

Information About the Research

Research Project Title: Study looking at the eyes of people with Alport syndrome

We would like to invite you to take part in a research study. Please take your time to decide whether or not you wish to participate. If you do agree to participate, you will still be free to withdraw at any time.

Why is this study being done?

People with Alport syndrome may have kidney problems and hearing problems. It has been shown that some people with Alport syndrome also have changes in their eyes that may or may not affect their vision. The purpose of the study is to examine the eyes of a number of individuals with Alport syndrome, to try to see what kinds of changes are present and how common they are. This will help us in our understanding of the condition, and may also help with better diagnosis in the future.

Why have you been chosen?

All patients with Alport syndrome are offered the chance to participate in this study.

What will this study entail?

An appointment will be offered for review in the eye department at St Thomas' Hospital, where you will be asked some questions about your eyes and general health, and then receive a full eye examination. You will also undergo a number of non-invasive investigations (which are routine in many eye clinics) that give us more detailed information about the eye and its function. Some of the tests will be done by technicians. In total, the whole examination would take approximately one hour. Travel expenses will be reimbursed,

Dilating drops will be used to enlarge your pupils to allow a better view of the back of the eye. These drops can blur your vision for 3 to 4 hours, so it is important not to drive after your appointment.

How will my details be used?

All data will be kept securely and only available to the investigators in the study.

What are the possible disadvantages and risks of taking part?

The tests involved in this study do not pose any risk to your health or vision.

What are the possible benefits of taking part?

You will be contributing to helping us understand how Alport Syndrome affects the eye and how this might be related to kidney problems. The main purpose of the study is research. This is not a clinic appointment, and the study will not benefit you directly. However, you will receive a very thorough eye examination and will be offered advice if any features are identified.

Who is doing this study?

Mr. Mohamed is a Consultant Ophthalmologist who runs the Medical Retina service and works at St. Thomas' Hospital. He and his team will undertake the work necessary for this study.

What do I need for the appointment?

Please bring along your distance and reading glasses if you have any, along with your optician's prescription for glasses if you have this with you.

If you have any other queries or if you need this information leaflet in large print please contact or leave a message with Mr. Mohamed's secretary at St Thomas' Hospital on (020) 7188 4329 or email Omar.Mahroo@gstt.nhs.uk