

Advancing Equity in Kidney Health

For generations, systemic and structural racism have perpetuated stark racial and ethnic inequities in the diagnosis, treatment, and progression of chronic kidney disease (CKD). Black and Hispanic populations are plagued with the most significant CKD burden and the highest rates of CKD mortality, yet life-threatening hurdles like inadequate health insurance coverage, discriminatory clinical practices, and deficient kidney disease education and awareness detrimentally reduce their access to early CKD diagnosis and management, nephrology care, home dialysis treatment options, and kidney transplantation.¹

The National Kidney Foundation (NKF) refuses to accept this as the status quo and is taking action to support policy changes that dismantle injustices and close gaps in kidney healthcare. Access to high-quality kidney health should never be affected by the patient's ethnicity or socioeconomic status. We are committed to creating a kidney health landscape that is fair and just, improving outcomes and quality of life for all patients.

To achieve these objectives, NKF advocates for policy changes that address inequity in kidney care with a goal of:

- 1) Enhancing CKD awareness, diagnosis, and management in underserved and marginalized communities
- 2) Improving kidney failure outcomes for underserved populations
- 3) Eliminating racial and ethnic disparities in access to transplantation
- 4) Making the health system more equitable and resilient

CKD's Impact on Communities of Color

Approximately 1 in 7 adults in the United States have CKD, yet 90% are unaware of their diagnosis, and the most significant disease burden falls on underserved populations. Population-level data from the 2020 U.S. Census show that CKD is more common in non-Hispanic Black adults (20%) than in non-Hispanic Asian adults (14%) or non-Hispanic White adults (12%). Diverse populations also have much higher rates of high blood pressure, diabetes, and heart disease – three of the leading causes of CKD. Social determinants of health (SDOH) that disproportionately affect communities of color often exacerbate risk for kidney disease and can accelerate progression of kidney disease. For example, CKD prevalence is nearly 25% higher in the uninsured population than in the insured,² and poorer access to health care contributes to the increased risk of CKD in structurally disadvantaged people.^{3,4} Diverse populations are not only more likely to be diagnosed with CKD, but they also experience worse outcomes than non-Hispanic White patients. In 2019, the U.S. Renal Data Service reported that Black

¹ United States Renal Data System. *2022 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*. National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, US Department of Health and Human Services; 2022. Accessed September 1, 2023. <https://usrds-adr.niddk.nih.gov/2022>

² *Id.*

³ Evans K, Coresh J, Bash LD, et al. Race differences in access to health care and disparities in incident chronic kidney disease in the US. *Nephrol Dial Transplant*. 2011;26(3):899-908. doi:10.1093/ndt/gfq473

⁴ Vart P, Gansevoort RT, Crews DC, Reijneveld SA, Bultmann U. Mediators of the Association Between Low Socioeconomic Status and Chronic Kidney Disease in the United States. *Am J Epidemiol*. 2015;181(6):385-396. doi:10.1093/aje/kwu316

individuals were affected by end-stage renal disease (ESRD) at a rate that was “nearly double that of Hispanic individuals, nearly triple that of Asian individuals, and more than quadruple that of White individuals.”⁵ Inequities in referral for nephrology, transplant evaluation, and consideration of home dialysis leave most Black and Hispanic kidney failure patients reliant on in-center dialysis.⁶ While kidney transplantation leads to a better quality of life and survival outcomes than dialysis, Black patients are half as likely to receive a life-saving kidney transplant as White patients.⁷

Kidney Equity for All: Policy Solutions to Close the Equity Gap

Enhancing CKD Awareness, Diagnosis, and Management in Underserved and Marginalized Communities

Access to health care and CKD detection is the foundation upon which all solutions to preserve kidney health and advance kidney equity rest. Health policy has a role to play in identifying and addressing risk factors to prevent CKD, to identify CKD early, and to delay its progression and associated adverse outcomes.⁸ NKF advocates for the following policy objectives that will help address inequities in CKD awareness, diagnosis, and management:

1. Accelerating Adoption of an Equitable Approach to Kidney Disease Diagnosis

In 2021, the National Kidney Foundation and the American Society of Nephrology (ASN) Joint Task Force reassessed the inclusion of race in the estimation of glomerular filtration rate (GFR) in the United States, leading to the development of a new creatinine-based **race-free** equation (known as the CKD-EPI equation) for first-line use and additional use of cystatin-C to confirm estimated kidney function.⁹ Approximately one-third of U.S. clinical laboratories have adopted the revised equation,¹⁰ but we must do more to ensure universal adoption of the race-free approach. **NKF calls on CMS, the Centers for Disease Control, and other health agencies to develop policies and programs that accelerate adoption of race-free CKD testing and diagnostics.**

⁵ United States Renal Data System. 2022 *USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*. National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, US Department of Health and Human Services; 2022. Accessed September 1, 2023. <https://usrds-adr.niddk.nih.gov/2022>

⁶ Shen, Jenny I et al. “Socioeconomic Factors and Racial and Ethnic Differences in the Initiation of Home Dialysis.” *Kidney medicine* vol. 2,2 105-115. 11 Feb. 2020, doi:10.1016/j.xkme.2019.11.006

⁷ Wesselman, H et al. “Social Determinants of Health and Race Disparities in Kidney Transplant.” *CJASN* Feb 2021, 16 (2) 262-274; DOI: 10.2215/CJN.04860420

⁸ Komenda P, Ferguson TW, Macdonald K, et al. Cost-effectiveness of primary screening for CKD: a systematic review. *Am J Kidney Dis* 2014; 63: 789-797.

⁹ Delgado, C., Baweja, M., Crews, D., et al. A Unifying Approach for GFR Estimation: Recommendations of the NKF-ASN Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Disease. *Am J Kidney Dis*. 2022; 79(2): 268-288. DOI: 10.1053/j.ajkd.2021.08.003

¹⁰ National Kidney Foundation. U.S. Pathology and Laboratory Society Leadership Endorses NKF-ASN Joint Task Force Recommendation to Use New Race-Free Equations to Diagnose Kidney Diseases. [Internet]. Cision US Inc.; [updated 2022 Feb 11; cited 2023 Aug 1]. Available from: <https://www.prnewswire.com/news-releases/us-pathology-and-laboratory-society-leadership-endorses-nkf-asn-joint-task-force-recommendation-to-use-new-race-free-equations-to-diagnose-kidney-diseases-301481056.html>.

2. *Incentivizing Screening in Underserved Communities*

A recent Mayo Clinic study on the fulfillment and validity of the Kidney Health Evaluation for Patients with Diabetes (KED) measure for use in the Healthcare Effectiveness Data and Information Set (HEDIS®) found that only 40% of diabetes patients get recommended kidney health testing for eGFR and uACR, despite comprehensive education on evidence-based guideline recommendations.¹¹ Lower fulfillment was associated with Black/African Americans, Medicare-Medicaid dual eligibility, lower neighborhood income, and lower education status. KED fulfillment was associated with improved diabetes care, CKD diagnosis, evidence-based drug prescriptions for CKD, blood pressure and blood sugar control, and interdisciplinary care. **NKF calls for the prioritization and inclusion of guideline-recommended CKD screening in the Affordable Care Act Preventative Care Benefits by the HHS Office of Disease Prevention and Health Promotion for widespread implementation by health plans and timely and equitable CKD detection and treatment.**

3. *Increase Investment in Kidney Health*

The CDC Chronic Kidney Disease Initiative supports disease surveillance, helps raise awareness of CKD and its complications, promotes early diagnosis and treatment, and improves the quality of life for people living with CKD. The initiative has also supported programs that focus on underserved and at-risk communities. Similarly, many state health departments fund activities that increase awareness, prevention, and management of CKD in low-income and marginalized communities.

NKF supports efforts to increase state and federal funding for these types of projects to accelerate and amplify activities to educate the public about their risk for kidney disease, educate clinical professionals, and spur innovation in diagnosis and treatment. By increasing our investment in awareness, early detection, and treatment, we can effectively slow the progression of kidney disease, reduce the economic burden of CKD and kidney failure, and dramatically improve patients' quality of life.

4. *Increase Investment in CKD Related Research, with a Focus on Health Equity*

In 2021, the National Kidney Foundation published a [Research Agenda to Advance Kidney Care](#), which recommended several research initiatives that would address underlying disparities in kidney disease. **NKF calls on Congress to significantly increase its investment into these areas, including research into endogenous filtration markers, activities that spur the adoption of race-free equations for estimating glomerular filtration rate (eGFR), and interventions to eliminate racial and ethnic disparities in diagnosis and treatment of CKD. We ask Congress to increase investment in research initiatives that address deficits in CKD diagnosis and treatment, clinical trials that test strategies for the prevention or delay of kidney failure, and**

¹¹ Ferrè, S, Storfer-Isser, A, Kinderknecht, K, et al. Fulfillment and Validity of the Kidney Health Evaluation Measure for People with Diabetes. *Mayo Clin Proc Inn Qual Out*. 2023;7(5):382-391. <https://doi.org/10.1016/j.mayocpiqo.2023.07.002>

research to identify methods to improve the delivery of evidenced-based care, especially in populations usually underrepresented in clinical trials.

5. *USPSTF CKD Screening Recommendation*

Primary care practitioners rely on U.S. Preventive Services Task Force (USPSTF) recommendations as a guide when administering preventive screenings and interventions. USPSTF recommended screenings and interventions are often covered at no expense to individuals, which is an important consideration in reaching underserved populations. Unfortunately, USPSTF does not currently recommend screening for CKD, an omission that exacerbates underdiagnosis and inequities in kidney care.

NKF advocated for USPSTF to take up CKD screening and are pleased that they are now in the midst of their evidence review. We strongly urge USPSTF to adopt a screening recommendation for CKD, with a particular focus on at-risk populations.

6. *Reward Providers who Provide Quality CKD Care:*

In partnership with the National Committee for Quality Assurance (NCQA), NKF developed the KED measure for use in the Healthcare Effectiveness Data and Information Set (HEDIS®) and the Medicare Merit-based Incentive Payment System (MIPS). This measure will ensure that health insurance plans and clinicians are empowered and accountable for improving the CKD testing rate among people with diabetes. Measuring and rewarding early CKD diagnosis will help close racial and ethnic gaps in CKD diagnosis. **NKF also supports introducing and building upon other quality measures that incentivize CKD diagnosis and management.**

Improving Kidney Failure Outcomes for Underserved Populations

“In-center hemodialysis patients are underserved. This has only become increasingly more evident due to lasting effects of the COVID-19 public health emergency and the on-going nursing shortage. My Grandfather was an in-center hemodialysis patient from 2015-2018. His dialysis experience was very poor. Dialysis centers have a high turnover rate, resulting in the entire care team being stretched thin. Ultimately, the patient suffers and receives substandard care at best. This is not only unfair but unethical. Patient lives depend on their treatment and if their treatment and care is substandard, sequentially the patient’s quality of life will be as well.”

M. Sanchez, NKF Kidney Patient Advocate

It is not uncommon for individuals from disenfranchised communities to find out about their CKD diagnosis once it has advanced to kidney failure or end-stage renal disease (ESRD), a clinical condition in which a person’s kidneys cease to function permanently and long-term dialysis or a kidney transplant are the only lifesaving solutions.¹² Often, kidney failure patients initiate dialysis treatment in a sudden

¹² End-Stage Renal Disease (ESRD) [Internet]. Baltimore (MD): Centers for Medicare & Medicaid Services; 2021 [modified 2021 Dec 1; cited 2023 Aug 1]. Available from <https://www.cms.gov/Medicare/Coordination-of-Benefits-and-Recovery/Coordination-of-Benefits-and-Recovery-Overview/End-Stage-Renal-Disease>

and unplanned way, known as a “crash start.” Crash starts are characterized by patients who receive minimal to no care from a nephrologist and are associated with increased risks for morbidity, mortality, and a lower quality of life.¹³ According to the U.S. Renal Data System 2022 Annual Data Report, “older Hispanic patients were more likely to initiate dialysis in the hospital than their White or Black counterparts” and “patients living in neighborhoods with a higher social deprivation index (SDI) score were more likely to initiate dialysis in the hospital than those living in neighborhoods with lower scores.”¹⁴ The missed opportunity to receive effective education on the available treatment modality options results in disparities across the utilization of home dialysis modalities, in-center dialysis modalities, transplant and conservative kidney health management. Barriers to equitable, informed decision-making and personalized dialysis care are multi-pronged, including the health-related social needs of patients, clinician and healthcare system factors, and the application of federal regulations and guidance.

1. *Bolstering Access to Equitable Home Dialysis*

Of the over 550,000 Americans living with kidney failure who require dialysis, almost 85% must travel to an in-center dialysis clinic three times a week. Dialysis facility closures, a lack of home training programs, and unreliable transportation are major barriers contributing to missed treatments for patients in rural and underserved areas, resulting in worsened physical well-being and increased psycho-emotional stress.¹⁵ One large dialysis organization closed 58 facilities in 2022 and 53 facilities in 2023. Another large dialysis organization recently closed approximately 170 facilities in 2023. In the examination of neighborhood-level SDI, of which a lack of transportation is a key domain, it was found that “White patients were more likely to dialyze at home [as the initial treatment modality] than Black or Hispanic patients” across three strata.¹⁶ Building upon the implementation of the 2011 Medicare ESRD Prospective Payment System provision for home dialysis training, the *Improving Access to Home Dialysis Act* is a monumental legislative effort to quell disparate home dialysis utilization rates. The proposed bill provides Medicare coverage for staff-assisted home dialysis and expands patient modality education and home dialysis training. **NKF calls on Congress to enact the *Improving Access to Home Dialysis Act*.**

[ESRD/ESRD#:~:text=End%2DStage%20Renal%20Disease%20\(ESRD\)%20is%20a%20medical%20condition,kidney%20transplant%20to%20maintain%20life](#)

¹³ Molnar, A., Hiremath, S., Brown, P., et al. Risk Factors for Unplanned and Crash Dialysis Starts: A Protocol for a Systematic Review And Meta-Analysis. *Systematic Reviews*. 2016; 5:117. DOI: 10.1186/s13643-016-0297-2

¹⁴ United States Renal Data System. *2022 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*. National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, US Department of Health and Human Services; 2022. Accessed September 1, 2023. Available from <https://usrdp-adr.niddk.nih.gov/2022/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities>

¹⁵ National Academies of Sciences, Engineering, and Medicine. 2019. *Dialysis Transportation: The Intersection of Transportation and Healthcare*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25385>.

¹⁶ United States Renal Data System. *2022 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*. National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, US Department of Health and Human Services; 2022. Accessed September 1, 2023. Available from <https://usrdp-adr.niddk.nih.gov/2022/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities>

2. *Optimizing the Medicare Kidney Disease Education Benefit*

NKF supports legislation to increase access to the KDE through expanding personnel qualified to provide the education, allowing education to be administered within dialysis facilities, and expanding the benefit to Medicare beneficiaries with diagnosed CKD stages 3-5.

Transplants for All: Advancing Health Equity in Kidney Transplantation

“As a Black patient who has collectively waited more than 14 years on the transplant list, the journey is daunting, and hope is diminished. Time is life when waiting for a life-saving transplant.”

M. Bensouda, NKF Kidney Patient Advocate

Research shows kidney transplantation leads to better quality of life and survival outcomes than dialysis, yet transplantation remains out of reach for many people of color.¹⁷ Of the approximately 90,000 individuals awaiting a life-saving kidney transplant, more than half identify as Black/African American or Hispanic. Despite making up the majority of the kidney transplant waitlist and a record-breaking 25,500 kidney transplants performed in 2022, only 7,362 Black/African American individuals and 5,141 Hispanic individuals received a kidney,¹⁸ NKF is championing the following policy solutions, which will make the U.S. transplant system operate more equitably and fairly:

1. *Pre-Waitlisting Data Collection*

Before a patient can get a transplant, they must receive a referral from their nephrologist, take all the necessary tests to assess their suitability for transplant, have the evaluation completed by the transplant center, receive their approval for the waitlist, and maintain their health so that they’re “transplant ready.” That journey is lengthy, disconnected, and littered with obstacles.

Unfortunately, data collection and reporting on this experience is inadequate. OPTN collects data on waitlisting, but very little is understood about the pre-waitlisting experience. We do not know when patients “fall through the cracks,” whether it’s at the point of referral, during evaluation, or prior to waitlisting. Little is understood about transplant center performance on the pre-waitlisting journey, and whether certain centers perform better in evaluating and listing patients of color.

NKF calls on CMS and HRSA to advanced policies that require nephrologists, dialysis centers, organ procurement organizations, and transplant centers to report data stratified by patient sociodemographics, to enforce the collection of this data in the new iteration of the OPTN contract, and to report data so that patients can make informed decisions about where they receive care. This information will provide a better understanding of who is not referred for a transplant evaluation and who may not complete a transplant evaluation to begin implementing interventions to improve patient access to the kidney transplant waitlist.

¹⁷ Kaballo, Mohammed A et al. “A comparative analysis of survival of patients on dialysis and after kidney transplantation.” *Clinical kidney journal* vol. 11,3 (2018): 389-393. doi:10.1093/ckj/sfx117

¹⁸ <https://optn.transplant.hrsa.gov/data/view-data-reports/build-advanced/>

2. Removing Financial Barriers to Transplantation

Oftentimes, patients are denied access to the transplant waitlist due to non-clinical factors. For example, some transplant centers require patients to demonstrate that they have access to reliable transportation so that they can be available “at a moment’s notice” should a donor organ become available. If a patient does not have a car or lives in a remote location, that could disqualify them from being eligible for the waitlist, even if they’re clinically a good candidate for transplant. Similarly, a patient who lives alone and does not have a care partner to help them during recovery might also be denied access to the waitlist. These criteria are often arbitrary, disproportionately affect low-income individuals, and could easily be addressed with financial support to the recipient.

NKF supports legislative efforts to provide financial resources to address transportation, lost wages, and child/eldercare for those interested in pursuing kidney transplantation.

3. Removing Race from Kidney Donor Risk Index

The Kidney Donor Risk Index (KDRI) is a clinical algorithm that scores the quality and predicted function of a kidney from a deceased organ donor. Under current practice, the KDRI includes a race coefficient that results in organs from black donors to be scored worse than those of a non-Black organ donor. This increases the risk that these kidneys will be discarded, and further delays patient access to transplant. Race has no place in clinical calculations, and **NKF calls on OPTN and HRSA to eliminate race from KDRI expeditiously to advance equity in deceased kidney donation and transplantation.**

Making the Health System More Equitable and Resilient

Many of the structural problems in our nation’s health care system -- lack of health insurance, inadequate coverage, poor access to providers, and unaffordable medications – exacerbate inequities in kidney care. A 2013 study using data collected by the National Kidney Foundation’s Kidney Early Evaluation Program (KEEP) found that uninsured participants were 82% more likely to die than insured participants and 72% more likely to develop kidney failure.¹⁹ By addressing these issues, we can not only reduce the burden of CKD on communities of color, we can improve the health of all Americans, bolster kidney patient quality of life, and save significant taxpayer resources from being expended on costly – oftentimes preventable – care.

1. Expand Access, Affordability, and Adequacy of Health Insurance

NKF partners with other patient advocacy organizations to develop, improve upon, and defend the programs and services our communities need to live longer, healthier lives. We do this primarily by advocating at the state and federal levels for health insurance that is adequate, affordable, and accessible.

¹⁹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3739048/>

Health Insurance Must be Affordable – Affordable plans ensure patients have equitable access to needed care in a timely manner from an experienced provider without undue financial burden. Affordable coverage includes reasonable premiums and cost sharing (such as deductibles, copays and coinsurance) and limits on out-of-pocket expenses. Adequate financial assistance must be available for people with low incomes and individuals with preexisting conditions should not be subject to increased premium costs based on their disease or health status.

Health Insurance Must be Accessible – All people, regardless of socioeconomic status, should be able to gain coverage without waiting periods through adequate open and special enrollment periods. Patient protections in current law should be retained, including prohibitions on preexisting condition exclusions, annual and lifetime limits, insurance policy rescissions, gender pricing and excessive premiums for older adults. Children should be allowed to remain on their parents' health plans until age 26 and coverage through Medicare and Medicaid should not be jeopardized through excessive cost-shifting, funding cuts, or per capita caps or block granting.

Health Insurance Must be Adequate and Understandable – All plans should be required to cover a full range of needed health benefits with a comprehensive and stable network of providers and plan features. Guaranteed access to and prioritization of preventive services without cost-sharing should be preserved. Information regarding costs and coverage must be available, transparent, and understandable to the consumer in a culturally competent manner prior to purchasing the plan.

Most recently, NKF lent its support to efforts to preserve coverage by asking Congress to oppose Medicaid work requirements, protect patients from surprise medical bills and advocate on behalf of patients experiencing medical debt. NKF is also part of an effort to fight non-compliant, or “junk” health plans that do not provide adequate coverage to our patients, including short-term, limited-duration plans, excepted benefit plans, and association health plans. We also advocate for making permanent the enhanced premium subsidies and fully funding healthcare navigators to ensure all patients can access adequate and affordable health coverage.

2. Assure Affordable and Adequate Prescription Drug Access

The introduction of new therapies that treat diabetes, hypertension, rare kidney diseases, and other underlying conditions that contribute to kidney disease are highly effective in preserving kidney function, slowing or preventing progression to kidney failure, and reducing kidney patients' risk of heart attack, stroke, or other cardiovascular events. Exciting as these innovative drugs are, they are of little value if a patient can't access them. Barriers to access include high cost, lack of insurance coverage, formularies that inhibit access, and policies that require patients to “fail first” on cheaper, less effective drugs, just to name a few.

NKF supports policies that allow patients to have timely, affordable access to the therapies they need, and spur innovation.



Kidney Health Should Be Inclusive

NKF is firmly committed to bridging racial and ethnic divides in kidney care and achieving kidney equity for communities disproportionately affected by kidney diseases. By advancing the aforementioned policies, we can foster a healthcare environment characterized by equity, respect, and responsible healthcare delivery. We envision a future where race and ethnicity are not barriers but indications for inclusive and holistic kidney healthcare. Rest assured; our endeavor remains tireless until superior kidney healthcare is not a privilege but a right for every individual.