Congress of the United States
Washington, DC 20515

September 3, 2019

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201-0004

The Honorable Seema Verma
Administrator
Centers for Medicare and Medicaid Services
200 Independence Avenue SW
Washington, DC 20201-0004

Dear Secretary Azar and Administrator Verma:

Given the Executive Order signed by President Donald Trump on July 10, 2019 to launch the *Advancing American Kidney Health* initiative, we are writing to respectfully request that the U.S. Department of Health and Human Services (HHS) and the Centers for Medicare and Medicaid Services (CMS) consider the impact of both current and future policies on vulnerable populations receiving dialysis treatment. As the Administration works to decrease the number of patients with end-stage renal disease (ESRD), we must discuss the factors affecting those receiving dialysis treatments in clinics and the barriers that prevent individuals from receiving kidney transplants.

Specifically, we want to ensure the effective and transparent use of dialysis services, particularly with regard to low-income individuals, as well as to increase preventive and alternative treatments when and where possible. Dialysis is an essential treatment for those with ESRD.

Medicare spends nearly $35 billion per year on dialysis treatments alone, representing fully seven percent of total Medicare costs.[1] Since the federal government pays 80 percent of all dialysis costs for most patients and at a time when there are few other options and patients are fighting for their lives, we must ensure that all patients, working with their doctors and clinicians, receive the most effective and appropriate care possible.[2]

Disproportionate Share of Dialysis Treatments

At this time, it is unknown why more individuals have kidney disease in low-income neighborhoods. Researchers have pointed to access to health care, environmental toxin exposures more commonly found in higher poverty areas, and individual lifestyle factors as possible contributing factors.[3] Since more patients in low-income areas have kidney disease, it comes as

[1] https://www.usrds.org/2017/view/v2_09.aspx
[2] https://www.kidney.org/atoz/content/dialysisinfo
[3] https://www.sciencedaily.com/releases/2015/06/150615162902.htm

no surprise that they receive more dialysis treatment, but the numbers of low-income and minority individuals receiving dialysis treatment for ESRD are still striking.

The percentage of adults beginning dialysis for ESRD who live in zip codes with high poverty rates continues to increase. According to a study completed by the Loyola University Chicago Stritch School of Medicine, this percentage rose from 27.4 percent to 34 percent between 1995 and 2010 (an increase of 6.6 percentage points).[4] At the same time, the general population saw an increase from 11 percent to 12.5 percent (an increase of 1.5 percentage points).[5]

Additionally, Medicaid expansion under the Affordable Care Act has had a beneficial impact on those with ESRD. Between 2014 and 2017, the number of patients with ESRD who died within the first year of dialysis treatment decreased in states that expanded Medicaid, while it remained the same or worsened in non-expansion states. According to a recent research study, this was due not just to increased adherence to dialysis treatments (due to reduced cost), but was also the result of improved access to pre-dialysis care for kidney disease. More patients received an arteriovenous fistula or graft before beginning dialysis, which are methods to improve access to the bloodstream during treatment and reduce the likelihood of infection. In Medicaid expansion states, there was an increase of 2.3 percentage points in the number of patients receiving a fistula or graft.[6]

The Relationship Between Income and Dialysis Options

Recent research from the University of Michigan's Kidney Epidemiology and Cost Center examined the employment status of 496,989 patients who initiated maintenance hemodialysis (HD) from 2006 to 2015. The study found that "patients who maintained employment 6 months prior to initiating dialysis had a lower risk for death and a higher likelihood of receiving a kidney transplant than those who left their jobs, according to a new study. Likewise, not-for-profit dialysis centers offered patients the best chance of maintaining employment through their dialysis treatments."[7] The causes of this finding may be directly related to the pre-dialysis care that many low-income patients are unable to afford.

The benefits of pre-dialysis kidney care are similar to other preventive care for those with pre-existing conditions. Unfortunately, as many as 40 percent of U.S. patients with ESRD do not see a nephrologist before its onset.[8] Individuals who do not receive good preventive care early and consistently from their condition's onset are more likely to require dialysis treatment during or after a health crisis. These events, often referred to as "crashing" into dialysis, leave little, if any, time for a patient's physicians to explain treatment options. Studies have shown that over time, patients who crash into in-center dialysis become less likely to consider other options. This means

---

[4] https://www.sciencedaily.com/releases/2015/06/150615162902.htm
[5] https://consumer.healthday.com/diseases-and-conditions-information-37/misc-kidney-problem-news-432/u-s-dialysis-patients-increasingly-live-in-poor-areas-700497.html
[6] https://www.brown.edu/news/2018-10-26/dialysis
[7] https://www.healio.com/nephrology/kidney-care-community/news/online/%7Ba21d3b78-f101-4a18-ac91-265ea77cd898%7D/patients-employed-6-months-before-dialysis-have-lower-mortality-more-transplants
[8] https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-12-252

is allowing more low-income patients to reach the point of ESRD and is forcing more patients into an expensive and often endless cycle of treatments.

The relationship between those receiving dialysis and their zip code remains alarming. As such, we are concerned about predatory practices targeting the most vulnerable in our communities and by the rapid explosion of dialysis centers in poorer, largely minority, areas. We respectfully request that HHS and CMS consider the following questions as you implement the Executive Order:

1) Why is the dialysis rate so much higher for adults in low-income zip codes compared to the general population and is there any evidence of systematic steering of low-income patients into dialysis treatment, leading to the increased number of dialysis centers in low-income areas?

2) Because low-income patients are less likely to engage in preventative care and regular doctor visits, what measures could be implemented to reduce the rates of low-income individuals reaching ESRD and requiring dialysis treatment?

3) Are individuals given the full range of options when discussing dialysis with their doctors, and how soon are patients being given these options? Is there any pressure unduly exerted on patients to sign up for dialysis at dialysis centers?

4) Are patients, especially low-income patients, being encouraged to receive dialysis treatments in centers rather than in the home setting? What is the cost difference between Medicare, Medicaid, and private insurance for both clinic-based dialysis treatments and in-home care? What is the difference in reimbursement to providers of each of these options? Are the current Medicare and Medicaid payment rates sufficient to cover the cost of care and provide a strong foundation for expansion of care as needed in low-income and minority communities?

5) While the majority of dialysis recipients require dialysis treatments for the rest of their lives unless they receive a kidney transplant, are there patients who are placed on dialysis temporarily? If so, how many? Are these individuals given a plan to stop their dialysis treatment and when is this plan generally formulated?

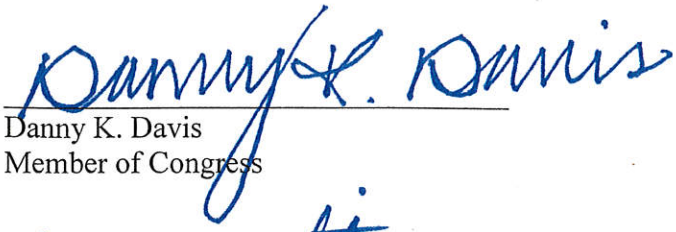
We appreciate your diligent and timely consideration of these questions and concerns and look forward to your response on how the *Advancing American Kidney Health* initiative will address these issues. We hope to receive a response prior to the release of any such proposed rule.

Sincerely,

Bobby L. Rush
Member of Congress

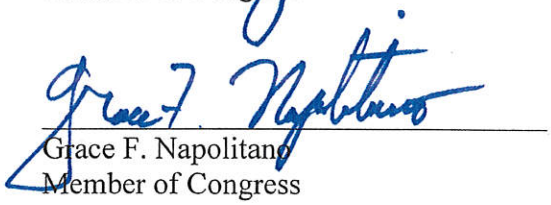
Katie Porter
Member of Congress

Rosa L. DeLauro
Member of Congress



Danny K. Davis
Member of Congress

Barbara Lee
Member of Congress



Grace F. Napolitano
Member of Congress

Jan Schakowsky
Member of Congress

Susan A. Davis
Member of Congress

Raúl M. Grijalva
Member of Congress

Steve Cohen
Member of Congress

André Carson
Member of Congress

Marcia L. Fudge
Member of Congress

Alan S. Lowenthal
Member of Congress

Bonnie Watson Coleman
Member of Congress

Lisa Blunt Rochester
Member of Congress

TJ Cox
Member of Congress