



## **Create a PKD Research Program in the Congressionally Directed Medical Research Programs**

### **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 asks Congress to establish a PKD research program funded at \$5 million in the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense (DoD).**

### **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**

PKD is a life-threatening genetic disease affecting more than 600,000 American adults and children and 12.5 million people worldwide. PKD has a negative impact on military readiness, lost investment in training, and future impact on military and Veterans health care expenses. Approximately 5,000 active and reserve military personnel have PKD, being diagnosed sometime between their late twenties to mid-thirties.

PKD costs the military and other federal health programs, such as the Veterans Health Administration (VHA), more than \$2 billion annually for dialysis, transplantation, and related therapies. The PKD Foundation and PKD Champions are confident that funding PKD research under the CDMRP will help meet the demand and needs of researchers, patients and their families.



## Supporting Rationale

- The Federal Government invests approximately \$1 million per soldier in military training. With approximately 4,500 troops being at risk for discharge because they have PKD, the disease represents a significant financial loss to the Federal Government. It also has a negative effect on combat readiness.
- Investing in PKD research to help find treatments and someday a cure will save the federal government money. PKD costs the military and other federal health programs, such as the VHA, more than \$2 billion annually to pay for dialysis, transplantation and related treatments. Costs include \$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.
- Research and clinical trials conducted under the CDMRP may lead to the discovery of a treatment that can delay the progression of PKD long enough so patients will not experience medical symptoms or renal failure requiring a medical discharge from their military service.
- The CDMRP funds high-risk, high-reward research. This nimble program takes prudent measures to ensure that none of its work duplicates or unnecessarily overlaps work done by other federal research organizations such as the National Institutes of Health (NIH).
- The prevalence of PKD in the military is significant. Approximately 5,000 active military troops have the disease.
- We are very close to discovering effective treatments and finding a cure for PKD. Research in PKD is the most progressive, robust and “therapy-ripe” of all kidney diseases. Although several funding sources are available for PKD research, such as the NIH and non-profit organizations like the Foundation, the PRMRP offers a broader array of clinical trial, technological and therapeutic development awards, in addition to investigator-initiated awards, all of which help PKD researchers in their quest to develop therapies.

\*\* Please note: This request is a programmatic request.