

ADPKD: Autosomal Dominant Polycystic Kidney Disease

What is ADPKD?

ADPKD is a kidney disease in which the kidneys have **cysts**. Cysts are collections of fluid. The cysts start out very small, but they can grow over time. Do not confuse ADPKD with autosomal **recessive** polycystic kidney disease (ARPKD), a completely different disease.

What causes ADPKD?

Genes cause ADPKD. Genes are the “instructions” on how to build your body. Genes control many things, such as the color of your hair or eyes. Children get genes from both of their parents. Genes also control some kidney diseases. When a child has ADPKD, it usually means that one parent has ADPKD, too. The parent may not know that he or she has ADPKD. A small number of patients have a “spontaneous” form of ADPKD. This form does not come from the parents.

ADPKD is **not** contagious. You can’t “catch” it from someone else. ADPKD is **not** a form of cancer.

What are the symptoms of ADPKD?

Most children with ADPKD feel fine. They have **no** symptoms at all. Many adults with ADPKD also do not have any symptoms. When people have problems from ADPKD, they may have:

- High blood pressure
- Blood in the urine
- Back or stomach pain
- Kidney stones
- Urinary infection

Many other diseases can also cause these symptoms. Your doctor can help you find out if the symptoms are from ADPKD.

Does ADPKD affect other parts of the body?

People with ADPKD often develop cysts in the liver. These cysts usually don’t cause problems. Some people with ADPKD have **aneurysms** (“an-yur-isms”) in the brain. An aneurysm is a weak spot in a blood vessel. Aneurysms can leak or burst, causing brain damage or even

death. The risk is higher if someone in your family who has ADPKD has had an aneurysm. If someone in your family had an aneurysm, you should have a test for one. Ask your doctor for more information.

How is ADPKD treated?

No current treatment makes the cysts go away. Doctors only treat problems related to the cysts. People with ADPKD who don't have any problems don't need any treatment. Some of the problems and treatments are:

Problem	Treatment options
High blood pressure	Low sodium diet, exercise, medicine
Blood in the urine	No treatment
Protein in the Urine	Medicine
Back or stomach pain	Medicine, surgery to drain large cysts
Kidney stones	Medicines, surgery, lithotripsy (breaking stones with sound waves)
Urinary infection	Medicine (antibiotics)

A little more than half of people with ADPKD develop kidney failure during their lifetime. This almost never happens during childhood. It usually happens around age 40 to 50. People with kidney failure must have **dialysis** or a **kidney transplant**. People with ADPKD need to see a doctor regularly for checkups. These checkups can help prevent problems, or treat them before they get worse.

Should other family members get tested for ADPKD?

If you have ADPKD, it's possible that your parent, brothers or sisters also have the disease. They may not have any symptoms. Many people have ADPKD and don't know it. Your doctor will probably suggest that these relatives get ultrasounds of their kidneys. There is also a blood test for ADPKD, but it is much more expensive.

You can give your relatives an information sheet called “When a relative has ADPKD.” Ask your doctor for a copy, or download it at:

<http://kidneyweb.net/handouts/ADPKD-Relatives.doc>

Where can I get more information?

Your kidney doctor is your first source for information. Be sure to ask any questions you have. You may want to write down questions so you can ask them at the next visit. The PKD Foundation provides information and support for people with ADPKD.

PKD Foundation

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Kansas City, MO 64114-3367

Web: www.pkdcure.org

Phone: 1-800-PKD-CURE

Fax: 816-931-8655

E-mail: pkdcure@pkdcure.org

The National Library of Medicine has additional information online at:

<http://www.nlm.nih.gov/medlineplus/ency/article/000502.htm>

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