Fragile X Society

Annual Review 2024 to 2025

35th Anniversary

In this issue:

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Welcome!

Steve Harris, Chair, Board of Directors

I want to take this opportunity to reflect on the highlights of 2024 and extend a heartfelt thank you to all of our members, supporters, families and wonderful staff who make the work of the Fragile X Society possible.

This year has been a time of real progress and renewed connection. We were delighted to hold a conference in Edinburgh, which provided fabulous opportunities for families and professionals to come together, learn from both experts and one another, and share experiences. The sense of community at these events was truly inspiring, and reminded us all of the strength and resilience that exists within the Fragile X network.

We've also continued to develop and improve our resources, including launching new guides on sleep and puberty, all designed to offer practical, compassionate support to families navigating the challenges and joys of life with Fragile X Syndrome. Our family support and counselling services have remained a lifeline to many, and we are deeply grateful to our dedicated office and volunteer team for their ongoing commitment.

During this our 35th birthday year, I am reminded of the inspiring determination, courage and generosity that has shaped this organisation since its earliest days. From family members reaching out to support others, to professionals who champion our cause, and to the incredible fundraisers who keep our work going, you are all part of something truly special.

On behalf of the Board of Trustees, thank you for being part of the Fragile X Society. We look ahead to 2025 with gratitude, pride, and a shared sense of purpose.

Warmest wishes, Steve Harris
Chair, Fragile X Society

Issue Contents

Please note that all information is correct at time of going to press, but may be subject to change

Welcome from Pete!

Pete Richardson, Managing Director

Dear Families, professionals and supporters,

As we reach the end of another busy and inspiring year, I wanted to take a moment to thank you, our wonderful Fragile X community, for your continued support, trust and connection.

This year has seen so many positive developments across the Fragile X Society. One of the biggest highlights was our Edinburgh Conference, which brought together families, researchers and professionals to share knowledge, listen, and learn from one another. It was a powerful reminder of the strength that comes from being part of a community that truly understands.

We've also been proud to grow awareness of Fragile X more widely, with opportunities to speak at Leeds, Bath, Cardiff, Queen's University Belfast, and Edinburgh, helping to ensure the next generation of professionals better understand the condition and the families we support. A very successful 10th October Awareness day 2024 saw us reaching further than we have ever done before, with articles in 7 UK wide and 5 Regional newspapers thanks to our fabulous media volunteers.

Our counselling service has gone from strength to strength. We're so pleased that more families than ever have been able to access emotional support through our specialist counsellor, Vicky. Thank you to everyone who has helped to spread the word or referred others to the service.

Thanks to successful grant applications and your own sterling fundraising efforts, new partnerships in Northern Ireland and Scotland, we've been able to extend our reach and develop more targeted support especially for families who may feel more isolated.

We also want to extend our heartfelt thanks to our fundraisers, volunteers, and corporate donors, whose generosity makes this work possible. In particular, we are deeply grateful to the Chapman family for their incredible and continuing support.

Whether you've shared a post, raised funds, spoken at your child's school, or simply reached out to ask a question you've been part of this journey. We are here because of you, and we are here for you.

Finally, I'd like to give an enormous thank you to the wonderful office team, Steve our Chair who has done a brilliant job this year, along with all the Trustees who freely give us their time and expertise.

With warm wishes and gratitude,
Pete Richardson

Finances 2024 to 2025

Summary 2024 - 2025, Tim Eccleshall, Treasurer

As Treasurer of the Fragile X Society, I am pleased to share a brief overview of our financial performance for the past year. Despite ongoing economic uncertainty and pressure on charitable giving across the UK, we have remained financially stable, thanks to the enormous generosity of our supporters, the careful stewardship of our resources, and the dedication of our small team.

Over the last financial year, we have continued to prioritise services that directly support individuals with Fragile X Syndrome and their families. We maintained core activities such as our family support helpline, counselling services, and the development of new resources all while carefully managing our expenditure and delivering Conferences with the kind support of corporate sponsors. We are proud to report that our spending was directed towards charitable activities, ensuring that funds were used where they are needed most.

Income from fundraising events, trusts, and individual donations has seen a modest but encouraging recovery following the challenges of the pandemic years. We were especially grateful for the incredible membership support which brought in much-needed funds and strengthened our community connections.

Looking ahead to 2025/26, we remain focused on ensuring the long-term sustainability of the Society. We are actively seeking new funding opportunities, expanding corporate partnerships, and exploring ways to diversify our income, while continuing to be transparent and accountable in all financial matters. Your support makes our work possible, and we are committed to using every pound wisely to build a better future for everyone affected by Fragile X.

Thank you for standing with us.

Tim Eccleshall

Treasurer, Fragile X Society

Annual General Meeting

Notice of AGM 18th September 2025

The Annual General Meeting (AGM) is an important part of the Fragile X Society's year. At the AGM, we present the financial accounts from the previous year and discuss the recent achievements of the Fragile X Society.

The AGM is also an important opportunity to vote on key issues facing the Fragile X Society, and to find out more about the Society's future plans. An important part of the AGM is the election of Directors. As you may know, we can have up to 15 Directors to lead the Fragile X Society. The majority of our Directors have a personal or family connection to Fragile X. Each year a third resign by rotation and are eligible for re-election. The elections are for three-year terms.

We are very grateful to our Directors for giving us their time and expertise to help lead the Society.

Our AGM will take place on 18th September 2025 at 19.00. If you are unable to attend the meeting but would like someone to vote for you, then please complete the proxy form (below) so that someone can vote on your behalf. Please return this form by 18th August 2025 at the latest.

Agenda

1. Apologies for absence
2. Minutes of the Annual General Meeting held on 16th September 2024
3. Matters Arising
4. To receive the audited accounts and the Auditors report
5. To receive the Report of the Directors
6 Directors Status Overview
7. To re-appoint Critchleys as the Fragile X Society Auditors for 2025/26
8. Any other business (please contact us in advance of the meeting)

Proxy Form

Please complete/delete as appropriate and return by 18th August 2025 to Fragile X Society, Suite 5, The Chestnuts, 4 Stortford Road, Great Dunmow, Essex, CM6 1DA.

I/We (name/s).. of
(address)..

....

being a member/members of the above named company, hereby appoint:

(name)... of (address)..

....

or failing him/her the Chair of the Meeting, as my/our proxy to vote in my/our names and on my/our behalf at the Annual General Meeting of the company to be held on the above date and at any adjournment thereof.

Signed:... Date:..

Fragile X Conference

Edinburgh Conference

On Saturday, March 22nd 2025, the Fragile X Society and the Patrick Wild Centre hosted our second Edinburgh Conference at Novotel Edinburgh Park, marking an extremely successful consecutive year for this event.

The conference was a triumph, brimming with support, valuable insights and opportunities for families affected by Fragile X to connect and engage with each other.

The day featured an array of remarkable speakers, beginning with Olia Hercules, who discussed the experience of a parent receiving a diagnosis.

Olia Hercules - Getting a Diagnosis

At the Conference, Olia Hercules delivered a deeply moving and personal talk, sharing her experiences as a mother to a child with Fragile X Syndrome. Speaking with honesty and warmth, Olia reflected on her journey from first noticing developmental differences to receiving a diagnosis and the emotional and practical challenges that followed.

As both a renowned chef and a passionate advocate, she highlighted the importance of community, understanding, and early support for families navigating Fragile X. Her speech resonated strongly with attendees, offering comfort, solidarity, and a sense of shared strength to all those present.

Sibs For brothers and sisters of disabled children and adults

SIBS Support Siblings

The talk from SIBS at this year's conference was a powerful and moving session that focused on the experiences of siblings growing up alongside a brother or sister with Fragile X Syndrome.

SIBS shared insights into the unique challenges siblings may face including feelings of responsibility, being overlooked, or finding it hard to talk about their experiences.

The session also celebrated the deep bonds siblings often have and offered practical ideas for supporting them emotionally and socially. It was a valuable reminder that siblings are an important part of the Fragile X journey, and that their voices deserve to be heard.

Edinburgh Conference

Continued........

Edel Harris - Growing & Navigating Relationships

Just one of the many memorable moments from the 2025 Fragile X Conference came when we welcomed Edel Harris OBE, former CEO of Mencap.

Edel's speech was delivered with warmth, honesty, and clarity from a deeply personal place. She spoke powerfully about the challenges families face, and the strength, determination and compassion that so often lie at the heart of change. Her message resonated strongly with parents, carers, professionals and advocates in the room, many of whom commented afterwards on how deeply her words had moved them.

Throughout her talk, Edel championed the importance of family voices in influencing services and creating a future where inclusion is not an afterthought, but a starting point. She reminded us that while structural change is important, real transformation begins with human connection.

Her reflections encouraged us to continue our work with renewed energy, building on what families have already achieved, and striving for a society where people with Fragile X Syndrome, and those who love and support them, are seen, heard and valued.

Edel's presence at the conference was a real privilege and we are incredibly grateful for her contribution. Her words helped set the tone for a day full of connection, learning and shared hope, and reminded us why the voice of the Fragile X community is such a powerful force for change.

Dr Andrew Stanfield Director of The Patrick Wild Centre Research updates

We were delighted, once again, to hear from Dr Andrew Stanfield at the conference this year. As one of the UK's leading researchers into Fragile X Syndrome and associated conditions.

Andrew is Professor of Psychiatry at the University of Edinburgh and Clinical Director of the Patrick Wild Centre, where he leads ground-breaking research into the biology, behaviour and support needs of individuals with Fragile X Syndrome, autism and intellectual disabilities. His session gave families a valuable and accessible update on the latest research developments, including studies into learning and memory, clinical trials, and efforts to better understand anxiety and sensory sensitivities in Fragile X.

He spoke candidly about the challenges of developing effective treatments and interventions, but also shared reasons to feel hopeful particularly around international collaboration, increasing awareness among clinicians, and the potential of targeted supports. Importantly, he acknowledged the critical role that families play in research, both in shaping priorities and in contributing to studies. His work continues to put Fragile X on the map in academic and clinical settings and we are incredibly grateful for his long-standing support of our community.

Dr Sundus Alusi Consultant Neurologist FXTAS

At this year's Fragile X Conference, Dr Sundus Alusi, Consultant Neurologist delivered an important and compassionate presentation on Fragile X-associated Tremor/Ataxia Syndrome (FXTAS).

In her talk, Dr Alusi explained that FXTAS is a neurodegenerative condition linked to changes in the FMR1 gene, most often affecting male carriers, though some females may also be impacted. Symptoms may include intention tremor, balance problems, memory difficulties, and changes in mood or behaviour. She emphasised that FXTAS is not the same as Fragile X Syndrome and usually develops much later in life, often in individuals who had no earlier signs of any condition.

Dr Alusi took time to explain what to look out for, how diagnosis is made, and what kinds of support might help, including referrals to neurology, physiotherapy, and emotional wellbeing services.

Her talk also highlighted the importance of supporting older carriers who may be experiencing unexplained symptoms. Many in the audience expressed gratitude for raising awareness of a lesser-known aspect of Fragile X, and for reminding us that support must be lifelong and whole-family focused.

Quick Guides - Adult Life with FX

from Jane Oliver, Senior Families and Professionals Advisor (Adult Enquiries)

🆕 New Quick Guides to Adult Life with Fragile X Syndrome

We're excited to share three new Quick Guides designed to support adults with Fragile X Syndrome as an introduction for services. These guides are ideal for support workers and other professionals and provide simple, accessible advice. Let's help create a world where adults with fragile X syndrome are included and supported to thrive. These guides are a place to start....

🔹 👩 Women and Fragile X Syndrome – A Quick Guide

Women and girls with Fragile X often face subtle but significant challenges—especially in areas like social anxiety, executive functioning, numeracy, and masking.

This guide includes:
- Communication tips for reducing anxiety
- How to support in daily life
- Supporting emotional wellbeing with compassion

🔹 🤝 Supporting an Adult with Fragile X – A Quick Guide

Every adult with Fragile X is different, but many face common issues in communication, change, and sensory processing.

This guide includes:
- Core adult Fragile X profile (behaviours, strengths, and needs)
- Best practice support tips.
- Communicating clearly and calmly—what works

There is a separate quick guide for agency workers.

🔹 💬 Communication and Fragile X – A Quick Guide

Social anxiety, sensory overload and processing delays can all make communication difficult—but there are ways to help.

This guide includes:
- Using visuals, objects of reference and Talking Mats
- Creating low-pressure environments for expression
- Supporting understanding through predictability

For copies contact the Fragile X Society
🌐 Visit: www.fragilex.org.uk
📧 Email: info@fragilex.org.uk
📞 Call: 01371 875100

Back to School: Helping You and Your Child Feel Prepared ✏️

by Alison Field, Families and Professionals Advisor (Child Enquiries)

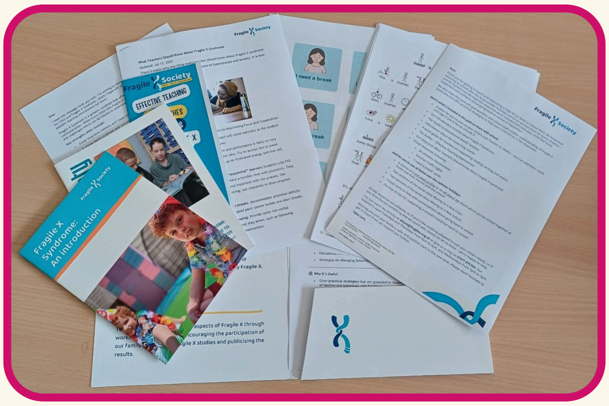
As we begin the summer holidays, many families will already be thinking ahead to the new school year. Whether your child is returning to a familiar classroom or transitioning to a new setting or teacher, we know that change can bring a mix of excitement and anxiety — especially for children with Fragile X Syndrome.

To support you during this time, we’ve created a Back to School Pack full of helpful tips, visuals, and practical strategies based on the learning profile of children with Fragile X. These resources are designed to help reduce anxiety, support transitions, and ensure a smoother return to school for everyone involved.
Here’s what’s included in the pack:-

- A guide packed with practical strategies for teachers and support staff
- Easy-to-use visual supports
- Further details about the Fragile X learning profile
- Social stories and visuals to use at home over the summer
- Information about our eLearning course
- Guide specifically about females and tips on how to support in education

We encourage families to share these materials with school staff, especially if your child is moving to a new classroom or working with unfamiliar adults. The more they understand the Fragile X learning style, the better they can support your child from day one.

If you'd like a copy of our Back to School pack, tailored advice or personalised visuals, just get in touch with us — we’re happy to help.
(alison@fragilex.org.uk)



Here’s to a smooth and positive start to the new school year!

FX Fundraisers

We're incredibly thankful to everyone who has taken the time to fundraise and raise awareness for the society over the past year. Whether the challenge is large or small, your generosity and dedication warm our hearts. We truly appreciate every single penny raised. Thank you!

Sutton Fun Run

Amelia and Albie, along with their friends and family, joined the Sutton Fun Run on June 1, 2025, and completed the 8.5-mile course through the town. Amelia shines as a fantastic big sister to her two-year-old brother, while Albie participated for the second year in a row in honor of his brother, Bobby. What a fantastic achievement for both of them!

Winter Half Marathon

Eddie and Ciara proudly crossed the finish line of the Winter Milton Keynes half marathon. Despite the terrible weather conditions, Eddie achieved an impressive official time of 2 hours, 10 minutes, and 57 seconds, completing the race without stopping even once!

Cardiff Half Marathon

Erin Williams took part in the Cardiff Marathon this October, having devoted her summer to training during her time home from university in Leeds. She is excited to honor her uncle, Elliot, through her participation! This truly reflects the pride he feels for her accomplishments!

Great North Run

Michael, who participated in The Great North Run, has successfully completed the race with an impressive running time of 2:29. This is truly an outstanding accomplishment! Michael is passionate about running and has taken part in numerous races.

FX Fundraisers

Continued........

Edinburgh Half Marathon

Andrew and Catriona completed the Edinburgh Half Marathon, enjoying themselves thoroughly and creating a memorable and fulfilling experience.

Glasgow 10K

A huge thank you to Lorraine for her amazing dedication in raising awareness and funds for the Fragile X Society. Her participation in the Women's 10K in Glasgow on June 15, 2025, is truly awesome!

Raising Awareness

Stephen, who has Fragile X syndrome, is dedicated to raising awareness and supporting the Fragile X Society. His friend Keith has been helping Stephen with various campaigns. Recently, Stephen created a mug for sale, with proceeds going to the society. With Keith's son, they designed a mug featuring the Fragile X logo and Stephen's favourite football jersey.

A devoted Brentford Football Club fan, Stephen has always cheered for them. They aimed to sell 20 mugs but sold 50.

Glasgow Green 5k

On 18th May 2025 Kate ran in the Glasgow Green 5K. Katie and her sister Robyn both have full mutation. Their mum said " My daughter Katie is fundraising for Fragile X, I'm so proud of her as she has been challenging herself going to gym 5 days a week and out running, which is outside her comfort zone."

FX Fundraisers

Continued........

Glasgow Bakers

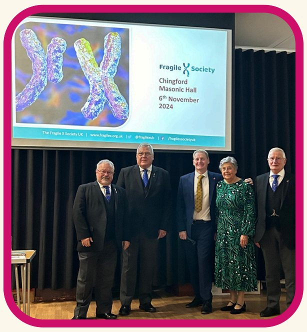
A huge thank you to the amazing Glasgow Bakers for organising a fantastic dinner, auction, and raffle! Your generosity helped raise a great sum for the FX Society.

Your hard work made a big difference, and we're so grateful for your support!

The Charity Stewards Meeting

We're grateful to the Chingford Masonic for welcoming Pete, to speak about Fragile X Syndrome at a recent gathering. This event marked another step in our growing relationship with the Masonic Lodges in Essex, who have been incredibly generous in their support.

Our connection began when we met Derek and his wife Susan from the Charity Stewards Lodge, both of whom attended the evening and thoroughly supported our work.



Pete shared his thanks in person, highlighting how their donations are making a real impact, supporting families and helping carriers plan for the future.

The Snake Davis Trio

On July 15th, one of our members organized a special performance showcasing the remarkable talents of The Snake Davis Trio. This event offered an enchanting evening filled with beautiful mellow jazz, soul, and pop music. All proceeds from the event were generously donated to the Fragile X Society, a cause that holds great significance for them.

If you're excited about starting your own fundraising challenge, we'd be absolutely delighted to connect with you! Please feel free to reach out to us at info@fragilex.org.uk—we can't wait to hear from you!

FX Fundraisers

Continued........

In Memory of

Vicki

Pictured here is Freddy with his grandmother, Vicki. She was a valued and supportive presence in the lives of her family. Following Vicki's recent passing, the family chose to support the Fragile X Society through donations made in her memory. We are very grateful for these contributions and thank everyone who donated during this time.

Lillian

We are deeply grateful for the generous donations made to the Fragile X Society in memory of a devoted mother and grandmother, Lillian.
She shared a close and joyful bond with her grandson Jack, who has Fragile X. She loved hearing about his music, dancing, and especially his spot-on impersonations of her which never failed to make her laugh.
A proud and supportive grandmother, she took great interest in all three of her grandsons and their lives and achievements.

The Society received some touching letters, reflecting the strong impact she had on her community, her church, and through her work as a funeral director. Although this is a sad time, her family reflects on a life well lived in Jersey, a place she loved dearly. As she once said after the loss of a close friend: "We don't get sad—we remember the laughs and have a good drink!"

We would like to extend our heartfelt thanks to everyone who has supported, raised awareness, and contributed to our community through their generous donations.
We truly appreciate your kindness!

New to the Fragile X Society

We would like to extend a warm welcome to the following trustees and new staff members joining the Fragile X Society.

Vicki Johnstone, Scotland Contract Manager

I am so excited to be able to say that I have taken up the role of Fragile X Contractor Manager for Scotland. My name is Vicki and I am a full time mum to a not so little, lovely boy, Rohan, who is almost thirteen with full mutation Fragile X, Autism and ADHD. As such, I am also Rohan's full time carer and understand the difficulties and challenges that can happen day-to-day or even out of the blue, but also the joy and happiness that can be found looking after someone with Fragile X Syndrome.

I have taken up this post because I have always valued the support and care provided by the society since our own family diagnosis. The Fragile X Society is a superb charity which exists to meet the needs of families wherever they may be on their FX journey and wherever they are in the UK. I believe that it is a great opportunity for Scotland, and the society, to have a FXS worker in Scotland. As someone who is personally affected, I feel a strong association to the work which is being undertaken to support and develop key information and initiatives to those affected, their families, communities and professionals who can help. I ultimately believe, now more than ever, there is a need for engagement, further research, support and raising awareness of Fragile X Syndrome.

Jan Wright, Northern Ireland Contract Manager

Hello everyone! I'm Jan and I'm delighted to be back working with the Fragile X Society. Some of you may remember me from my time as Northern Ireland Development Officer, based in Belfast. Although that role ended in early 2023. I've now returned in a part-time freelance capacity, working alongside Pete and the team.

My focus is on reconnecting with local families and strengthening partnerships with key organisations—across voluntary, statutory, and health sectors—to raise awareness and improve support for those affected by Fragile X in Northern Ireland.

With over 35 years' experience in the voluntary and community sector, including roles with NIACRO, Housing Rights, The National Lottery Community Fund. I've also supported family-focused charities such as Changing Faces and Family Fund.

My recent work has included collaboration with Queen's University Belfast and the Northern Ireland Rare Disease Partnership, as well as engagement with the All-Party Group on Rare Disease at Stormont which is an exciting opportunity to share lived experiences and raise the profile of Fragile X locally.

On a personal note, I'm a devoted dog mum to Sally, a rescue collie cross who proudly sports her Fragile X bandana (and is ready for her social media debut!).

New to the Fragile X Society

Continued........

Olia Hercules - Ambassador

We're thrilled to announce that Ukrainian-British chef, author, and broadcaster Olia Hercules has taken on the pivotal role of Ambassador for the Fragile X Society in the UK and delivered an amazing heartfelt speech at the Edinburgh Conference.

As a mum to Wilfred diagnosed with Fragile X syndrome, Olia brings both personal insight and immense passion to raising awareness and support for families across the UK.

Olia's advocacy is deeply meaningful and she speaks from lived experience, adding authenticity and heart to her voice. In Her Own Words Olia shared on social media:

"This year I became an ambassador for @fragilexuk. To me this is something that's connected to my very being. So I thought I'd share my story with you."

Her mission is clear and she shares her real-life experiences of a Fragile X family with compassion and candour, inspiring collective action and support. Olia's story helps amplify the voices of families living with Fragile X, especially parents and children navigating diagnosis, daily challenges, and access to support. As a well-known advocate, Olia helps raise wider recognition of Fragile X Syndrome reaching new audiences through media, events, and public conversations. Her passion and platform can inspire action driving fundraising, encouraging research participation, and ultimately improving outcomes for the Fragile X community.

Michelle Flynn - Trustee

Hello, I'm Michelle Flynn, and I'm delighted to be introducing myself as a new trustee of the Fragile X Society. Becoming part of this charity is something very close to my heart, the Society has supported members of my family, and I'm incredibly grateful for the difference it has made to their lives.

I bring over 15 years of experience in strategic and sales leadership across the public and private sectors in the UK and Europe.

In 2024, I completed an MSc in Sustainable Development, which has further shaped my interest in organisational strategy, positive change, and inclusive services. I hope to use this experience to support the Society's long-term stability, reach, and impact.

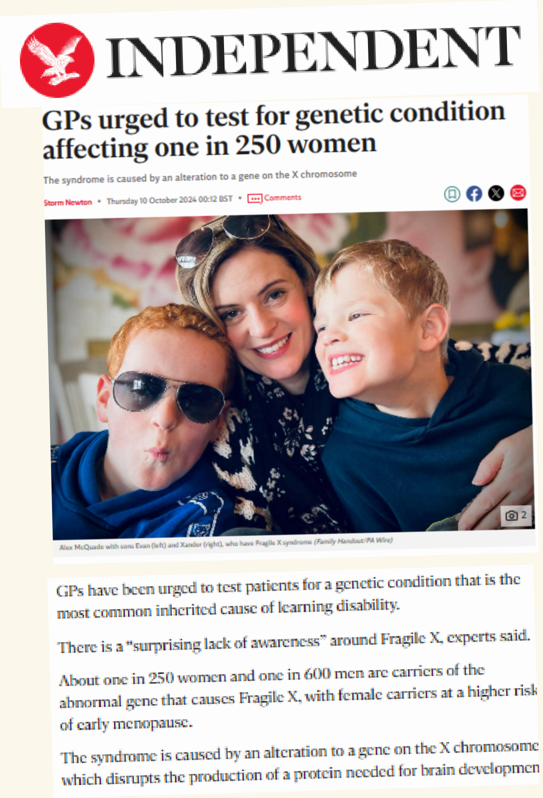
I know first-hand how important it is for families to feel supported, not just at the point of diagnosis, but at every stage of life. I'm passionate about strengthening the Society's work in these areas and ensuring that those affected by Fragile X continue to have a strong, supportive voice behind them. I'm really looking forward to meeting more of our members and contributing to the exciting journey ahead.

FX Awareness Day 2024

We extend our gratitude and thanks to everyone who took part in Fragile X Awareness Day on 10th October2024, especially those who shared their photos, stories, and experiences across social media.

A special thank you goes to our amazing media volunteers - Ashley, Lisa, Alex, Rachel, Andrew, and Jonny, who attended an intensive training session to prepare for interviews and represent the Fragile X community.

We were thrilled to see our efforts gain national attention, with Fragile X stories featured in The Independent, The Mirror, MSN, Yahoo, The Liverpool Echo, and several other regional newspapers. This visibility is a major milestone in our mission to raise awareness and reduce the time it takes for families to get the right support.



INDEPENDENT

GPs urged to test for genetic condition affecting one in 250 women

The syndrome is caused by an alteration to a gene on the X chromosome

Storm Newton • Thursday 10 October 2024 00:12 BST • Comments

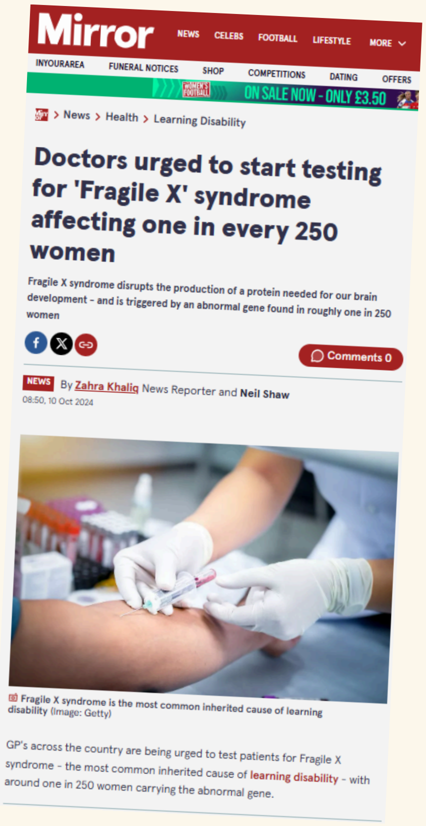
Alex McQuade with sons Evan (left) and Xander (right), who have Fragile X syndrome *(Family Handout/PA Wire)*

GPs have been urged to test patients for a genetic condition that is the most common inherited cause of learning disability.

There is a "surprising lack of awareness" around Fragile X, experts said.

About one in 250 women and one in 600 men are carriers of the abnormal gene that causes Fragile X, with female carriers at a higher risk of early menopause.

The syndrome is caused by an alteration to a gene on the X chromosome which disrupts the production of a protein needed for brain developmen



Mirror

NEWS CELEBS FOOTBALL LIFESTYLE MORE

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> News > Health > Learning Disability

Doctors urged to start testing for 'Fragile X' syndrome affecting one in every 250 women

Fragile X syndrome disrupts the production of a protein needed for our brain development - and is triggered by an abnormal gene found in roughly one in 250 women

Comments 0

NEWS By Zahra Khaliq News Reporter and **Neil Shaw**
08:50, 10 Oct 2024

Fragile X syndrome is the most common inherited cause of learning disability (Image: Getty)

GP's across the country are being urged to test patients for Fragile X syndrome - the most common inherited cause of learning disability - with around one in 250 women carrying the abnormal gene.

FX Awareness Day 2024

Continued........

One of the highlights of this year's campaign was an interview from our ambassador, Olia Hercules, who shared her perspective as a mother of a child with Fragile X. Her honest and heartfelt words truly captured the spirit of Awareness Day and you can watch the video now on our website.

Awareness also continued across the UK, with our Managing Director, Pete Richardson, speaking at events in Leeds, Bath, Cardiff, Queen's University Belfast, and Edinburgh. These events are a crucial part of building understanding among future professionals and strengthening support for families.

While we know there is still more to do, Awareness Day 2024 marked real progress. Together, we're making Fragile X better known, better understood, and better supported.




ECHO

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GPs urged to test for genetic condition affecting one in 250 women

Fragile X syndrome is caused by an alteration to a gene on the X chromosome

NEWS By Hannah Rees Social Media Editor, **Storm Newton** and **PA Health Reporter**

05:00, 10 Oct 2024



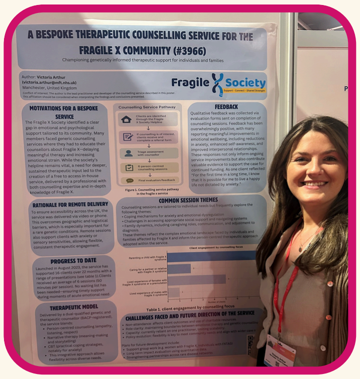






Counselling Service

Vicky Arthur - Counselling Service



A BESPOKE THERAPEUTIC COUNSELLING SERVICE FOR THE FRAGILE X COMMUNITY (#3966)

Championing genetically informed therapeutic support for individuals and families

Author: **Victoria Arthur**
(victoria.arthur@mft.nhs.uk)
Manchester, United Kingdom

Conflict of interest: The author is the lead practitioner and developer of the counselling service described in this poster. This affiliation should be considered when interpreting the findings and conclusions presented.

MOTIVATIONS FOR A BESPOKE SERVICE

The Fragile X Society identified a clear gap in emotional and psychological support tailored to its community. Many members faced generic counselling services where they had to educate their counsellors about Fragile X—delaying meaningful therapy and increasing emotional strain. While the society's helpline remains vital, a need for deeper, sustained therapeutic input led to the creation of a free to access in-house service, delivered by a professional with both counselling expertise and in-depth knowledge of Fragile X.

Counselling Service Pathway

Clients are identified through the Fragile X Society Helpline
↓
If counselling is of interest, clients receive and complete a referral form
↓
Triage assessment with counsellor
↓
6 person-centred counselling sessions
↓
Final evaluation/feedback

Figure 1. Counselling service pathway in the fragile x service

FEEDBACK

Qualitative feedback was collected via evaluation forms sent on completion of counselling sessions. Feedback has been overwhelmingly positive, with many reporting meaningful improvements in emotional wellbeing, including reductions in anxiety, enhanced self-awareness, and improved interpersonal relationships. These responses not only inform ongoing service improvements but also contribute valuable evidence to support the case for continued funding. As one client reflected: "For the first time in a long time, I know that it is possible for me to live a happy life not dictated by anxiety."

RATIONALE FOR REMOTE DELIVERY

To ensure accessibility across the UK, the service was delivered via video or phone. This overcomes geographic and logistical barriers, which is especially important for a rare genetic conditions. Remote sessions also support clients with anxiety or sensory sensitivities, allowing flexible, consistent therapeutic engagement.

COMMON SESSION THEMES

Counselling sessions are tailored to individual needs but frequently explore the following themes:

- Coping mechanisms for anxiety and emotional dysregulation
- Challenges in accessing appropriate social support and navigating systems
- Family dynamics, including caregiving roles, communication, and adjustment to diagnosis.

These themes reflect the complex emotional landscape faced by individuals and families affected by Fragile X and inform the person-centred therapeutic approach adopted within the service.

Table 1. client engagement by counselling focus

PROGRESS TO DATE

Launched in August 2023, the service has supported 16 clients over 22 months with a range of presentations (see table 1).Clients received an average of 6 sessions (50 minutes per session). No waiting list has been needed—ensuring timely support during moments of acute emotional need.

THERAPEUTIC MODEL

Delivered by a dual-qualified genetic and therapeutic counsellor (BACP-registered), the service blends:

- Person-centred counselling (empathy, listening, respect)
- Narrative therapy (meaning-making and storytelling)
- CBT (practical coping strategies, notably for anxiety)
- This integrative approach allows flexibility across diverse needs.

CHALLENGES FACED AND FUTURE DIRECTION OF THE SERVICE

- Non-attendance: affects client outcomes and use of charitable resources.
- Role clarity: maintaining boundaries between emotional therapy and genetic counselling
- Capacity: currently reliant on one practitioner, limiting scalability
- Policy evolution: flexibility is key to meet community needs and align with wider care

Plans for future development include:

- Support group work (e.g. women with Fragile X, individuals with FXTAS)
- Long-term impact evaluation using quantitative data.
- Strengthening partnerships across rare disease networks

We know that living with or caring for someone with Fragile X Syndrome can bring unique challenges and sometimes, you just need someone to talk to. That's why the Fragile X Society offers a specialised counselling service for individuals and families affected by Fragile X.

This service is designed to provide emotional support that's not just general – but tailored. Our counsellor has specialist knowledge of Fragile X, which means they understand the condition, the common experiences families face, and how to offer compassionate, relevant support.

You can talk to our counsellor about anything you're finding difficult, from coming to terms with a diagnosis, to managing stress, navigating transitions, or coping with relationship or family tensions. Support is also available for feelings of anxiety, grief, or simply feeling overwhelmed.

Sessions are free, confidential, and available online or by phone, so you can access support in a way that works for you.

You're not alone. We're here to help

If you'd like to learn more or request a session, please get in touch with us at info@fragilex.org.uk or visit our website at www.fragilex.org.uk

Work Scheme

Help Us Reach Further

Could Your Workplace, School or College Support the Fragile X Society?

As a small charity making a big impact, the Fragile X Society relies on the generosity and creativity of our community to keep vital support, awareness and research going strong. One of the most powerful ways you can help is by introducing us to new supporters, starting with your own workplace, school, college, or community group.

Many organisations are looking for a good cause to support – whether it's through fundraising events, selecting a Charity of the Year, holding dress-down days, hosting bake sales, or taking on sponsored challenges. Your connection to Fragile X makes it real and meaningful and that personal link is what inspires people to get involved.

Schools & Colleges – Could your child's school hold a sponsored walk, non-uniform day, or run a cake sale for Fragile X Awareness? It's a great opportunity to start conversations about inclusion and neurodiversity too.

Workplaces – Many employers actively support charities through matched funding, employee-nominated Charity of the Year schemes, or organising events like quiz nights, raffles, or fitness challenges. Some even offer volunteering time or payroll giving schemes.

Clubs & Groups – Do you belong to a local running club, church group, Masonic Lodge or hobby class? Why not suggest a fun fundraiser or collection to support families living with Fragile X?

Every connection can open a door. Your voice could lead to a new partnership, raise awareness in your community, and help us reach more families who need our support.

If you'd like a fundraising pack, some leaflets or a presentation to share with your workplace or group, we're here to help! Email info@fragilex.org.uk or call us on 01371 875100.

Together, we can make Fragile X better understood, better supported and better funded.

Thank you so much for being part of our community.

Friends of Fragile X

Friends of Fragile X is a way you can support the Fragile X Society on a regular basis through monthly donations. We receive no government funding and are dependent on the kindness of others so we can continue to provide our services. This includes staffing, office costs, and maintaining our helpline, to deliver our objectives.

Become a Friend of Fragile X by committing to a monthly donation to the Fragile X Society. For individual sign-ups, you can contribute starting at £5 per month. If you're joining as part of a family group, the minimum donation is £10 per month. If you're able, feel free to pledge a higher amount. Your generous contributions provide essential support, ensuring we can assist the Fragile X community throughout the UK. Scan the QR code to access our 'Frequently Asked Questions' and to enroll in the Friends of Fragile X program.

Friends of Fragile X

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e-learning

The eLearning course on Fragile X Syndrome was created to support parents, educators and health and social care professionals, who want to better understand and support individuals with Fragile X.

The objectives of the course are to give people the ability to recognise the characteristics of the condition and to help identify ways to support people with Fragile X. The course includes real-life examples and involves interactive slides. The course covers a variety of issues including genetics of Fragile X, physical features, language, learning styles, sensory issues, anxiety/hyperarousal, strategies for supporting individuals in daily life, educational strategies and strategies for managing behaviour.

The course is fully self-paced and designed to work around your schedule. Whether you're just starting your journey or looking to refresh your knowledge

> **"I found the course really informative and easy to follow – it gave me new tools to support my son and explain his needs to others." – Parent and course participant**

Fragile X Shop - Raise Awareness

Wear a Fragile X Item to promote awareness among colleagues and friends. We offer a diverse range of products designed to help raise awareness while you enjoy wearing them.
We invite you to explore our collection by visiting our website at www.fragilex.org.uk/shop

I have Fragile X Syndrome

a genetic condition that causes
learning disabilities

Please turn over to see how you can help

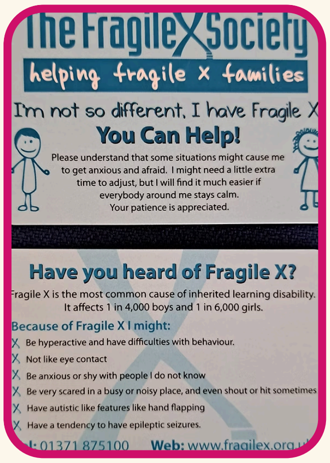
www.fragilex.org.uk

Fragile X Society

You can help by:

- Giving me a little more time
- Being aware that I might feel anxious
- Understanding that I am listening, even if I can't give eye contact
- Understanding my dislike of busy places

FX Christmas Cards Available Soon



The Fragile X Society

helping fragile x families

I'm not so different, I have Fragile X

You Can Help!

Please understand that some situations might cause me to get anxious and afraid. I might need a little extra time to adjust, but I will find it much easier if everybody around me stays calm.
Your patience is appreciated.

Have you heard of Fragile X?

ragile X is the most common cause of inherited learning disability.
It affects 1 in 4,000 boys and 1 in 6,000 girls.

Because of Fragile X I might:

- Be hyperactive and have difficulties with behaviour.
- Not like eye contact
- Be anxious or shy with people I do not know
- Be very scared in a busy or noisy place, and even shout or hit sometimes
- Have autistic like features like hand flapping
- Have a tendency to have epileptic seizures.

l: 01371 875100 Web: www.fragilex.org.u

The Fragile X Society Team

Pete Richardson, Managing Director

Pete holds responsibility for delivering the Fragile X Society's Charitable Objectives in accordance with best practice and charity law, ensuring that the organisation operates effectively raising funds and meeting the needs of its members. (pete@fragilex.org.uk)

Jane Oliver, Senior Families & Professionals Advisor (Adult Enquiries)

Jane is the Society's Senior Families and Professionals Advisor dealing with adult enquiries for individuals and families. (jane@fragilex.org.uk)

Alison Field, Families & Professionals Advisor (Child Enquiries)

Alison is the Society's Families and Professionals Advisor managing enquiries relating to children with Fragile X Syndrome. (alison@fragilex.org.uk)

Claire Denyer, Communications & Office Manager

Claire is responsible for supporting our office, our website, email communications and database, and our events. (claire@fragilex.org.uk)

Vicky Arthur, Counsellor

Vicky will be providing person centred counselling service for the Fragile X Society. (info@fragilex.org.uk)

Vicki Johnstone, Scotland Contract Manager

Vicki will be providing support and develop key information and initiatives to families, communities and professionals. (vicki@fragilex.org.uk)

Jan Wright, Northern Ireland Contract Manager

Jan's focus is on reconnecting with local families and strengthening partnerships with key organisations, to raise awareness and improve support for those affected by Fragile X in Northern Ireland. (jan@fragilex.org.uk)

For individuals and families

We offer up-to-date information, resources, literature, and publications regarding Fragile X, while facilitating peer-to-peer support networking through online forums, events, training, and conferences. Additionally, we provide support and opportunities for participation in research related to Fragile X Syndrome and its associated conditions.

How to contact us

You can call our helpline on 01371 875100, available Tuesday and Thursday 9am - 5pm and Wednesday 1pm - 5pm; email us on info@fragilex.org.uk or write to us at: Suite 5, The Chestnuts, 4 Stortford Road, Great Dunmow, CM6 1DA.

Our website has lots of useful information: www.fragilex.org.uk
Follow our social media for more updates.

Fragile X Society

www.fragilex.org.uk

info@fragilex.org.uk

01371 875 100

**The Fragile X Society, The Chestnuts, 4 Stortford Road, Great Dunmow,
Essex, CM6 1DA**

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