



## Information for Patients

# Your appointment at the Genetic Eye Clinic

This leaflet provides information for patients newly referred to the Genetic Eye Clinic in Manchester.

**Please note: Eye drops are likely to be used in order to assist the examination**

### Where is the Genetic Eye Clinic held?

The Genetic Eye Clinic takes place either on the ground floor of Manchester Royal Eye Hospital or in the Genomic Medicine Department on the 6th floor of Saint Mary's Hospital. Please check your appointment letter for the location of the clinic for your appointment.

### What is the Genetic Eye Clinic?

A number of conditions affecting the eye have a genetic cause. This means they are due to a change in a person's genetic make-up. The clinic brings together experts in both Ophthalmology and Genetics to provide a specialist service for individuals and families with inherited eye conditions.

### Why have I been referred to the Genetic Eye Clinic?

You have been referred because either:

- You or your child have or are suspected to have an eye condition which has a genetic cause.
- You or your child may be at risk of inheriting an eye condition due to a family history of eye problems.

## Who will I see at the clinic?

- Ophthalmologists - Medical doctors with specialist training in conditions affecting the eye.
- Clinical Geneticists - Medical doctors with specialist training in conditions that have a genetic cause.
- Genetic Counsellors - Health care professionals with training and expertise in communicating genetic information and supporting families with genetic conditions.
- Eye Clinic Liaison Officers (ECLO) - Professionals who provide support and advice around issues such as registering as sight impaired, accessing welfare benefits and local support organisations.

## How long will the appointment take?

You will need to allow at least 2 hours for the first appointment. If a review appointment is needed, this is likely to be shorter.

## Do I need to bring anything with me?

- Your glasses or contact lenses.
- You should be prepared to provide information about your family history, particularly any family members who have had visual problems.
- You are encouraged to bring someone with you such as a partner, family member or friend.

If you have copies of letters from other hospitals these will be useful.

## What should I expect at the appointment?

- Your family tree will be drawn and we will ask for more information about the eye condition in the family.
- You and/or your child are likely to have an eye test and eye examination by an Ophthalmologist.
- Eye drops to dilate your pupils are likely to be used. Depending on the type of drops used these may result in blurred vision for a few hours following their use and so it will not be possible for you to drive immediately after your appointment. You may need to come with a driver or make alternative transport arrangements. Parents of children seen in clinic may also need to have their eyes examined if this has not been done previously.

- You may have photographs taken and scans of the back of the eye.
- In some cases we will ask to carry out a general examination on you or your child, including measurement of height and weight.
- In some cases, a blood sample may be collected to test the genes that can cause an inherited eye condition.
- You will have the opportunity to discuss:
  - The details of your/your child's eye condition including how it may affect eye sight, how it may progress in the long term and how it can be managed.
  - Any further investigations or tests that may be helpful.
  - How the condition is inherited (passed on in families), including the chance of other family members being affected.
  - For some conditions it is possible to offer genetic testing and this will be discussed with you if relevant. A blood test may be needed for this.
  - Research updates including current studies you may be eligible to take part in.
- Referral to other services, such as social services and local support.
- How you are coping practically and emotionally with the impact of the eye condition.
- Diagrams may be used in clinic to aid explanations about genetics. We encourage you to ask if you require these in a larger size or tactile format.

## What will happen after my appointment?

- You will be sent a letter summarising what happened at the appointment. Your GP and any other specialists you see will usually receive a copy of this letter.
- It is not always possible to answer all questions in the first appointment. You may only need to attend for one appointment or several appointments may be needed. You will be told at your appointment whether you need to be seen again.

**If you require this leaflet or any correspondence in an alternative format, such as large print or electronically, please contact Genetic Medicine on: (0161) 276 6506, 9.00 am – 5.00 pm, Monday – Friday.**