PKD FOUNDATION
Polycystic kidney disease

PKD Centers of Excellence Program

Program Mission

Understand PKD through research

To advance research to improve the lives of patients with PKD and their families through participation in the ADPKD Registry and studies led by our network of care centers.

Ultimately, clinical data collected through the ADPKD Registry will provide an evidence-base upon which to create standards of care in the United States, and specialized PKD training for healthcare professionals.

Ensure better care for all individuals with PKD

To identify and recognize gaps in clinical care to improve PKD 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.

Educate and empower the PKD community

To utilize patient education and engagement activities among the regional community to increase awareness of the disease and form relationships with their patient community.

Vision

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



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Care Team Expectations and Services

Adults

Centers of Excellence (COE)* 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 Service

Non-core specialist 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 includes, at a minimum, a nephrologist experienced in specialized management of ADPKD.

Pediatric

Pediatric COEs* offer comprehensive diagnostic and therapeutic services with identified staff responsible for most services in each of the following disciplines:

- Pediatric nephrology
- Genetics
- Pediatric hepatology
- Pediatric renal nutrition
- Social work
- Pediatric-to-adult care transition

Non-core specialists that are preferred but not required:

- Gynecologist/adolescent medicine
- Neurosurgeon or neurologists
- Pain specialists
- Pediatric intensivists
- Pediatric radiologists
- Pediatric surgeons
- Pediatric urologists

Pediatric Clinic core personnel includes, at a minimum, a nephrologist experienced in specialized management of pediatric PKD.

Core clinic personnel at adult Centers must demonstrate expertise in ADPKD, while those at pediatric Centers must have demonstrated expertise in pediatric PKD (ARPKD or pediatric ADPKD). Based on the scope of services provided, Centers will be designated as either a COE or a Partner Clinic, and similarly as a Pediatric COE or Pediatric Clinic. **We welcome all interested clinics to apply and join the program.**

***COEs** and **Pediatric COEs** provide comprehensive, multidisciplinary care for families affected by PKD, centered around a dedicated PKD clinic that assesses individual needs, creates care plans, and ensures ongoing follow-up for optimal management.

Apply to the Program

pkdcure.org/coe-apply

Have questions or want to explore future opportunities? Contact us at carecenters@pkdcure.org

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