

About Us

Looking to the Future

The Fragile X Society

Annual Review 2019 - 2020



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

www.fragilex.org.uk

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

- Due to society's attitudes, difficulties in 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 support **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 30 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 throughout their lives.

Our charity is led predominantly 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.

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:



Pete Richardson, Managing Director

- Enhancing our digital offer, to support and empower the community.
- With the support of a new Managing Director, building upon our fundraising strategy, in order to provide a more secure footing moving forward.
- Promoting the understanding of all aspects of Fragile X, including Fragile X Premutation Associated Conditions (FXPAC).
- Supporting research efforts in Fragile X, including how the condition affects girls and women.
- Developing our work in Wales, Northern Ireland and Scotland, as resources allow.

“

It is fair to say that the Society, including its national helpline, has been of overwhelming benefit to enormous numbers of individuals and families, too many to count, both nationally and further afield, and has actually on occasion saved lives when service users, family members and carers have at times quite understandably reached the end of their tether. *(Fragile X Parent)*

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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.

Friends of Fragile X is a way you can support the Society on a regular basis through monthly donations, which provides an essential, steady stream of income to allow us to build our services (you can find out more and join at: fragilex.org.uk/friends-of-fragile-x). We also need folk to take on challenges and arrange fundraisers to support us, please contact us if you want to get involved!

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 give us the chance to inspire and encourage fundraising support. You could be helping us make the world of difference.

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 the genetic condition Fragile X Syndrome (affects approx. 1/4000 boys and men, 1/6000 girls and women).
- 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 (premutation), meaning that they may pass Fragile X to future generations.
- There are several **Fragile X Premutation Associated Conditions (FXPAC)**, which may affect carriers.
 - In later life, carriers may experience **Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS)**: a late onset neurodegenerative condition which causes problems with memory, balance and tremors.
 - In addition, women may experience **Fragile X Associated Primary Ovarian Insufficiency (FXPOI)**, which is associated with early menopausal-like symptoms and may cause infertility.
 - Being a Fragile X Carrier is also associated with other physical and mental health symptoms.



“ You went above and beyond to help and guide us. You responded swiftly to all our calls, emails and we seriously cannot thank you enough. There is nothing you could improve upon. You are a god-send. ”

Summary of Our Year

2019 - 2020

Information and Guidance

Supporting individuals and families through their lives.

- Our **total membership currently stands at 2,339**, comprised of individuals and families with Fragile X and our associate members (professionals with an interest in Fragile X). Our Families and Professionals Advisors responded to **790 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. As a result (based on feedback forms) people felt better informed (100%), reassured (100%) and better able to deal with their challenge (94%).
- We held a Family Day (May '19): 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 (such as communication tools).
- In Sept '19 we hosted a Research Conference, providing accessible updates about: gene editing research, adulthood, anxiety assessment, behaviour management and FXTAS.

“ Thank you so much for the incredible help - I really appreciate it all - I now feel confident explaining [Fragile X] 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. ”



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.

- 72 professionals trained through our eLearning course
- The Society's team and volunteers gave lectures and talks to people from various backgrounds, including: clinical psychology, medical students, nurses and the public.
- 58 enquiries from professionals on our helpline
- Our website was visited by over 50,000 users, and our social media following has grown.

With our friends at the European Fragile X Network, we are also working to review the language being used by researchers and professionals in relation to the Fragile X Premutation, including proposing the revised terminology Fragile X Premutation Associated Conditions (FXPAC).

We extend special thanks to the Trusts and Foundations who have supported us this year: Chapman Charitable Trust, Douglas Heath Eves Charitable Trust, Thomas Sivewright Catto Charitable Trust, The Sir James Roll Charitable Trust.

Improving Support & Understanding

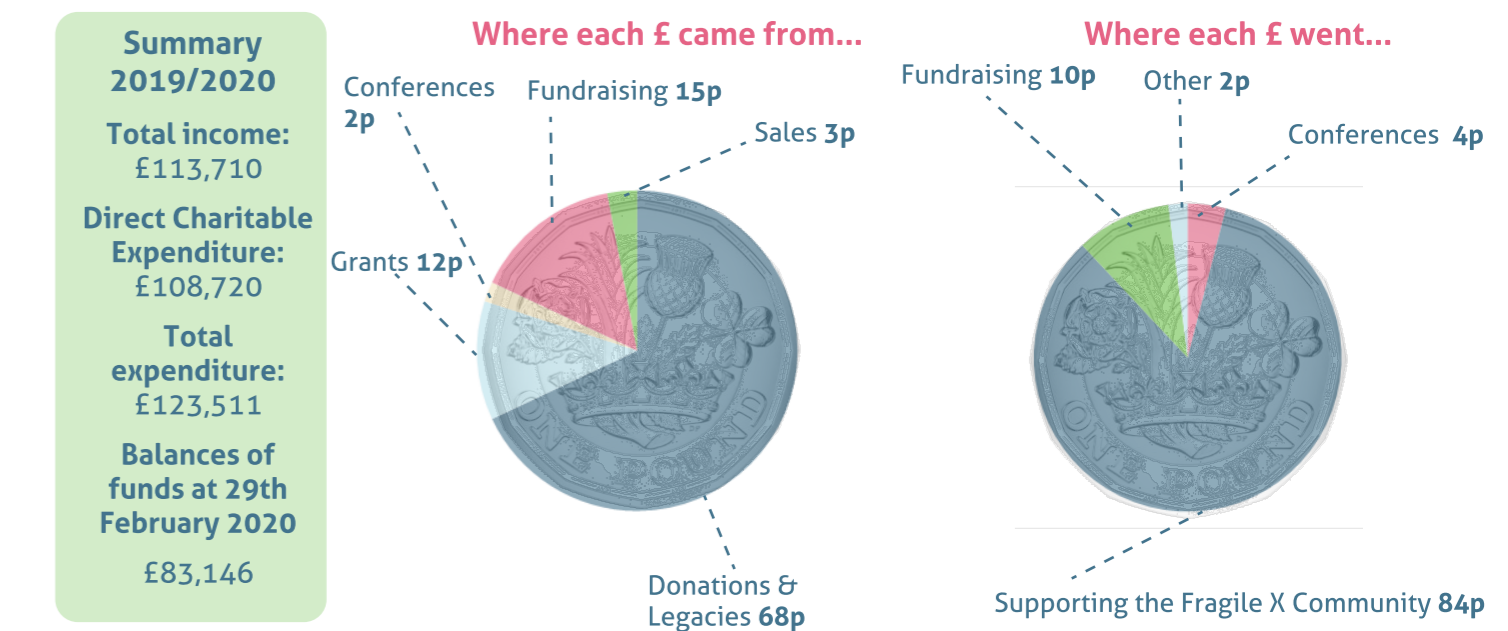
Supporting and inputting into research.



- 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 '19- 29th Feb '20



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 2019/2020. Please contact The Fragile X Society or Critchleys, who conducted the independent examination, for a copy of full accounts and trustees report.