

## Fragile X International's Policy for collaborating with other organisations

A good corporate partnership can be mutually beneficial for both Fragile X International (FraXI) and its collaborators. These benefits include the potential for pro-bono support, funding, and increasing FraXI's visibility; and corporate organisations can benefit from 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 is prevalent.

This document sets out how FraXI will consider all its collaborations, including partnerships, pro-bono support, 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 FraXI whilst adhering to our core values.

### **Our Mission:**

- Advance the health and well-being of individuals affected by Fragile X Syndrome (FXS) and Fragile X Premutation Associated Conditions (FXPAC)
- Advance public education and awareness internationally in order to help improve the environment and services offered to people with FXS, FXPAC, and their families.
- Promote and encourage research on the holistic approach to FXS and FXPAC
- FraXI strives for social inclusion, equal opportunity and a recognition of the value that those with Fragile X and FXPAC bring to society
- We aim to help those living with FXS and FXPAC and their families anywhere in the world enjoy a happy and fulfilling life

### **Our Core Values are:**

- Recognise:** The talent and potential in everyone.  
That diagnosis does not define an individual, we recognise and value the whole person.
- Support:** Provide caring, understanding, empathetic and holistic support.  
Make available information and toolkits to empower and support.
- 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.

## Guiding Principles

### Independence

FraXI 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. FraXI will not be led by money into positions which are not in the interests of those living with FXS and FXPAC.

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 our core mission and values in any way.

### Mutual Respect

FraXI collaborations are intended to influence change, and generate shared learning. FraXI will not share or sell the details of its membership or networks. FraXI 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 FraXI and in accordance with GDPR regulations.

### Integrity

FraXI 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 FraXI and its work. It should always be made explicit what each party is bringing and gaining from a formal relationship. FraXI will also be transparent about who it is working with and the nature of the relationship and work.

### Shared Values

FraXI 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 FraXI as soon as reasonably practicable. FraXI 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.
- FraXI 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 FraXI that is supported/sponsored by a supporter or partner organisation or individual.



- At no time can “Fragile X International” be used without express written permission for every occasion it is used.
- At no time can press releases be issued that refer to Fragile X International 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. This covers details FraXI may share of itself and members.

## Conflicts of Interest

FraXI’s 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:

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

## Evaluation Process

If required, a written proposal should be submitted to FraXI for approval before formal collaboration is established.. 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

FraXI 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.