

# ADPKD Centers of Excellence Program

## Program Goals

- > To identify and recognize gaps in clinical care to improve ADPKD outcomes, encourage disease-specific management strategies, and improve health equity.
- > To directly support the mission of the PKD Foundation by developing and maintaining mentoring relationships between recognized PKD experts and less experienced nephrologists and community specialists.
- > To utilize patient education and engagement activities among the regional community to increase awareness of the disease and form relationships with their patient community.
- > To advance research to improve the lives of patients with ADPKD and their families managed at centers, and participate in the ADPKD Registry. Ultimately, clinical data collected through the Registry will provide an evidence-base upon which to create standards of care in the United States, and specialized PKD training for healthcare professionals.

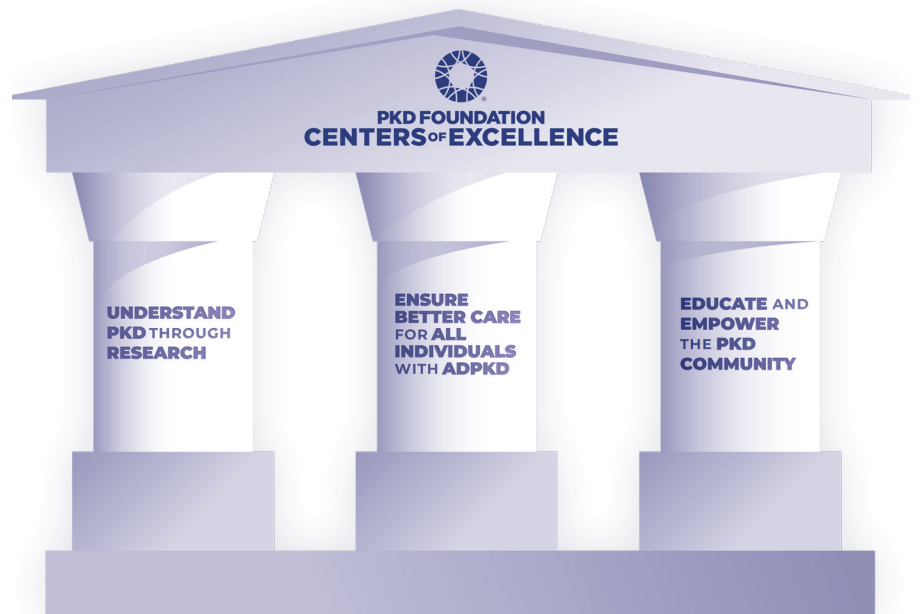
## Vision

The PKD Foundation Centers of Excellence (COE) program is built upon the belief that the best way to provide ADPKD-centered care is through patient-focused, comprehensive care with the coordination and support of an integrated care team.



## Mission

The program's mission stands on three pillars.



## Care team and services

ADPKD Centers of Excellence provide comprehensive multidisciplinary clinical services for families affected by ADPKD. Services are centered around an organized ADPKD clinic in which:

- > an individual's clinical care needs are defined
- > plans are made to fulfill those needs
- > follow-up is provided to continually optimize clinical management.

Core clinic personnel must have established and demonstrated expertise in caring for a person with ADPKD. Depending on the level of services offered, ADPKD Centers will be categorized as Centers of Excellence or Partner Clinics. Whether it's to become a Center of Excellence or a Partner Clinic, we encourage all interested clinics to apply for the program.

## Care team expectations



A CENTER OF EXCELLENCE will offer comprehensive diagnostic and therapeutic services with identified staff responsible for most services in each of the following disciplines:

- > Nephrology
  - > Radiology
  - > Nutrition
  - > Genetics
  - > Pain
  - > Hepatology
  - > Patient navigator services
- Funding support and grants are available for patient navigators. Learn more on our website or email [eliseh@pkdcure.org](mailto:eliseh@pkdcure.org).*

Non-core specialists that are preferred but not required:

- > Pediatric nephrologists
- > Renal nutritionists or dieticians
- > Urologists
- > Neurosurgeon or neurologists
- > Transplant surgeons
- > Liver surgeons
- > Cardiologists
- > Obstetricians (high-risk pregnancy specialization)
- > Psychologists or psychiatrists
- > Social workers

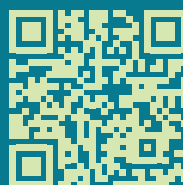


PARTNER CLINIC core personnel will include, at a minimum, a nephrologist interested in specialized management of ADPKD.

## Important dates

- Application site opens — April 2024
- Application deadline — Aug 26 2024
- Review period — Sept to Oct 2024
- Applicant notification — Oct 2024

## Apply for the program



[pkdcure.org/coe-apply](https://pkdcure.org/coe-apply)

### Questions?

To view funding opportunities, ask questions, or make comments, please contact [eliseh@pkdcure.org](mailto:eliseh@pkdcure.org).