About Us

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 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.

2021 and beyond

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.

2020 and 2021 has been a time of exceptional circumstances and challenges, with global Coronavirus Pandemic having a devastating effect upon the UK. We have adapted and changed and this year we will focus upon:

Pete Richardson, Managing Director

- Adopting a new digital and social media-based strategy to communicate more effectively with members, supported by Costello Medical who are leading a substantial *pro-bono* project on our behalf.
- Increasing our fundraising efforts to move from a break-even position to a small surplus, building upon the grant successes of 2020/21.
- Consolidating our existing membership and ensuring that they both feel part of, and contribute to, our community.
- Asking our members for feedback on our approach to research to hep us proactively influence research studies.
- Developing our work in Wales, Northern Ireland and Scotland, as resources allow.

> "Once again, we thank you for your advice and time. Speaking to someone who understands has made us feel more able to deal with the situation."
>
> "We feel we are not the only voices speaking on behalf of our family member and this gives us hope that his needs will be met and understood."

How You Can Help

A huge thank you to everyone for continuing to support us with your donations during this last year. Your support, combined with the additional grants that we successfully applied for, have made an enormous difference, enabling us to continue to provide a full service to you without the need to furlough any staff; a significant achievement during the pandemic. We are also very grateful to the new Volunteers and Special Advisors that have started providing us with their expertise during 2021.

Please do continue to send us any fundraising ideas that you may have as well as your own stories and photos which we love to receive here and share with everyone. If you aren't able to meet, to run, to swim, to dance, to sing or take part in fundraising activities, please do consider donating to us on a monthly basis or through your employer's salary scheme. It's that simple. So, if you can commit an additional amount to the Society on a monthly basis, that would be fabulous and make a world of difference to us all.

Thank you!

The Fragile X Society

Annual Review 2020 - 2021

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

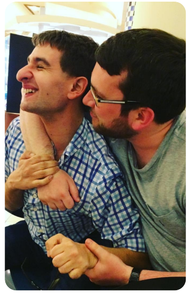
www.fragilex.org.uk

info@fragilex.org.uk | 01371875100 | Rood End House, 6 Stortford Road, Great Dunmow, Essex, CM6 1DA

Charity Registration Number: 1127861 Company Registration Number: 6724061 **Scottish Charity:** SC047332

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.

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

Summary of Our Year — 2020 - 2021

Information and Guidance

Supporting individuals and families throughout their lives.

We achieved our primary objectives for the year, continuing to provide support and information to families affected by Fragile X and professionals working in the field of Fragile X. Feedback on our support has continued to be extremely positive during 2020/21.

Online support and resources became increasingly important to our community during the Covid pandemic. This year we have continued to develop our online presence and we are proud to now have a large community in our Facebook Group (2667 members) and a growing following on social media including 2898 followers (5.5% increase) on Twitter and 1437 followers (10% increase) on Instagram.

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

> "Thank you so much for your helpful and extremely kind reply - you brought tears to a very sleep-deprived mum's eye!....
>
> Thank you again - I can only imagine how reassuring being in touch with you guys is for parents whose children are under investigation/have been diagnosed."

Educate and Inform

Teaching professionals and the wider public about Fragile X.

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

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

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.

Fragile X Society members (with a direct link to Fragile X) have the option to agree to be contacted about research projects which may be relevant to them. In total, 1521 families (79% of our 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 are proud to have supported recruitment to 5 research projects addressing key aspects of Fragile X Syndrome and Fragile X Premutation-Associated Conditions this year. These projects could not take place without the support and participation of our members.

Finances

Overview of income and expenditure for the year 1 Mar '20- 28 Feb '21

Summary 2020/2021

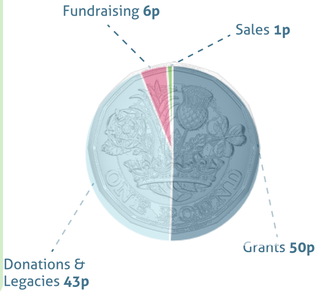
Total income: £148,121

Direct charitable expenditure: £111,313

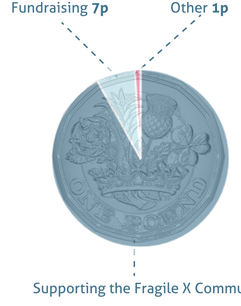
Total expenditure: £120,841

Balances of funds at 28 February 2021 £110,426

Where each £ came from...



Where each £ went...



We are very grateful for the generous support of all our members, our donors and grant givers as well as the Trusts and Foundations that have helped us record a small financial surplus during 2020 - 21. This is an enormous achievement given the challenges we all faced within the charity sector.

We are grateful for all who have supported the Society's 'Friends of Fragile X' and 100+ Club initiatives, which have provided vital funding for the Society's work.

The figures above are a summary of the figures from The Fragile X Society's Independently Examined Accounts for the financial year 2020/2021. Please contact The Fragile X Society or Critchleys, who conducted the independent examination, for a copy of full accounts and trustees report.