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**How to Talk about PKD and the PKD Foundation**

**About PKD**

* Polycystic kidney disease (PKD) is one of the most common, life-threatening genetic diseases. It affects hundreds of thousands in America and millions worldwide, who are in urgent need of treatments and a cure.
* Approximately 600,000 Americans and 12.5 million worldwide have PKD.
* In PKD, fluid-filled cysts develop leading to the enlargement of both kidneys and, eventually, to kidney failure.
* PKD is the fourth leading cause of kidney failure. More than 50 percent of people who have PKD will develop kidney failure by age 50.
* Once a person has kidney failure, dialysis or a transplant are the only options to treat the damage the disease has caused.
* 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.
* Parents have a 50 percent chance of passing the disease to each of their children. Unlike some genetic diseases, PKD does not skip a generation. 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.
* A relatively rare form of PKD, autosomal recessive polycystic kidney disease (ARPKD), affects approximately one 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.

 **About the PKD Foundation**

* We are 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, raising patients’ voices through advocacy and awareness, and providing patient education and support on a national level. We also offer direct services in local communities across the country through 62 volunteer-led Chapters. We rely on private donations to fund this work.
* Since our founding in 1982, we have funded more than $42 million in research toward our vision of ending PKD, making us the largest private funder of PKD research.
* Our vision is that one day no one will suffer the full effects of PKD.