



## Media Talking Points

### PKD Foundation media spokesperson contact information:

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Visit [pkdcure.org](http://pkdcure.org) for more information about PKD and the PKD Foundation.

## About PKD

- Polycystic kidney disease (PKD) is one of the most common, life-threatening genetic diseases. It affects thousands in America and millions worldwide, who are in urgent need of treatments and a cure. About 1 in 500 to 1 in 1,000 people have PKD, approximately 600,000 in America and more than 12 million worldwide.
- In PKD, fluid-filled cysts develop and enlarge in both kidneys, eventually leading to kidney failure.
- The average size of a normal kidney is a human fist. Polycystic kidneys can get much larger, some getting as large as a football, and weighing up to 30 pounds each.
- Once a person has kidney failure, dialysis or a transplant are the only options to treat the damage the disease has caused.
- Parents have a 50 percent chance of passing the disease to each of their children. Because it is passed from generation to generation, PKD often affects many people in one family.
- Approximately 10 percent of the people diagnosed with PKD have no family history of the disease, with PKD developing as a spontaneous (new) mutation. Once they have it, they have a 50 percent chance of passing it on to each of their children.
- PKD equally affects people of all races, genders, nationalities, geographic locations and income levels.
- PKD is the fourth leading cause of kidney failure. More than 50 percent of people with PKD will develop kidney failure by age 50.

## About ARPKD

- A relatively rare form of PKD, autosomal recessive polycystic kidney disease (ARPKD), affects approximately 1 in 20,000 children, and often causes death in the first month of life.
- For ARPKD children who survive the newborn period (about 70 percent), approximately one-third will need dialysis or transplantation by age 10. Previously thought to be a fatal condition, the prognosis for children with ARPKD has improved dramatically.
- Twenty years ago, only half of the children born with the disease survived to their 10th birthday, but now that percentage has increased to 85 percent.

- ARPKD is still a disease that devastates families, and dramatically affects quality of life for children who have it. For those who have lost a child to ARPKD, their lives are changed forever.
- Parents and families look to the PKD Foundation for compassion and support, to fund research toward finding treatments and for education. Because of this, the PKD Foundation provides focused funding for ARPKD-related research, support and education. These investments also benefit children with ADPKD, and congenital hepatic fibrosis (CHF), a disease closely associated with ARPKD. The Foundation has invested more than \$2 million since 2006.
- The PKD Parents Chapter provides support for parents of children with ARPKD as well as ADPKD. The Chapter has served more than 600 families since 2000. Once a family with a child living with PKD reaches out to the Foundation, a volunteer from the PKD Parents Chapter contacts them for support, compassion and guidance. Families can be connected with experts and other local families and are supported in many ways through the Chapter.

## **About the PKD Foundation**

- The PKD Foundation is the only organization in the United States solely dedicated to finding treatments and a cure for PKD to improve the lives of those it affects.
- We do this through funding research, and promoting education, advocacy, support and awareness on a national level, along with direct services in local communities across the country. We rely on private donations to fund this work.
- Since its founding in 1982, the Foundation has invested more than \$40 million in research, clinical and scientific grants, fellowships and meetings, making us the largest private funder of PKD research.
- Our vision is that one day no one will suffer the full effects of PKD.