Guide to talking about ADPKD with your family

What is Autosomal Dominant Polycystic Kidney Disease (ADPKD)?

Autosomal dominant polycystic kidney disease, or ADPKD, is a genetic disorder that causes fluid-filled cysts to grow in your kidneys. These cysts can cause kidney damage and over time, lead to kidney failure.

ADPKD is the most common kind of polycystic kidney disease and is the 4th leading cause of kidney failure globally.

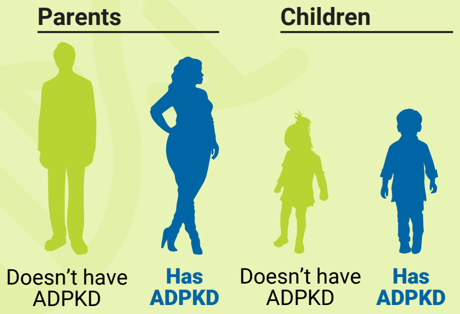
Why is it important to talk to my family about ADPKD?

ADPKD is a genetic condition which means it is passed down through families. If you have ADPKD, close relatives such as your grandparents, parents, and siblings may also have the disease. And there is a 50% chance your children could have ADPKD, even if the other parent does not have the disease.

It can be difficult to talk about a chronic condition with your family members. But, if you have ADPKD, you can help your family get the information they need.

Talking to your family about ADPKD is important to help them understand their risk and what they can do to help keep their kidneys healthy.

If just one parent has ADPKD, there is a 50% chance that each child will have it.



What do my family members need to know?

Your family members should understand their risk. If one of their parents has ADPKD, there is a 50% chance that they have the disease. Even if they have not been diagnosed, they could have ADPKD. Symptoms often start between 30 and 50 years old, so it is possible they have the disease but no symptoms.

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Talk to your family members about some of the symptoms of ADPKD so they can recognize them if they occur:

- Pain in your back and sides
- Headaches
- Blood in your urine (pee)
- High blood pressure
- Urinary tract infections
- Kidney Stones

If a family member experiences any of these symptoms, they should work with their healthcare provider to get tested.

You can also tell your family about genetic testing. If they have no symptoms but a close relative like a parent or sibling with ADPKD, they can get genetic testing to see if they have a gene mutation that causes ADPKD. This will help them better understand their risk.

Even if your family members are unsure if they have ADPKD, encourage them to take care of their kidney health by:

- Keeping a healthy weight.
- Staying hydrated.
- Taking all medicines as told by their doctor.
- Limiting or drinking less alcohol (no more than 2 drinks per day for men and 1 drink per day for women).
- Following a kidney-friendly eating plan.
- Quitting smoking or using tobacco.
- Being active for at least 30 minutes most days of the week.

Supporting one another with ADPKD

Living with ADPKD can take a mental and emotional toll. Your family can play a big part in your support system, and you can be a source of information and support for those who may receive an ADPKD diagnosis in the future.

Together, you and your family can talk about your risks for ADPKD and be there for one another.

Tips you can use to support each other:

- Be open and honest about your ADPKD experiences with your family members
- Share what has and what hasn't worked to help you manage your disease
- Make lifestyle changes together
    - Make kidney-friendly recipes
    - Be active, like taking walks or gardening
- Set aside time for activities not related to ADPKD
    - Family movie nights
    - Walks
    - Puzzles and board games

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This campaign is made possible with the support of: Otsuka