



# ABOUT PKD

## PKD Facts

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.

- ▶ In autosomal dominant PKD (ADPKD), fluid-filled cysts develop and enlarge in both kidneys, eventually leading to kidney failure.
- ▶ PKD is the fourth leading cause of kidney failure. More than 50 percent of people with 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.
- ▶ It is a painful disease that impacts quality of life. The average size of a normal kidney is a human fist. Polycystic kidneys can get much larger, some growing 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, it does not skip a generation. Because it can be 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, there is 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.

## Symptoms of PKD

People living with PKD can experience these common symptoms:

- ▶ High blood pressure (hypertension)
- ▶ Frequent urinary tract infections
- ▶ Blood in urine (hematuria)
- ▶ Protein in urine (proteinuria)
- ▶ Mitral valve prolapse
- ▶ Hernia
- ▶ Back/flank pain
- ▶ Kidney stones
- ▶ Enlarged kidneys
- ▶ Depression and anxiety (due to stress and emotional impact)

## ARPKD Facts

Autosomal recessive polycystic kidney disease (ARPKD) is a relatively rare form of PKD, affecting approximately 1 in 20,000 children. It 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.





# ABOUT THE PKD FOUNDATION

The PKD Foundation is the only organization in the U.S. solely dedicated to finding treatments and a cure for PKD to improve the lives of those it affects. We do this through promoting research, education, advocacy, support and awareness on a national level, along with direct services to local communities across the country.

Our vision is that one day no one will suffer the full effects of PKD.

## Research

Since its founding in 1982, the PKD Foundation has invested more than \$38 million in research, clinical and scientific grants, as well as fellowships and scientific meetings, making us the second largest funder of PKD research after the National Institutes of Health (NIH). This has led to new discoveries about PKD, including identifying the genes responsible for PKD, which enables researchers to investigate possible treatments.

## Education

The Foundation provides in-depth resources and education about living with PKD to empower people to manage their health. Offerings include webinars, videos, a multi-faceted website ([pkdcure.org/learn](http://pkdcure.org/learn)), online communities and print materials. The biannual PKD National Convention is the Foundation's largest education event.

## Advocacy

The Foundation plays a key role in legislative advocacy to support PKD-related initiatives. The PKD Advocacy Action Center ([pkdcure.org/advocate](http://pkdcure.org/advocate)) provides resources and ways for people to advocate, and the Foundation sends Advocacy Alerts for legislative and public policy issues impacting PKD patients and families.

## Support

The PKD Connection is a blog for people to be inspired and empowered, and to connect with others affected by PKD. Discussion boards provide a forum for PKD patients, family and friends to make connections, ask questions and share stories and experiences.

## Awareness

The Foundation raises awareness through marketing and public relations so people know what PKD is, about the Foundation and how to donate. Marketing materials include PKD Progress magazine and PKDnews monthly email newsletter. Voices of PKD ([pkdcure.org/voicesofpkd](http://pkdcure.org/voicesofpkd)) features testimonials and stories about people's experiences with the disease.

## Walk for PKD

The Walk for PKD ([walkforpkd.org](http://walkforpkd.org)) is the Foundation's signature event to raise funds and awareness. Walks take place in more than 50 cities across the nation each year, with more than 11,000 walkers. The event has raised nearly \$24 million since 2000.

## Chapters

The Foundation provides local services through its more than 60 volunteer-run Chapters across the country. These volunteers bring to life the mission of the organization by ensuring that no one faces this disease alone.

- ▶ Education meetings provide valuable information from health care professionals, while support activities range from lending a listening ear to organized group outings.
- ▶ Chapters raise funds for the Foundation through events like the Walk for PKD and Cocktails for a Cure.

## How You Can Help

- ▶ Donate: The research, advocacy, education, support and awareness the PKD Foundation promotes would not be possible without you.
- ▶ Get involved: Volunteer, advocate, join a Chapter and spread the word.

## Join

- ▶ [walkforpkd.org](http://walkforpkd.org)
- ▶ [pkdcure.org/chapters](http://pkdcure.org/chapters)

## Connect

- ▶ Visit [pkdcure.org](http://pkdcure.org).
- ▶ For parents of children with ARPKD or ADPKD, email [pkdparents@pkdcure.org](mailto:pkdparents@pkdcure.org).
- ▶ Call 1.800.PKD.CURE (753.2873).
- ▶ Follow us on Facebook and Twitter (@PKDFoundation).
- ▶ Visit Voices of PKD for stories about people affected by PKD: [pkdcure.org/voicesofpkd](http://pkdcure.org/voicesofpkd).

