The ADPKD Registry has **3,005** enrolled participants as of October 19th, 2023. These participants are from all 50 states and the District of Columbia. The Registry is an opportunity to collect patient perspectives, recruit for clinical trials, and add depth to the knowledge of ADPKD progression through an IRB approved study.

**Electronic Health Records (EHR)**

In August of 2023, the ADPKD Registry introduced patient-mediated EHR donation. This is made possible due to the 21st Century Cures Act.

**Data from over 90 unique Medical Centers**

**150+ linked health records**

*as of 10/23/23

**Registry Data Sharing Portal**

PKDF is excited to invite applications for access to Registry data!

Email research@pkdcure.org with details of your research question. Data Dictionaries and Quarterly Data Profiles are available to help determine if our data is appropriate for your project.

**Refer Patients Today!**

pkdcure.org/registry


**NON-WHITE PARTICIPANT DEMOGRAPHICS OVER TIME**

- **Identify as Hispanic or Latino**
  - 2020: 4%
  - 2022: 8%

- **Gender**
  - Male: 28%
  - Female: 71.5%
  - Nonbinary, transgender, or other: 0.5%

- **CKD Stage**
  - Stage 1: 13%
  - Stage 2: 15%
  - Stage 3a: 15%
  - Stage 3b: 13%
  - Stage 4: 11%
  - Stage 5: 5%
  - Unknown: 24%

**ANNUAL IMPACT REPORT 2022 FINDINGS**

- **Nearly 9,000 Recruitment Contacts for Likely-Eligible Patients!**
  - 7 Clinical Trials
  - 11 Observational Studies

**POPULATION DEMOGRAPHICS**

- Nearly 9,000 Recruitment Contacts for Likely-Eligible Patients!
Race and Ethnicity in the ADPKD Registry
Needed to modify lifestyle because of PKD pain & discomfort

Relationships affected by dull kidney pain

Relationships affected by fullness or discomfort