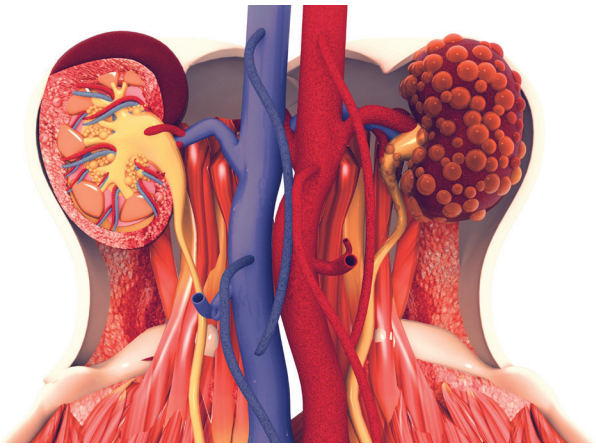
Understanding Polycystic Kidney Disease

Polycystic Kidney Disease (PKD) is a hereditary (inherited) disorder in which cysts form in the kidneys. This causes your kidneys to enlarge and lose function over time. Patients with PKD also may have cysts in other organs in the body including the liver, ovaries, pancreas, spleen and large bowel. Cysts in these areas typically do not cause organ failure as they do in your kidneys. In more rare cases, PKD can also cause problems with the brain or heart, which can cause serious damage, including brain aneurysms.



PKD is a fairly common disease with about 600,000 people having it in the United States[1]. That said, many people do not develop symptoms until they are in their 30's or 40's so this number is likely higher than the reported numbers state. There has been no research proving that this disease is more common in specific races or genders.

Approximately 50% of patients with PKD will experience kidney failure by the time they are 60 and 60% by the time they are 70[1]. Patients who have kidney failure will require a kidney transplant or dialysis. It is also important to note that not everyone with PKD will have kidney damage so severe that they will need dialysis in their lifetime. There is also a lot of research being done in this area that will hopefully result in even better results one day!

Types of PKD

As mentioned before, PKD is inherited and therefore runs in families. Parents pass the genes for this disease to their children. The parent only has to carry the gene and does not necessarily show symptoms of PKD themselves. There are three types of PKD:

1. **Autosomal Dominant PKD (ADPKD)**
   - This is the most common form of PDK with almost 90% of all PKD cases being ADPKD. Because most cases aren't discovered until someone is an adult, this type is also commonly referred to as "adult PKD".
   - This form of PKD is inherited by the child from one of their parents through dominant inheritance. This means that one parent already has PKD and passes that abnormal gene down to their child. Children who receive this gene through dominant inheritance have a 50% chance of also contracting the disease.
2. **Acquired Cystic Kidney Disease (ACKD)**
   - This form of PKD is the only form that is not hereditary and is most commonly associated with kidney failure and dialysis.
   - It occurs in patients who already have long-term damage or severe scarring on their kidneys. A very high percentage of dialysis patients end up with ACKD if they have been on dialysis for 5 or more years.
3. **Infantile or Autosomal Recessive PKD (ARPKD)**
   - This is the rarest form of PKD, occurring only 1 out of 25,000 times.
   - This is also the most severe form of PKD and typically forms in a fetus or in the first months of an infant's life.
   - ARPKD is a rapidly progressive disease and needs to be treated aggressively by the healthcare team.
   - It is contracted through recessive inheritance that means that both parents carry the gene (but don't necessarily have PKD) and they both pass this abnormal gene to their child.

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Symptoms

This disease is rarely diagnosed in children as most people don't begin to experience symptoms of PKD until later in life (except if you have ARPKD), typically in their 30's or 40's. If you are experiencing any of these symptoms, contact your physician:

- Back or side pain
- Blood in urine (this is especially common in ACKD)
- Feeling of fullness in your abdomen
- Fluttering, pounding or pain in the chest
- Headache
- High Blood Pressure
- Chronic Kidney Disease
- Kidney Stones
- Swelling of the abdomen (this is because your kidneys have become enlarged and are taking up more room
- Urinary tract or kidney infections

Additionally, if a parent, sibling or child of yours has been diagnosed with PKD, make sure to discuss this with your physician in your routine checkups, as you may be at a higher risk of contracting.

Diagnosis

1. **Ultrasound:** If you or your doctor suspect that you may have PKD, you may be asked to have an ultrasound. Ultrasounds are a reliable, inexpensive and non-invasive first step in determining if you have PKD
2. **CT Scan or MRI:** If you have an abnormal ultrasound, you may be asked to undergo a CT scan or MRI. These tests can uncover smaller cysts that an ultrasound may not be able to see and may also be able to measure the volume and growth of both your kidneys and cysts.
3. **Genetic Blood Test:** You may also be asked to have genetic blood testing. This testing will determine if you carry the abnormal gene that causes PKD.

Treatment Options

The main treatment of PKD is maintaining an overall healthy lifestyle. There is currently no cure for this disease but by working with your physician and following the appropriate steps below, you can continue to live a normal life. Monitor and control blood pressure

- Monitor and control blood pressure
- Seek treatment of bladder or kidney infections immediately
- Consume as much fluid as possible if you notice blood in your urine
- Engage in regular exercise (but avoid contact sports or other exercises that could further damage your kidneys)
- Maintain a healthy weight through a healthy diet and exercise
- Minimize your sale intake
- Consume plenty of water
- Limit caffeine

Sources:

[1] https://www.kidney.org/atoz/content/polycystic

https://www.mayoclinic.org/diseases-conditions/polycystic-kidney-disease/symptoms-causes/syc-20352820

https://www.niddk.nih.gov/health-information/kidney-disease/polycystic-kidney-disease