

Comprehensive services offer unified care for polycystic kidney disease patients



The Polycystic Kidney Disease (PKD) Program at UCLA is dedicated to leading the fight against PKD by providing the highest-quality patient care, performing cutting-edge research and educating patients and healthcare professionals about the disease.

Polycystic kidney disease is a systemic disease characterized by the accumulation of numerous fluid-filled cysts in the renal parenchyma and other organs, including the liver. It's the third most common cause of kidney failure and the most common inherited form of kidney disease, often affecting multiple members and generations of the same family, including newborns, children and adults.

The fragmentation of patient services has been a longstanding challenge for both PKD patients and healthcare providers. At UCLA, a multidisciplinary team offers comprehensive care for both autosomal dominant polycystic kidney disease (ADPKD) and autosomal recessive polycystic kidney disease (ARPKD).

A focus on patient education

Early diagnosis is critical to preserving good health. Like most other kidney diseases, PKD tends to progress without clear symptoms, meaning the diagnosis can be easily missed. PKD is diagnosed using kidney ultrasound, and UCLA nephrologists with the Polycystic Kidney Disease Program are available to consult with primary-care physicians to assess cases of suspected PKD.

Translational research improves patient outcomes

Polycystic kidney disease is the focus of significant research, and patients are now benefiting from a more sophisticated understanding of the molecular underpinnings of kidney injury and cyst formation. This research has identified new potential therapeutic targets in effector molecules, says Dr. Anjay Rastogi, MD, PhD, associate professor and PKD program director.

“There is a lot of excitement in the field regarding effector molecules,” he explains.

“Researchers are increasingly interested in how those molecules can be modulated to slow down the progression of kidney disease.”

Patients in the Polycystic Kidney Disease Program can access clinical trials that represent the leading edge of translational research, including studies on new therapies that could significantly delay the need for dialysis. An equally important part of care is providing patient education, Dr. Rastogi adds.

These include patients with hypertension that is resistant to treatment, those with family members diagnosed with PKD, and patients with non-specific symptoms — including backache and abdominal distention — that may be due to abnormal kidney size. Although there is no cure for the disease, a growing understanding of PKD has led to significant advances in slowing disease progression and postponing the need for dialysis to well into middle age in many cases. Patient education is the foundation for these quality-of-life gains. UCLA's patient-education efforts include diet and hydration, exercise, pain control and psychological health.

PKD is a systemic disorder that is frequently accompanied by other morbidities, such as hernias and problems related to grossly enlarged kidneys, cysts in surrounding organs including the liver and pancreas, brain aneurysms and cardiac abnormalities. Because the disease can present at any stage of life, a comprehensive PKD program must include expertise in both adult and pediatric care. UCLA's program is based on a team approach that includes collaboration among specialists in nephrology, neurosurgery, urology, radiology, transplantation, dialysis, hepatology, genetics, OB/GYN, pain, infectious disease, social work, patient advocacy, psychiatry and pediatrics.

Genetic counseling and pregnancy support

Due to the hereditary nature of the disease, many adults of reproductive age have important questions regarding family planning and the likelihood of passing on the disease to offspring. Patients have access to genetic counselors who can provide detailed information about the disease. Moreover, pregnant women or those who are planning a pregnancy are referred to obstetricians who are experienced in ensuring the health and safety of PKD patients.

Options in dialysis and kidney transplantation

About half of all PKD patients will have kidney failure by age 60. Patients at UCLA's highly regarded kidney dialysis program receive an in-depth consultation with a nephrologist to select the most appropriate modality, including in-center dialysis, home hemodialysis and home peritoneal dialysis.

Patients who qualify for kidney transplantation are referred to our state-of-the-art transplant program. UCLA's transplant success rates are among the highest in the country and the program offers all transplant surgery options, including paired-exchange, blood-group-incompatible and living-donor programs that might not be available at other centers.

Clinical trials provide optimal care

Recent research has elucidated some of the disorder's underlying genetic, molecular and cellular mechanisms, which has resulted in new investigational treatments. The UCLA PKD Program is committed to basic science, applied clinical science and outcomes research in its mission to develop new treatments and cures for the disease.

Clinical trial participation is encouraged because it offers promising treatments to help manage the disease along with close medical supervision and follow-up care.

Participating Physicians

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