Increase PKD Research Funding at the National Institutes of Health (NIH)

Request

On behalf of patients and their families suffering from polycystic kidney disease (PKD), a life-threatening, genetic disease affecting more than 600,000 Americans, **the PKD Foundation urges Congress to increase funding for the National Institutes of Health (NIH) in FY 2010, and ask you stress the importance of allocating additional funding for PKD research at the National Institute for Diabetes and Digestion and Kidney Diseases (NIDDK).**

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 ethnic origin. 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 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 may 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

PKD is a life-threatening genetic disease affecting more than 600,000 American adults and children and 12.5 million people worldwide. Without steady, reasonable increases to the NIH budget and funding directed at PKD, biomedical inflation and other increasing costs associated with basic, clinical, and translation research will continue to negatively affect research efforts to develop treatments and discover a cure for PKD.

With PKD's scope and impact on Americans, it is surprising that PKD receives significantly less federal research funding per person than many other less prevalent genetic diseases. The PKD Foundation supports moving the needle forward and increasing PKD research dollars to truly meet the demand and needs of researchers, patients, and their families.

Supporting Rationale

- PKD research offers a tremendous "return on investment." Dr. Francis Collins, former director of the Human Genome Research Institute and current NIH Director, called PKD one of the "hottest, most promising areas of research in all of bio-chemistry." Scientists discovered the genes that cause PKD in 1994. There are currently more than 16 clinical trials underway to help find a treatment.

- PKD is the No. 1 genetic cause of End Stage Renal Disease (ESRD or kidney failure) in the United States and the No. 4 cause, overall. PKD patients currently occupy more than 5,000 spots on the kidney transplant waiting list.

- To date, NIH has invested $315 million in PKD research. This investment is helping 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.

- 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.

- The prevalence rate of PKD makes it more common than the combined number of persons affected by cystic fibrosis, muscular dystrophy, hemophilia, Downs syndrome, and sickle cell anemia.

- PKD research is not well funded at NIH when compared to other less prevalent genetic diseases. For example in FY 2008, PKD per person funding level was $68, which is nearly $700 less than the per person investment in sickle cell anemia and $2,900 less than the per person investment in cystic fibrosis.

- PKD costs the Medicare program at least $2 billion annually to pay for dialysis, transplantation and related treatments, which 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 the cost of immunosuppressive drugs for kidney transplant patients. Investing in PKD research to help find treatments and someday a cure will save Medicare money.