What is polycystic kidney disease?

Polycystic kidney disease (PKD), a hereditary disorder, prevents the kidneys from functioning normally. PKD is one of the most common hereditary diseases, impacting about 600,000 people in the U.S. alone. There are two forms of this disease:

- Autosomal Dominant (AD-PKD).
- Autosomal Recessive (AR-PKD).

Each disorder can impact other organs in addition to the kidneys. Right now, there is no known cure or specific treatment for either form of PKD.

Often, the symptoms of PKD are not seen until a child reaches adulthood. The PKD Clinic, a specialized clinic of the Dialysis and Renal (Kidney) Program at Children's Hospital of Wisconsin, provides early diagnosis to prevent complications of PKD and to provide patient education. Research conducted in conjunction with this multidisciplinary, comprehensive clinic will lead to new treatments and clinical trials in the near future.



experts on the science and clinical aspects of PKD, having devoted more than 20 years of his professional life to PKD patients. He directs one of only two NIH-funded Pediatric Nephrology Centers of Excellence in the U.S. He also is the senior editor of the standard reference textbook, "Pediatric Nephrology."

Specialized services

The PKD Clinic is headed by Ellis D. Avner, MD, director and associate dean at Children's Research Institute and professor of Pediatrics and associate dean of Research at Medical College of Wisconsin. The program provides unique outpatient services in a multidisciplinary setting – it is the only clinic of its kind in the world.

In one visit, patients will have access to specialists who will play a role in their per sonalized treatment, including:

- Pediatric nephrologist, Ellis D. Avner, MD
- Genetic counselors.
- Geneticists.
- Hepatologists, including Grzegorz Telega, MD.
- Nephrology faculty, including
- Cynthia Pan, MD.
- Scott Van Why, MD
- Rajasree Sreedharan, MBBS
- Nutritionists.
- 444100
- Pharmacologists.
- Program coordinator
- Psychologists.
- Social workers.
- Specialized nurses

In addition to patient care and treatment plans, laboratory research will be translated into clinical trials, finding new approaches and advanced treatment options not available in other centers.

Comprehensive

care

The goal of the clinic is to better control symptoms, prevent complications, preserve quality of life and prolong survival. Unique long- and short-term care includes:

- Complete diagnostic services, including molecular genetic diagnosis when appropriate.
- Complete evaluation of the kidney and all potentially affected organ systems for all diagnosed patients.
 Dialysis and kidney transplantation are therapies available to children with

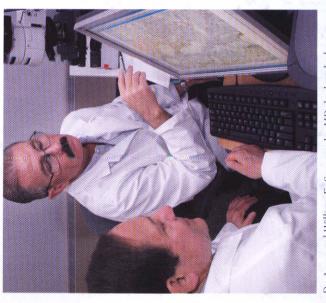
end stage renal disease.

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- Complete genetic counseling, including a unique program of pre-implantation genetic diagnosis and in vitro fertilization. This program may be of value for parents wishing to have additional children following the birth of a child with AR-PKD.
- Comprehensive management plans developed by specialists that are shared with referring physicians and families. These plans help all involved to understand the treatment, including medications, guidance for complications, blood pressure monitoring and control, nutrition, social work assistance and psychological health.

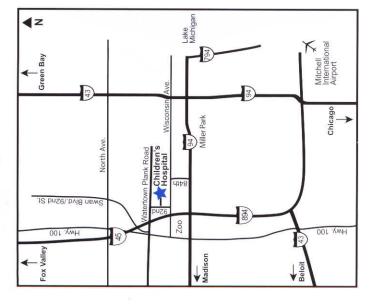
The clinic offers a home for new clinical trials and innovative therapies as they are developed in the basic research laboratories of Children's Research Institute.



Dr. Avmer and William E. Sweeney, Jr., MD, lead nephrology research at Children's Research Institute. The NIH-funded lab focuses on the development of new drug therapies for polycystic kidney disease.

Location

Clinics occur at least once a month in Clinic H at Children's Hospital of Wisconsin. For more information, contact Alison Schaffart, the nurse coordinator for the PKD Clinic, (414) 337-7755.





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