



Support Research Funding at the National Institutes of Health (NIH)

Request

On behalf of patients and their families living with polycystic kidney disease (PKD), a life-threatening, genetic disease affecting more than 600,000 Americans, **the PKD Foundation urges Congress to support \$35 billion for the National Institutes of Health (NIH) in the FY 2011 Labor-Health and Human Services-Education Appropriations Act.**

What is PKD?

- Polycystic kidney disease (PKD) is one of the world's most life-threatening, genetic diseases affecting an estimated 1 in 500 people including newborns, children, and adults regardless of sex, age, race or ethnicity. It comes in two forms: autosomal dominant (ADPKD); and, autosomal recessive (ARPKD).
- With the presence of PKD, multiple cysts develop in both kidneys, leading to an increase in kidney size and weight. Cysts can range in size from a pinhead to a grapefruit.
- Patients often experience no symptoms early in the disease, and many do not realize they have PKD until other organs become affected. Symptoms can include high blood pressure, chronic pain in the back, sides or abdomen, blood in the urine, urinary tract infection, and the presence of kidney stones.
- Deterioration in PKD patients varies, but ultimately more than half will end up in renal failure and require dialysis or a kidney transplant.
- There is no treatment or cure for PKD.

Position

The PKD Foundation and PKD Champions want to move PKD research forward by supporting the NIH and its mission. Without steady and reasonable increases to the NIH budget, biomedical inflation and the rising cost of research will continue to negatively affect efforts to develop treatments and discover a cure for the more than 600,000 Americans living with PKD.



Supporting Rationale

- In FY 2009, the NIH funded \$45 million in PKD research. Approximately \$7 million of this was directed through the American Recovery and Reinvestment Act (ARRA).
- Since 1993, NIH has invested \$360 million in PKD research. This investment helps generate promising therapeutic opportunities, that once realized, will save billions in health care costs and free up several thousand spots on the kidney transplant waiting list.
- Dr. Francis Collins, current NIH Director and former director of the Human Genome Research Institute, called PKD one of the “hottest, most promising areas of research in all of biochemistry.” Scientists discovered the genes that cause PKD in 1994. More than 20 clinical trials are now underway to find a treatment for PKD, but more research is needed.
- PKD research is at a critical stage.
- Without steady and reasonable support of the NIH budget, biomedical inflation and the increasing costs of basic, clinical and translation research will negatively affect efforts to develop treatments and discover a cure for people living with PKD.
- Advancing PKD research at the NIH can be accomplished through Congress’ commitment to increase the overall NIH budget, which will in turn allow the agency to fund more disease-specific research.
- PKD costs federal government health care programs more than \$2 billion annually. This includes: \$50,000 to \$75,000 per patient, per year for dialysis; \$100,000 to \$125,000 per kidney transplant; and, \$15,000 to \$20,000 per patient, per year for immunosuppressive drugs for kidney transplant patients. Investing in PKD research to help find treatments and someday a cure could result in substantial savings to federal health care programs such as Medicare.