

INFORMED CONSENT

Title of the study: A genetic study on idiopathic mental retardation

IEC Number: IEC-N1/09/OCT/12/25

Description of the study

In this study, we propose to estimate the frequency of submicroscopic chromosomal rearrangements in the whole genome of patients with idiopathic mental retardation (MR) to establish a causative link between genotype and phenotype. You/your ward have been selected as a participant based on the inclusion and exclusion criteria of the proposed study. If you agree to participate, you will be given a structured questionnaire by the investigator. The questionnaire will have questions related to clinical history and family history.

The participation in the study for answering the questionnaire will require approximately one hour of your time. We will perform a physical examination and collect blood.

Possible Risks to the participants: There are no risks involved in this study.

Possible benefits to the participants: The gain of accurate knowledge about the consequences of specific subtelomeric rearrangements with the phenotypic observations will allow the development of genotype-phenotype correlations to aid in the diagnosis, prognosis and clinical management of individuals with idiopathic MR.

Cost and payments to the participants: There is no cost for participation in this study. Participation is completely voluntary and no payment will be provided.

Confidentiality: Information obtained for the study will be kept strictly confidential. You will be assigned a research number. Your name will not be used in reporting of information in publications or conference presentations.

Participants' right to withdraw from the study: You have the right to refuse to participate in the study, the right to withdraw from the study and the right to have your data destroyed at any point during or after the study without penalty.

Voluntary consent by the participant: Participation in this study is completely voluntary, and your consent is required before you/your ward can participate in this study.

Storage of samples: The samples processed for this study will be fixed in carnoy's fixative and stored in micro-centrifuge tubes, appropriately labelled with the patients' ID no. and stored at -50°C. The samples may be used for statistical analysis and research purposes other than the proposed research work in the institute.

"I have read this consent form (or it has been read to me) and I fully understand the contents of this document and voluntarily consent to participate/allow my ward to participate in this study. All of my questions concerning this study have been answered. If I have any questions in the future about this study they will be answered by the investigator. I understand that this consent ends at the conclusion of this study."

Name & Contact Information:

Signature