



ADPKD Centers of Excellence Program

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.



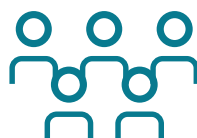
The program's mission stands on three pillars:



Understanding PKD through research



Ensuring better care for all individuals with ADPKD



Educating and empowering the community

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.



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Care team and services



ADPKD Centers of Excellence provide comprehensive multidisciplinary clinical service 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, and 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.

COE 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
- > Hepatology
- > Genetics
- > Pain
- > Patient navigator services

Non-core specialists that are preferred but not required include:

- > Pediatric nephrologists
- > Renal nutritionists/ dieticians
- > Urologists
- > Cardiologists
- > Liver surgeons
- > Neurosurgeons/ neurologists
- > Obstetricians (high-risk pregnancy specialization)
- > Psychologists/ Psychiatrists
- > Social Workers
- > Transplant surgeons

Core personnel at a Partner Clinic will include, at a minimum, a nephrologist interested in specialized management of ADPKD.

We encourage both Centers of Excellence and Partner Clinics to apply.

There is funding support and grants available for patient navigators. You can learn more about applying for a grant on our website or email eliseh@pkdcure.org.

Apply for the program

- > Application site opens — June 2022
- > Application deadline — Aug 29 2022
- > Review period — Sept to Oct 2022
- > Applicant notification — Oct 2022



pkdcure.org/coe-apply

To view funding opportunities, have questions or comments, please contact eliseh@pkdcure.org.