

Advocating for Health Equity in Kidney Care: An Urgent Need



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The tremendous and disproportionate impact of the coronavirus disease 2019 (COVID-19) pandemic on Black/African American, Hispanic/Latino, Asian American, and American Indian/Alaska Native people living in the United States has created urgency around the long-standing need for policy solutions that move the nation toward greater health equity.¹ As a society, our obligation to leverage public policy to intervene in the health disparities that unjustly disadvantage Black/African American and Hispanic/Latino patients with kidney disease is especially acute. At the end of 2020, Lizzie Presser, a reporter for *ProPublica*, published the story of JaMarcus Crews, a young Black husband and father dependent on dialysis for survival, who died of COVID-19 infection while awaiting a kidney transplant (Fig 1).² The story of JaMarcus and his family lays bare the myriad barriers that racially and ethnically diverse communities face in achieving kidney health. The National Kidney Foundation (NKF) is advocating for policy makers to address these barriers, which span the societal factors that put people at risk for kidney disease up to and extending through accessing a kidney transplant. These barriers span the spectrum of kidney risk factors and kidney disease therapies, beginning with societal factors that put people at risk for kidney disease and extending through accessing a kidney transplant.

Increase Public Investment in Kidney Health Equity

"JaMarcus' path to kidney disease began before he was born. His mother, who raised her family on \$4 an hour, had diabetes, which put JaMarcus at increased risk for developing it as well. JaMarcus had type 2 diabetes diagnosed while in the ninth grade. Although he made every effort to manage his diabetes, he was never given information about chronic kidney disease (CKD) and the steps he might have taken to slow its progression. His kidneys had nearly failed by the time he was 30 years old."

Population-based interventions are effective at reducing the incidence of kidney failure among American Indian and Alaska Native people with diabetes, communities that also are disproportionately affected by

both diabetes and end-stage kidney disease (ESKD). Federally Qualified Health Centers (FQHCs) are essential safety net providers of comprehensive health services for the medically and geographically underserved, provided regardless of someone's ability to pay. NKF is working closely with the Health Resources and Services Administration to ensure that FQHCs are screening populations at especially high risk for CKD. The NKF is advocating for increased federal funding to support FQHCs and other health organizations in implementing targeted, culturally competent, community-based outreach and programming to populations disproportionately affected by kidney disease.

Investment in FQHCs is only one element of a public health strategy for kidney disease rooted in equity. Social determinants of health, "the conditions in which people are born, grow, live, work, and age," also account for a significant proportion of health outcomes.³ Lifestyle, nutritional, and pharmacologic interventions are essential to preserving kidney health; however, these interventions cannot be applied equally by all at-risk people, reflecting disadvantages across determinants of health. At present, there is no national public health strategy for kidney disease and no programming or funding specific to CKD

that targets the social determinants of health that contribute to CKD prevalence, progression, and outcomes, including food insecurity, homelessness, poverty, and poor access to care.^{4,5} NKF is advocating for an appropriation to the Centers for Disease Control and Prevention to support the development and implementation of a national kidney disease public health strategy, deployed by state and local departments of health and community partners, to intervene in kidney disease through the lens of social determinants.

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Close the Race and Ethnicity Gap in Access to Living Donor Kidney Transplants

"A transplant from a living donor was not an option for JaMarcus. His wife and most of his siblings had diabetes and were ineligible, and he wasn't given the support he needed to feel comfortable asking an acquaintance or even a stranger to consider living kidney donation."

Next Steps



Read NKF's comments to CME at www.kidney.org/sites/default/files/20190729_Comments_on_ILDA_role_in_05242019_Interpretive_guidance_Final.pdf



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Figure 1. Quilt celebrating JaMarcus' life. © Irene Antonia Diane Reece, 2020 (www.irenereece.com); reprinted with permission.

Racial concordance is not required for living donation. Nevertheless, racial concordance in living donation is >95%, and most living donors, ~75%, are White.^{6,7} As a result, of the 5,692 transplants that Black/African American dialysis patients received in 2018, only 755 (13%) of them were from living donors. Among Hispanic/Latino dialysis patients, 23% of transplants were from living donors. In contrast, in 2018, living donors accounted for ~36% of transplants received by White dialysis patients.⁸ These disparities also exist in Asian American and American Indian or Alaska Native populations.⁸ The reasons for the lower rates of living donation in diverse populations are multifactorial and are through no fault of the communities in which these disparities exist. As in JaMarcus' case, some populations are more likely to have disqualifying medical conditions. Medical mistrust, cultural and religious values, lack of awareness, and obstacles to care may all also play a role.⁹ There is a clear need for culturally competent education and support for organ donation in racially and ethnically diverse communities. NKF

supports a 3-pronged approach to eliminating disparities in living donation, including funding for the Office of Minority Health to support novel approaches to educating racially and ethnically diverse communities on organ donation (specifically living donation), funding to support community organizations in outreach and educational activities related to organ donation, and other efforts to facilitate patient access to culturally competent educational resources about transplantation.

Better Understand Why Structurally Disadvantaged Populations Are Left Behind in Access to Deceased Donor Transplantation

"At the time he initiated dialysis in 2013, JaMarcus was identified as suitable for transplant referral once he became eligible for Medicare. He was not actually referred to a transplant center until more than a year later, at which point he no longer met the transplant center's criteria for waitlisting. JaMarcus was never told about other local transplant centers to which he might have been referred and at which he might have more quickly qualified for the waitlist. When the nearest transplant center raised its body mass index cutoff, nobody told JaMarcus that his body mass index no longer disqualified him and he could now be referred to the center."

Black/African American and Hispanic/Latino people, as well as people from other structurally disadvantaged groups, are less likely to access a kidney transplant than White patients. Moving from dialysis to transplantation is a multistep process, beginning with referral to a transplant center for evaluation. People from structurally disadvantaged populations fall behind at every step of the process. Black/African American 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 posttransplantation.^{7,10} It is hypothesized that people from structurally disadvantaged populations may be less likely to receive a timely referral to a transplant center. Transplant referral continues to be the topic of study and quality improvement projects; however, these efforts are limited by the lack of national data collection on referral and time to evaluation. NKF supports national data collection efforts on the early steps of the transplant process, such as transplant referral and start of the transplant evaluation, that will provide greater insight into roadblocks to transplantation that may disproportionately affect people of racial and ethnic minorities.

Ensure Equitable Access to Home Dialysis Success

"JaMarcus had a college degree in business administration and a reliable job as a bank teller. But his

Box 1. How Can You Help?

- Patients and professionals are invited to get involved with the National Kidney Foundation to develop and advocate for policies that fight the impact of racism on health. Join the Kidney Advocacy Committee (KAC) or the Kidney Outreach team (KO Team): <https://www.kidney.org/advocacy/advocate>
- Learn more about how the American Society of Nephrology (ASN) is advocating for policymakers to address kidney disease inequities and disparities: <https://www.kidneynews.org/policy-advocacy/leading-edge/challenges-to-kidney-care-how-asn-is-creating-positive-change>
- Get involved with ASN's advocacy and public policy activities: <https://www.asn-online.org/policy/advocacy.aspx>
- Engage with the NKF Patient Registry: <https://www.kidney.org/nkfpatientnetwork>. Patient data from the registry will help researchers better understand and tackle disparities, determinants of health in kidney care, and patients' challenges and experiences of care

3-times-a-week dialysis schedule led him to leave his career. The only work he was able to find that could accommodate dialysis was part-time work as a cashier. JaMarcus was never afforded the kind of support that might have enabled him to use home dialysis successfully."

Despite being preferred by many dialysis patients, home dialysis is underused, particularly among patients from structurally disadvantaged populations. Black/African American and Hispanic/Latino patients are less likely to initiate home dialysis and are more likely to return to in-center hemodialysis. This may be because of bias on the part of the physician and dialysis facility staff and/or because common barriers to home dialysis such as unstable living situations, poor health literacy, and lower socioeconomic status are overrepresented among Black or African American and Hispanic or Latino dialysis patients. Disparities in selection of modality narrow when adjusted for demographic, medical, and socioeconomic factors.¹¹ Providing paid assistance for home dialysis patients may help overcome common socioeconomic barriers to home dialysis in social and health literacy domains.¹² Though the Medicare program has done so in the past, Medicare does not currently cover staff-assisted home dialysis. Some private payors do reimburse for assistance for home dialysis patients dialyzing in their homes and in skilled nursing facilities.

NKF supports authorization by the Medicare program of reimbursement to dialysis providers for in-home assistance for home dialysis patients. Doing so will provide necessary support for all patients who may benefit from home dialysis to transition to and be successful with home dialysis, including those who are more socioeconomically disadvantaged and may

not be able to afford to pay for help or who may not have care partners with the available time to aid with dialysis.

Extend Medigap to all ESKD Beneficiaries

"Lack of access to comprehensive insurance coverage presented JaMarcus with challenges throughout his life. Even when he had qualified for Medicare, he switched to nighttime dialysis sessions to seek out a job with insurance that would help cover his expenses."

Most US citizens with irreversible kidney failure are entitled to Medicare benefits. When enrolled in the program, ESKD beneficiaries are typically accountable for 20% 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 plan. However, federal law does not require insurance companies to sell Medigap plans to Medicare beneficiaries younger than 65 years. As a result, ESKD beneficiaries in many states who are younger than 65 years cannot get supplemental insurance. Extending Medigap coverage to all ESKD beneficiaries, regardless of age, will reduce the out-of-pocket expenditures associated with kidney failure that are likely to disproportionately fall on racial and ethnic minorities. NKF is advocating for Congress to guarantee that all ESKD beneficiaries, regardless of age, are able to access a Medigap plan. Legislative efforts can follow the model of the Jack Reynolds Memorial Medigap Expansion Act, introduced by Congresswoman Cindy Axne (IA-03) and Jaime Herrera Beutler (WA-3) in March 2021.

The NKF and the broader kidney community are working to shed new light on a problem that has existed for far too long. A 4-times higher risk for kidney failure among Black Americans living in Jefferson County, Alabama, was first reported in the *New England Journal of Medicine* nearly 40 years ago, in 1982.¹³ JaMarcus was born in Bibb County, part of the same 7-county metropolitan area in Alabama as Jefferson County, just 1 year later in 1983. In the intervening years, too little has changed for people like JaMarcus and his family. In **Box 1**, we provide specific suggestions for how patients, family members, and clinicians can advocate for change.

We invite the kidney community to join us in this mission to enhance health equity and help improve the lives of individuals with kidney disease, their family members, and their communities.

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The National Kidney Foundation helps to shape public policy on behalf of individuals at all stages of kidney disease, working with Congress, federal agencies, and state governments to further legislation and regulations that improve the care and quality of life for people with kidney disease. Miriam Godwin joined NKF as a Health Policy Analyst in early 2019. She holds a Master of Public Policy and has five years of experience in product development regulatory policy in the pharmaceutical industry and three years of experience working in basic science research.