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Advanced American Kidney Health Initiative

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Government Affairs and Policy Shaping in the US with Case Study: Advancing American Kidney Health Initiative (AAKHI)

I. Intro: Why Kidney Disease?

I have been actively advocating for equitable access to kidney disease treatment, with an emphasis on home dialysis, for over a decade.

As a Foundation board member of the National Association for Advancement of Colored People (NAACP), and a former board member of the American Diabetes Association, I have long been passionate about ensuring that under-resourced populations can access the best available health care modalities. In the United States, where Black Americans are almost four times as likely as white Americans to develop kidney failure[1] and other minorities also suffer disproportionately from kidney failure, and where Black and other minorities are less likely to receive a kidney transplant or home dialysis therapy, we have a lot of work to do.

As executive director of the Alliance for Home Dialysis (AHD), I am proud that we have been successful in driving improved access to home dialysis for all under-resourced communities – through partnerships with the government, clinicians, patients and key stakeholders like the NAACP – but the progress we have made, which shows up as the percentage of incident patients receiving home dialysis almost doubling over ten years,[2] is just the beginning of what we must do as a community.

II. US Health Policy Landscape – End Stage Renal Disease

The most recent US data[3] on kidney disease is from 2020-the first half of 2021, which means that we are seeing the first data that encompasses the majority of the COVID-19 pandemic. The pandemic has been particularly difficult for patients with ESRD, with rates of infection up to 200% higher than Medicare beneficiaries without ESRD and a higher mortality rate as well.[4]

The total number of patients with ESRD in 2020 was 807,920. In 2020, 109,107 patients began in-center hemodialysis, representing 83.9% of patients with incident ESRD. Of those, 12.7% of patients initiated peritoneal dialysis at home and 3.1% received a transplant, and those statistics reflect an important increase over prior years.[5] Home hemodialysis utilization is still very low in the US: in 2020 only 0.3% of incident patients began HDD. As stated above, these numbers are slowly increasing. However, Black and Hispanic patients are still less likely to dialyze at home than white and Asian patients.

Related to the U.S. regulatory “ETC Model,” which was implemented in January 2021, “home dialysis utilization at dialysis initiation was slightly lower in ETC markets, but this difference was not evident after the launch of ETC.”[6]