



The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (H.R. 1458/S. 565)

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 requests you co-sponsor and support passage of The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (H.R. 1458/S. 565)**. This bill would end the 36-month limit for anti-rejection medications post kidney transplantation.

What is PKD?

- Polycystic kidney disease (PKD) is one of the world's most life-threatening, genetic diseases affecting an estimated one 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 are affected. Symptoms can include high blood pressure, chronic pain in the back, sides or abdomen, blood in the urine, urinary tract infection, and 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. Nearly 60 percent of PKD patients will end up with End Stage Renal Disease (ESRD) or kidney failure, requiring them to go on dialysis or undergo a kidney transplant.

Medicare covers the full cost of dialysis for a patient's lifetime; however, Medicare will only cover vital immunosuppressive/anti-rejection drugs for 36 months after the transplant. The benefits of providing these necessary medications far outweigh the cost of these drugs.



Supporting Rationale

- Many kidney transplant patients cannot afford immunosuppressive drugs without the help of Medicare. Without these drugs, the likelihood that a patient's body will reject the transplanted kidney greatly increases. If the kidney is rejected, the patient will be forced to go back on dialysis or undergo another transplant.
- Under current Medicare coverage policy once the 36-month period ends, kidney transplant patients are forced to find other ways to pay for the expensive immunosuppressive medications. H.R. 1458/S. 565 would end the 36-month limit for anti-rejection medications.
- PKD is the No. 1 genetic cause of ESRD or kidney failure in the U.S. and the No. 4 cause overall.
- According to the United Network for Organ Sharing (UNOS), as of January 2010, more than 85,000 people are waiting for a kidney transplant. PKD patients currently occupy more than 5,000 spots on the kidney transplant wait list.
- PKD costs federal government health care programs, including Medicare, 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.
- Extending coverage to include the cost of immunosuppressive drugs (\$15,000-\$20,000 per year) is far less costly to Medicare than resuming dialysis (\$50,000-\$75,000 per year) or covering a second transplant surgery (\$100,000-\$125,000).