

AUSTRALASIAN REGISTRY OF RARE AND GENETIC KIDNEY DISEASE (ARRK)

PATIENT INFORMATION SHEET (Children)

Title:	The Australasian Registry of Rare and Genetic Kidney Disease
Short Title:	ARRK
Protocol Number:	HREC Protocol Number: HREC/15/SCHN/517
Project Sponsor:	This research project is supported by an Enabling Grant from the Australian And New Zealand Society of Nephrology (ANZSN)
Coordinating Principal Investigator:	Dr Hugh McCarthy
Principal Investigators:	Professor Stephen Alexander, Dr Jeffery Fletcher, Dr Andrew Mallett, Dr Cathy Quinlan, and Dr Chirag Patel

We would like to invite you to take part in a study that helps us find out more about kidneys and why they sometimes go wrong.

This information sheet tells you about our study and what is involved.

Please read this information sheet carefully and ask if you have any questions.

The problem with your kidneys is rare – that means not many people have it. Doctors want to know more about it (and so do families!) but it is difficult to find out more information.

So we have set up a new group to collect as much information as possible from people with rare kidney diseases. This group is called ARRK and we will collect information on people from all over Australia and New Zealand to allow us to understand better how these kidney problems affect people like you.

There are already doctors and scientists working to try and find out about your condition and they are going to start working together to find out more.

If you and your family agree, information about you and how your kidney problem has affected you (like what age you were when you first got it and what medicine your doctor gave you) will be put on a computer database.

You and your family can look at the information on the computer, at any time, with a special password. Your kidney doctor will know all about it and can talk to you about it.

Sometimes the doctors and scientists may find out something which helps and they will let you, your family and your doctor know this new information.

You have to have a password to read the computer program so only you and a few people can see the information about you.

Do you want to ask any questions now?