

Your Child's Clinical Genetics Appointment

Information for parents or guardians of children attending a clinical genetics appointment for the first time

This leaflet has been produced to give you some information on what to expect when you and your child attend your Clinical Genetics appointment. It also details some of the services that we can offer you and your family.

Why has my child been offered a Clinical Genetics appointment?

Your paediatrician, GP or hospital specialist has requested that your child is offered an appointment in Clinical Genetics.

Patients are seen in Clinical Genetics for a variety of reasons:

- Your doctor may be asking for a genetics opinion to help to make a diagnosis for your child.
- Some individuals may be planning to start (or to add to) their family. They would like information on the risk to current or future children and to discuss their options.
- Some people may know there is a genetic condition running in their family and wish to seek advice or explore the possibility of testing.
- Others may be concerned that a condition in their family might be genetic. They may wish to find out whether or not they are at increased risk.
- Some patients may be referred to us for management of their condition, and this might include being referred for screening.

Before your child's Clinical Genetics appointment

A member of the Clinical Genetics Team may contact you by telephone before your appointment to discuss your family's medical history and to gather a family tree.

If they have difficulty contacting you, they may leave a message.

If you have any concerns regarding this, please contact the department on **0131 537 1116**.

What will my child's Clinical Genetics appointment involve?

Your child will be seen by a doctor. A clinical genetics support member of staff may also attend this appointment. The appointment may be face-to-face or take place over NearMe video conferencing.

The appointment will last approximately 30-45 minutes. Your family's medical history will be discussed and there may be further questions about your relatives. All of this information will then be used to draw (or to add to) your family tree.

If your genetic appointment is to try and make a diagnosis for your child, it may be helpful to bring along one or two photographs of your child at different ages.

A full physical examination may be required, and a sample of blood or saliva may be taken. Height and weight may be measured and, with your permission, photographs may be taken. Your child's developmental and medical history will also be discussed. The clinician may also wish to arrange some other tests. It is sometimes helpful to have sample from parents and this will be discussed, if appropriate.

We realise that you may have many questions and we hope to answer these at your appointment.

If you are unable to attend your appointment, or need to reschedule, please let the department know as soon as possible, via the Appointments Secretary on 0131 537 1266. The appointment line is open Monday to Friday 9.30am–12.30pm.

Genetics is a fast developing area of medicine, and therefore, if a diagnosis is not made initially, your family may be asked to return later to discuss any new information. If there are any changes to your family history in the meantime, please contact the department on **0131 537 1116** to let us know so we can review as required.

What will happen after the Clinical Genetics appointment?

You will usually receive a letter summarising the information that was discussed. You are welcome to contact us at any point in the future if you have any further questions or concerns.

If you are waiting for results, you will be contacted when they become available, and you may be offered a further appointment to discuss them.

Other family members

If any of your family members have previously been seen by the Clinical Genetics Team, please let us know as we may have already obtained some of the relevant information.

Feedback

The Clinical Genetics Team wants to provide you with the best possible service. You may therefore be asked to comment on your experience at the Clinical Genetics Clinic so we can continue to give you the best possible care in the future.

Contact information

Your local genetics service:

South East of Scotland Clinical Genetic Services
Institute of Cancer and Genetics
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

Telephone: 0131 537 1116

Email: loth.wghclinicalgenetics@nhs.scot Please note, due to NHS Lothian Confidentiality Policy, we are not permitted to respond by email, and cannot correspond about patient management.

