

## **Welcome to Liverpool Centre for Genomic Medicine (LCGM)**

### **A guide to your referral**

### **Information Leaflet**

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This leaflet provides important information to help people who are referred to us. It aims to answer some of the common questions we are asked.

### **Why have I been referred to Liverpool Centre for Genomic Medicine?**

Genomic medicine is the medical specialty for individuals or families with, or at risk of, conditions which may have a genetic basis. Genetic disorders can affect any body system and any age group.

### **Before your appointment**

We offer different types of appointments in different hospitals in the region. You may see a Doctor or Genetic Counsellor in clinic and we also offer telephone and video appointments.

Therefore we ask patients to carefully note the **time, date and location** of their appointment to avoid missing it

We will always try and provide you an appointment that is closest to you but this is not always possible due to waiting times or suitability e.g. some of our clinics are only suitable for children.

**Please note:** our clinic rooms at the Liverpool Women's Hospital are in the antenatal clinic. If you feel it would be difficult for you to be seen in an antenatal department please ring and we may be able to offer you an appointment at one of our other clinic sites.

### **Family History Collection Team (FHCT)**

The FHCT may contact you before your appointment. Their job is to gather information in preparation for your appointment to make the appointment as useful as possible. They may take details of people in your family who have had genetic testing, draw a family tree or make a note of the growth and development of your child. The FHCT are non-clinical members of staff and will not be able to answer any questions in relation to the reason you have been referred to LCGM. However they can note down any specific questions you would like answering in your appointment.

### **What if I have a disability such as a visual or hearing impairment or I need support to get to or at an appointment or I need a translator?**

Please ring or email us to let us know if you require additional support in your appointment and we will do our best to accommodate your needs. See contact details below.

### **Parking**

Parking availability and cost of parking varies. Please check where your appointment is and look at that hospital's website for parking details.

## At my appointment

You will be seen by a member of the genomic medicine team. This may be a Doctor who specialises in genetics or a Genetic Counsellor.

Most genetic appointments are 45 to 60 minutes long, so you should not feel rushed. We are happy for friends or family to attend with you to provide support.

What happens in your appointment will vary depending on the reason for your referral but may include:

- A detailed discussion of the reason that has brought you to the clinic
- The drawing of a family tree (if not drawn up beforehand) and medical details of relatives may be asked about (such as the cause and age of their death). It is useful to have found out these details before you come to the clinic, or bring a relative who will know.
- A medical examination may be carried out if appropriate.

The doctor/genetic counsellor will explain their assessment to you, and discuss your options and choices. You will be encouraged to ask questions and to make your own decisions.

In some situations, tests (such as blood tests) may be offered. Some tests are available on the day of your appointment, but often you will be asked to take some time to make a decision, and come back. The results from genetic testing often take several weeks to several months, so, even if you have a blood sample taken on the day of your appointment, you will not receive any results the same day.

At the end of the appointment a plan will be made. This may include information gathering, special tests and/or another appointment

## My child has been referred to the LCGM, should I bring them to the appointment?

Your child will need to come to the appointment if an examination is required. However, we can offer you another appointment without your child if you have any questions you would rather not ask in front of them. We always encourage children to be involved in their appointment and we will not offer genetic testing to a child without including them in any discussions if possible. We will always try and tailor the appointment to be age appropriate.

## After your appointment

We will send you a summary letter. If anything in this is unclear, please do not hesitate to contact the department with any queries.

**Please note: there is an option to have your letter and any other correspondence sent via email. Do not hesitate to ask your clinician for this option if you have not been asked.**

We will write to your GP and the referring doctor unless you specifically ask us not to do so. If genetic tests have been done, we will arrange to give you the results once they are available. Arrangements may be suggested for other family members to be referred.

## Where else can I get information before my appointment?

- Liverpool Women's Hospital Website: [www.liverpoolwomens.nhs.uk](http://www.liverpoolwomens.nhs.uk)
- NHS Choices: <https://www.nhs.uk>
- Genetic Alliance: [https://www.geneticalliance.org.uk/cancer research UK](https://www.geneticalliance.org.uk/cancer-research-uk)
- The Association of British Insurers: <https://www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetics-faqs>

## Feedback welcome

We strive to continually improve the service we deliver in the best way we can and your feedback is very important to us. You will receive a 'friends and family' text after your appointment which will provide you with the opportunity to feedback your experience. Comments, suggestions and complaints can also be made through PALS. Call 0151 702 4353 or email [PALS@lwh.nhs.uk](mailto:PALS@lwh.nhs.uk)

**If you need more advice about any aspect of your referral into Genomic Medicine, you are welcome to contact:**

Liverpool Centre for Genomic Medicine

Liverpool Women's Hospital NHS Foundation Trust

Crown St. Liverpool, Merseyside L8 7SS

Telephone 0151 802 5001 or 5008

Email: [lwft.clingen@nhs.net](mailto:lwft.clingen@nhs.net)

This leaflet can be made available in different formats on request. If you would like to make any suggestions or comments about the content of this leaflet, then please contact the Patient Experience Team on 0151 702 4353 or by email at [pals@lwh.nhs.uk](mailto:pals@lwh.nhs.uk)

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