



2022 LEGISLATIVE PRIORITIES

Founded in 1982, the PKD Foundation is dedicated to supporting and improving the lives of all affected by PKD. As the largest private funder of PKD research, the Foundation promotes research and provides education, advocacy and awareness on a national level. The organization has 35,000 constituents active in 49 states and Washington D.C.

PKD is a chronic, genetic condition which causes uncontrolled growth of fluid-filled cysts in the kidneys, often leading to kidney failure. Beyond the impact on the kidney, PKD is a systemic disease that also increases risk for liver cysts, aneurysms, mitral valve prolapse, hernias, diverticulosis and diabetes. There are two types of PKD:

PKD affects an estimated 600,000 Americans

and millions worldwide.¹



- Autosomal Dominant (ADPKD) is the more common type and affects an estimated 12.4 million people worldwide.
- Autosomal Recessive (ARPKD) is a rare form of the disease that occurs in 1 in 20,000 individuals.

2022 LEGISLATIVE PRIORITIES

1 Support the continued inclusion of PKD as a designated research topic under the Peer Reviewed Medical Research Program (PRMRP) at the Department of Defense (DoD).

2 Support the passage of the Living Donor Protection Act to prevent any discrimination in insurance coverage for living donors across America.

3 Prioritize and support legislation that would reduce racial disparities in kidney transplantation, treatment, and care.



Racial Disparities in Kidney Disease Transplantation and Care

Kidney disease – including ADPKD and PKD – disproportionately affects communities of color. Black/African Americans and Hispanic/Latinos are disproportionately impacted.

- Black/African Americans and Hispanic/Latinos with PKD reach kidney failure 2.5 and 4.8 years earlier than White PKD patients, respectively.
- Black/African Americans and Hispanic/Latinos with PKD are 69% and 54% less likely to receive a preemptive transplant than White Americans, respectively.

Congress should prioritize and support legislation that would reduce racial disparities in kidney transplantation, treatment, and care.

1. <https://www.niddk.nih.gov/health-information/kidney-disease/polycystic-kidney-disease/what-is-pkd#common>



Congressionally Directed Medical Research Program (CDMRP)

The CDRMP supports novel approaches to biomedical research in response to needs of military personnel, their families, and the American public.



Roughly 50 percent of patients with ADPKD experience kidney failure by the age of 59², at which point the only options for survival are dialysis or a kidney transplant.

PKD has been a research topic since 2006, allocating over \$40 million for PKD research



Of our country's 2.15 million service members, an estimated 5,000 may have ADPKD, which could translate into a significant loss of military training investment when these individuals reach kidney failure.



Expanded PKD treatments or cures would not only save all PKD patients from pain and suffering caused by the disease, it would allow affected service members to stay in active duty longer.



Kidney failure in mid-life essentially removes an individual from military service when they are in their prime.

\$603.3 million was spent on training and recruiting service members in FY18.³



Living Donor Protection Act

Currently, there is no federal legislation protecting living organ donors from losing their jobs to take time off to recover from transplant surgery. Living donors may experience higher premiums or denial of coverage for life, disability and long-term care insurance.

There are currently over **100,000** individuals on the **kidney transplant waiting list**.⁴

Just 22,817 transplants were performed in the year 2020.⁵

The case for better laws:

- There are no federal laws to protect donors from losing their jobs while on leave for organ donation.
- 25% of living donors were denied or charged more for life insurance.⁶
- Nearly 7,000 of the 23,401 kidney transplants in 2018 were living donations.⁷

Proposed protections:

- 1** Prohibit insurance companies from denying or limiting life, disability or long-term care insurance to living donors.
- 2** Prohibit insurance companies from charging higher premiums to living donors.
- 3** Living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from donation.

Please consider cosponsoring the Living Donor Protection Act

2. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6592047/>

3. comptroller.defense.gov/Portals/45/Documents/defbudget/fy2016/fy2016_OM_Overview.pdf — page 13

4. <https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#>

5. <https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#>

6. Sources of Facts and Statistics: Organ Procurement and Transplant Network United States Renal Data System (USRDS)

7. <https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#>