



#### Will I need to come back?

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.

#### What does it cost?

Your child's consultation is free of charge. You may be asked to contribute or pay for tests that are not funded by Medicare or the State Government.

## Where can I get further information?

Ms Ella Wilkins - Associate Genetic Counsellor

Telephone: (03) 9936 6333 E-mail: <u>ella.wilkins@vcgs.org.au</u>

If your child is unable to attend their appointment or you do not wish for them 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.

This clinic is provided in conjunction with the Victorian Clinical Genetics Services.



#### The Royal Children's Hospital Melbourne

50 Flemington Road Parkville Victoria 3052 Australia www.rch.org.au









### **Renal Genetics Clinic**

An information leaflet for patients and families





#### What does the clinic do?

The renal genetics clinic was set up to bring together staff from the RCH Nephrology Department and the Victorian Clinical Genetics Services to see patients who have or are suspected of having an inherited kidney condition.

## Why is my child attending this clinic?

Your child has been referred to this clinic because they have a condition that affects the kidneys. This condition may be inherited (passed within families) and this clinic can give you an opportunity to find out more about the condition, the way it may be passed within the family, and to ask questions.

# What can I do to prepare for the clinic?

Your child's kidney problem may be inherited. It would be helpful for you to find out if any of your relatives have had problems with their kidneys, high blood pressure, or diabetes.

A genetic counsellor will contact you prior to your child's appointment to ask you questions about your child's personal and family health history.

Asking about this in advance helps us to prepare for the appointment, and provide your child with the best possible advice.

### What will happen in clinic?

There will usually be two doctors in the clinic: a kidney doctor (Nephrologist) and a genetics doctor (Clinical Geneticist), as well as a genetic counsellor (an allied health professional trained in genetics and providing support to families). The specialists work together, to try and give you the best possible advice.

The appointment usually lasts 45-60 minutes. The doctors and genetic counsellor may discuss some or all of the following:

- How the kidney condition affects your child and your family, and the plan of care
- Whether any genetic tests are available, and the implications of any test results for your child and your family
- Screening other members of your family for the same condition
- Options of testing in a pregnancy
- Opportunities to participate in research

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

It is important to note that although your child's nephrologist may be present at the appointment, the focus will be on discussing genetic issues rather than management of your child's kidney condition.

### Will any testing be done?

If an appropriate genetic test is available, your child may be asked to provide a blood or saliva sample. If a genetic test is performed, the results can take many months.

# What happens after the appointment?

You will be sent a letter after your child has been seen in the clinic, to summarise the main points of the discussion. This also provides information about contacting the clinic staff if you have any outstanding questions. If further issues are raised and you would like more time to talk these through, please contact the clinic via the genetic counsellor.