



Information for families

**Regional Genetics Service North Thames (East) based at
Great Ormond Street Hospital for Children NHS Trust**

This leaflet explains about the genetics service based at Great Ormond Street Hospital (GOSH) and what to expect when you come for an appointment. The service covers North East London and Essex and deals with adults as well as children.

Why have I been offered an appointment at the genetics clinic?

People are seen in the clinic for many different reasons. Some people know that there is a genetic condition in their family and want to find out the chance of developing the condition themselves or of having a child with it. Other families come to the clinic because someone else in the family has a problem and they want to know whether it has a genetic cause. The clinic team may be able to make a diagnosis, or discuss with you the chances of other people in the family having similar problems. It is also possible to arrange testing during pregnancy for some conditions and you will be told whether this would be possible for you.

Who will I see at the clinic appointment?

This clinic is run by doctors and genetic nurses/counsellors from GOSH, although appointments are often offered in other hospitals. You will be seen by either a doctor or a genetic nurse/counsellor. As some medical conditions diagnosed in this clinic are rare, we may ask the opinion of other specialist doctors, and these doctors may also come to a clinic appointment to give more information. We also have visiting doctors who have come to the clinic to learn more about genetics. If you would prefer to see just the genetics doctor or the genetics nurse /counsellor, please let us know before the appointment.

If you have any questions, please ring the number on your appointment letter or the Clinical Genetics Unit, on 020 7905 2647

What is the aim of the clinic appointment?

Families where one or more members of the family have or might have a genetic condition can be referred to the clinic by their consultant or family doctor (GP). The aim of the appointment (or series of appointments) will be different for different families, but may include making a diagnosis, and discussing whether other people in the family, or future children, could have similar problems.

What will the clinic appointment involve?

Each appointment lasts about 30-45 minutes. The doctor will draw your family tree, making notes of any existing genetic problems and ask you various questions about your relatives. The doctor may also want to do a blood test, take some photographs or arrange some other tests.

We realise you will have lots of questions too, and will hope to answer these for you.

You and your partner should attend the appointment if possible. If the appointment is to try to make a diagnosis in your child, you should bring the child. It can also help us if you bring to your appointment one or two photographs of them at different ages.

After the clinic appointment, we will send you a summary letter about what was discussed, the results of any tests, and contact information for us at the clinic. We are happy for you to contact us at any point in the future if you have any further questions or worries.

We will also send a copy of the letter which we send you to your family doctor (GP) and any other doctors who look after your family, unless you ask us not to. We will not reveal any information about you to other people such as mortgage brokers or insurance companies unless you ask us to. Occasionally we will liaise with other Genetics Centres if it is helpful for you or your family.

Notes



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