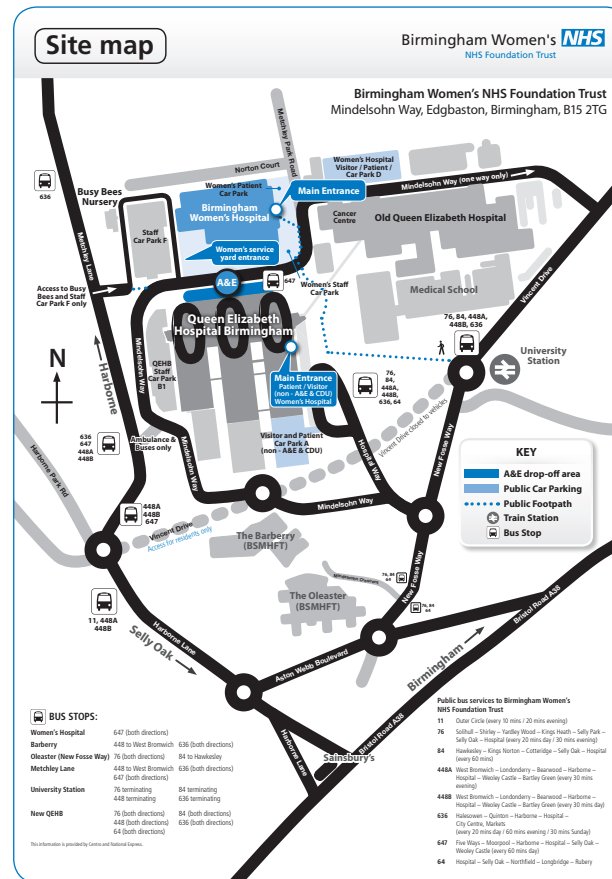


## Whom can I contact with questions?

- Renal Genetics Nurse Specialist and / or Clinical Genetic Service, Birmingham Women's Hospital 0121 627 2630
- Renal Outpatients Department, Queen Elizabeth Hospital 0121 472 1311 or 0121 627 2000

## Further information

- PKD charity [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk)
- National Kidney Federation [www.kidney.org.uk](http://www.kidney.org.uk)
- Cystinosis UK [www.cystinosis.org.uk](http://www.cystinosis.org.uk)
- CLIMB (children living with inherited Metabolic diseases): [www.climb.org.uk](http://www.climb.org.uk)
- MPS society for Mucopolysaccharide Diseases: [www.mpsociety.co.uk](http://www.mpsociety.co.uk)
- Orphanet (information on rare diseases and drugs) and links to support across Europe: [www.orpha.net](http://www.orpha.net)
- The Genetic Interest Group: [www.gig.org.uk](http://www.gig.org.uk)



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Birmingham Women's NHS Foundation Trust

# Renal Genetics Clinic

An information leaflet for parents and families

If you need more advice about the Renal Genetics Clinic please contact:

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Edgbaston  
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B15 2TG

Telephone: 0121 627 2630  
Fax: 0121 627 2618

Email: [Clinicalgenetics.info@bwhct.nhs.uk](mailto:Clinicalgenetics.info@bwhct.nhs.uk)

## Introduction

The renal genetics clinic was setup to bring together staff from the kidney department (nephrology) and the clinical genetics department to see patients who have or are suspected of having an inherited kidney disease in their family.

## Why have I been referred to this clinic?

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

## Do I need to bring anything?

You may have been contacted by the renal genetics nurse specialist and been asked about the kidney condition in the family and whether or not there is a family history, or been sent a family history form. If you have not, it would be helpful if you could try and gather some information about kidney conditions in your family. It is sometimes helpful to assess other family members (e.g. brothers, 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: a kidney and a genetics doctor, as well as a renal genetics nurse specialist. This saves you coming to two separate appointments on different days. The specialists work together, to try and give you the best possible advice.

The appointment usually lasts for 15-30 minutes, although we recommend that you allow 1 hour as this normally accounts for waiting times and various measurements (e.g. checking your blood pressure and urine).

The doctors and counsellor will discuss:

- How the kidney condition affects you and your family, and the plan of care
- Whether any genetic tests are available, and the implications of any test results for you and your family
- Screening other members of your family for the same condition
- Genetic testing in children who are at risk
- Options of testing in a pregnancy
- Any issues relating to kidney donation

They will also give you a chance to ask any questions. You may like to write these down before your appointment, and bring them with you to your appointment.

## Will other tests be done?

We may need to arrange for scans to be performed at a later date. A blood sample may be taken to check your kidney function. A blood sample may also be taken and sent to a genetics laboratory for testing, but this is not always possible. If a genetic test is performed then the results can take many months.

## What will happen after the clinic?

You will be sent a letter after you have been seen in the clinic, to summarise the main points of the discussion. This also provides information about contacting the department if you have any outstanding questions. If further counselling issues are raised and you would like more time to talk these through, then clinical genetics team can arrange to see you at another appointment.

## 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.

**If you are unable to make your appointment or do not wish to have an appointment in this clinic, please let us know as soon as possible so that the appointment can be offered to another patient.**