

FXF Mini-survey: Participation in Clinical Trials

Have you participated or considered participating in a Fragile X syndrome clinical trial?

If the answer is "yes," we want your feedback!

You are eligible to complete this survey if you are

- You are a parent/caregiver of an individual with full mutation Fragile X syndrome (FM FXS) who has participated or considered participating in a Fragile X syndrome clinical trial **OR**
- You have FM FXS and have participated in or considered participating in a Fragile X syndrome clinical trial.

Clinical trial is defined as a research study where one or more individuals are assigned to one or more interventions (which may include placebo) to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes. A lot of the clinical trials in Fragile X syndrome have involved a medication. Some trials have also involved a different intervention, like a language or behavior intervention.

You will be asked a series of questions about you or the individual with Fragile X syndrome's participation in a clinical trial. **This survey is only 6 questions long and should take you no longer than 10 minutes!**

All of your answers will remain anonymous. Your de-identified (that means no link to who you are or anonymous) answers may be shared with researchers and possibly the FDA. None of your private personal health information will be obtained or shared by the NFXF. The NFXF may summarize your answers to help families like yours better understand participating in clinical trials.

* 1. Have you ever participated in a Fragile X clinical trial?

If you have considered participating in a trial but chose not participate, please answer "no".

- Yes
- No

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You answered "yes," you or an individual you care for with FXS participated in a trial.

Please answer the following questions about your experience participating in a clinical trial.

Question Title

* 2. Why did you choose to participate in a clinical trial? Please explain.

Question Title

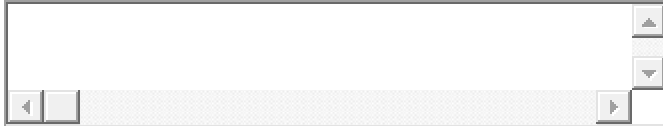
* 3. What were the positives or good things about participating in a clinical trial? Please explain.

Question Title

* 4. What were the negatives or challenges and barriers to participating in a clinical trial? Please explain.

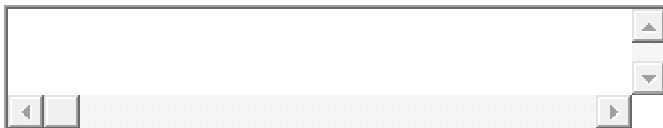
Question Title

* 5. What advice would you give to individuals or parents/caregivers who are considering participating in a clinical trial?



Question Title

* 6. Do you have anything else you would like to share about clinical trials?



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You answered "no," you or an individual you care for with FXS have not participated.

Please answer the following questions about why you chose not to participate in a clinical trial.

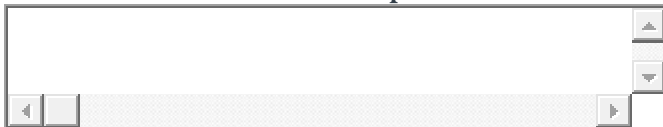
Question Title

* 2. Why did you choose not to participate in the clinical trial? Please explain.



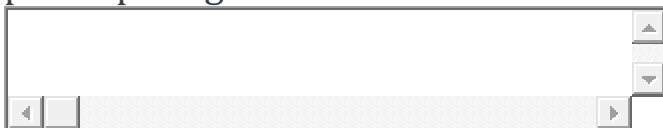
Question Title

* 3. What would have made you more comfortable participating in a clinical trial? Please explain.



Question Title

* 4. Do you think there are any positives or good things about participating in clinical trials?



Question Title

* 5. What advice would you give to individuals or parents/caregivers who are considering participating in a clinical trial?

Question Title

* 6. Do you have anything else you would like to share about clinical trials?

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Thank you for participating in our mini-survey on Clinical Trials!

This is the end of the survey. Please click "done" to complete the survey.