

Disease

Autosomal Dominant Polycystic Kidney Disease

Protocol Title

Autosomal Dominant Polycystic Kidney Disease Data Repository

Principal Investigator

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Enrollment Status:

Open to Enrollment

Brief Summary of Protocol:

Autosomal dominant polycystic kidney disease (ADPKD) is the most common inherited kidney disease, affecting more than 500,000 people in the U.S. and 10 million people worldwide. PKD is the 4th most common cause of kidney failure requiring dialysis and/or transplantation. Over half of all PKD patients develop kidney failure by age 60 years, although age of onset of kidney disease varies widely, even among members of the same family.

Although this is a relatively common problem, relatively few patients have been studied for a sufficient period to fully understand how patients are affected over the course of their lifetime. The reason for creating this repository is to collect information about PKD so that we may fully understand its complications, including high blood pressure, kidney failure, stroke, and heart disease. This information may also aid in the development of improved methods for diagnosis of ADPKD and of strategies for treatment.

If you join the research study, you will take part for as long as you wish to continue. About 300 people will take part in the research study.

What specifically makes a person eligible for the study?

You may be eligible to enter this study if you are 18 and older and have been previously diagnosed with ADPKD.

Potential Benefits:

You and others may one day benefit by the increased understanding that this information may give us about polycystic kidney disease. However, we cannot guarantee that you will benefit personally from this study.

Compensation:

There is no cost to you for being in this research study.