



If you are an adult with Autosomal Dominant Polycystic Kidney Disease (ADPKD) who has slightly reduced kidney function and treatment with tolvaptan is not suitable for you, we invite you to learn more about a new clinical trial called STAGED-PKD. This clinical trial will look to see how well a new drug (venglustat) works in slowing the rate of kidney function decline and how safe it is. This treatment is only available to people who are enrolled in the clinical trial and we would like to extend you the opportunity to be involved in this important research.

MISSION

The STAGED-PKD Study is currently recruiting adults who have been diagnosed with ADPKD, have mildly reduced kidney function and aged between 18 and 50 years. The study is being conducted in many countries and also at two sites in Australia (Sydney and Brisbane).

BACKGROUND

Autosomal Dominant Polycystic Kidney Disease (ADPKD) is the most common genetic kidney disease, caused by variations in one of two genes (PKD1 or PKD2). This leads to formation and progressive growth of fluid filled cysts in kidneys. Polycystic Kidney Disease affects approximately 6000 Australian families.

If you are interested in STAGED-PKD please take the following short quiz to see if you might be eligible:



1. Have you been diagnosed with Autosomal Dominant Polycystic Kidney disease?

✓ Yes > *If yes, move on to question 2*

✗ No > *Sorry, currently you do not qualify for this research project*

2. Are you between the ages of 18 and 50 years old?

✓ Yes > *If yes, move on to question 3*

✗ No > *Sorry, currently you do not qualify for this research project*

3. Are you willing to travel to the study site 13 times over 2 years? You will be reimbursed for your travel expenses, including if you live outside of Sydney or Brisbane.

✓ Yes > *If yes, please contact the site*

✗ No > *Sorry, currently you do not qualify for this research project*

If you have answered yes to all of these questions you may be eligible for participation in the STAGED-PKD clinical trial. Please contact your nearest site:

Royal Brisbane and Women's Hospital, Brisbane, QLD:

email - Belinda.Elford@health.qld.gov.au

Principal Investigator: A/Prof Andrew Mallett

Study Coordinator: Belinda Elford

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Principal Investigator: A/Prof Gopi Rangan

Study Coordinators: Dr Annette Wong and Alex Munt

Details: <https://clinicaltrials.gov/ct2/show/NCT03523728?term=venglustat&cond=ADPKD&rank=1>