



Media Talking Points

PKD Foundation media contact information:

- Email marketing@pkdcure.org or
- Call 1-800-PKD-CURE

Visit pkdcure.org for more information about PKD and the PKD Foundation.

About PKD

- Polycystic kidney disease (PKD) is a chronic, genetic disease causing uncontrolled growth of fluid-filled cysts in the kidneys, often leading to kidney failure
- PKD affects all racial and ethnic groups equally
- A typical kidney is the size of a human fist and weighs about a third of a pound. Polycystic kidneys can be much larger, some growing as large as a football and weighing 30 pounds.
- Kidneys can develop cysts ranging in size from as small as a pinhead to as large as a grapefruit.
- The first treatment for adults with ADPKD (tolvaptan) was approved by the FDA in April 2018
- There are two types of PKD: autosomal dominant (ADPKD) and autosomal recessive (ARPKD). ADPKD is more common and affects an estimated 600,000 Americans and 12.4 million people worldwide. ARPKD is a rare form of the disease that occurs in 1 in 20,000 children.

PKD Facts

Autosomal dominant

- ADPKD is the fourth leading cause of kidney failure
- Approximately 10% of patients with PKD have no family history of the disease, as ADPKD may develop as a spontaneous (new) mutation
- More than 50% of people with ADPKD will develop kidney failure by age 50
- Once a person has kidney failure, dialysis or a transplant are the only treatment options
- Parents have a 50% chance of passing the disease to their children, so it often affects many people in one family

Autosomal recessive

- Only 70% of children born with ARPKD survive the newborn period and one-third of those who survive will need dialysis or transplantation by age 10
- The prognosis for children with ARPKD has improved dramatically. In the past 20 years, only half of the children born with ARPKD survived to age 10, but now the survival percentage has increased to 85%
- Parents of children with ARPKD, as well as ADPKD, can reach out to the [PKD Parents Chapter](#) for support, compassion and guidance; this virtual Chapter connects families with experts and other local families

Symptoms of PKD

- High-blood pressure (hypertension)
- Frequent urinary tract infections
- Blood in urine (hematuria)

- Protein in urine (proteinuria)
- Back/flank pain
- Enlarged kidneys
- Mitral valve prolapse
- Hernia
- Kidney stones
- Depression
- Anxiety

About the PKD Foundation

The PKD Foundation is the only organization in the United States solely dedicated to finding treatments and a cure for polycystic kidney disease. Since 1982, we have been dedicated to supporting and improving the lives of patients and families impacted by PKD. These efforts are accomplished through promoting research to find treatments and a cure, as well as providing education, advocacy, and awareness on a national level. We provide direct services to local communities nationwide and are the largest private funder of PKD research.

Research

We are committed to finding treatments and a cure for PKD. Since 1982, we have invested in more than 1,300 research, clinical and scientific grants, fellowships and scientific meetings.

Advocacy

Our footprint in Washington, D.C., helps us advocate for the PKD community and keep them aware of critical action on the Hill.

Community

We provide opportunities for patients and families to connect, share, and help one another cope with the emotional aspects of a PKD diagnosis. Learn more at [PKD Connect](#).

Our mission: We give hope. We fund research, advocate for patients and build a community for all impacted by PKD.

Our vision: #endPKD