

# About Us

# Looking to the Future

# The FragileX Society

## Annual Review 2018 - 2019



Providing information and practical guidance to support and empower individuals and families living with Fragile X Syndrome

[www.fragilex.org.uk](http://www.fragilex.org.uk)

Charity Registration Number: 1127861 Company Registration Number: 6724061 Scottish Charity: SC047732

Our vision is a world where people living with Fragile X are:

- **Valued, included and have their individual needs met** - and that Fragile X is recognised and understood by professionals and the public.
- **Not alone** - that they have access to an active community of people who understand.
- **Empowered** - through evidence-based knowledge about Fragile X.

In order to work towards this aspiration via our charity's aims, we have some exciting plans for the up-coming year:



- Continuing to develop additional resources for individuals with Fragile X associated conditions and their families, as well as professionals.
- Developing and implementing a renewed fundraising strategy to ensure sustainable income to both maintain and develop our vital services.
- Consulting our membership to inform a strategy which works to meet the needs of our community, and support the effective communication of the benefits of our work.
- Running a variety of events to educate and inform about Fragile X, as well as enabling our community to meet and share experiences.

“ I have no doubt the Fragile X Society changes people's lives with the wonderful work you all do. Thank you so much. ”

## How You Can Help

Although national, the Fragile X Society is a relatively small charity which receives no Government funding and relies entirely on voluntary income. With the high demand for our services and support, as well as our desire to raise awareness and reach more families, we know we need to raise both our profile and income potential.

Grant making trusts and foundations play a big part in our future growth, along with community fundraising, and this may be where you could help us. We need to reach deeper into local communities and encourage and inspire local organisations, community groups and schools, to consider supporting the Fragile X Society as their Charity of the year. We also need folk to come on board and take on challenges and arranging fundraisers to support us, or taking the amazing step of becoming a donor.

So please remember our need and let us know of any fundraising opportunities in your local community; annual events, local grant making trusts or local school or corporate connections that might enable us the chance to inspire and encourage fundraising support and you could be helping us make the world of difference.

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We exist to support and empower individuals and families with Fragile X:

- Due to society's attitudes, challenges with accessing services and features caused by the condition, people living with Fragile X and their families face **wide-ranging challenges**.
- Families regularly tell us that generic supports and **services did not understand** their needs adequately, or that **they felt lost** in broader organisations relating to autism or learning disability.
- A lack of awareness also means that Fragile X is being overlooked or misunderstood as a diagnosis.
- A lack of understanding of the condition can contribute to feelings of loneliness and isolation.

For the past 28 years, the Fragile X Society has been the only specialised charity in the UK dedicated to individuals and families living with Fragile X. We are there for people from the point of diagnosis and through their lives.

Our charity is led predominately by people with a personal link to Fragile X on our board and is supported by a small, dedicated team in our office. Together, we work together towards our charity's aims, for the benefit of the Fragile X community.



## Aims of the Fragile X Society

- To provide information and practical guidance to support and empower individuals and families living with 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 sufficient funds to enable The Fragile X Society to achieve its aims, and to meet the growing needs of the Fragile X Community.

# What is Fragile X?

## Fragile X Syndrome is the most common cause of inherited learning disability

- Approximately **15,000 people in the UK** are living with Fragile X Syndrome.
- Fragile X Syndrome is associated with autistic-like behaviour and is the underlying cause for up to **1 in 20 people with autism**.
- Common features of the condition include: difficulties with learning; social anxiety; difficulty with attention; challenges with communication; and health-related issues.
- Diagnosis requires a blood test and is available via the NHS. Correct diagnosis can mean improved support and understanding for whole families.
- A lack of awareness and understanding is a key barrier to accessing diagnosis and appropriate support.



## Fragile X is a Family of Conditions

The effects of Fragile X are wider than Fragile X Syndrome, and may affect multiple members of families in different ways.

- 1 in 250 women and 1 in 800 men are carriers, who carry a smaller change to their Fragile X gene, meaning that they may pass Fragile X to future generations.
- There are several Fragile X-Associated conditions:
  - In later life, carriers may experience **Fragile X Tremor Associated Axtaxia (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.
  - Being a Fragile X Carrier is also associated with other physical and mental health challenges.

“ 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. ”

# Summary of Our Year

## 2018 - 2019

## Information and Guidance

Supporting individuals and families through their lives.

- Our **total membership currently stands at 2,307**, comprised of individuals families with Fragile X based in the UK and abroad, and our associate members (professionals with an interest in Fragile X).
- Our Families and Professionals Advisors responded to **967 enquiries via our national helpline service**, providing in-depth, emotional, and practical support to individuals and families affected by Fragile X, undiagnosed families, and professionals.
- We also held our second Family Weekend Conference: an accessible event for individuals with Fragile X Syndrome and their families to meet, share experiences and learn about Fragile X and practical strategies for daily life. This year we were able to run dedicated sessions for adults and young people with Fragile X Syndrome, such as teaching practical skills to manage anxiety.

“ It was vital for my daughter to finally meet others with Fragile X as this was the first time meeting since her diagnosis. My daughter finally discovered she was normal and can achieve anything she sets her mind on. ”



## Educate and Inform

Teaching professionals and the wider public about Fragile X.

We want to raise awareness, in order to enable the most effective support and understanding for people living with Fragile X.

- 158 enquiries from professionals
- 57 professionals trained through our eLearning course

Of note, this year our Scottish Project, which in recent years has focussed upon developing professional awareness and understanding of Fragile X, came to an end due to funding for the project finishing. However, the impact that this work has had will continue to make a positive difference to the community in Scotland and beyond, far past its end. We are grateful to all those who made the work possible.

We extend special thanks to the Trusts and Foundations who have supported us this year: Chapman Charitable Trust, The Hugh Fraser Foundation, Sylvia Aitken Charitable Trust, AMW Charitable Trust, Douglas Heath Eves Charitable Trust, Evelyn May Charitable Trust and the March Christian Trust.

## Improving Support & Understanding

Supporting and inputting into research.

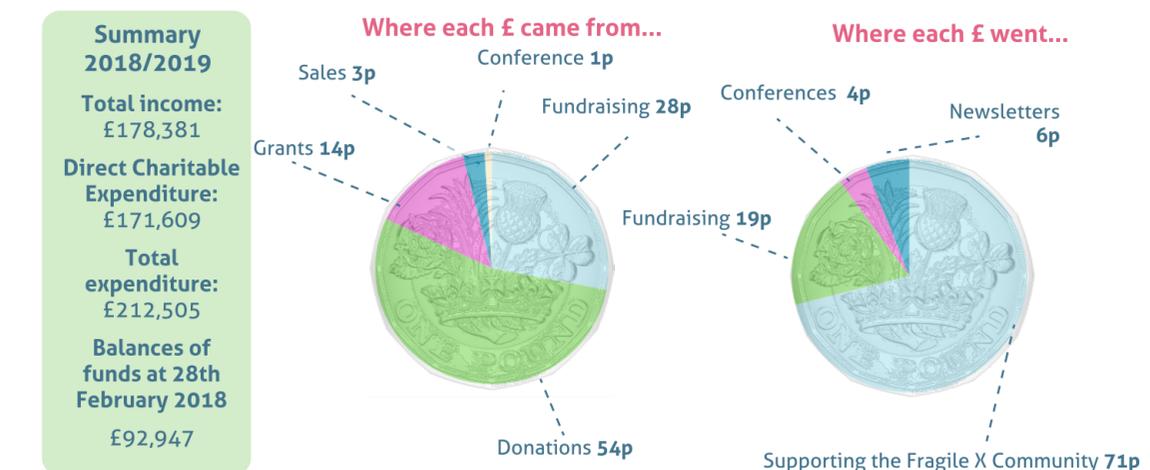


This image shows a young person participating in a research project about attention, which was supported by the charity.

- 95% of our UK community agree that research into Fragile X is important
- 80% of our members have agreed to be contacted about taking part in research, which is a vital resource for the research community
- This year, we supported 14 research projects, taking the total to over 100. This involved review and input, taking into account personal experiences of life with Fragile X, into the project and advertising for recruitment of participants.

## Finances

Overview of income and expenditure for the year 1st Mar '18- 28th Feb '19



As a relatively small charity with a national reach, we receive no Government funding and rely totally on voluntary donations to continue our vital work. So we would like to take this opportunity to thank all of those who have raised funds for us this year. This heart-warming support shows belief in the Fragile X Society, the appreciation and value of the work that we do and passion for our future. Thank you to all of our members and supporters. Just talking about the difference we have made to your lives has immense value and can inspire others to support us so please continue, to be our voice.

The figures above are a summary of the figures from The Fragile X Society's Independently Examined Accounts for the financial year 2018/2019. Please contact The Fragile X Society or Critchleys Audit LLP, who conducted the independent examination, for a copy of full accounts and trustees report.