



WAISMAN CENTER

Seeking Families to Participate in New Longitudinal Study on Family Adaptation to Fragile X Syndrome

- Principal Investigators -

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Researchers at the Waisman Center, University of Wisconsin-Madison are seeking to understand the challenges faced by parents who are caring for an adolescent or adult son or daughter with fragile X syndrome. This new study is funded by the National Institutes of Health and is part of the national network of NIH-funded centers on fragile X syndrome. This study is part of the only fragile X center grant to be focused on families. The purpose of this 5-year study is to learn about the well-being of mothers and their children with fragile X syndrome, how mothers manage their day-to-day lives, and the stressful events which they may experience. We also want to learn about the quality of life of the sons and daughters with fragile X in regards to their social and recreational activities, friendships, and family relationships.

To qualify for the study, mothers must meet the following criteria:

- the son or daughter with fragile X must be 12 years of age or older
- the mother must be the biological parent
- the mother must provide documentation from an appropriate health care professional confirming that the son/daughter has the full mutation of the gene causing fragile X syndrome
- the son or daughter lives in the parental home, or the mother has at least weekly contact in person or by phone with the son or daughter

Mothers will be interviewed over the telephone and will complete self-administered questionnaires. We would like to interview each participant three times (once every 18 months) during the five-year study period. During the course of the study, periodic summary reports on the study findings will be shared with families.

All information will be kept strictly confidential. If you choose to participate, you can feel 100% confident that no one outside of the research project staff will know anything that you said, not even the other members of your family.

If you are interested in learning more about this study or would like to participate, please complete and return this form in the enclosed postage paid envelope to:

Renee A Makuch, Project Manager
Waisman Center
University of Wisconsin - Madison
1500 Highland Ave, Rm 551
Madison, WI 53705

Toll free ph: 1-877-558-7595
Fax: 1-608-265-4862
Email: makuch@waisman.wisc.edu

***** detach form here (please print) *****

Study on Family Adaptation to Fragile X Syndrome

Mother's Name: _____

Son/Daughter Name: _____ Age: _____

Mother's Address: _____

Phone days: _____

Phone evening: _____

Email: _____

Best times to call: _____