



PKD Clinical Center Database

FIND A CLINIC WEB PAGE LISTING FORM

Clinic/Medical Center name:

Clinic/Medical Center address:

Name of person filling out form:

Date:

The PKD Foundation is hosting a Clinical Center Database on our Find a Clinic web page to improve access to quality care for PKD management. The information you provide will help patients assess the best clinics in proximity to where they live and work. It is important that PKD patients have access to quality care by clinicians who are up-to-date on the latest PKD research and clinical standards. This is not intended to be a certification or favorites list, but instead a patient-facing database that will help them identify the best centers for their PKD care.

Data will be collected from each listed center and will rely on self-report; the Foundation will not validate or verify any information provided. However, the Foundation reserves the right to remove or refuse to list any center/clinic/clinician for any reason.

NOTE: not all of the below fields need to be filled out in order to be included in the database. Instead, these will serve as sorting criteria on our web page.

Please fill out the following about your clinic/medical center.

A. Currently follows ADPKD patients

Number of patients currently followed:

- a. <10
- b. 10-100
- c. 100+

B. Currently follows ARPKD patients

Number of patients currently followed:

- a. <3
- b. 3-10
- c. 10+

C. Pediatric PKD clinic

Number of patients currently followed:

- a. <3
- b. 3-10
- c. 10+

ASSOCIATED SPECIALTIES

- D. Affiliated kidney transplant center
Patients are interested in whether transplant centers consider steroid-free protocols post-transplant. Please specify if applicable.

Number of kidney transplants per year (on average):

- a. <10
 b. 10–100
 c. 100+

Number of live donor transplants per year (on average):

- d. <10
 e. 10–100
 f. 100+

- E. Genetic testing and counseling center
- F. Liver specialists with expertise in PKD (or PLD specialists)
- G. Neurosurgeons/neurologists (familiar with aneurysm screening and treatment)
- H. Cardiologists
- I. Dialysis services
Check all that apply.
- a. Hemodialysis
 b. Home hemodialysis
 c. Peritoneal dialysis
- J. Dietitians or nutritionists
- K. Interventional radiologist (familiar with cyst aspiration)
- L. Urologists
- M. High-risk pregnancy obstetricians
- N. Dermatologist
- O. Performs nephrectomy procedure
Patients are interested in whether transplant centers consider simultaneous transplant nephrectomies. Please specify if applicable.

- P. Mental health specialist
- Q. Social worker

PEDIATRIC PKD CLINIC

- R. Hepatologists (familiar with congenital hepatic fibrosis)
- S. Dedicated pediatric dialysis unit
- T. Pediatric dietitians
- U. Child life specialists

ADDITIONAL ITEMS

- V. Participation in current clinical studies
Please list all clinical trials, observational studies and registries specific to PKD currently ongoing at your institution. Example: [name of study], [name of drug, if applicable], [name of sponsor]
- W. Provides mentorships for trainees (e.g. postdocs, fellows) in PKD-specific areas
- X. Prescribes tolvaptan
- Y. Please indicate if you are willing to display brochures on the ADPKD Patient Registry and other PKDF resources in your clinic waiting room.
If yes, please provide the best mailing address to which we can send the materials.

Please list the nephrologists at your clinic **with PKD as their primary focus** (include email addresses and links to their bio on the clinic web page if applicable.)
Clinician email addresses to be used internally by the Foundation only, and will not be shared on the public-facing web page.

Please list the nephrologists at your clinic **familiar with PKD** (include email addresses and links to their bio on the clinic web page if applicable)
Clinician email addresses to be used internally by the Foundation only, and will not be shared on the public-facing web page.

Indicate which of the above clinicians work with pediatric patients

Please provide the contact information for the appropriate staff member patients may contact when confirming health insurance coverage for your clinic.

What is the best way for new patients to schedule an appointment with your clinic?

If applicable, provide addresses for other locations affiliated with this clinic. If the clinic characteristics and associated specialties differ, please fill out separate forms for each.

Additional miscellaneous services and details that you would like to highlight

CLINICIAN ENGAGEMENT

By signing up to be featured in the PKD Clinical Centers Database, each clinical center/ listed clinician agrees to receive PKDF correspondence regarding continuing education resources focused on PKD for the clinician, ongoing PKD studies in their area (for referral), and free access to relevant UpToDate content including the following:

- Diagnosis of and screening for autosomal dominant polycystic kidney disease.
- Course and treatment of autosomal dominant polycystic kidney disease.
- Renal manifestations of autosomal dominant polycystic kidney disease.
- Extra-renal manifestations of autosomal dominant polycystic kidney disease.
- Hypertension in autosomal dominant polycystic kidney disease.
- Pain syndromes in autosomal dominant polycystic kidney disease.
- Urinary tract infection in autosomal dominant polycystic kidney disease.
- Genetics of autosomal dominant polycystic kidney disease and mechanisms of cyst growth.
- Autosomal dominant polycystic kidney disease in children.
- Autosomal recessive polycystic kidney disease in children.
- Patient information: Polycystic kidney disease.

Please return this form, along with a photo of your clinic/institution and logo to
Elise Hoover at eliseh@pkdcure.org.