

How often do I attend?

Some patients only need to attend this clinic once. Others will be asked to return for follow up. This will be decided at the first appointment. After your first appointment a letter will usually be sent to you to summarise the main points of the discussion. This also provides information about contacting the department if you have any outstanding questions, or if you would like a further appointment.

Who can I contact with questions?

Sue Carless,
Specialist genetic counsellor,
Clinical Genetics Service
Tel: 0121 627 2630

Further information

Birmingham Focus on Blindness
48-62 Woodville Road
Harborne, Birmingham, B17 9AT
Tel: 0121 478 5200
www.focusbirmingham.org.uk

Contact a Family
209-211 City Road
London EC1V 1JN
Tel: 020 7608 8700
www.cafamily.org.uk

Royal National Institute of Blind People
105 Judd Street
London, WC1H 9NE
Tel: 020 7388 1266
www.rnib.org.uk

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Birmingham Women's 
NHS Foundation Trust

Eye Genetic Clinic

An information leaflet for
patients and families

If you need more advice about any
aspect of the Eye Genetic Clinic
please contact:

Clinical Genetics Unit
Birmingham Women's
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Mindelsohn Way
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Birmingham
B15 2TG

Telephone: 0121 627 2630

Fax: 0121 627 2618

Email: Clinicalgenetics.info@bwhct.nhs.uk

Introduction

The eye genetic clinic was set up to bring together staff from the eye department (ophthalmology) and the clinical genetics department to see patients who have or are suspected of having an inherited eye condition in their family.

Why have I/my child been referred to the Clinic?

You have been referred to this clinic because you or a member of your family has a condition that affects the eyes. This condition may be inherited and the clinic can give you an opportunity to discuss relevant issues.

Do I need to bring anything?

You may have been contacted by a genetic counsellor and been asked about the eye condition in the family and whether or not there is a family history. If you have not, it would be helpful if you could try and gather some information about eye conditions in your family. It is sometimes helpful to assess other family members e.g. brothers and sisters, as well as parents, and this is why several members of the family may be sent appointment letters for the same day.

What can I expect?

There will usually be two doctors in the clinic; an eye doctor and a genetics doctor, as well as a specialist genetic counsellor. They will examine your eyes and then talk to you about their findings.

Discussions may include:

- How the condition affects you, your child and plan of care
- Screening other members of your family for the same condition
- Availability of genetic testing

The appointment will usually last for 30 to 60 minutes, although we recommend that you allow 2 to 3 hours as this normally allows us to arrange any unexpected assessments.

Will other tests be done?

We may need to arrange investigations of how your eyes work. These will often be arranged immediately before seeing the doctors. The results of these tests are usually reported straightaway and will be discussed with you by the doctors. Some of these tests and the examination require eye drops. These are needed to enlarge (dilate) the pupil (the black part of the eye), so that it is easier to examine the back of the eye. This is a routine test done on people referred to the eye department.

A blood sample may be taken and sent to a genetics laboratory for testing, but this is not always possible. If a blood sample is taken for genetic testing the results can take many months.

What effects do the eye drops have?

The drops affect the ability to focus causing blurred vision for around 4 to 5 hours. For a child this means they will need close supervision until their vision returns to normal. Playing on climbing frames, cycling, skating etc should be avoided.

FOR ADULTS: YOU WILL NOT BE ABLE TO DRIVE OR OPERATE MACHINERY FOR AT LEAST 4 HOURS

You may also need somebody to escort you who would be able to supervise your children adequately on the journey home.

While your pupils are dilated you may be sensitive to light until the pupils return to normal. Wearing sunglasses or a peaked cap may help the discomfort. If you or your child's eyes become red or sore, a reaction to the eye drops may have occurred. Please inform the doctor before leaving the clinic if you think this has occurred.