



ADPKD Registry Basics

The PKD Foundation created and operates the ADPKD Registry to collect de-identified data from individuals with autosomal dominant polycystic kidney disease (ADPKD). By sharing their disease experience with scientists, Registry participants help accelerate research. As of January 2025, there are more than 3,000 participants in the Registry.

- › **WHY IT MATTERS** The ADPKD Registry is an opportunity to collect patient perspectives, add depth to the knowledge of ADPKD disease progression, and directly contribute to research through an IRB-approved clinical study.
- › **HOW IT WORKS** There are 10 available modules, including:
 - » Core Questionnaire
 - » Family History
 - » Diet and Lifestyle
 - » ADPKD Pain and Discomfort Scale
- › **USING REGISTRY DATA** Within the Registry, participants can see how their disease experience fits into the larger population.
- › **SHARING DEIDENTIFIED HEALTH RECORDS** The ADPKD Registry houses a powerful database of clinical PKD patient data. By consenting to include your de-identified electronic health record with the Registry you get personalized clinical trial recommendations. This accelerates trial recruitment, which enables studies to be completed in less time.
- › **JOINING THE REGISTRY** The ADPKD Registry uses a secure platform—we prioritize protecting your data. Joining involves three steps.
 1. Create an online account
 2. Agree to an informed consent
 3. Complete the core questionnaire

Join the ADPKD Registry today!



JOIN TODAY
pkdcure.org/registry