



September 25, 2020

The Honorable Richard Neal
Chair
Committee on Ways and Means
US House of Representatives
1102 Longworth House Office Building
Washington, DC 20515

Dear Chairman Neal:

On behalf of the more than 37 million Americans living with kidney diseases as well as the more than 21,000 nephrologists, scientists, and other kidney health care professionals who are members of the American Society of Nephrology (ASN), thank you for your efforts to address the racial health inequity and systemic racism that plagues the US health care system. As Black, Hispanic and Latinx, South Asian, Asian, Indigenous, and White health professionals of US and international origin who are committed to advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients, ASN's members, leaders, and staff stand with you in your commitment to end systemic racism.

ASN is proud of its efforts to promote diversity, equity, and inclusion among kidney health professionals and to eliminate health disparities in the communities the society's members serve in the United States and more than 130 countries worldwide. ASN takes seriously the critical reassessment of the inclusion of race in kidney function estimation and appreciates this opportunity to engage with you and the Committee on Ways and Means of the US House of Representatives regarding the society's efforts.

A disproportionate number of the more than 37 million people in the United States with kidney diseases are of African, Hispanic and Latinx, and Indigenous descent. As you note in your letter to ASN dated Friday, September 3, 2020, the most commonly used equation for estimated glomerular filtration rate (eGFR) includes a "correction" for Black race.¹ ASN agrees that unlike age, sex, and body weight, race is a social, not a biological, construct. Adjusting for race in the eGFR equation may not address the diversity within self-identified Black or African American patients as well as other racial or ethnic groups. The importance of ensuring the kidney community addresses this issue is paramount given the known disparities in care delivery among Black and other communities of color. Therefore, any recommendation on how to apply this equation warrants a comprehensive and critical examination on the impact it has on Black patients with, or at risk for, kidney diseases. Because more than 33% of the US population is at risk for kidney diseases, the implications of such a change to the US health care system are staggering, and a thorough, multi-faceted, patient-centered approach to reviewing this issue is required.

¹ Neal R. Letter to Anupam Agarwal. September 3, 2020.



As described in detail in response to your questions below, ASN, in partnership with the National Kidney Foundation (NKF)—a leading voluntary health organization including key representation of kidney patients—formed the [NKF-ASN Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Diseases on July 2, 2020](#).² The formation of this task force reflects both organizations' commitment to ensuring that GFR estimation equation provide an unbiased assessment of kidney function so that laboratories, clinicians, patients, and public health officials can make informed decisions to ensure equity and personalized care for patients with kidney diseases. The goal of this care is to detect kidney diseases equitably and as early as possible, slow the progression of disease, identify significant changes in the severity of kidney diseases that warrant timely intervention, and provide appropriate patient-centered management of advancing kidney failure, including, ideally, pre-emptive kidney transplantation or home dialysis.

In light of the complexities and far-reaching implications involved in ensuring the eGFR equation represents an unbiased assessment of kidney function, the NKF-ASN Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Diseases is undertaking a thorough and comprehensive process to fulfill its charge. Through this process, the two organizations will ensure that any change in eGFR reporting carefully consider the multiple social and clinical implications, be based on rigorous science, and be part of a national conversation about uniform reporting of eGFR within, between, and among health care delivery systems. The safety of patients, particularly among patients of color, is of supreme importance. ASN and NKF anticipate that the task force will issue its initial recommendations later this year.

In addition to working with NKF on the eGFR equation via the task force, ASN is committed to tackling a broad range of challenges to equity in health care, research, and education, many of which are targeted at the principal causes of disparities. This letter describes some of these ongoing and planned efforts. ASN welcomes the opportunity to partner with the committee to address these efforts with other stakeholders in federal government, within the kidney community, or across health care.

Q.1

Please update the Committee on ASN's education efforts that specifically describe the lack of scientific rigor in defining race and differences in "muscle mass" in the research studies that led to the current equation that guides eGFR calculation. How will the ASN inform [clinicians of the connection between race correction in eGFR calculation and racial health inequities in CKD, ESRD, and kidney transplantation](#)?

As you noted, race is a social construct. It is a product of racism that has manifested in health care in many ways, resulting in grave health disparities (which you also highlighted). The

² American Society of Nephrology, National Kidney Foundation. Joint Statement on Establishing a Task Force to Reassess the Inclusion of Race in Diagnosing Kidney Diseases. July 2, 2020. Retrieved from https://www.kidneynews.org/sites/default/files/NKF-ASN%20eGFR%20Statement_July%202020.pdf

consideration of the role of race in the eGFR equation and racial health inequities is a complex matter that must be given serious attention and the weight it deserves. For this reason, ASN (representing the spectrum of kidney health professionals) has joined with NKF (representing kidney patients) in establishing a task force to gain insight on the implications of using race in the diagnosis of kidney diseases in order to ensure equitable care (described below in this letter).

You also noted that differences in eGFR and serum creatinine that have been noted in racial groups have been explained previously using anthropometric studies, but these results may be imprecise as hydration status introduces high variability to anthropometric measures. Other studies using estimated lean body mass have not supported this consideration of differences due to "muscle mass." In sum, prior research that has investigated this topic has been mixed in conclusions. The task force is critically examining these studies, as well as all studies that have derived eGFR from gold-standard measured GFR procedures in Black patients, to determine whether any conclusions can be determined from published work as well as whether a call for more research to explore this relationship is needed.^{3, 4, 5, 6, 7}

When the NKF-ASN Task Force, described in detail below, provides its final recommendations, ASN intends to undertake a multi-pronged approach to informing the ASN membership, the kidney community, and stakeholders in the broader field of health care of the recommendations. In addition, ASN plans to work with NKF to ensure that the nation's laboratories adjust their policies to adopt the new methodology. Finally, ASN and NKF plan to engage primary care physicians to help them understand and embrace the change as well as to increase their efforts to screen, identify, and treat (or refer) patients at-risk for (or with) kidney diseases, particularly among patients of color.

ASN also recognizes that the causes of racial health inequities are multifactorial: disparities within kidney diseases are not limited to algorithms but have powerful forces and complexities that will need to be addressed beyond the NKF-ASN Task Force. Disparities in health care—particularly as they pertain to kidney diseases, kidney failure, and kidney transplantation—require ASN, the rest of the kidney community, and the rest of US society, to address racism on

³ Stevens, L. A., et al. Development and validation of GFR-estimating equations using diabetes, transplant and weight. *Nephrol Dial Transplant*. 2010. doi: 10.1093/ndt/gfp510.

⁴ Levey, A. S. et al. Estimation of Glomerular Filtration Rate With vs Without Including Patient Race. *JAMA Intern Med*. 2020. doi:10.1001/jamainternmed.2020.0045

⁵ Poggio, E. D., et al. Demographic and clinical characteristics associated with glomerular filtration rates in living kidney donors. *Kidney International*. 2009. <https://doi.org/10.1038/ki.2009.11>

⁶ Baxmann, A. C., et al. Influence of Muscle Mass and Physical Activity on Serum and Urinary Creatinine and Serum Cystatin C. *CJASN*. 2008. doi: <https://doi.org/10.2215/CJN.02870707>

⁷ Hsu, J., et al. Higher Serum Creatinine Concentrations in Black Patients with Chronic Kidney Disease: Beyond Nutritional Status and Body Composition. *CJASN*. 2008. doi: <https://doi.org/10.2215/CJN.00090108>



a personal, systemic, and institutional level. ASN has been and will continue to be steadfast in achieving health equity for all.

As ASN noted in testimony on Wednesday, June 10, 2020,⁸ Black Americans and Hispanic/Latinx Americans as compared to White Americans are more likely to have kidney diseases but are also up to 3.5 times⁹ more likely to progress to kidney failure. The federal government can implement solutions (described below) to help address this unacceptable reality. ASN and other stakeholders in the kidney community, such as NKF, welcome the opportunity to lead and partner with the Committee on Ways and Means in synergy to explore solutions to eliminate these inequities.

Q.2

What strategies is the ASN undertaking to reevaluate the scientific basis for the use of Black race in eGFR calculation? How will the ASN work to support, encourage, and coordinate with other specialty organizations that are also conducting a reevaluation?

As an outgrowth of ASN's ongoing efforts to promote diversity, equity, and inclusion in health care delivery, ASN on Thursday, July 2, 2020, announced the establishment of a task force to reassess the inclusion of race in diagnosing kidney diseases, in partnership with NKF. NKF is a major voluntary health organization in the United States, headquartered in New York, NY, with more than 30 local offices across the country. According to its mission, NKF "is dedicated to preventing kidney and urinary tract diseases, improving the health and well-being of individuals and families affected by kidney diseases and increasing the availability of all organs for transplantation."

The task force is co-chaired by Cynthia Delgado MD, FASN, and Neil R. Powe, MD, FASN, and includes a total of 14 members. Given the importance, implications, and complexity of the expected recommendations, the task force includes experts in many key stakeholder domains, such as health disparities, health care equity, lab medicine and clinical chemistry, pharmacology, social sciences, health services and disparities research, clinical trials, kidney diseases epidemiology, and research funding.

Besides attempting to make sure the task force included expertise in these domains, NKF and ASN made every effort to ensure that the task force itself would be diverse in terms of sex, ethnicity, age, professional focus, experience, and perspective. To help identify its seven

⁸ Baweja M, Josephson, MA. Written Testimony on the Disproportionate Impact of COVID-19 on Communities of Color. Retrieved September 3, 2020 from https://www.asn-online.org/policy/webdocs/ASN_TESTIMONY_DISPROPORTIONATE_IMPACT_OF_COVID-19_ON_COMMUNITIES_OF_COLOR.pdf

⁹ National Institute of Diabetes and Digestive and Kidney Diseases. Kidney Disease Statistics for the United States. National Institutes of Health. Retrieved September 25, 2020 from <https://www.niddk.nih.gov/health-information/health-statistics/kidney-disease>

members of the task force, ASN relied on the ASN Diversity and Inclusion Committee's "Value's Statement:"¹⁰

- Inclusion: Encourage contributions and collaboration among colleagues.
- Mentorship: Improving career opportunities for professionals dedicated to curing kidney diseases.
- Health Equity: Working strategically to eliminate disparities in the diagnosis, treatment, and prevention of kidney diseases.
- Patient Advocacy: Promoting universal access to quality care for all people living with kidney diseases.
- Engagement: Supporting civic engagement and community service as part of the professional experience

Appendix A lists the task force members.

For example, Nwamaka D. Eneanya, MD, MPH, FASN, a rising clinical investigator, is a member of the task force because of her substantial contribution to discussions on race adjustment and eGFR, while Marva Moxey-Mims, MD, FASN, is a division chief of pediatric nephrology who used to work at NIDDK, making her expert in both kidney diseases in children and the research enterprise. ASN and NKF each appointed one member to the task force who are kidney patients known for their tireless efforts to advocate for people with kidney diseases, kidney failure, and kidney transplants.

Every member of the task force has committed to achieving consensus and producing initial recommendations by the end of the year. The NKF-ASN Task Force is charged with:

- Examining the inclusion of race in the estimation of GFR and its implications for the diagnosis and subsequent management of patients with, or at risk for, kidney diseases.
- Recognizing that any change in eGFR reporting must consider the multiple social and clinical implications, be based on rigorous science, and be part of a national conversation about uniform reporting of eGFR across health care systems.
- Attempting to incorporate the concerns of patients and the public, especially in marginalized and disadvantaged communities, while rigorously assessing the underlying scientific and ethical issues embedded in current practice.
- Ensuring that the GFR estimation equation provides an unbiased assessment of kidney function so that laboratories, clinicians, patients, and public health officials can make informed decisions to ensure equity and personalized care for patients with kidney diseases.
- Keeping laboratories, clinicians, and other kidney health professionals apprised of any potential long-term implications of removing race from the eGFR formula.

¹⁰ American Society of Nephrology. Diversity and Inclusion Committee. Retrieved September 25, 2020 from <https://www.asn-online.org/about/committees/committee.aspx?panel=DI>



The members of the task force have agreed to maintain confidentiality in the deliberations as they consider expert panel testimony covering the following areas:

- Patients, patient perspective, and shared decision making.
- eGFR measurement and estimation.
- Race, racism, and genetic ancestry.
- Approaches to address race in the equation.
- Clinical consequences of different approaches.
- System and societal consequences of different approaches.

The task force's recommendations will promote consistency in eGFR measurement (an essential goal for patient safety) and the potential impact this new methodology may have on the health and well-being of individual patients. For this reason, the task force has taken a holistic approach driven by science, and scientific methods will be employed to examine clinical, psychosocial, and financial tradeoffs of benefits and harms balanced across racial/ethnic groups.

As an additional review on the integrity of recommendations, ASN has leveraged the overwhelming interest in this task force and the high visibility of this effort to plan to establish an "eGFR Advisory Board" with NKF. This broad and diverse board will review and comment on the draft recommendations before the task force finalizes them. ASN delegates on the eGFR Advisory Board will include members of the ASN Council (the society's governing body), Diversity and Inclusion Committee, Policy and Advocacy Committee, Quality Committee, and other interested expert panels as well as members of the kidney community who have volunteered (or been recommended). ASN and NKF also hope to include a public comment period in the review process.

While ASN understands the need to be expeditious in these deliberations, a considerable undertaking of this nature will take time because of the substantial impact changes may have on the health and safety of patients. Implementation of recommendations of this magnitude will also require extensive attention and effort to safeguard patient safety and health equity. ASN and NKF anticipate that the task force will issue its initial recommendations in 2020.

In addition, ASN and the rest of the kidney community depend on Kidney Disease: Improving Global Outcomes (KDIGO) and Kidney Disease Outcomes Quality Initiative (KDOQI), which have historically served as the clinical practice guideline developers to disseminate evidence-based guidelines. Given their roles in disseminating practice guidelines, ASN plans to gain insight on how KDIGO and KDOQI anticipate responding to or incorporating the task force's recommendations into their existing and future guidelines and processes to improve clinical



practice. Because ASN lacks any role in or oversight of KDIGO and KDOQI, the society has no ability to direct either entity to remove race from their clinical practice guidelines.

In terms of engagement with other specialties (in addition to ongoing work with NKF and planned future outreach to KDIGO and KDOQI), ASN Executive Vice President Tod Ibrahim has contacted the other health professional societies ASN understands are re-examining the use of race in clinical algorithms. Mr. Ibrahim has expressed ASN's interest in discussing our organizations' respective efforts, identifying best practices for education and dissemination of findings and changes, and coordinating to ensure our respective members are apprised of similar modifications to improve health equity elsewhere in clinical practice.

Additionally, as described in detail later in this letter, ASN is also leveraging its membership and leadership in the Council of Medical Specialty Societies (CMSS) to support, encourage, and coordinate with other specialty organizations to address and eliminate systemic racism in health care, research, and education. These relationships will also help increase the likelihood that primary care physicians embrace the final recommendations of the NKF-ASN Task Force.

Q.3

While ending the use of Black race in eGFR calculation could take some time to implement, what guidance can the ASN issue quickly to redirect clinicians' practice? What guidance would the ASN offer on how this should be communicated to patients?

The task force's charge includes being "part of a national conversation about uniform reporting of eGFR across health care systems," and "keeping laboratories, clinicians, and other kidney health professionals apprised of any potential long-term implications of removing race from the eGFR formula." With the initial recommendations forthcoming later this year, ASN will work as expeditiously as possible to share the task force's guidance with its membership and the broader kidney and health care communities, including working with other professional and patient organizations and approaching KDIGO and KQODI (as noted above). Approximately 90% of US nephrologists are ASN members, and the society is the largest publisher with the most communications channels (including social media) in the field. As such, ASN is well positioned to trumpet the recommendations. The society would be pleased to detail some of the avenues it has available and intends to pursue to disseminate this information, if helpful.

Clinicians and researchers who have advocated for the removal of the race adjustment have voiced concerns that its inclusion leads to a potential overestimation of kidney function and result in less care offered (such as referral to nephrology or referral for transplant) for Black, Hispanic and Latinx, and Indigenous people. At the same time, other researchers and clinicians who have advocated for the continued inclusion of the race adjustment have voiced concerns

that removal could lead to an underestimation of kidney function and impact decisions and subsequent outcomes related to drug dosing, imaging, and kidney donation, for which there are existing disparities for Black patients documented in credible research. The perspective of patients—particularly Black patients—is an essential component to keep at the center of this conversation.

For this reason, the ASN leadership felt it was critically important to partner with NKF in its effort to reassess the use of race in the eGFR formula. This important partnership helps ensure that guidance on use of the race adjustment and implications for care delivery, is directly informed by patients and patient advocates.

Just as ASN is working in collaboration with NKF to examine the inclusion of race in the estimation of GFR and its implications for the diagnosis and subsequent management of patients with, or at risk for, kidney diseases, the society plans to work in tandem with NKF to disseminate the task force's recommendations to the kidney patient community. By partnering with NKF, as a patient organization, ASN will help ensure that these recommendations, and the multiple social and clinical implications, are conveyed in the most patient-centered manner possible, such as potentially NKF's patient-facing communications platforms.

Q.4

What remedies could be implemented to ensure appropriate care for patients who have not received it because of race correction in eGFR calculation? What role could the federal government play in this implementation? What role should the ASN play in the implementation?

In terms of eGFR, ASN has been focused on the foundational steps to address the issue of race correlation in the eGFR equation, via the formation of the NKF-ASN Task Force. The society is committed to ensuring appropriate care for all patients—particularly for historically under-served communities of color—who bear a disproportionate burden of kidney diseases in the United States. As the task force is deliberating with experts about the role of race adjustment in eGFR and its influence on appropriate and equitable care, ASN also notes that racial disparities in care are multifaceted. The society has a long history of working with the federal government and stands ready to continue and expand upon its efforts to help rectify disparities and social determinants ultimately tied to systemic racism that are broader than the issue of the race adjustment in eGFR.

Health status is closely correlated with socioeconomic status and systemic racism, which can further be understood by social determinants of health (including economic stability, education, social and community contexts, environment, as well as access to health care).¹¹ ASN's understanding of the depths of the disparities within kidney diseases and health care as a whole continues to increase, and it is clear that disparities are traced to systemic racism and will not

¹¹ Harper, S., Lynch, J. Trends in Socioeconomic Inequalities in Adult Health Behaviors Among U.S. States, 1990–2004. Public Health Rep. 2007. doi: [10.1177/003335490712200207](https://doi.org/10.1177/003335490712200207)

be adequately addressed in the absence of dismantling these racist structures in and outside of health care.

Below, ASN highlights several kidney health disparities that could be addressed in part through changes in federal policy. While recognizing that broad efforts to reduce disparities among Black and other communities of color is not the focus of the committee’s inquiry at this time, ASN calls attention to these troubling facts as areas for collaboration to rectify together with the Committee on Ways and Means, you as the committee’s chair, the kidney community, federal agencies, and other stakeholders. ASN welcomes a discussion about nephrology-specific interventions that would help address health disparities and racism in kidney care in the United States. This discussion could address several topics, including:

Table A. Select Racial Kidney Health Disparities and Potential Policy Levers	
Kidney Health Disparities	Potential Policy Levers
<p>Disparities Within and To Transplantation Transplantation is the best available therapy for kidney failure. However, Black Americans face disparities in nearly every step of transplant care. Black Americans are less likely than White Americans to be identified as a transplant candidate,¹² referred for evaluation,¹³ put on the kidney transplant waitlist,¹⁴ receive a kidney transplant,¹⁵ receive a higher-quality kidney from a living donor,¹⁶ while also being more likely to receive lower quality kidneys¹⁷ and have poorer transplant graft survival.¹⁸ Critically, while it is possible the use of race-adjusted eGFR may lead to a lower number of Black Americans waitlisted for a kidney transplant, there are many additional and distinct</p>	<ul style="list-style-type: none"> • Design or require development of systems to elevate patient voice into decision-making on waitlisting, living donation, and organ acceptance. • Overhaul organ procurement metric and accountability reform to increase organ supply. • Reform transplant center metrics to promote increased access to transplantation, organ and patient acceptance, and speed of organ placement. • Identify and remove transplant evaluation criteria that lead to racial inequity and have little impact on clinical success of transplant, such as patient income, substance use, obesity, transportation,

¹² Patzer, R. E., et al. The Role of Race and Poverty on Steps to Kidney Transplantation in the Southeastern United States. *Am J Transplant*. 2012. doi: [10.1111/j.1600-6143.2011.03927.x](https://doi.org/10.1111/j.1600-6143.2011.03927.x)

¹³ Epstein, A. M., et al. Racial Disparities in Access to Renal Transplantation — Clinically Appropriate or Due to Underuse or Overuse? *N Engl J Med*. 2000. doi: [10.1056/NEJM200011233432106](https://doi.org/10.1056/NEJM200011233432106)

¹⁴ Kasiske B. L., Ellison, M. D. Race and socioeconomic factors influencing early placement on the kidney transplant waiting list. *JASN*. November 1998, 9 (11) 2142-2147.

¹⁵ Ibid

¹⁶ Purnell, S. T. et al. Association of Race and Ethnicity With Live Donor Kidney Transplantation in the United States From 1995 to 2014. *JAMA*. 2018. doi: [10.1001/jama.2017.19152](https://doi.org/10.1001/jama.2017.19152).

¹⁷ Mohandas, R. et al. Racial and Socioeconomic Disparities in the Allocation of Expanded Criteria Donor Kidneys. *Clin J Am Soc Nephrol*. 2013. doi: [10.2215/CJN.01430213](https://doi.org/10.2215/CJN.01430213)

¹⁸ Purnell, S.T., et al. Reduced Racial Disparity in Kidney Transplant Outcomes in the United States from 1990 to 2012. *J Am Soc Nephrol*. 2016. doi: [10.1681/ASN.2015030293](https://doi.org/10.1681/ASN.2015030293)

<p>interventions federal policy makers should enact to more potently dismantle systemic racism in kidney transplantation. For example, donors and recipients of the same ethnicity are more likely to match, so OPOs' failure to recover organs from Black donors or the fact that Black race results in a donor kidney getting a poorer quality KDPI score, hurts potential Black recipients.¹⁹</p>	<p>and the use of race in the kidney donor profile index (KDPI) algorithm.</p> <ul style="list-style-type: none"> • Remove dual insurance requirement for consideration to receive a kidney transplant. • Enact legislation to provide lifetime Medicare coverage of immunosuppressive drugs for kidney transplant patients. • Ensure living kidney donation is a cost-neutral act. • Mandate cultural competency training for health professionals involved in living donor recruitment and organ procurement and increase the cultural representativeness of organ procurement organization staff. • Modernize the organ matching IT systems and otherwise improve infrastructure to expedite organ matching and placement. • Create payment systems that appropriately account for the cost of transplanting higher-risk organs and patients, with appropriate guardrails, to increase the overall organ supply and give more patients with kidney failure an alternative to dialysis • Recognize, as described elsewhere in this letter, that the Kidney Donor Profile Index (KDPI) equation will be revisited and that change may have implications for these and other existing policies to increase and ensure health equity
<p>Disparities in Access to Care</p> <ul style="list-style-type: none"> • Black Americans are less likely to receive pre-kidney failure care than all other racial groups, and similar—but smaller—disparities exist in access to pre-kidney failure care for all non-White Americans. Black and non-White patients are less likely to be insured and as a result have less access to preventative care for kidney diseases and other related 	<ul style="list-style-type: none"> • Mandate the inclusion of appropriate screening for kidney diseases for patients with risk factors upon Medicare and Medicaid enrollment. • Ensure each US state offers a Medigap plan. • Continue expansion of Medicaid programs in each US state.

¹⁹ ¹⁹ Vyas DA et al. Hidden in plain sight – reconsidering the use of race correction in clinical algorithms. 2020; doi: 10.1056/NEJMms2004740.

<p>chronic diseases,²⁰ leading to adverse health outcomes and medical debt.²¹ There number of Black nephrologists needs to be increased to mirror the population with kidney diseases and to instill trust by patients in the health care system. Further, the intersection of decreased access to pre-kidney failure care and decreased access to prenatal and maternal care leads to adverse pregnancy outcomes that may increase the lifelong risk of kidney diseases, cementing racial disparities in kidney health across generations.^{22, 23}</p>	<ul style="list-style-type: none"> • Support increased access to nutritional resources and medical nutrition therapy, especially kidney-specific diets. • Prioritize the development of a diverse and inclusive adult and pediatric primary and specialty care workforce that reflects the makeup of the population in need of care by increasing funding for federal loan repayment programs that support Black, Hispanic and Latinx, and Indigenous trainees or requiring community review boards for health systems that receive federal funding. • Emphasize the provision of culturally appropriate and competent care by requiring fellowship programs to establish cultural competency training as part of certification for training programs that do not already include implicit bias training. • Increase federal funding of research and innovation, such as the National Institutes of Health (NIH) and the Patient-Centered Outcomes Research Institute (PCORI) that identifies more accurate biomarkers of kidney diseases and improves screening practices and diagnostics. • Support increased federal funding to mitigate health disparities in vulnerable populations, particularly Black Americans, with kidney diseases.
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²⁰ Artiga, S., Orgera, K. Changes in Health Coverage by Race and Ethnicity since the ACA, 2010-2018. Kaiser Family Foundation. 2020. Retrieved September 25, 2020 from <https://www.kff.org/racial-equity-and-health-policy/issue-brief/changes-in-health-coverage-by-race-and-ethnicity-since-the-aca-2010-2018/>

²¹ Tolbert, J., Orgera, K., Singer, N. Key Facts about the Uninsured Population. Kaiser Family Foundation. 2019. Retrieved September 25, 2020 from <https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/>

²² Norton, J. M., et al., Social Determinants of Racial Disparities in CKD. JASN. 2016. doi: <https://doi.org/10.1681/ASN.2016010027>

²³ Hladunewic, M. Pregnancy in young women with kidney disease — a most worthwhile journey. The Lancet. Retrieved September 25, 2020 from <https://www.thelancet.com/campaigns/kidney/updates/pregnancy-in-young-women-with-kidney-disease#:~:text=Pregnancy%20is%20a%20significant%20physiological,progression%2C%20prematernity%20and%20growth%20restriction.>

	<ul style="list-style-type: none"> • Support the development of community engagement and kidney health education programming within communities hardest hit by racial disparities in kidney health, including recruiting and incentivizing community-based organizations to serve as patient navigators. • Fund community health workers. • Optimize access to and quality of prenatal care in federal health care programs. • Increase federal funding of broadband expansion to improve access to telehealth.
<p>Disparities Resulting from Social Determinants of Health (SDOH)</p> <ul style="list-style-type: none"> • Kidney failure, a consequence of failed prevention the progression of kidney diseases and closely tied to other chronic diseases that are prevalent among Black Americans such as diabetes and hypertension, is associated with lower employment in Black and Hispanic Americans,²⁴ further exacerbating the socioeconomic status (SES) of vulnerable groups and reinforcing the systemic structure of racism. SDOH can also be identified in the care of patients with kidney failure, residential areas where there are more Black residents are more likely to have dialysis centers that are less likely to meet performance targets and have higher-than expected mortality.²⁵ In addition, home dialysis modalities are associated with a higher quality of life and lower mortality compared to in-center modalities and present a care choice that may provide better outcomes, but Black Americans are less likely to be candidates for home 	<ul style="list-style-type: none"> • Expand supplemental nutritional assistance programs. • Ensure the success of new Centers for Medicare and Medicaid Services (CMMI) voluntary Kidney Care Choices models, which promote kidney care that slows the progression of diseases before kidney failure—the ultimate goal. • Support the goals of the ESRD Treatment Choices (ETC) Program, which places emphasis on improving access to home dialysis and transplantation and ensure that the Centers for Medicare and Medicaid Services (CMS) collects data with respect to equitable access to these modalities. • Develop or improve CMS’ quality metrics to assess and improve health disparities. • Assure population tracking of kidney diseases and its social determinants in communities of color to assess progress of policy interventions. • Equalize access to care choices by advocating for the provision funding for staff-assisted home dialysis care, revisiting the requirement of social support for home dialysis, and identifying

²⁴ Hallab, A., Wish, J. Employment among Patients on Dialysis. *Clin J Am Soc Nephrol*. 2018. doi: [10.2215/CJN.13491217](https://doi.org/10.2215/CJN.13491217)

²⁵ Rodriguez, R. A. et al. Geography Matters: Relationships among Urban Residential Segregation, Dialysis Facilities, and Patient Outcomes. *Annals of Internal Medicine*. 2007. <https://doi.org/10.7326/0003-4819-146-7-200704030-00005>

<p>dialysis²⁶ due to SDOH that include immigration status, unstable housing, access to childcare, access to home health aides, and limitations in employment that would prohibit proper dialysis modality training.</p>	<p>mechanisms to provide more equitable kidney care to people experiencing housing instability or other factors that lead to decreased care access.</p>
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Q.5

Black, Indigenous, and Latinx scholars have a leading and vital perspective on these issues and the proposed solutions, despite being underrepresented in medicine. How is ASN ensuring racial diversity in the discussion and strategy development relating to health equity?

ASN recognizes the need to enhance diversity and embrace inclusion in nephrology and more broadly in health care. Diversity initiatives have been a major goal in the ASN Strategic Plan for the past decade. To this end, ASN convened a Diversity and Inclusion Summit in 2013 that led to the establishment of the ASN Diversity and Inclusion Committee, one of the society's eight mission-based committees (continuing education, workforce and training, communications, publications, policy and advocacy, quality, career advancement, and diversity and inclusion).

Currently chaired by Cynthia Delgado, MD, FASN, the ASN Diversity and Inclusion Committee is comprised of physicians and scientists of racially diverse backgrounds with broad nephrology expertise and includes ASN Council Liaison Crystal A. Gadegbeku, MD, FASN, a founding member of the committee. With support from the ASN leadership, this committee promotes diversity and inclusion organization-wide by multiple activities, including:

- Incorporating a highly successful networking event with the society's leadership that celebrates under-represented populations at ASN Kidney Week. More than 14,000 health professionals worldwide participate annually in Kidney Week.
- Partnering with the Robert Wood Johnson (RWJ) Foundation to fund two ASN-Harold Amos Medical Faculty Development Program Scholars (each ASN-Harold Amos Medical Faculty Development Program Scholar receives \$105,000 per year for four years). Through this program, ASN and RWJ Foundation aim to increase diversity among future leaders in nephrology by supporting the career development of kidney research scholars. ASN members, Neil Powe, MD, and Aubrey Morrison MD are members of the program's National Advisory Committee.
- Supporting a travel grant program for ASN members to attend the NIH National Institute for Diabetes and Digestive and Kidney Diseases' (NIDDK's) Network of Minority Health Research Investigators Annual Workshop (97 individuals over the last five years). This workshop brings together successful NIDDK-funded investigators and developing under-

²⁶ Mehrotra. R. et al. Racial and Ethnic Disparities in Use of and Outcomes with Home Dialysis in the United States. J Am Soc Nephrol. 2016. doi: 10.1681/ASN.201505047



represented minority faculty for mentorship activities to promote scientific career development and networking.

In addition, to better support all ASN members, particularly members of diverse backgrounds, the diversity and inclusion committee has led efforts to expand collection of demographic information on ASN members, improve diversity within all ASN committees, and implement implicit/unconscious bias training for ASN leaders, committee members, and staff. Currently, four of the eight ASN Councilors are women, and two of the eight Councilors are Black women. This diversity on the society's leadership—and therefore the leadership of the specialty of nephrology—is a direct result of the committee's activities and ASN's overall commitment to a diverse and inclusive leadership.

Collaborating with the ASN Policy and Advocacy Committee and the ASN Quality Committee, the ASN Diversity and Inclusion Committee has shared information and highlighted initiatives to address health disparities in kidney diseases with the Congressional Asian Pacific American Caucus, the Congressional Black Caucus, the Congressional Hispanic Caucus, the Congressional Kidney Caucus, and other members of Congress (many of these initiatives were noted in response to Question Four, above). Working together, these committees have also supported presentations on topics of race and health disparities in nephrology at the annual ASN Kidney Week.

In the wake of recent events, ASN has redoubled its commitment to promote diversity, inclusion, and health equity. Since Monday, June 1, 2020, ASN has:

- Issued a statement against racism as well as signed the Council of Medical Specialty Societies (CMSS) and Association of American Medical Colleges' statements against racism.^{27, 28}
- Testified to the Committee on Ways and Means on the "Disproportionate Impact of COVID-19 on Communities of Color."²⁹

²⁷ American Society of Nephrology. ASN Statement Against Racism. 2020. Retrieved September 25, 2020 from [https://www.asn-online.org/news/item.aspx?ID=173#:~:text=ASN%20Statement%20Against%20Racism,-Washington%2C%20DC%20\(June&text=ASN%20strongly%20supports%20and%20will,health%20and%20in%20health%20care.&text=The%20COVID%2D19%20pandemic%20is,for%20pe ople%20with%20kidney%20diseases](https://www.asn-online.org/news/item.aspx?ID=173#:~:text=ASN%20Statement%20Against%20Racism,-Washington%2C%20DC%20(June&text=ASN%20strongly%20supports%20and%20will,health%20and%20in%20health%20care.&text=The%20COVID%2D19%20pandemic%20is,for%20pe ople%20with%20kidney%20diseases).

²⁸ Council of Medical Specialty Societies. CMSS Statement on Racism in Healthcare. Retrieved September 25, 2020 from <https://cmss.org/cmss-statement-on-racism-in-healthcare/#:~:text=With%20more%20than%20800%2C000%20physicians,as%20it%20underm ines%20public%20health>.

²⁹ Baweja M, Josephson, MA. Written Testimony on the Disproportionate Impact of COVID-19 on Communities of Color. Retrieved September 3, 2020 from https://www.asn-online.org/policy/webdocs/ASN_TESTIMONY_DISPROPORTIONATE_IMPACT_OF_COVID-19_ON_COMMUNITIES_OF_COLOR.pdf

- Co-established with NKF the NKF-ASN Task Force to Reassess the Inclusion of Race in Diagnosing Kidney Diseases.³⁰
- Held a pre-Kidney Week 2020 webinar, “Going Beyond the Statement,” which reaffirmed ASN’s commitment to diversity and anti-racism and publicly announced the inception of a process to encourage and inform future initiatives within and outside ASN. ASN Secretary-Treasurer (and University of North Carolina School of Medicine Department of Medicine Vice Chair of Diversity and Inclusion) Keisha L. Gibson, MD, FASN, and I (ASN President and Executive Vice Dean of the School of Medicine at the University of Alabama at Birmingham) co-facilitated the webinar, which had nearly 500 combined participants and viewers. [A recording of the webinar can be accessed here.](#)³¹
- Called on Congress to pass the Health Equity and Accountability Act of 2020 (legislation which ASN had contributed to in collaboration with the Tri-Caucus, together with kidney patient organizations).
- Recorded a podcast on Fighting Institutional Racism with Dr. Delgado, who chairs the ASN Diversity and Inclusion Committee and co-chairs the NKF-ASN Task Force.³²
- Invited Dr. Gibson to meet by videoconference with every member of the society’s staff to discuss systemic racism and ASN’s commitment to eliminating it within kidney medicine and more broadly.
- Initiated efforts to reevaluate every aspect of the annual process for identifying, nominating, and selecting candidates to run for ASN Council to ensure diversity, equity, and inclusion.
- Added sessions for ASN Kidney Week 2020 focusing specifically on systemic racism, eGFR estimation, and COVID-19-related racial health inequities in the US health care system, listed in **Appendix B**.

ASN invites you and any members of your staff who would like to attend ASN Kidney Week 2020 to do so and will gladly offer complimentary registration (provided you or staff are able to accept it under House ethics rules).

Through guidance from its Diversity and Inclusion Committee, ASN has identified, prioritized, and begun to implement a “Work Plan to Address Systemic Racism in Nephrology,” including the following goals already in progress:

³⁰ American Society of Nephrology, National Kidney Foundation. Joint Statement on Establishing a Task Force to Reassess the Inclusion of Race in Diagnosing Kidney Diseases. July 2, 2020. Retrieved from https://www.kidneynews.org/sites/default/files/NKF-ASN%20eGFR%20Statement_July%202020.pdf

³¹ American Society of Nephrology. Going Beyond the Statement: Dismantling Systemic Racism in Nephrology. 2020. Retrieved September 25, 2020 from https://www.youtube.com/watch?v=bE0kmXLibx0&feature=youtu.be&ab_channel=AmericanSocietyofNephrology

³² American Society of Nephrology. Fighting Institutional Racism. 2020. Retrieved September 25, 2020 from <https://www.asn-online.org/media/podcast.aspx?p=ASN&s=Fighting%20Institutional%20Racism>



- Develop and disseminate recommendations of the NKF-ASN Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Diseases.
- Establish a similar task force to address the use of race in kidney transplantation, including the calculation for the KDPI.
- Establish a Loan Mitigation Pilot Program for underrepresented nephrology fellowship candidates. To help mitigate the exorbitant combined cost of undergraduate and graduate medical education, this three-year pilot program will award six nephrology career-committed M.D. and/or D.O. candidates who have completed Internal Medicine, Pediatrics, or Medicine-Pediatrics residency training, a total of \$50,000 over three years.
- Launch the ASN Health Disparities and Social Determinants of Health Committee in January 2021.
- Align ASN committees and task forces to focus on one (or more) of five key areas: 1) Equity in Private Practice 2) Evaluate and re-design training programs and their leadership 3) Examine Career Development 4) Engage federal funding agencies 5) Evaluate ASN award selection committees and council nomination.
- Produce an online compendium of anti-racism articles, editorials, videos, and other media as well as a curriculum on how nephrologists and other kidney health professionals can be anti-racist.

Through this work plan, ASN is deeply committed to providing a platform ensuring that Black, Hispanic and Latinx, and Indigenous nephrologists—today and in the future—are empowered to engage, influence, and lead in the process to achieve health equity and to involve all ASN members and kidney health professionals, to the extent possible, in promoting equitable and inclusive health care.

However, to make significant strides, the ASN members, leadership, and staff are well aware that the society cannot do this alone. Therefore, ASN is eager to partner with the Committee on Ways and Means, you as the committee's chair, and other stakeholders on addressing the broader health care, research, and education issues that are significant barriers to successful advancement.

As noted above in response to Question Four, ASN would be honored to collaborate with you on ensuring that policy and advocacy priorities toward health equity are implemented. Regarding health care research, where less than 1% of the cost of dialysis care is invested in NIH research, ASN would be delighted to collaborate on approaches to increase and focus federal funding on, social determinants of health and inclusive clinical trials. For example, very little of the just over \$620 million NIH dedicates to kidney research annually has been allocated to the understanding of the construct of race as it relates to the development of kidney diseases.

An urgent need exists for public and private funding to identify genetic biomarkers of kidney diseases and to develop clinical decision-support tools based on these genetic differences.



Groundwork being laid by NIDDK's Kidney Precision Medicine Program may help advance this important objective. The APOL1 Long-term Kidney Transplantation Outcomes (APOLLO) study, also conducted by NIDDK, has been exemplary in exploring the implications of a common gene variant in people of African ancestry. ASN encourages Congress to urge the Agency for Healthcare Research and Quality, the NIH (including potentially institute centers, such as NIDDK, the National Institute for Biomedical Imaging and Bioengineering, the National Center for Advancing Translational Sciences and the National Institute of Minority Health and Diseases) as well as patient-directed research programs (such as PCORI) and private funders to support the research of genetic biomarkers of kidney diseases and the development of more accurate diagnostics and clinical decision support tools.

Importantly, in terms of education and training, ASN invites your ideas and efforts to help the society strengthen the pipeline to create a diverse health care work force in nephrology in addition to ASN's work with the RWJ Foundation and the NIDDK Network of Minority Health Research Investigators Annual Workshop. Currently, communities of color collectively represent barely 12% of medical school graduates and just under 13% of nephrology trainees, which falls far short of reflecting the US population and the disproportionate number of Americans with kidney diseases, kidney failure, and kidney transplants. Achieving a diverse and inclusive workforce is critical to the pursuit of health equity and will involve collaborative, persistent efforts from government, academic institutions, and medical specialty societies such as ASN.

ASN is one of 45 specialty societies within CMSS. This coalition, representing more than 800,000 physicians across health care, from primary care to surgery, is catalyzing improvements across specialties through convening, speaking collectively, and acting collaboratively. In addition to serving as ASN Executive Vice President, Mr. Ibrahim is the current CMSS President. He has been working closely with the council's leadership—particularly CMSS Chief Executive Officer Helen Burstin, MD, MPH, FACP, and President-Elect Darilyn V. Moyer, MD, FACP—to engage specialty societies on the impact of racism on health care and the medical profession.

Given its breadth and depth, CMSS is uniquely positioned to provide a critical platform to share innovative strategies across specialties to support engagement, inclusion, and mentorship of historically underrepresented communities across the entire pipeline from medical students to residents, fellows, and practicing physicians. More broadly, CMSS will convene digitally for its annual meeting next month and dedicate a special session on racism to facilitate interaction among the 45 medical specialties and identify opportunities for collaboration. Through CMSS involvement, ASN is well positioned to participate in comprehensive efforts to address systemic racism across health care.

Again, thank you for your attention to the critically important issue of ensuring health equity in kidney medicine. ASN appreciates the opportunity to collaborate with the committee and looks



forward to continuing this important dialogue with you and your colleagues. To discuss this letter, ASN's commitment to eliminating systemic racism, or ASN, please contact Mr. Ibrahim at (202) 640-4676 or tibrahim@asn-online.org.

Sincerely,





A handwritten signature in black ink, appearing to read "Anupam Agarwal", with a long horizontal line extending to the right.


Anupam Agarwal, MD, FASN

President

Appendices.

Appendix A. Members of the NKF-ASN Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Diseases

Name		Role	Nominated by
Cynthia Delgado, MD, FASN		Co-Chair	ASN
Neil R. Powe, MD, FASN		Co-Chair	NKF
Mukta Baweja, MD		Member	ASN
Nilka Rios Burrows, MPH, MT		Member	NKF

Deidra C. Crews, MD, FASN		Member	NKF
Nwamaka D. Eneanya, MD, MPH, FASN		Member	ASN
Crystal A. Gadegbeku, MD, FASN		Member	ASN
Lesley Inker, MD		Member	NKF
Mallika L. Mendu, MD, MBA		Member	ASN
W. Greg Miller, PhD		Member	NKF

Marva M. Moxey-Mims, MD, FASN		Member	ASN
Glenda V. Roberts*		Member	ASN
Wendy L. St. Peter, PharmD, FASN		Member	NKF
Curtis Warfield, MS*		Member	NKF

* Glenda V. Roberts and Curtis Warfield, MS, are kidney patients and well-recognized patient advocates.

Appendix B. Sessions at ASN Kidney Week 2020 Focusing Specifically on Systemic Racism and COVID-19-Related Health Inequities in the US Health Care System.

Table X. Race & Equity Sessions
<p>Policy in a Post-COVID World, Including the Christopher R. Blagg, MD, Endowed Lectureship in Kidney Diseases and Public Policy</p> <p><i>This session examines the role of policy and policymakers at the federal, state, and local levels in the context of COVID-19. It delves into what lessons we have learned about policies that were successful versus unsuccessful in the immediate response, strengths and weaknesses in our existing healthcare infrastructure and how those can improve, and what lasting implications COVID-19 will have on nephrology health policy. (Note: Continuing education credits are not being offered.)</i></p>
<p>Race and Ethnicity Considerations in CKD</p> <p><i>Racial and ethnic disparities in CKD are profound. Some have argued that the very approach to detecting CKD (using an GFR estimating equation inclusive of a coefficient for race) is worth rethinking due to its potential contribution to these disparities. This session covers recent findings regarding determinants of racial and ethnic disparities and highlights viewpoints on the use of race in the GFR estimating equation.</i></p>
<p>A Slice of Humble Pie: Enhancing Sociocultural Humility in Nephrology</p> <p><i>People from socially marginalized or disadvantaged groups have unique experiences and face unique challenges in society and healthcare. In the setting of kidney diseases, these experiences may affect their clinical outcomes. This session sheds light on four historically marginalized or disadvantaged groups, in and outside the context of kidney care, to enhance humility and competence in providing care for people from these groups.</i></p>
<p>Personalizing Care in Dialysis Vascular Access: Putting the Patient First</p> <p><i>Viable vascular access is the lifeline for the hemodialysis patient. Maintaining the long-term function of vascular access is dependent on both biological factors and patient selection. This session presents innovative biological approaches for more personalized vascular access selection and treatment in combination with an individualized ESKD life plan. This session includes a presentation on “Vascular Access in Unique Patient Populations: Race, Sex, and Elderly Age.”</i></p>
<p>Facilitating Change with Patient-Centered Interventions in Hemodialysis</p>

Millions of patients with ESKD are kept alive with maintenance hemodialysis and peritoneal dialysis. Emerging barriers include workforce changes among nephrology clinicians and the US goal of having 80% of patients with incident ESKD receive RRT at home or undergo a transplant by 2025. This session discusses the innovative nonclinical and clinical interventions needed to meet these challenges, including a presentation on “Public Policy and Access to Home Dialysis Programs.”

More Than X or Y: Sex in Transplantation

This session is a bench-to-bedside progression of lectures that discuss sex-based differences in immune system function and kidney transplant outcomes, including a presentation on “Leveling the Playing Field: Sex Disparities in Kidney Transplantation.”

A Clinician's Guide to Managing Patients with HIV and CKD

This session provides an update on antiretroviral therapy in the prevention and management of HIV infection with a specific review of the safety of tenofovir in HIV. Discussions include an exploration of other contemporary issues such as the estimation of renal function in transgender patients. This session includes a presentation on “Assessing Kidney Function in Transgender Patients with HIV.”