) were reimbursed.

When appointing a new part-time Chief Executive Officer in the autumn of 2014, after a thorough recruitment process and including interviewing several candidates including Ms R Hardiman, an existing trustee, the board of trustees found Ms Hardiman to be clearly the best candidate. Ms Hardiman played no part in the recruitment process.

The board consider all potential conflicts of interest and ensure that Ms Hardiman takes no part in decisions where her independence could be questioned, leaving the room at appropriate agenda items. Her expenses are all approved by directors, with any large individual amounts being cleared by the Chairman before being submitted.

There is a clear understanding that the two roles are different and there is no payment to her for being a Trustee.

#### Trustees' expenses

Travel expenses amounting to £3,249 (2015 - £3,287) were reimbursed to 10 trustees (2015 - 10).

### 11. STAFF COSTS

	29.2.16	28.2.15
	£	£
Wages and salaries	<u>117,825</u>	<u>143,684</u>

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

	29.2.16	28.2.15
Directorate	1	1
Support worker	3	3
Other administration	<u>2</u>	<u>2</u>
	<u>6</u>	<u>6</u>

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

### 12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	189,775	62,525	252,300
<b>Charitable activities</b>			
DVDs	135	-	135
Members' subscriptions	45	-	45
Conferences	987	-	987
Other trading activities	58,253	-	58,253
Investment income	<u>225</u>	<u>-</u>	<u>225</u>
<b>Total</b>	<b>249,420</b>	<b>62,525</b>	<b>311,945</b>

THE FRAGILE X SOCIETY

Notes to the Financial Statements - continued  
for the year ended 29th February 2016

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted funds £	Restricted funds £	Total funds £
<b>EXPENDITURE ON</b>			
Raising funds	18,133	-	18,133
<b>Charitable activities</b>			
Conferences	23,170	-	23,170
Newsletters	9,807	-	9,807
Link	375	-	375
Charitable activities	99,065	62,499	161,564
Other	<u>8,531</u>	<u>-</u>	<u>8,531</u>
<b>Total</b>	<u>159,081</u>	<u>62,499</u>	<u>221,580</u>
<b>NET INCOME/(EXPENDITURE)</b>	90,339	26	90,365
<b>RECONCILIATION OF FUNDS</b>			
<b>Total funds brought forward</b>	<u>77,778</u>	<u>4,676</u>	<u>82,454</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u><u>168,117</u></u>	<u><u>4,702</u></u>	<u><u>172,819</u></u>

13. TANGIBLE FIXED ASSETS

	Fixtures and fittings £	Computer equipment £	Totals £
<b>COST</b>			
At 1st March 2015	1,684	16,651	18,335
Additions	<u>-</u>	<u>555</u>	<u>555</u>
At 29th February 2016	<u>1,684</u>	<u>17,206</u>	<u>18,890</u>
<b>DEPRECIATION</b>			
At 1st March 2015	1,527	11,656	13,183
Charge for year	<u>110</u>	<u>712</u>	<u>822</u>
At 29th February 2016	<u>1,637</u>	<u>12,368</u>	<u>14,005</u>
<b>NET BOOK VALUE</b>			
At 29th February 2016	<u><u>47</u></u>	<u><u>4,838</u></u>	<u><u>4,885</u></u>
At 28th February 2015	<u><u>157</u></u>	<u><u>4,995</u></u>	<u><u>5,152</u></u>

**THE FRAGILE X SOCIETY**

**Notes to the Financial Statements - continued  
for the year ended 29th February 2016**

**14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	29.2.16	28.2.15
	£	£
Prepayments and accrued income	<u>4,003</u>	<u>1,256</u>

**15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	29.2.16	28.2.15
	£	£
Bank loans and overdrafts	823	107
Trade creditors	47	325
Social security and other taxes	2,123	2,705
Accrued expenses	<u>4,560</u>	<u>8,392</u>
	<u>7,553</u>	<u>11,529</u>

**16. OPERATING LEASE COMMITMENTS**

The following operating lease payments are committed to be paid within one year:

	29.2.16	28.2.15
	£	£
Expiring:		
Within one year	3,600	3,600
Between one and five years	<u>1,302</u>	<u>-</u>
	<u>4,902</u>	<u>3,600</u>

**17. ANALYSIS OF NET ASSETS BETWEEN FUNDS**

	Unrestricted funds	Restricted funds	Total	29.2.16 funds	Total	28.2.15 funds
	£	£		£		£
Fixed assets	4,885	-		4,885		5,152
Current assets	110,724	925		111,649		179,196
Current liabilities	<u>(7,553)</u>	<u>-</u>		<u>(7,553)</u>		<u>(11,529)</u>
	<u>108,056</u>	<u>925</u>		<u>108,981</u>		<u>172,819</u>

THE FRAGILE X SOCIETY

Notes to the Financial Statements - continued  
for the year ended 29th February 2016

18. MOVEMENT IN FUNDS

	At 1.3.15 £	Net movement in funds £	At 29.2.16 £
<b>Unrestricted funds</b>			
General	168,117	(60,061)	108,056
<b>Restricted funds</b>			
Production of booklet for "Carriers"	925	-	925
Family support worker (Scotland)	<u>3,777</u>	<u>(3,777)</u>	<u>-</u>
	4,702	(3,777)	925
	<u>          </u>	<u>          </u>	<u>          </u>
<b>TOTAL FUNDS</b>	<u>172,819</u>	<u>(63,838)</u>	<u>108,981</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General	99,665	(159,726)	(60,061)
<b>Restricted funds</b>			
Family support worker (1)	8,000	(8,000)	-
Family support worker (2)	5,000	(5,000)	-
Family support worker (Scotland)	<u>15,000</u>	<u>(18,777)</u>	<u>(3,777)</u>
	28,000	(31,777)	(3,777)
	<u>          </u>	<u>          </u>	<u>          </u>
<b>TOTAL FUNDS</b>	<u>127,665</u>	<u>(191,503)</u>	<u>(63,838)</u>

(i) Family Support Worker (1)

Funding by Leathersellers Company and the FB Bailey Thomas Charitable Fund towards the salary of a family support worker.

(ii) Family Support Worker (2)

Funding by Next PLC towards the salary of a family support worker.

(iii) Production of Booklet "Carriers"

Previous donation by University of Nottingham.

(iv) Family Support Worker (Scotland)

Funding from The Robertson Trust for the post of a family support worker for Scotland.

19. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 29th February 2016.

**THE FRAGILE X SOCIETY**

**Notes to the Financial Statements - continued  
for the year ended 29th February 2016**

**20. APB ETHICAL STANDARD - PROVISIONS AVAILABLE FOR SMALL ENTITIES**

In common with many other businesses of our size and nature we use our auditors to assist with the preparation of the financial statements.

**THE FRAGILE X SOCIETY**

**Detailed Statement of Financial Activities  
for the year ended 29th February 2016**

	29.2.16 £	28.2.15 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations	52,248	144,500
Grants	<u>40,000</u>	<u>107,800</u>
	92,248	252,300
<b>Other trading activities</b>		
Voluntary fundraising events	23,143	46,767
100+ Club	3,500	2,398
Other sales	<u>5,869</u>	<u>9,088</u>
	32,512	58,253
<b>Investment income</b>		
Interest received	379	225
<b>Charitable activities</b>		
Sale of DVDs	81	135
Scottish conference	290	295
Subscriptions	45	45
AGM and National Family Conference	<u>2,110</u>	<u>692</u>
	<u>2,526</u>	<u>1,167</u>
<b>Total incoming resources</b>	127,665	311,945
<b>EXPENDITURE</b>		
<b>Other trading activities</b>		
Fundraising costs	11,153	8,050
<b>Charitable activities</b>		
Salaries	96,161	87,129
Telephone	2,794	3,468
Postage and stationery	4,895	2,571
Sundries	1,642	2,327
Scottish conference	2,864	4,572
Autumn conference	12,705	11,336
Newsletters	11,989	11,399
Link training and expenses	293	375
Internet and website costs	482	738
Printing	204	1,247
Photocopying	329	329
Subscriptions and affiliations	705	801
Staff training and expenses	426	2,055
Carried forward	135,489	128,347

This page does not form part of the statutory financial statements

THE FRAGILE X SOCIETY

Detailed Statement of Financial Activities  
for the year ended 29th February 2016

	29.2.16 £	28.2.15 £
<b>Charitable activities</b>		
Brought forward	135,489	128,347
Promotion	1,457	2,730
Family support worker expenses	<u>3,903</u>	<u>7,113</u>
	140,849	138,190
<b>Support costs</b>		
<b>Management</b>		
Rent	3,801	3,798
Insurance	1,288	1,247
Light and heat	1,913	2,438
Health and safety	480	456
Office maintenance	1,724	826
Fixtures and fittings	<u>822</u>	<u>2,433</u>
	10,028	11,198
<b>Other</b>		
Salaries	21,664	56,555
<b>Governance costs</b>		
Trustees' expenses	3,249	3,387
Auditors' remuneration	<u>4,560</u>	<u>4,200</u>
	<u>7,809</u>	<u>7,587</u>
<b>Total resources expended</b>	191,503	221,580
<b>Net (expenditure)/income</b>	<u>(63,838)</u>	<u>90,365</u>

This page does not form part of the statutory financial statements