

The Fragile X Society's Policy for collaborating with other organisations

A good corporate partnership can be mutually beneficial for both the Fragile X Society and its collaborators. These benefits include the potential for increased funding, support and visibility for the Fragile X Society, and corporate organisations can benefit from good PR, brand building and the chance to make a difference and support a worthwhile cause.

While corporate partnerships offer benefits for charities themselves, they also offer the opportunity for charities like ours to help a wider group of people by connecting them with teams and individuals who could benefit from the important work that we do. This is especially important in the context of Fragile X, where a lack of public awareness and understanding of the condition is prevalent.

This Policy details how the Fragile X Society will consider all its collaborations, including partnerships, sponsorship, and joint working.

Any relationship with an external organisation (or third party) should be entered into with the clear aim of helping us to achieve the mission of the Fragile X Society whilst adhering to our core values:

Our Mission is to:

- Advance the health and well-being of individuals affected by the genetic condition known as the Fragile X Syndrome and associated conditions.
- Advance public education about the condition in order to help improve the environment, conditions and services offered to people with Fragile X and associated conditions, and their families.
- Promote research into the condition and to publish the useful results thereof.

Our Core Values are:

Recognise: The talent and potential in everyone.
The achievement and hard work of our employees and volunteers.
That diagnosis does not define an individual, we recognise individuality.

Support: Provide caring, understanding, empathetic and sensitive support.
By providing a broad toolkit of support to empower all who need it.

Respect: Treat everyone as individuals adhering to the principles of equality and diversity.

Be Transparent: Be evidence based, factual and open on where all information has been sourced.

The simple question that we should ask ourselves, in the first instance, before we begin developing an external relationship is:

"Will this relationship ultimately benefit people within the UK affected by Fragile X?"

If the answer is yes, then we can proceed in accordance with the guiding principles outlined below. If the answer is no, then the relationship should not be taken any further.

Guiding Principles

Independence

The Fragile X Society is careful when collaborating with other organisations and individuals that its independent status and its autonomy is not compromised in any way. If there is any possibility that this may be placed in jeopardy, we will withdraw from any such activity or initiative. The Fragile X Society will not be led by money into positions which are not in the interests of those living with Fragile X and associated conditions.

However, we may pursue opportunities for sponsorship or financial support from corporate organisations, providing that these arrangements do not:

- Seek endorsement for any particular product or service.
- Run contrary to the core mission and values of the Society in any way.

Mutual Respect

The Fragile X Society collaborations are intended to influence change, and generate shared learning, as well as income. It is important that both parties respect the expertise and skills that the other brings over and above any financial benefits.

The Fragile X Society will not share or sell the details of its membership or networks. The Fragile X Society will not normally promote or endorse products or services from supporters, partners or third parties to our members and contacts through email. Any dissemination, promotion or endorsement will be at the discretion of The Fragile X Society and in accordance with GDPR regulations.

Integrity

The Fragile X Society aims to be transparent in its relationships with all organisations and individuals. There must be strong grounds for believing a formal collaboration will result in benefits to The Fragile X Society and its work. It should always be made explicit what each party is bringing and gaining from a formal relationship. The Fragile X Society will also be transparent about who it is working with and the nature of the relationship and work.

Shared Values

The Fragile X Society will seek collaborators whose goals, values and actions promote and/or enable good health. Specifically, we will not work with any organisation that is associated with products that are established as having a detrimental effect on wellbeing, for example tobacco. Each collaborator will be judged on a case-by-case basis.

Obligations of Supporters and Partners

- In the event of any matter arising which could significantly adversely affect the standing of the supporter or partner in their reasonable opinion, they must inform The Fragile X Society as soon as reasonably practical. The Fragile X Society reserves the right to take appropriate action to ensure its reputation is not adversely affected in any way as a result of such incidents.
- In formal collaborations all aspects must be clear and explicit to all parties involved. All agreements are exchanged in writing and supporters or partners are required to endorse and abide by the ethical collaboration policy.
- The Fragile X Society should be consulted whenever and wherever its name or its project names are used by supporters or partners, for both internal and external communications. Approval must be sought for any copy produced which refers to an initiative with The Fragile X Society that is supported/sponsored by a supporter or partner organisation or individual.
- At no time can "The Fragile X Society" be used without express written permission for every occasion it is used.
- At no time can press releases be issued that refer to The Fragile X Society without our prior approval.
- Staff, volunteers and trustees on both sides should beware the potential for bias generated through collaborations, where this might impinge on professional judgment and impartiality.
- Both parties commit to confidentiality requirements at all times.

Conflicts of Interest

The Fragile X Society mission, and values give guidance to establish which collaborations are appropriate. Successful collaboration requires mutual respect and transparency of benefits. When establishing a new collaboration, both parties should endeavour to ensure that there are no conflicts of interest that cannot be safely managed.

To help ensure potential conflicts of interest are identified and managed appropriately:

- The Fragile X Society gives no warranty that the deliverables of a collaboration will not contain any material that may be disadvantageous to its collaborator's business or area of work (for example, it will present research findings

determined by objective analysis of available evidence regardless of whether they support a collaborator's work or position).

- Funders of activities and projects will have no direct control over analysis, conclusions, positions or recommendations by The Fragile X Society. In the case of partnership projects or joint activities, the rules of engagement for establishing outcomes must be agreed beforehand and should be transparent.
- The Fragile X Society will be open about other collaborations with organisations working in the same areas or sectors and expects the same approach from its supporters. The Fragile X Society will not allow direct access to its members and wider networks by third parties (other than those generated directly by collaboration).
- The Fragile X Society will not allow supporters to link or imply direct material benefits for their products through an association with the charity.
- No trustee of the Fragile X Society should benefit directly or indirectly from any collaborative arrangement with a third party.
- Speaker places at The Fragile X Society events (and webinars) are determined by The Fragile X Society entirely on merit and cannot be determined by any formal supporter or sponsorship arrangements.

Evaluation Process

Before any formal collaboration is entered into, a written proposal should be submitted to the Fragile X Society Governance Committee for approval. If necessary, the proposal may be submitted to the full Board of Trustees.

It is anticipated that proposals will come from the Managing Director; if Trustees or members have proposals, they will be taken to the Managing Director who will develop these suggestions.

Proposals should clearly identify the benefits of the collaboration, the expectations of both parties and any potential risks or concerns that need to be considered.

In Summary

The Fragile X Society recognises the benefits and value of mutually supportive collaborations with third party organisations. By adhering to the guidance outlined within this document, we are confident that we can establish relationships which will ultimately benefit our members and people with Fragile X and associated conditions throughout the UK.