

Category	Metric	Value
Care Center Designations	Centers of Excellence	40
	Partner Clinics	33
	Pediatric Centers of Excellence	4
	Pediatric Clinics	4
	Total Care Centers	81
Patient Volume	Total ADPKD Patients	14,697
	Total ARPKD Patients	1,411
	Total Patients Served	16,108
Research Engagement	Clinical Trial Referrals	1,174
	ADPKD Registry Referrals	3,665
Clinical Metrics	hTKV Documented	69.20%
	Mayo Imaging Classification	68.70%
Research Activity	Industry-Sponsored Studies	34
	Investigator-Led Studies	29
	Other Research Activities	31
	Clinics with Publications (2025)	21

Activity	Number
PKD Foundation event promotion: Walk for PKD, webinars, conferences	93
Patient-facing education: community meetings, lab tours, webinars	63
Support for local PKD groups: meeting space, advisory panels	17
Educational outreach beyond meetings: pamphlets, physician CE, partnerships	6
Special events & community outreach: golf events, festivals, dialysis conferences	3

Care Center	Professional Collaborations / Partnerships	Educational Activities & Talks
Cleveland Clinic Children's / Mayo Clinic Children's	Pediatric nephrology collaborations	Grand Rounds and specialized PKD lectures
Emory University Hospital	Patient referrals for genetic and clinical trials	–
Geisinger Clinic	KDIGO Genetics Summit; PKD-MD program	–
Loma Linda University Health	Multi-center PKD COE webinars	AI in ADPKD sessions; Rare Kidney Diseases Conferences with dedicated PKD sessions
Mayo Clinic Rochester	National & international institution partnerships; ADPKD clinical trial collaborations	Webinars & invited talks on ADPKD and PKD Centers of Excellence; PKD Foundation advisory roles; patient symposium planning
Mount Sinai Hospital / Montefiore Medical Center	ADPKD Consortium with multiple regional hospitals	Core faculty for PKD Medical Directorship program
The Kidney and Hypertension Center	Multi-institutional study collaborations	Internal educational talks
The Rogosin Institute	Collaborations with PKD Foundation and academic institutions	PKD Open House, professional lectures, and podcasts
Tufts Medical Center	Multi-center trial support and regional mentorship	Guidance for establishing and optimizing regional PKD clinics
University of California San Diego	PKD advocacy programs supporting professional initiatives	PKD-free Alliance initiatives
University of Chicago	Collaborations with nearby academic institutions	CME ASN Pre-Course on Genetics & Kidney Medicine; local CME Genetics & Kidney Disease
University of Maryland School of Medicine	Collaborations with national academic centers	Co-Chair KDOQI PKD Guidelines; educational lectures on ADPKD diagnosis and genetics
University of Michigan Medicine – Mott Children's Hospital & Rady Children's (UCSD)	Pediatric nephrology teaching	Lectures on ARPKD, ADPKD, and related cystic kidney diseases
University of Oklahoma / The Ohio State University	External collaborations for extrarenal ADPKD and polycystic liver	Educational lectures for providers
University of Pennsylvania	Pediatric PKD transition programs	Invited lectures on ADPKD and KDIGO guidelines internationally
University of Southern California / UCLA	Clinical trial partnerships and PKD advocacy programs	Presentations at global KDIGO Genetics in Kidney Disease Summit
University of Vermont	Multi-center clinical trials (BEAT-PKD)	Participation in national outcomes and research consortiums
University of Wisconsin-Madison	Multi-center ADPKD study collaborations	PKD Foundation COE advisory/review roles; national webinars on clinical manifestations
Yale University School of Medicine	Collaborations with regional nephrology groups	–

Category	COE	Impact / Outcomes
Patient Education & Materials	Mayo Clinic Rochester; University of Kansas; University of Wisconsin–Madison	Developed welcome packets , improved educational materials, and enhanced visit preparation resources
	University of Chicago	Strengthened provider awareness and patient education quality
	UCSF; University of Iowa	Identified priority topics: pain, transplant, genetic testing, mental health, lifestyle
Clinical Care Improvements	University of Colorado Anschutz	Enabled nephrectomy at time of transplant
	UAB; UCLA	Created SOPs, transplant checklists, and standardized care pathways
	UC San Diego; UCLA	Improved pre-visit planning, lab coordination, and follow-up workflows
Patient Experience & Coordination	UC San Diego; University of Michigan	Improved continuity of care, scheduling, and communication
	University of Kansas	Enhanced transplant tour and patient-facing experience
	Indiana University	Identified resource gaps and navigation challenges
Programs & Services Expansion	University of Miami	Launched newsletter, peer support program, and hired patient navigator
	Geisinger	Expanded clinical trial and industry engagement
Community Engagement & Events	Rogosin; Columbia	Led PKD Open Houses and patient-driven events
	USC; University of Maryland	Guided symposium topics and education events
	Emory; MUSC	Initiated fundraising efforts and secured grant funding
Operations & Strategy	St. Luke's	Implemented Compass Rose tool for tracking outcomes and gaps
	Yale; UNC; Columbia	Used feedback to guide care delivery improvements and strategy
Panel Engagement Status	Wisconsin; Columbia	Strong engagement, repeat participation and leadership
	UPenn; BIDMC; SLU	Limited activity , plans to restart
	Vermont; Kidney Institute	Flexible/ad hoc models , planning expansion