



The 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 asks you to co-sponsor The 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 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. At least 50 to 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.

While Medicare covers dialysis indefinitely, it will only cover vital immunosuppressive drugs required post transplantation for up to 36 months. The benefits of providing these necessary medications far outweigh the costs of purchasing these drugs.



Supporting Rationale

- Many kidney transplant patients cannot afford immunosuppressive drugs without the help of Medicare. Without these drugs, the chances that a patient's transplanted kidney will be rejected greatly increases, which can force them back on to dialysis or require them to 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 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.
- 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.
- However, the cost of immunosuppressive drugs (\$15,000-\$20,000 per year) is far less than resuming dialysis (\$50,000-\$75,000 per year) or the cost of a new transplant (\$100,000-\$125,000).