

MEMORANDUM

To: Legislative Counsel
From: National Kidney Foundation
RE: Policies to Address Racial Disparities in Kidney Health

Kidney disease disproportionately affects communities of color. More than 37 million Americans have chronic kidney disease (CKD), including nearly 750,000 with irreversible kidney failure. Black or African Americans are almost four times more likely and Hispanics or Latinos are 1.3 times more likely to have kidney failure compared to White Americans. Although they make up only 13.5% of the population, Black or African Americans make up more than 35% of dialysis patients. The major causes of kidney disease, including diabetes, hypertension, and cardiovascular disease, are all more prevalent among Black Americans. Although a kidney transplant is the optimal treatment for kidney failure, Black patients face barriers to access at every step of the process and on average wait a year longer than white patients to receive a kidney transplant. Black patients are less likely to receive a transplant evaluation, have less access to the waitlist, spend longer on the transplant waitlist, are less likely to survive on the waitlist, and have lower rates of graft survival post-transplant.^{1,2}

To address these racial disparities in the awareness, diagnosis, and treatment of kidney disease, the National Kidney Foundation encourages the authors of the Health Equity and Accountability Act of 2021 to include provisions that focus on the following priorities, discussed in further detail below:

- 1) Eliminate racial and ethnic disparities in access to transplantation
- 2) Improve CKD Diagnosis and Treatment to Delay Kidney Failure
- 3) Increase access to home dialysis for diverse populations
- 4) Reduce out-of-pocket costs for kidney patients

Eliminate racial and ethnic disparities in access to transplantation

Black and Hispanic people are less likely to access a kidney transplant than white patients. Communities of color are disadvantaged at every step of the transplantation process that has been studied, from referral to post-transplant organ survival. For example, while 39% of people on the kidney waiting list are African American, only 23.0% of deceased donor organ recipients are African American.

Expand Access to Living Donation

Receiving a kidney transplant from a live donor provides better outcomes to the recipient than either dialysis or a deceased donor transplant. Unfortunately, Black/African Americans are more likely to oppose organ donation, and oppose living donation more strongly than deceased donation.³ While 5692 Black/African American patients received transplants in 2018, only 755 (13%) of them were from living donors.

The Health Equity and Accountability Act of 2021 should include provisions that:

- (1) *Improve national data collection on the early steps of the transplant process, such as transplant referral and start of the transplant evaluation.*
- (2) *Authorize programs that educate racially and ethnically diverse communities on organ donation, specifically living donation.*

Expand Access to Conflict-free Transplantation Options Counseling

Medicare regulations require that patients be informed about all treatment modalities for kidney failure including transplantation. Unfortunately, this education can be inadequate to meet the needs of all dialysis patients, especially people with

¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5827936/>

² <https://onlinelibrary.wiley.com/doi/10.1111/ajt.15672>

³ <https://cjasn.asnjournals.org/content/10/2/286>

lower health literacy, lower socioeconomic status, or those who have not seen a nephrologist prior to dialysis. Dialysis facilities that are often overburdened by caring for the highly frail dialysis population are not always best positioned to provide transplant education that is tailored to diverse populations.

The Health Equity and Accountability Act of 2021 should expand patient access to transplant education provided by an unbiased provider that is unaffiliated with a dialysis or transplant program.

Grant Program to Support Low-Income Transplant Candidates

Many patients are deemed ineligible for a transplant due to socio-economic factors such as not having a cellphone, lacking access to reliable transportation, or childcare difficulties. Addressing some of these basic needs that would assist a patient in getting to appointments, maintaining healthy routines, and ensuring compliance with medical directives would help ensure that all patients, regardless of income, have the opportunity to receive a life-saving transplant.

The Health Equity and Accountability Act of 2021 should create a discretionary grant program to support low-income transplant candidates by providing monetary assistance for transportation, technology, childcare, and other needs to improve their chance at a successful transplant.

Improve CKD Diagnosis and Treatment to Delay Kidney Failure

Federally Qualified Health Centers (FQHCs) are essential safety net providers of comprehensive health services for people living in underserved areas. Diabetes, the leading cause of CKD, is overrepresented in many of the populations served by FQHCs, which include diverse populations, people who are low-income or uninsured, people experiencing homelessness, agricultural workers, and residents of public housing. Well over half of the people served by FQHCs are people of color. Though FQHCs have shown success at blood glucose control, FQHCs do not currently screen these high-risk patients for CKD.

The Health Equity and Accountability Act of 2021 should authorize discretionary grants to health organizations serving high-risk communities, such as FQHCs, to implement targeted outreach, screening, and treatment for kidney disease.

Ensure Equitable Access to Home Dialysis

Despite being preferred by many patients, home dialysis is underutilized compared to dialysis delivered in a facility, particularly among communities of color. Black/African American and Hispanic patients are less likely to initiate home dialysis and are more likely to fail on the modality within the first 90 days, after which point disparities in home dialysis utilization widen. This may be because common barriers to home dialysis such as unstable living situations, poor health literacy and lower socioeconomic status may be overrepresented among Black/African American and Hispanic dialysis patients. Most barriers to home dialysis can be overcome with appropriate empowerment and support from trained staff who can assist with dialysis needs, address other physical or medical challenges, and provide emotional and moral support to patients as they transition to home dialysis.

The Health Equity and Accountability Act of 2021 should include provisions to expand patient access to home dialysis.

Reduce Out-of-Pocket Expenses

The majority of people with irreversible kidney failure are entitled to Medicare benefits, irrespective of their age or disability status. Once enrolled in the program, ESRD beneficiaries are typically accountable for twenty percent coinsurance on Part B services, including dialysis treatments and immunosuppressant drugs, and other copays and deductibles. To defray these still substantial out-of-pocket costs, many beneficiaries enroll in supplemental insurance, known as a Medigap. However, federal law does not require insurance companies to sell Medigap plans to Medicare beneficiaries under the age of 65. As a result, ESRD beneficiaries in many states who are younger than 65 years of age cannot get supplemental insurance. Extending Medigap coverage to all ESRD beneficiaries, regardless of age, will reduce the out-of-pocket expenditures associated with kidney failure.

The Health Equity and Accountability Act of 2021 should include language to expand Medigap eligibility to all ESRD beneficiaries, regardless of age.