

## **Creation of an International Fragile X Alliance**

***Creating a world where no one is alone with the diagnosis of Fragile X***

A white paper collection of proposals  
for consideration by Fragile X parent groups  
throughout the world

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## Overview

### Fragile X

Fragile X Syndrome (FXS), is the most common, known inherited form of intellectual and learning disabilities, and affects approximately two million people worldwide. Many, if not most, with the syndrome remain undiagnosed. Together with Fragile X-associated Tremor/Ataxia Syndrome (FXTAS) and Fragile X-associated Primary Ovarian Insufficiency (FXPOI), which result from the genetic premutation, over 20 million men and women worldwide are affected or at risk for developing a Fragile X-associated Disorder (FXD).

In some countries, family associations have been formed in order to help those affected by FXS. Many parents report how beneficial these groups have been to their sense of not feeling alone or isolated. The size of the organizations ranges from smaller support groups to large, national associations. Due to the impact of FXS on daily family life, most national family support associations are experiencing significant difficulties with keeping their services up and running. Many good ideas to help those affected by FXDs cannot be implemented, because of the lack of resources. And while much work needs to be done on a national or even regional level, there are areas that exceed both the possibilities and capabilities of the individual associations.

Thanks to the internet and conferences, there has already been very helpful informal sharing of information/material amongst some international groups in the past. Gatherings/meetings of parents and representatives of parent support organizations from many countries have taken place for almost two decades. These meetings and exchanges of information have consistently underscored the dire need for more and better information and for that information to be distributed worldwide. However, due to the challenges faced by mostly volunteer staffs, communication between international organizations has been inconsistent and irregular. And most parts of the globe, including almost all of Africa, Central America, much of Eastern Europe and significant areas of Asia have little to no parent support or proper therapeutic/clinical care for those impacted by a FXD.

### Mutual International Support

Promising international ties like the meetings at the American *National Fragile X Foundation's* (NFXF) biennial international conferences and the more recent creation of the *European Fragile X Network* (EFXN) have shown that a sustaining international Fragile X support and information structure will be both highly appreciated and effective. The most important areas of mutual support include:

- information exchange for existing national family associations/groups,
- guidance in the formation of new national associations/groups,

- direct help for families already diagnosed with FXDs,
- sharing experiences to improve the ability of clinicians to make the proper diagnosis and treatment of FXDs,
- helping to establish comprehensive and consistent standards for clinical care, therapies and treatment,
- enhancing education and training for families and professionals who are affected by and/or interested in FXDs

In order to achieve the above, we are proposing the creation of an International Fragile X Alliance (IFXA) consisting of all interested national Fragile X family support associations and professionals worldwide. In the following, ideas for common activities, some basic alliance characteristics and an implementation timeline are suggested.

### **Ideas for information exchange**

In addition to their parent contact databases, the "capital" of all Fragile X support associations is the information they gather and distribute to families affected by FXDs. Collecting all the existing information, in a centralized, online location, will create an invaluable source of knowledge about how to cope with Fragile X. Information exchange could include:

- A distribution system for new scientific and therapeutic knowledge
  - Breakthrough work should be made available to the member associations immediately so they can translate and share with interested families and professionals.
- An exchange of experiences and recommendations on how to increase the number of diagnoses and/or lower the average age of diagnosis of FXDs.
- A resource center for newsletter/family magazine articles and other relevant informational materials of all kinds that associations can translate and incorporate into their own online and print communications.
  - An agreement will need to be created to allow for free use of alliance member articles (along with a suitable disclaimer)
  - Agreed upon standards of material translation by appropriate professionals will need to be created.
  - Creation of a photo gallery of individuals with FXDs, along with signed permission forms allowing for use by all alliance members, needs to take place and should include layout files/templates for publications whenever possible.
- Create additional opportunities for meetings to supplement the NFXF biennial conference including:
  - conferences/meetings, seminars and workshops focussing on specific areas/topics around FXDs

- Collect direct parent experiences about participation in clinical trials and other research projects
  - Gather results about participant's experiences in order to get a better understanding of the results of the ongoing trials including experiences that may support or contradict official pronouncements by pharmaceutical companies and/or clinical researchers.
  - Create and provide general information about clinical trials that will help parents to make informed decisions about participating in clinical trials.
- Collection of fundraising ideas
  - Compile a fundraising encyclopedia containing examples of both successful and unsuccessful ways of raising money by alliance members.
- Help on creating, running and administering a family support organization
- Help on creating clinics/expert centers
- Help on financing projects
- Research project announcements
  - Note: Some projects are of international relevance. However, researchers often have difficulty finding enough participants. In addition, some countries or institutions may have different research cooperation protocols and ethics approval processes or laws. Information distribution can be different or even restricted and not every project will be announced or go through an approval process.
- Creation of an International Fragile X scientific advisory board
  - Note: Scientists are both sources and recipients of information (two way communication)
  - Alliance members existing structures, advisory bodies and research networks would be the source of the Alliance's Advisory Board

### **Media for information exchange**

- In today's electronic world, there are increasing opportunities for information exchange. We propose establishment of a well-organized and maintained system of communication utilizing a variety of media techniques and online systems designed to be accessible by both families and professionals regardless of location, including:
  - A comprehensive, internationally run, multilingual website
  - Email distribution lists
  - Online social networking

In addition to the above forms of electronic communication we suggest that in-person meetings will continue to play an important role in furthering information sharing. These meetings may involve select groups of families, association's representatives and professionals who gather to address specific topics (as mentioned above).

### **Basic characteristics of an International Fragile X Alliance**

Due to the substantial administrative overhead of a formal association, it is appropriate to start with an informal alliance of existing associations. A registered charity association might be a long or mid-term goal, but, at this time, it will only create a lot of unnecessary work (statutes, registration, etc.).

### **Structure**

- An overarching goal will be to keep things simple and to carefully prioritize the efforts of the alliance.
- Though the information platforms/communication channels should include all stakeholders in the field of FXDs, direct alliance membership will be limited to *national* (and not regional, etc.) family associations. If there are two or more FX family associations working on the national level in one country, all of them should be eligible to become a member.
- Alliance decisions must be made through an agreed upon process that ensures the opportunity for input from all members.

### **Independence**

- Membership in the alliance does not affect the internal decision making within the individual associations.
- Any organization that has been allowed to provide financial support for alliance activities will be prohibited from influencing any decision-making by the alliance.

### **Costs**

- Membership in the International Fragile X Alliance will be free of charge.
- The International FX Alliance should not create additional obligations but be helpful and save time. Those who find the time and resources to give shall be able to do so, those who are at a time unable to actively contribute on top of their national obligations shall find help and use the resources that others can provide. It must be fun to be working within the alliance!