

AUSTRALASIAN REGISTRY OF RARE AND GENETIC KIDNEY DISEASE (ARRK)

PATIENT INFORMATION SHEET (Adolescents)

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 you to invite you to participate in a research study that aims to enable research into rare and genetic kidney diseases.

This Participant Information Sheet and Consent Form tells you about the Registry and what your participation would involve. It will help you to decide whether or not you would like to take part.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Participation in this registry is voluntary.

What is the research about?

The disease the doctors are treating you for is quite rare. It is often difficult to find out about a rare disease. Clinical research helps doctors (and patients!) learn more about diseases but this is difficult when only a small number of people are affected. Sometimes it is difficult for doctors to make progress and patients may struggle to get any good information about their illness.

The **Australasian Registry of Rare and Genetic Kidney Disease**, also known as **ARRK**, is an initiative of kidney specialists in Australia and New Zealand that aims to bring together as much information as possible from patients throughout Australia and New Zealand who have certain rare and/or genetic kidney diseases to enable us to get a much better understanding of how these illnesses affect people.

How does the registry work?

Any person who has a rare or genetic kidney condition is able to join this study.

If you agree (consent) to participate, clinical information about you and your disease, for example when it started and what treatment you've had, will be copied from your medical record and put onto the ARRK database. Your kidney doctor will update your information so we can keep note of any changes over time.

Any person who consents to participate in the registry will be given special access to the registry via the internet and you will be able to see, at any time, the information that is being collected about you.

Doctors and scientists who are already researching your specific disease are working together as a group known as the **Disease-Specific Research Group**. An agreement has been signed between the DSRG and the ARRK such that they will only be able to see your clinical information once they have your permission (consent). ARRK will tell you before you give permission what information the DSRG want. They will be able to view the data but not amend it. The DSRG may also contact you/your family directly through the registry to provide you with general updated information, or to invite you to participate in new research projects. This would allow the DSRG to use the information about you and other patients with the same condition in their research. If you give permission to join the registry, you would also be giving permission for the DSRG to contact you or your family about new research projects.

Up to the age of 18 we need your parent/guardian's permission for you to participate in this study, although we would like you to give your permission as well if you want by co-signing the Parent/Guardian Consent form. When you reach 18 years of age, we will send you an Adult Participant Information Sheet and Consent Form for you to sign and consent for yourself if you wish to remain in

the registry. If you haven't consented when you reach 18 years of age, ARRK and DSRG will stop contacting you or collecting information on you.

What would I be agreeing to?

By consenting to participate in the registry you are agreeing to your clinical information being held on a secure server operated by ARRK. You will be given a password that gives you secure access to your information via the internet. You are also consenting to receive information from ARRK and the DSRG whilst your information is stored in the registry. ARRK will not share any of your personal information with any other organization.

Consenting to participate in the registry does not commit you to have to be part of any research projects in the future if you don't want to.

Who else will know that I am participating in the registry?

Your kidney doctor will know that you are participating in the registry (ARRK). They will be responsible for entering your clinical information onto the registry. They will also be provided with feedback from the registry, and will be told if the DSRG investigating your condition wants to contact you. Your GP will also be informed that you are participating in the registry.

How secure is my clinical information?

The registry is designed so that all your information will remain secure. Once your information is uploaded to the system, it will be encrypted for extra security. The database will be hosted and maintained by the Centre for Comparative Genomics, Murdoch University, WA using the Rare Disease Registry Framework (RDRF). This institute is used to the handling and storage of many other databases like this one.

Can I have time to think about this?

Yes, you can take as much time as you need. If you decide you would like to participate, we would ask that you co-sign the Parent/Guardian Consent Form.

What happens if I change my mind?

You can withdraw from ARRK (pull out of the registry) at any time without affecting your relationship with the hospital or kidney specialist. If you would like

to withdraw consent, we advise that you speak with your parent or guardian and they can either write to ARRK directly or contact your kidney specialist to make this change.

Who is responsible for ARRK?

ARRK has been set up with the support of the National Kidney Research Organization known as the Australia and New Zealand Society of Nephrology (ANZSN) and the registry has been ethically reviewed and approved by the Sydney Children's Hospital Network Human Research Ethics Committee.

Who can I contact for further information?

If you would like further information about the registry or have any concerns please discuss these with your family and your kidney specialist. If you have any questions that they may not be able to answer, please contact the study lead, Dr Hugh McCarthy of the ARRK Registry program at the address below.

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