

Saint Mary's Hospital
Manchester Centre for Genomic Medicine

Information for Patients

The Genetic Clinic

Important information about your appointment

This leaflet explains what to expect at your appointment in the genetic clinic and also asks you to do a few things before you come, to help you get the most out of your appointment.

Why have I been referred to the Genetic Clinic?

Some medical conditions are due to changes in a person's genetic make-up and some of these run in families. Clinical geneticists and genetic counsellors give people information about these conditions and how they are inherited, provide genetic testing, help draw up management plans and discuss reproductive options.

There are many reasons for being referred. Not everybody who comes to our clinic has an inherited condition.

How may the genetic clinic help me?

- A genetic condition has been identified in your family.
- You have a child with a physical or developmental problem.
- Problems have been identified during pregnancy.
- Genetic testing may be needed to reach a diagnosis.
- Information about a specific condition has been requested.
- Explanation of a genetic test result has been requested.
- Information about recurrence risks been requested.
- Information about pregnancy options has been requested.

Before your appointment:

- The genetic clinic is based in the Genomic Medicine department at Saint Mary's Hospital, Manchester. However, some clinics are held at other hospitals, so please check your appointment letter to ensure you know the location of your clinic.
- You will receive a text reminder about your appointment one week and one day before you are due in clinic. It would be helpful to inform us if your telephone number changes.
- 30-45 minutes have been allocated for your appointment. If you are unable to attend please ring us straight away on **(0161) 701 1845** or **1847** so we can allocate your appointment to another patient waiting to be seen.
- If another member of your family has been seen in the genetic clinic, please let us know their name, date of birth and Genetic Clinic file number (if known) before your appointment. You can ring us with this information on **(0161) 276 5430**.
- You may receive a letter from the clinic co-ordinator asking for specific information or consent for us to obtain relevant information from another relative if this is considered essential. Please try to provide this information before your appointment.
- Your appointment is for you (or where a child is referred, for the child and their parents). You may wish to bring a partner, family member or friend to the clinic. However, if another relative has also been referred to our clinic, they will usually need a separate appointment.
- If you require an interpreter, please telephone us in advance of your appointment on **(0161) 701 1845** or **1847**.
- If you have questions you want to ask before attending your clinic appointment, please telephone us **(0161) 276 6506**.

Family history details

To give you accurate information, we need to ask you for details about your family history and to draw a family tree. Please come to the appointment with as much of the following information that you can gather in advance.

However, please do not worry if the information available to you is limited.

For any affected relatives:

- Full name and date of birth.
- When and where they were diagnosed.
- Address when they were seen, if known.

For your parents, siblings and children:

- Full name and date of birth

We will not ask for medical records of any relatives without their signed consent and we will not contact your relatives directly unless you specifically ask us to do so.

At your appointment:

- You will be seen by a clinical geneticist (a medical doctor specialising in genetic disorders) or a genetic counsellor, or both, depending on the reason you have been referred.
- You will be given time to discuss your concerns and ask questions. Some people find it helpful to write down their questions beforehand.
- We will go through your medical and family history details with you.
- You (or your child) may be examined by the doctor if necessary.
- We will give you information about the condition, explain how it might be inherited and discuss the implications of this with you.
- We will discuss choices about genetic testing and reproductive implications if appropriate and support your decision making.
- We can provide information about patient support groups relevant to you.
- A blood sample may be taken for genetic tests if clinically relevant and if you wish to go ahead with this.
- Your medical records and tests results will remain confidential, however, we may ask your permission to use information about the result of your genetic tests to guide testing of other members of your family.
- If there are any ongoing research or clinical trials for your condition, we may discuss these with you.

After your appointment

- We will send you a summary letter.
- We will write to your GP and the referring doctor unless you specifically ask us not to do so.
- If we need to gather further information, we can arrange to see you again when we have this.
- If genetic tests have been done, we will arrange to give you the results once they are available.

- You will be given a telephone number to contact the genetic counsellor or doctor if you have further questions.
- You will be able to request further appointments in the clinic.
- Arrangements may be suggested for other family members to be referred.
- Some patients will continue to have long term follow up contact with us and for some conditions there is a Genetic Family Register Service. If this is relevant to you, this will be discussed in the clinic.

For more information

If you need more advice about any aspect of your appointment, you are welcome to contact:

Manchester Centre for Genomic Medicine

Sixth Floor
Saint Mary's Hospital
Oxford Road
Manchester
M13 9WL

Telephone: (0161) 276 6506 (Reception)

Facsimile: (0161) 276 6145

The department is staffed Monday - Friday, 9.00 am to 5.00 pm.

Website: www.mangen.co.uk

Please let us know if you would like this leaflet in another format (e.g. large print, Braille, audio).

We would like to acknowledge our Clinical Genetics colleagues at Guy's and St Thomas' Hospital NHS Trust who originally designed and wrote this leaflet.

Seen in clinic by (doctor): _____

And (Genetic Counsellor): _____

Telephone number: _____

Family reference number: _____