



October 7, 2020

The Honorable Seema Verma
Administrator, Centers for Medicare & Medicaid Services
U. S. Department of Health and Human Services
200 Independence Avenue, SW
Washington DC 20201

Dear Administrator Verma:

On behalf of the National Kidney Foundation (NKF) and the American Society of Nephrology (ASN), thank you for your outstanding leadership and efforts to combat the novel coronavirus. We applaud your prompt and decisive actions to protect all Americans, but especially Americans affected by kidney diseases and the professionals who care for them.

The COVID-19 pandemic has taken a disproportionately high toll on patients with chronic kidney disease (CKD), end-stage kidney disease (ESKD), and transplant recipients. As you know, the first reported death due to COVID-19 occurred in a patient receiving in-center hemodialysis in the state of Washington. Since then, thousands of patients with kidney failure have succumbed to COVID-19. Per the Centers for Disease Control and Prevention (CDC), patients with CKD, patients on dialysis, and patients with immunocompromised status due to solid organ transplant are at a significantly increased risk of developing severe SARS-CoV2 infection-related morbidity and mortality. Therefore, it is imperative that we develop better preventive strategies and policies to protect these vulnerable populations, which can be facilitated through a comprehensive understanding of the epidemiology of COVID-19 in these vulnerable patient populations. To achieve this, the community needs access to accurate, complete, and more up-to-date data than are currently available.

Our organizations are writing to CMS to request that data on COVID-19 infection rates, hospitalizations, and death rates among patients with ESKD be made publicly available. These data will allow our community to extend the groundwork CMS has laid for providing the highest possible quality care to dialysis patients during the Public Health Emergency (PHE).

Almost 90 percent of dialysis patients rely on in-center hemodialysis. These patients frequent come in close contact with other patients -- including dialysis patients who come to the facility from nursing homes, emergency rooms and hospitals -- for approximately 4 hours at a time, 3 days a week. As the primary site of care for these patients, the dialysis facility is often where a patient's COVID-19 symptoms are first identified and managed. As a result, dialysis facilities have in many cases been wrongly identified as sites of COVID-19 outbreaks. Throughout the pandemic, dialysis facilities have been at the forefront of identifying and cohorting symptomatic patients to reduce the risk of transmission. However, like in many healthcare settings, managing asymptomatic and pre-symptomatic spread in dialysis facilities continues to be challenging. Preliminary data in the U.S. shows that COVID-19 rates among home dialysis patients are much lower than rates among in-center dialysis patients. However, this inference is difficult to confirm without access to data from CMS. Comprehensively understanding the

spread of COVID-19 among symptomatic, asymptomatic, and pre-symptomatic dialysis patients has been challenging because CMS has not thus far made data on COVID-19 infection rates among in-center and home dialysis patients available to researchers, patients, or practitioners.

The need for these data is especially crucial given the intersection between the dialysis and nursing home populations. Many dialysis patients are also nursing home residents. Using data from CMS and the US Renal Data System, we estimate that approximately 10 percent of dialysis patients spend some portion of the year in a Skilled Nursing Facility (SNF). According to CMS data, nursing homes have been the site of more than 300,000 confirmed or suspected cases of COVID-19 and more than 48,000 deaths. By some estimates, residents of nursing facilities and long-term care facilities account for 40% of all COVID-19 related deaths. Unfortunately, while CMS data on COVID-19 infections in nursing homes are widely available and regularly updated, similar data on dialysis centers and ESKD patients are not accessible.

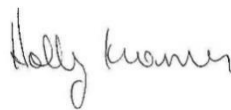
With appropriate information, patients and their families will be able to make informed choices about where to receive dialysis care, and dialysis care teams can tailor prevention and response efforts to maintain safety within their facilities. Further, these data can help researchers and academicians to identify potential areas for practice improvement and policy changes, while also allowing clinicians to identify interventions that were effective at minimizing COVID-19 transmission within and across these settings.

We welcome the opportunity to schedule a call to further discuss this request. Please contact Sharon Pearce, Senior Vice President for Government Relations at the NKF at Sharon.pearce@kidney.org, or Rachel Meyer, Senior Director of Policy and Government Affairs at ASN at rmeyer@asn-online.org, if you have questions or need additional information.

Sincerely,



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CEO and transplant patient
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