

AUSTRALASIAN REGISTRY OF RARE AND GENETIC KIDNEY DISEASE (ARRK)

Letter of Invitation

Thank you for taking a moment to read this invitation.

This letter is sent from a new initiative of the Australasian Renal medical community known as the Australasian Registry of Rare and Genetic Kidney Disease or ARRK.

Your local team has identified that you would be suitable to participate in this study (if you choose). The initiative has been formed to improve our understanding of rare and genetic kidney diseases and to increase the level of research that is undertaken into these conditions within Australasia.

The team leading the research includes both doctors of kidney medicine (for children and adults) and doctors of clinical genetics as well as patient representatives. A contact is provided at the end of this letter.

The purpose of this registry (ARRK) is to collect information about rare and genetic kidney diseases so that we may better understand them. It allows us to collate data from participants throughout Australasia. This information will show the impact of these conditions on individual patients and on the health system and could help us to improve our ability to diagnose, investigate and ultimately treat these conditions.

We have developed a secure, web-based database to hold clinical data for participants from throughout Australasia. It is held on a secure server hosted and maintained by the Centre for Comparative Genomics, Murdoch University, WA using the Rare Disease Registry Framework (RDRF). Participants are given secure password access to be able to look at their own data.

The second aim of the project is to develop an information website for patients and their families who are affected by rare or genetic kidney disease. The information will include all aspects of problems that patients are faced with and is open to the public.

An information sheet is enclosed with this letter, which describes the registry in more detail. Your local team will discuss this with you when you are next seen.

Should you have any questions, please do not hesitate to discuss them with your local team or contact the group.

Yours sincerely,

On behalf of ARRK, The Australasian Registry of Rare and Genetic Kidney Disease

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