

Newsletter

Summer 2023

Latest Updates



Welcome!

Steve Harris, Chair, Board of Directors

Welcome!

Welcome to our printed newsletter. On behalf of your board, I very much hope that you enjoy the content.

It has been quite a year of change for your society but I am pleased to report that the “new”, (some of us can hardly claim to be that, obviously!) is in place and coming together really well.



You will read about the genuinely new faces, Claire Denyer, who is going to lead for us on admin and communications, and Alison Field who is our new Families and Professionals Advisor focused on Children. They are both settling in really well and are exceptional recruits for us.

We said goodbye to Caroline and Kate with heavy hearts as they had both served our families really well and I thank them personally for everything they did for us. A big thanks also to our existing staff, Pete and Jane, who will be known to many of you.

A big miss for us this year has been a conference or family day. However, we are going to make up for it next year so watch out for news!

Thank you so much to all of you who fundraise for us. Times are difficult for everyone and fundraising is more important than ever.

My last thanks are to my predecessor as Chair, Kirsten Johnson. Kirsten’s energy, knowledge and commitment are a hard act to follow.

Pete Richardson, Managing Director



I would like to echo Steve Harris’ sentiments and add that, after a year of transition, we are now going from strength to strength. I am both hugely encouraged to see the resilience of our membership during challenging economic times and equally determined that the staff team, volunteers, trustees and I will do everything that we possibly can to continue to support you, over the next twelve months.

We’ve lots to look forward to from now onwards; a landmark event in March 2024, the launch of a new counselling service during September this year and a grassroots development worker to begin working with families in NI (supported by a grant from the National Lottery in Northern Ireland).

We are also developing partnerships with external organisations, to help promote Fragile X and are delighted to be part of the very exciting plans to establish a Fragile X hub in Leicester.



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

Annual General Meeting



Notice of AGM: Saturday 30th September 2023

The 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 or to find out and ask about the Society's future plans.

An important part of the AGM is the election of Directors. As you 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. People who have been nominated for the vacancies are listed in the agenda. The elections are for three-year terms. We are very grateful to each of them for giving us their time and expertise to help lead the Society.

If you are unable to attend the meeting but would like someone to vote for you, then please complete the proxy form so that someone can vote on your behalf. Please return this form by Wednesday 27th September at the latest. We hope to see you there. Please confirm your attendance by emailing info@fragilex.org.uk

Agenda

1. Apologies for absence
2. Minutes of the Annual General Meeting held on 18th June 2022
3. Matters Arising
4. To receive the audited accounts for the year ending 28th February 2023 and the Auditors report.
5. To receive the Report of the Directors
6. To elect up to 7 members to the Board of Directors: 6 Directors, Kirsten Johnson, Tamara Martin, John Quaye, Katherine Zwink, Mark Smith, and Professor Gaia Scerif resigned during 2022/23 and we thank them for their service.
5 Directors, Steve Harris, Rosie Martin, Tim Eccleshall, Anne Eccleshall and Mary Martin have reached the end of their 3-year terms and will stand for re-election.
Rebecca Mayers and Zeinab Ali have completed nomination forms and wish to be appointed by this meeting as Directors of the Society.
7. To re-appoint Critchleys as the Fragile Society Auditors for 2024
8. Any other business (please contact us in advance of the meeting)

Proxy Form

Please complete, delete as appropriate and return by Wednesday 27th September 2023:

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:.....

Summary of the year

The Need for Our Services

Our specialist helpline is a vital resource for supporting and empowering people with evidence-based information and practical guidance. Throughout 2022-23 we supported the continued employment of our Families and Professionals Advisors to run this essential unique service.

We are proud to have maintained all our services during a difficult economic period ensuring that our members continued to be fully supported. And equally proud that support from our members remained steadfast. (We now have a membership of 2510 individuals or families which represents a 4% growth on the previous year)

Again, my thanks for all of your help and kindness, you will never know how much talking with you on the phone that afternoon meant to me, I had been so afraid, and you took away a lot of the fear.

Conferences and Events

In 2022/23 we were able to resume face-to-face conferences and events, successfully hosting a weekend at Thomley on 18th June, and a UK wide Conference on the 24th of September. The events included updates on Fragile X research studies, managing behaviours and ADHD and family workshops.

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, 1620 families agreed to be contacted. This is very encouraging as it shows a 7% increase in families wanting to be contacted compared to the previous year.

Positive feedback was received at a successful Academic Workshop held in Oxford on April 26, 2022, and at our two conferences held at Thomley and Birmingham in June and September 2022 respectively.

How we have supported individuals and families living with Fragile X

In total this year we responded to 796 enquiries (generating 3543 contacts) via our helpline, which represents a 24% and a 26% increase respectively.

Thank you for being so helpful. It's definitely nice to know there is someone I can discuss things with when experiencing difficulties who truly understands the disability.

Measuring our impact

Feedback on our support has continued to be extremely positive during 2022/23.

This year we have continued to develop our online presence and are proud to have a large community in our Facebook group amounting to just under 3,000 members: who post daily to seek support, celebrate successes and share resources. We also have a growing following on social media including: a page and profile reach of 222k, 1626 followers including an additional 510 followers that came on board. Altogether we published 680 posts across networks and had an engagement rate of 5.63% (a good social media influencer usually achieves 2-3%).

Our website attracted nearly 55,000 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. You guys as ever are such a lifeline for us!"



Fragile X Counselling Service

Finally, I am delighted to introduce Vicky, who will be delivering an entirely new counselling service for Fragile X Society Members. We have set up this service as we recognise the need within our membership for counselling to help you address some of your emotional and psychological support needs. You will be able to use this service free of charge by either speaking to one of our families and professional advisors for a referral or by contacting us using the info@fragilex.org.uk email address.

"Hello, I'm Vicky Arthur, and my journey in the healthcare field began in 2012 when I first started working for the NHS. Over the years, I have had the privilege of working in various areas, gaining valuable experience and insights into the diverse challenges faced by patients and their families.

In 2018, I found my true passion when I decided to specialise in supporting families impacted by genetic conditions, witnessing for the first time the impact these conditions can have on individuals and their loved ones. Since then, I have felt motivated to provide families with the care and support they deserve.



Fragile X Counselling Service (Continued)

More recently, I have been committed to merging my knowledge in genetics with my counselling skills and I hope this unique combination will allow me to provide a truly person-centered counselling service for the Fragile X Society. By understanding the intricacies of genetic conditions and incorporating counselling techniques, I believe I can offer a holistic approach that will be able to address the emotional and psychological needs of individuals and families impacted by Fragile X Syndrome.

My counselling service for the Fragile X Society focuses on creating a safe and supportive space where clients can openly express their concerns and emotions. By putting the individual at the centre of their own healing process, I aim to empower them to navigate the challenges of Fragile X Syndrome and find strength in their journey".

2022 - 2023

Finances

Overview of income and expenditure for the year 1 March 2022 - 28 February 2023

Summary 2022 - 23

Total income
£137,695

Direct charitable expenditure
£142,210

Total expenditure
£162,967

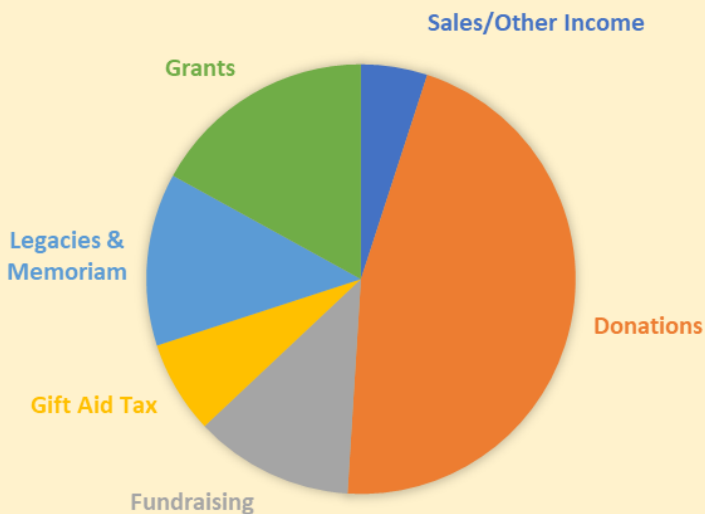
Balance of Funds at
28 February 2023
£163,021



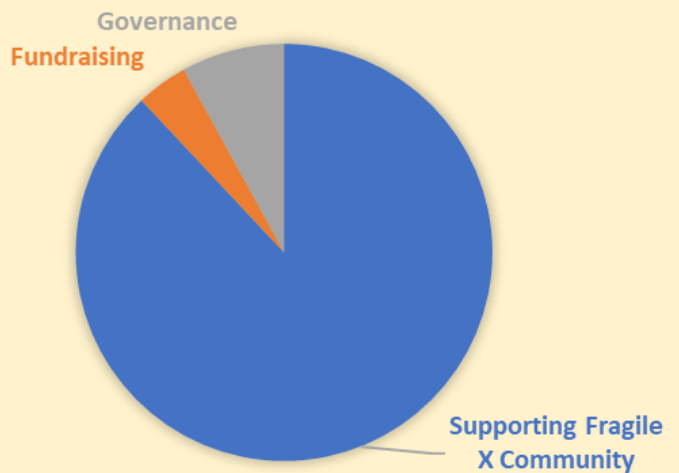
We are grateful for the generous support of all our members, our donors and grant providers, who have helped us during 2022 - 23. We also thank those who have supported the Society's 'Friends of Fragile X' and 100+ Club initiatives, both of which have provided vital funding for our work. We recorded a deficit of £25,272 over the year and although this is disappointing, it is not surprising given the challenges faced by the charity sector. We are now carefully controlling costs to ensure that we can continue to offer support to the Fragile X community.



WHERE EACH £ CAME FROM



WHERE EACH £ WENT



Snippets of Advice: The New School Year



Before we know it, the school summer holidays will be here, and it will be another change of routine for your child. It will then be the preparation for the transition back for the new school year. This may mean a new class teacher or even a move to secondary school in the Autumn term.

Should your child be moving to secondary school there should be a transition plan in place and introductory visits to their new school. They then have to deal with the long summer break before their start. However, most secondary schools use a staggered start date in the Autumn term to allow year 7 pupils to familiarise themselves with their new surroundings. It may also be that you have to carry out some 'travel training' with them if they are getting a bus to their new school.

Both your child's primary school and the new secondary school will be providing you with resources, However, an Essex based charity SNAP have developed a useful downloadable guide full of practical ideas to help with the transition and changes associated with the move to secondary school.



For those children moving to a new class, it is important to reassure them that some things may not change i.e. they will still have lunch in the dining hall, play times will be the same, they will still have the same class mates. In addition, an end of term transition booklet is often provided with photos of the child's new classroom, desk, coat hook etc. It may be a rather last minute resource as often families and pupils are not informed of their new teacher until a few days before the end of term and then a photo of them needs to be included in the booklet.

Here is an example of a booklet used for a child



Transition to New Class

Transition from one environment to another and change of routine can cause high levels of anxiety for a child with fragile x. These changes will be difficult for them to process along with the long summer holiday. So, it is knowing how your child will react and then decide when the right time is to share the information with them. Some can cope with the preparation throughout the summer break as they are getting new items for school, for others it might be just a few days before the start of term.

Visual schedules and reminders will be helpful for the new school year but don't forget that they can be useful resources for the holidays to enable your child to know the daily activities and what is going to happen next.

Please don't forget to contact us should you want help with visual prompts and social stories to meet your child's specific needs. I trust the school holidays and the transition to the new school year goes well for you all.

Ten Tips for Tremor (if you have a FXTAS diagnosis)

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

- 1** Perhaps consider touch sensitive switches in the home, or even an Alexa type device that can be voice activated. There will be tech involved in setting this up though.
- 2** Velcro onto your stick or cane handle and on a frequently used chair or resting place so you can place your cane without risk of it falling to the floor.
- 3** Avoid low or soft chairs. Straight back chairs with arm rests are easier to get out of.
- 4** Consider using a non-slip mat and/or plate guard to help to keep your plate still and to get your food onto a utensil. Weighted cups and cutlery might help and there are also angled handles on cutlery to help reduce tremor. Perhaps a book under the plate will reduce the distance from the plate to your mouth.
- 5** Consider the use of special devices that might help in the kitchen. For example jar and bottle openers, a kettle tipper, perhaps a perching stool which you can rest on in between tasks.
- 6** Try tucking your elbow into your side when trying to brush your teeth, shaving, putting makeup on etc. This might reduce the shaking.
- 7** Consider using long handled implements like shoehorns, a pick up stick, brushes etc to help with personal care and dressing.
- 8** Seems a bit obvious I know but don't try to do things at the same time. You don't have to multi task.
- 9** Keep exercising-its good physically and mentally too by helping the brains plasticity.
- 10** Checkout hand exercises for tremor. They might help with grip and reducing the tremor over time.

Ten Tips for Tremor (if you have a FXTAS diagnosis) Continued

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

These are a few ideas and tips. There is an organization called the National Tremor Foundation. They have many more ideas on their website. Of course you should try and get an occupational therapy referral for an individualised tailored programme including where to put grab rails, getting safely in and out of the shower, toilet seats-all that sort of thing.

You could also try Independent Living Centres for more advice about adaptations and aids. These are also called Assisted Living Centres or Disabled Living Centres. Some equipment can be hired out, but they may also charge for some things. A google search should point you in the right direction or I'll see what I can find for you if you don't have access. Many of these centres may have closed recently however.

Dunmow Carnival Supporting Fragile X



One of our committee members put forward Fragile X this year as a local charity to support at the Dunmow Carnival and we are pleased to say we were selected.

Each September, Great Dunmow town hosts a family friendly carnival which includes a traditional procession, show-ground events, a variety of stalls, delicious food and drink stands, free evening concert and a stunning fireworks display. The event is taking place on Saturday 16th September 2023. Entry to the Carnival is free, however those attending are asked to make a donation towards the local charities that have been chosen to support.

There will be a couple of different opportunities for people to donate which includes the collection buckets throughout the procession and on entry to the recreation ground where the main event is held. We will be included in the programme, which is delivered to approximately 7000 houses within the local area and also displays at the event.

This is such a great opportunity to share the brilliant work that we do and raise awareness for Fragile X.

Leaving a Legacy

We are really keen to ensure that every one of our families receives the best possible support from the Fragile X Society and that we can lobby on your behalf to improve services and raise awareness of Fragile X amongst clinicians. One of the best ways of ensuring that this happens, is by leaving a legacy in your Will. As I'm sure you're aware, the Fragile X Society receives no government funding and relies entirely on donations, legacies and grants. A gift in your Will, however small or large, can help ensure we can always be here for individuals and families affected by Fragile X. By leaving a gift to the Fragile X Society you can shape the future, ensuring that we are always here to provide support, information, resources, events, and a listening ear.



Every single gift is vital to the Fragile X Society and we appreciate any gift you choose to leave us. Whatever the value of your gift, it will go a long way to help someone who needs us and make a lasting and positive difference to the support we can offer.

We've partnered with FreeWills.co.uk to provide all our supporters with the opportunity to make their own fully-comprehensive Will for free. With FreeWills.co.uk award-winning online service (Alternatively, you can telephone FreeWills on 0800 612 8352) you can make a free, legally-binding Will in just fifteen minutes. Each Will is checked by their legal experts and your Will can be updated quickly and easily for free, forever.

So in short, we would be enormously grateful if, after you've looked after your family and friends, you would consider leaving a gift in your Will. For more information please visit www.fragilex.org.uk/leave-a-legacy.



Fragile X Stories and Fundraising



by Freya Woods

I'm not less than you.
I have Fragile X but it doesn't define me, or make me less than anyone else.
My disability isn't a negative. I'm proud of who I am.
I have a full life, a job, I'm a member of a professional theatre company for neurodivergent people.
My family are the most important people because they are always there for me.
I'm happy most of the time, but sometimes I'm sad. I have good days and bad days.
Really I'm just like anyone else.
Just because I have Fragile X doesn't mean to say I can't have ambitions.
My goal is to raise awareness about people with learning disabilities and what they can do.
They can work, have friends, they can live independently with support, they can go on holiday.
They can play sport, go to the theatre and go shopping.
Just like anyone else.
Next time you see someone with a learning disability don't judge them.
Have respect for them.
You never know what they will achieve when they follow their dreams!

Fragile X Stories and Fundraising

My name is Kunal Panchal. On Thursday my friends and I visited Audley End Gardens and House. We looked inside the house, it has a library with 150 books in it, as well as a gallery with lots of hand painted pictures. We enjoyed our picnic lunch on the benches outside on the grass.



I recently went to visit the Art Trail in Old Leigh, where I saw lots of different pieces of art created by a number of different artists. There was a painting of an old woman which I really liked. I like to joke with my support worker Sophie, that it looks like her.

I have also visited the 'Herd in the City' which is based in Southend. There is a trail of 46 large elephant sculptures and 72 baby elephants. On the elephants are lots of different designs like the pier, the arcades, the Sealife centre and even the big wheel.



Fragile X Stories & Fundraising

We are so grateful to everyone who is able to fundraise for us; no matter or how big or how small the challenge, your kindness and efforts are heart-warming and we appreciate every penny you are able to raise. Here are some recent fantastic fundraising stories. If they've inspired you to undertake your own fundraising challenge, please do get in touch - we'd love to hear from you!

Tim's Bike Ride



I am raising funds for the Fragile X Society UK because I am close to people living with Fragile X



Until early 2003, when my nephew James, the youngest member of the family at the time, was diagnosed, none of us had ever heard of Fragile X. Since then we have all learnt a great deal about the very different ways Fragile X can impact individuals and families.

Although it is the most common cause of learning difficulties, Fragile X is often misdiagnosed, misunderstood or simply unknown - even to some health professionals. It was even confused with brittle bone disease when James had to visit the fracture clinic.

For people living with Fragile X, unfamiliar situations can cause severe anxiety, so a visit to the hairdresser or a check-up at the dentist can be challenging and upsetting for everyone.



I would like to support the fantastic work done by the Fragile X society, not only by raising money by completing the 2023 RideLondon-Essex 100 mile bike ride, but also by raising awareness among my friends, colleagues and business contacts. James is a lovely, caring boy who turns 22 this year. He is a very special part of our family and I would love to try and help the world understand him just a little bit better.



Fragile X Stories & Fundraising

Soraya - Great North Run



I'm running the Great North Run on 10th September to raise funds for Fragile X Charity. This charity is very close to my heart as my nephew Colt has this condition. Colt is one of the most loving, quick witted, funny, happiest wee boys I know.. but sometimes the normal day to day things we do without even thinking about it like dressing, showering, brushing our teeth and even just communicating with us can be really hard for wee Colty and at times he gets really stressed out about these things.

Charities like this one help to improve the lives of those affected by Fragile X by providing information and continued support to families.

Working together with those affected, the Society supports an inclusive community of people who understand the specific needs of Fragile X. I've gotten loads of info from this charity for our family on how to best help Colt in his day to day life and activities, how to understand his condition more so we can help him manage it better in order for him to be less stressed and upset and more of a happy boy.

Bronze Medallist - Emily

Here is a picture of Emily who has Fragile X Syndrome. Emily was selected to play tennis at the Special Olympics for Great Britain, which was held in Berlin. She won a bronze medal in the mixed doubles and came 4th in the singles in Berlin. Her family are so proud of her and so they should be what an achievement. Well done Emily.

Emily also features on the NHS75 video alongside other athletes such as Andy Murray and Johnny Peacock amongst others, celebrating 75 years of the NHS.



Fragile X Stories & Fundraising

Pavers

We are delighted to have been supported by the Pavers Foundation and would like to express our gratitude to members of the Paver family (Ian and Debbie Paver) for their grant. The Pavers Foundation does a fabulous job in supporting UK charities.

Launched in 2018, with an incredible initial donation of £2.5 million from Pavers Shoes and the private estate of the late Catherine Paver, they enable charitable giving by their business and its 1500 employees. Thank you for supporting the Fragile X Society!



Janet's - Judge Day

One of members Janet, was asked to take part as a Craft Judge at the Brisham Horticultural Society Summer Show. Not only did she do an amazing job at being a judge for the day, she did a fantastic job at raising awareness and support for Fragile X Society UK. There was a lot of inquiring into Fragile X and leaflets handed out. One of ladies at the show opens her gardens and they are hoping to raise more awareness and support at this. Thank you Janet for all your hard work for Fragile X Society UK.

Paul - 90th Birthday



We would like to say a BIG thank you and a very Happy 90th Birthday to one of our members John Robson. John is an MBE and cares deeply about the affect of FXS and the affect it has on their family. John had no hesitation and asked for donations from the very start of planning his very special birthday. His family are extremely proud, that they were able to raise funds and collecting donations for the Fragile X Society. THANK YOU.

Fragile X Stories & Fundraising

Steven and Jennifer



Congratulations Steven & Jennifer on their wedding day. Instead of receiving gifts they asked for donations to be made to the Fragile X Society which has raised an incredible amount for the Society - Thank you.



Stuart and Rebecca

We would also like to congratulate Stuart & Rebecca Gardiner on their wedding day. Their brother with Fragile X did an amazing job as the best man on the day and delivered a fantastic speech that had everyone on their feet. Stuart & Rebecca made a generous donation to the Fragile X Society, which they raised by the lovely gesture of donating to the Society instead of having wedding favours. - Thank you



Chris and Lois

Two of the Fragile X Society Trustees Chris and Lois married this summer. We hope they had a amazing day and we wish them all the best for the future from all of us at the Fragile X Society.



Research News

Leicester HUB - Shape the Future

Thursday 5th October 2023 - College Court Hotel & Conference Centre

The Vision

We recently shared some really exciting news about plans to develop a Specialist Fragile X Hub in Leicester and how you can be involved!

Professor Julian Barwell, Clinical Genetics, together with Alex & Chris McQuade who are parents of two boys with Fragile X syndrome, have been working together for a few years to raise awareness of Fragile X in the medical and wider community and think about how best to support similar families in the future. They have been forming ambitious plans to build the first Fragile X specific holistic and integrated clinic in the UK starting with an individualised care plan. The aim is to have a social, emotional and educational component that will consider the needs of not only affected individuals but crucially also the whole family, including couples, other siblings and other relatives. As part of this and for those interested, we hope to be able to offer research studies aiming to improve the lives of individuals with Fragile X, although there will be no obligation to take part. While initial assessments would need to be in person future appointments could be virtual where possible and they have an innovative approach of wanting to "train the trainer/teach the parents" so spending more time with you to help with ideals, techniques and tips so that you are empowered to help support your loved ones.

Progress So Far

After the conference, Julian and the team at the Leicester Royal Infirmary purpose-built Research Space team agreed to participate in a current cannabinoid-based trial called RECONNECT. Leicester has the highest number of recruits for this international study which aims to help children and young people cope with the stresses of everyday life and provide a better emotional platform for future learning. Research Space is a quiet area of the hospital that has been carefully designed with children with additional needs and autism in mind with a sensory room and multiple distraction aids, play therapists and highly experienced and skilled paediatric nurses.

Next Steps

Supported by the Fragile X Community and the Fragile X Society, the next step is to demonstrate to the University of Leicester NHS Trust that we need a service and experts in Fragile X and therefore the Leicester initiative is planning a "medical supermarket" event in October this year. At this event "you", the families, will get to meet and hear from Julian, Chris and Alex about their plans and more importantly there will be stalls to meet the other stakeholders, which we hope will include genetic counsellors, a GP with a special interest in Fragile X, family counsellors, psychologists, speech and language therapists, charity support networks and play therapists. There will be an opportunity to meet the research team and talk about updates in Fragile X related therapies.









What we need from you

PLEASE, please put a note in your diary for October. But they need you, we need you and the FX community needs you! In order to demonstrate that FX has a community requiring support, we need you to attend the event so that the trust can see first-hand the audience/parents/guardians/carers who will support and use a Fragile X clinic in the UK. It's early days, but this novel, bold and exciting Leicester initiative is working with our community and thinking about the wider needs of families with Fragile X. Based in the middle of the country and all under one roof, this is our chance to develop a brighter future together.

Research News

BEOND STUDY





Behavioural and Emotional Outcomes in Neurodevelopmental Disorders (BEOND)

What is the study about?
We are wanting to collect information about changes in behaviour, emotion, physical and mental health for people with genetic syndromes, neurodevelopmental disorders and intellectual disabilities. This is so we can understand the impact of these experiences and hopefully offer better ideas of support.

Who can take part?
You can take part if you are a parent or carer of an individual diagnosed with either a genetic syndrome, autism and/or an intellectual disability. The person you care for must be at least one year old.

What will you ask me?
We will ask you to complete a range of questionnaires that will ask you about topics such as the person you care for's diagnosis, health, behaviour, and mood. We expect these questions will take you 60 minutes to complete. You don't need to answer them all in one sitting. We may also ask to do a phone interview with you.

BEOND


The Project Leads:



Dr Caroline Richards



Dr Jane Waite




Dr Jo Moss



Dr Hayley Crawford

Now recruiting families of people with Fragile X Syndrome!



For more information or to take part scan the QR code or go to:
www.cerebranetwork.com/beond-fxs

Behavioural and Emotional Outcomes in individuals with Neurodevelopmental Disorders (BEOND) Study

About the study

The Cerebra Network for Neurodevelopmental Disorders is conducting a survey to learn more about behaviour, social functioning, sleep, hyperactivity, mood, physical and mental health, as well as family functioning and wellbeing, and how these change over time.

Who can participate?

Parents and carers of a child (at least 1 year old) or an adult with full mutation FXS.

What will happen in the study?

Participants will be asked to respond to a variety of questions. The survey should take about 60 minutes to complete and may be completed in more than one sitting.

We know that FXS, other genetic syndromes, neurodevelopmental disorders, and intellectual disabilities can affect people's lives in lots of different ways. Our hope is that by collecting a range of data from lots of people with FXS and other genetic syndromes at different points in their lives, we can develop a better understanding of common areas of difficulty, as well as challenges that might be specific to FXS. Through this we may be able to offer better ideas for how to support people with FXS in the future.



You can learn more about this study by visiting the study website:

<https://www.cerebranetwork.com/beond-fxs>

Research News

Woman aged 16-50 with Fragile X Premutation - We Need Your Help

Take Part in Research!


UNIVERSITY OF SURREY  The Academy of Medical Sciences 

Social and emotional wellbeing in females with the fragile X premutation




What is the study about: We want to understand social preferences and mental health in **girls and women with the fragile X premutation**.

Who can take part: We are looking for girls and women (**16-50** years old) with the fragile x premutation.

What is involved: Participation involves two sessions (in-person and remote), including clinical interviews, eye-tracking tasks, self-report questionnaires and a saliva sample. Each session will take 1-1.5h. The total duration will be **3 hours**. You will also be reimbursed for your time and travel expenses if you decide to travel to the university.

 You can visit us at the [University of Surrey](https://www.surrey.ac.uk) to take part, or we can visit you at [home](#).
This study has received a favourable ethical opinion (FHMS 21-22 084 EGA).

Interested? Please scan the QR code or email gillian.hughes@surrey.ac.uk for more details

 Dr Jo Moss
 Gillian Hughes
 Holly Snellgrove

Thank you to all who have participated in University of Surrey's research on social and emotional wellbeing in women with the fragile X premutation so far! We are almost at our recruitment goal, but we still need a few more participants to get us over the finish line. Please be aware that you do not need to travel to participate – for the in-person portion of the study, we are happy to come to you to do the session at your home. If you are a woman, aged 16-50, with the fragile X premutation, please email gillian.hughes@surrey.ac.uk if you are interested or have any questions.

Thank you for helping us in our research!

Fragile X International (FraXI)

The Fragile X Society is a member of Fragile X International (FraXI). Founded in April 2022 by 17 family X associations, two more country organisations (India and Morocco) joined in November 2022. This coming November 2023, at FraXI's AGM in Brussels, full member applications will be processed from the Fragile X Association of Australia and Fragile X New Zealand, and from the National Fragile X Foundation (U.S.) for associate membership. Further information on the new countries joining FraXI is in FraXI's July 2023 newsletter, available at www.fraxi.org. You can sign up to receive FraXI's newsletter in the Contact Form on their website.

FraXI's newsletter is full of inspiring stories from member associations, including news of France's Family Weekend, Germany's Kongress weekend, Belgium's family events, the Netherland's seminar for health professionals, Italy's support groups, but perhaps topped by Spain. Spain is a federation of regional associations, and the Galicia region celebrated their 25th anniversary this year. They write, "It has become one of the events of the year and on this occasion it brought together the 73 Michelin stars held by 33 great chefs, who participated in the ninth edition of "Estrelas no Camiño". Located in Santiago de Compostela, an "almuerzo" (lunch) was prepared by 33 of Spain's most famous cooks. This year's funds were raised for the Galician Association of Fragile X Syndrome whose Spanish name is Asociación Galega da Síndrome X Fráxil." What a meal that must have been!

FraXI has published on their website information on their new Board of Advisors, which consists of scientists, researchers, clinicians and academics across the world. FraXI welcomes volunteers to help on their Research Committee, Communications Committee and Fundraising Committee. Any member of the Society can be involved, please email Kirsten@fragilex.org.uk if you would like further information.

FraXI is member of Rare Disease International (RDI, <https://www.rarediseasesinternational.org/>), a global body for rare disease charities and organisations. Kirsten Johnson, Society member and President of FraXI, was elected to the Council of Rare Disease International in June. This is a real opportunity for the Fragile X community to be heard on the world stage. RDI has initiatives with the UN, WHO, and other international bodies, and works to support all those living with a rare condition. October 10, 2023 is International Fragile X Awareness Day, and FraXI is planning social media and awareness-raising. Please like and follow FraXI on social media, and share the posts on your own accounts so that we can raise as much awareness as possible.



LinkedIn <https://www.linkedin.com/company/fragile-x-international/>

Facebook [@FragileXInt](https://www.facebook.com/FragileXInt)

Twitter [@FraXI_FragileX](https://twitter.com/FraXI_FragileX)

Instagram [@fragilexinternational](https://www.instagram.com/fragilexinternational)

The Fragile X Society



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)



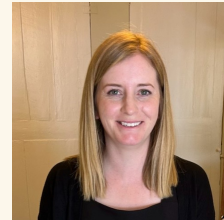
Jane Oliver, Senior Families and Professionals Advisor (Adult Enquiries)

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 and 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 and Office Manager

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



For individuals and families

We provide the latest information, resources, literature and publications about Fragile X and enable peer to peer support networking through online forums, events and training, and our Family Weekends and conferences. We also offer support and opportunities to take part in research into Fragile X Syndrome and associated conditions.

For professionals

We offer helpline support, resources, e-learning to educate about Fragile X.

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 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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