

# AUSTRALASIAN REGISTRY OF RARE AND GENETIC KIDNEY DISEASE (ARRK)

## CONSENT FORM – Parent and Guardian

**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

### Declaration by Parent / Guardian

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I give permission for my child's treating doctor, other health professionals, hospitals or laboratories outside this hospital to release information to the ARRK registry concerning my child's kidney disease for the purposes of this project. I understand that such information will remain confidential. I understand that ARRK will data share with ANZDATA where appropriate. I understand that we may be approached through the registry regarding secondary research studies within Australasia.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to my child participating in this research project as described and understand that I am free to withdraw them at any time during the research project without affecting their future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Child or Adolescent (please print):

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Signature of Adolescent: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Parent / Guardian (please print)

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Signature of Parent / Guardian: \_\_\_\_\_ Date: \_\_\_\_\_

*Under certain circumstances (see Note for Guidance on Good Clinical Practice CPMP/ICH/135/95 at 4.8.9) a witness\* to informed consent is required.*

Name of Witness\* to Parent / Guardian's Signature (please print):

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Signature of Witness: \_\_\_\_\_ Date: \_\_\_\_\_

\* The Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witnesses must be over 18 years of age.