PKD FOUNDATION
Polycystic kidney disease

ADPKD Registry Basics

The PKD Foundation's ADPKD Registry is a growing, patient-powered research tool that captures real-world insights from people living with autosomal dominant polycystic kidney disease (ADPKD).

Why it Matters

Recent advances in ADPKD research have made it increasingly realistic to slow — and potentially even stop or reverse — cyst growth. To move these breakthroughs forward, dozens of clinical trials are already underway or in development. These studies will require thousands of people with ADPKD to participate.

Timely enrollment is critical. Delays in filling clinical trials can postpone research progress and slow the approval of promising new treatments by years.

The ADPKD Registry helps address this challenge by connecting patients with research opportunities more quickly and efficiently.

Advancing Research Beyond Clinical Trials

The ADPKD Registry also supports research in other important ways. Data collected through the Registry can help researchers:

- Identify new biomarkers that track disease progression.
- Improve predictive tools that help researchers design clinical trials.

These benefits reduce the number of participants needed for future studies and accelerate the path to new drug approvals.

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 informed consent
3. Complete the core questionnaire

Participating in the ADPKD Registry is your opportunity to play a meaningful role in curing ADPKD.

See reverse side to see how it works.

Join today!

Learn more at
pkdcure.org/registry

How It Works

There are two ways to participate in the ADPKD Registry.

---

1. Link Your Electronic Health Records

Participants can securely link their electronic health records (EHRs) to the Registry. This automatically provides up-to-date clinical information that can help match patients with clinical trials they may qualify for.

Linking health records also allows de-identified disease progression data to be combined with information from thousands of other participants. Researchers can use these data to:

- Improve clinical trial design.
- Better understand how ADPKD progresses over time.

2. Complete Patient-Reported Questionnaires

Participants can also contribute directly by completing questionnaires, called “modules,” that capture experiences not typically included in medical records.

These modules provide valuable insights into the lived experience of ADPKD and may include topics such as:

- Family history.
- Diet and lifestyle.
- Pain and discomfort.
- Daily quality of life experiences.

Together, these patient-reported insights help researchers gain a more complete understanding of ADPKD and identify areas where new treatments and support are needed most.

Participating in the ADPKD Registry is your opportunity to play a meaningful role in curing ADPKD.
Join today!

Learn more at
pkdcure.org/registry