Fragile X syndrome research participants are essential partners in furthering research, discovery and new therapies.

This NIH research study is conducted at the NIH Clinical Center in Bethesda, Maryland. The study enrolls eligible participants from across the United States and worldwide.

Travel, food, and lodging are provided for the study participant and one or two accompanying family members. You will receive compensation for your time and participation.

The **National Institutes of Health (NIH)** is an agency of the U.S. Department of Health & Human Services that supports medical research and scientific studies that seek to turn discovery into health.

NIH Clinical Center
A hospital devoted exclusively to clinical research where research patients receive highly specialized care during study participation.

Safra Family Lodge
A home-like place on the NIH campus for study volunteers and family members to stay while participating in research at the NIH Clinical Center.

For further information, please contact:
Inna Loutaev, DNP-CRNP, study clinician
Phone: 301-496-4707
E-mail: loutaev.inna@nih.gov

Carolyn Beebe Smith, Ph.D.
Phone: 301-402-3120
E-mail: beebe@mail.nih.gov

http://patientinfo.nimh.nih.gov

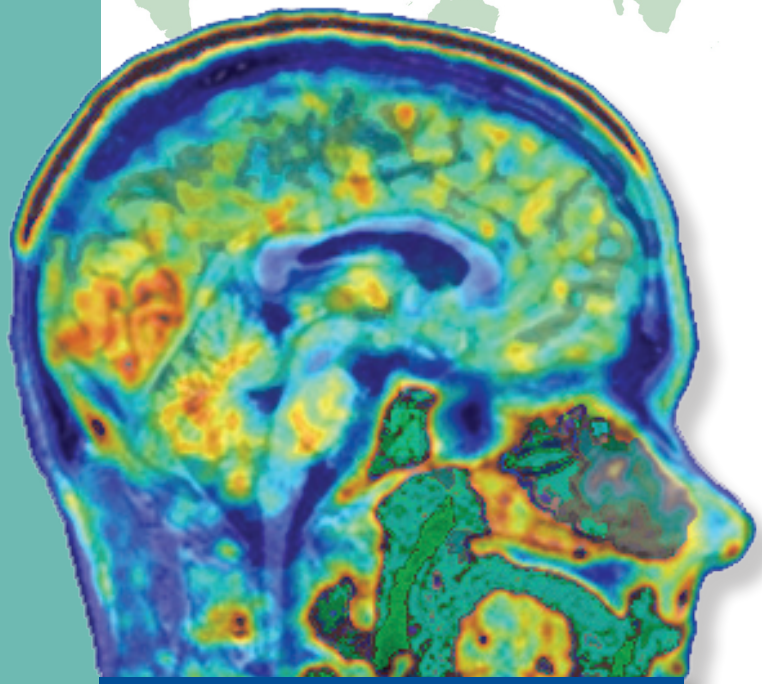
Department of Health & Human Services
National Institutes of Health
National Institute of Mental Health
Section on Neuroadaptation & Protein Metabolism
10 Center Drive, MSC 1298, Rm 2D54
Bethesda, Maryland 20892

NIH National Institutes of Health

PARTICIPATE IN

FragileX

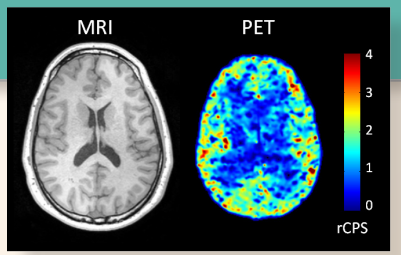
RESEARCH



NATIONAL INSTITUTES OF HEALTH

Turning Discovery into Health

NIH RESEARCH SEEKS TO UNDERSTAND...



How is protein formation in the brain affected in fragile X syndrome?

This study is enrolling eligible young men ages 18-24 with fragile X syndrome into a study of brain function.

What is the purpose of this study?

The study purpose is to measure the rate at which the brain makes proteins (protein synthesis) in patients with fragile X syndrome (FXS).

Proteins are basic building blocks of life and are required for memory. Persons with FXS lack a protein called FMRP. FMRP is thought to control the formation of brain proteins. Without FMRP, the brain may not effectively control the formation of proteins.

This study may help us to understand how the essential process of protein synthesis is affected in FXS. We may also be able to identify specific parts of the brain affected in FXS. In the future, measurement of protein synthesis in FXS may help us to develop and test new therapies.

What does this study involve?

The study takes place over several days and includes blood draws, psychological testing, and two types of brain imaging scans: a positron emission tomography (PET) scan and a magnetic resonance imaging (MRI) scan. Participants may be sedated to minimize stress.

How can my family benefit?

There will be no direct benefit to you and your family, but your participation will further our understanding of FXS, and may lead to new treatments. You may have the results of psychological tests and MRI scans.

What are the study risks?

The risks of participating in our study include sedation, an arterial catheter, and a small amount of radiation exposure. These risks are discussed in detail in the written consent form, and we will answer any questions you might have. After careful consideration by our Institutional Review Board, the risks involved in our study are believed to be 'slightly above minimal.' As a participant in the study, you may withdraw at any time.

Who is the research team?

Principal Investigator, Carolyn Beebe Smith, Ph.D.

Members of the fragile X investigative team. From left to right: Clinical Psychologist, Audrey Thurm, Ph.D.; Nurse Practitioner, Inna Loutaev, DNP; Research Coordinator, Britt Evans, B.A.

Join a Study!

This study has enrolled participants from around the world.

http://patientinfo.nimh.nih.gov

Protocol No. 06-M-0214

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Turning Discovery Into Health