Performa and Informed consent
Project Title:

Genetic Studies on Nephrotic Syndrome

Patient Details

- Name:
- ID #:
- Date of Birth:
- Sex:
- Type of interventional procedure:

SAMPLE DETAILS

Amount of blood collected:

Collected on:

Time of sampling:

CONTACT DETAILS:

Informed consent – English & local language
Nephrotic syndrome is a disorder in which the kidneys are damaged, causing them to leak large amounts of proteins. It is a disease characterized by disruption of the glomerular filtration barrier of the kidney. Mutations in the genes encoding for these proteins cause severe podocyte changes and nephrotic syndrome in turn leads to end-stage renal disease (ESRD).

Hence the aim of the study is to investigate the significance of the gene mutations in correlation with the pathogenesis of Idiopathic Nephrotic syndrome. On the investigations of the nephrologists and on his confirmation that you are Nephrotic syndrome patient I have included in the present study. If you agree to participate you parent/guardian will be administered a structured questionnaire by a trained field investigator. The questionnaire will have questions related to Nephrotic Syndrome. The participation in this study for answering the questionnaire will require approximately one hour of your time. A trained and authorized hospital employee will collect 3-5ml of blood from your child.

**Possible Risks to the participant:** There are NO risks involved or anticipated in the study. Blood collected will be performed by a trained and authorized hospital employee.

**Possible Benefits to the participant:** It is expected that once we identify the Genetic basic of disease is useful for the clinician to provide better treatment and genetic counseling.

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

**Confidentiality:** Information obtained in this study is strictly confidential. The volunteer will be assigned a specific code and his/her name will not be used in reporting of information in publications or conference presentations.
Participants’ right to withdraw from the study: The volunteer parent/guardian of the child has the right to refuse to participate in this study, the right to withdraw from the study and the right to have his/her 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 (PARENT/GUARDIAN) CONSENT IS REQUIRED BEFORE YOU CAN PARTICIPATE IN THIS STUDY. ISOLATED DNA SAMPLE STORED MAY BE USED FOR FUTURE RESEARCH STUDIES IF PERMITTED.

Storage of Samples: The samples processed for this study will be appropriately labeled with the patients ID number and refrigerated.

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 in the study. All of my questions concerning this study have been answered. I understand that this consent ends at the conclusion of this study.

By signing this form, I agree to participate in this study. A copy of this form has been given to me.

Date: Parent/Guardian Signature
Place: Name:

For any further queries please contact:

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CERTIFICATION OF INFORMED CONSENT

I certify that I have explained the nature and purpose of this study to the above-named individual, and I have discussed the potential benefits of this study participation. The questions the individual had about this study have been answered, and we will always be available to address future questions.

Date: ____________________________  Signature of person obtaining consent/assent

Name: ______________________________
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