



FRAGILE X INTERNATIONAL

We are delighted to announce the official launch of Fragile X International (FraXI), a new organisation for fragile x family organisations around the world. FraXI's vision is to help those living with Fragile X Syndrome (FXS), Fragile X Premutation Associated Conditions (FXPAC) and their families anywhere in the world to enjoy a happy life.

FraXI is a conduit for countries to work together and an official entity for sharing of international knowledge and expertise. FraXI aims to drive research, encourage international collaborations and contribute with a unified voice of lived experience from the network of international countries that it comprises.



FraXI was founded by a network of 17 country family organisations from the European Fragile X Network. We very much welcome new members to join as either full members or associate members. Full membership is open to all fragile x family organisations around the world. Associate membership is available to corporations, non-family organisations and other charities. FraXI will work closely with all members to provide advice and support in setting up and

maintaining country organisations and act as a conduit so that countries can share best practice with each other. This will involve proactive raising of awareness of FXS and FXPAC internationally; and promotion of social inclusion of FXS at all levels of society. FraXI will oversee communication of latest research and influence the direction of research internationally on FXS and FXPAC through work with our Board of Scientific and Clinical Advisors.

Quote from family member: "Having a child with a rare condition can feel so isolating but with FraXI, I now feel a presence of support and sharing of knowledge that is working for the best outcomes for my child with Fragile X."

Dr Kirsten Johnson, Chair of FraXI's Board says: "FraXI will be a proactive organisation, with all countries working together to share best practices related to support and interventions to make a

real impact in all aspects of the lives of people with FXS and Fragile X Premutation Associated Conditions (FXPAC).”

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About FraXI and Key messages

What is Fragile X Syndrome? Fragile X Syndrome (FXS) is the most common inherited cause of autism and intellectual disabilities. It affects 1 in 4,000 boys and 1 in 8,000 girls worldwide. It is a genetic condition that causes intellectual disability, behavioural, sensory, physical and learning challenges. Fragile X Syndrome occurs when a single gene on the X chromosome shuts down. This gene makes a protein needed for normal brain development. In FXS it does not work properly, the protein is not made, and the brain does not develop as it should. Fragile X International is a network of 17 international family organisations. It is a registered INPO/AISBL in Brussels, Belgium. FraXI's mission is to work together to promote, support and strengthen the FX identity as an added value to society. FraXI will promote the strengths of people with FXS and have FX recognised for the benefit people with FX bring to society. FraXI aims to raise awareness and increase knowledge about and highlight the areas where people with FX often need support and inform policy makers.