KIDNEY CARE PARTNERS

August 2, 2021

The Honorable Patty Murray
U.S. Senate
154 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Richard Burr
U.S. Senate
217 Russell Senate Office Building
Washington, D.C. 20510

Dear Chairwoman Murray and Ranking Member Burr:

On behalf of the Kidney Care Partners (KCP), I want to thank you for your effort to improve the nation's public health and medical preparedness and response programs. The effort will use the lessons learned from the COVID-19 pandemic to inform important changes to our pandemic preparedness capabilities so that vulnerable patient populations, like those living with kidney disease, are protected when future pandemics arise. KCP applauds this effort and we send this letter to share the unique perspective of the kidney patient population and stakeholder community as you consider legislation in this area.

KCP was founded in May of 2003 as a coalition of patient advocates, dialysis professionals, care providers, researchers, and manufacturers dedicated to working together to improve the quality of care for individuals living with kidney diseases. In 2019, KCP released *Kidney Care First: A Framework for Improving Renal Disease Support & Treatment*, which outlines the community's policy priorities for improving the quality of care for patients with chronic kidney disease (CKD). These priorities include improving research, enhancing prevention, increasing surveillance, improving treatment, and addressing disparities.

Kidney disease has a disproportionate impact on communities of color. Black Americans are almost four times as likely as whites to develop kidney failure, accounting for 35 percent of those with kidney failure, despite making up 13 percent of the population.[1] Hispanics are nearly 1.3 times more likely to be diagnosed with kidney failure compared to non-Hispanics.[2] Twenty-two percent of dialysis patients live in rural areas, compared to 19 percent of the general population.[3] Dialysis patients who live more than 100 miles away from a dialysis center have a higher mortality rate than those who live closer.[4] Therefore, it is important that any legislation on disaster preparedness consider the unique needs of this vulnerable population.

---

[1] National Institute of Diabetes and Digestive and Kidney Diseases; Race, Ethnicity, & Kidney Disease; https://www.niddk.nih.gov/health-information/kidney-disease/race-ethnicity

[2] ibid

[3] Rural and Minority Health Research Center (2012). Dialysis Availability in Rural America. https://www.ruralhealthresearch.org/projects/100002186#:~:text=The%20disease%20disproportionately%20affects%20poor,or%20leave%20a%20particular%20area

[4] Aminu Bello, John Gill, Scott Klarenbach, Raj Padwal, Rick Pelletier, Marcello Tonelli, Stephanie Thompson, Xiaoming Wang (2012). Higher mortality among remote compared to rural or urban dwelling hemodialysis patients in the United States. Kidney International, Volume 82 (3), 352-359. https://www.sciencedirect.com/science/article/pii/S0085253815555476

Throughout the pandemic, KCP members were on the front lines, ensuring continued access to care for individuals with kidney disease that in many cases required dialysis up to three times per week. Through this experience, KCP has distilled some key themes and lessons learned:

Coordination is Crucial to Protect Vulnerable Populations like those with Kidney Disease

KCP members learned that coordination between federal, state, and local officials and the stakeholders responsible for caring for the patient population is crucial. Where coordination was strong, these entities were able to adapt quickly to the pandemic to meet the needs of the patient population while limiting the potential for exposure to COVID-19. Coordination with infection prevention and control entities was critical.

An area that clearly lacked coordination early on was vaccine distribution and COVID-19 testing. For example, dialysis clinics were unable to acquire vaccines for their staff early in the pandemic even when they were providing lifesaving care to a uniquely vulnerable patient population. State and local processes to allocate to dialysis facilities were inconsistent and time consuming. Often states did not have an allocation process for dialysis facilities, leaving the vulnerable patient population to navigate obtaining vaccine on their own. Dialysis providers were granted federal allocations of vaccines late in the Public Health Emergency, but also had to work through each individual state process in order to be able to administer and account for the allocations.

Takeaways:

- Coordination between stakeholders and the local, state, and federal government on behalf of patients early on is crucial.
- Local, state, and federal governments should identify vulnerable patient populations, like those with CKD and end-stage renal disease (ESRD), early and work with stakeholders within the patient community to meet their needs.

Disruptions in Care

The pandemic disrupted care for patients with kidney disease in many ways. There were widespread disruptions in the supply lines of basic medical equipment such as personal protection equipment (PPE) and dialysis supplies for patients in dialysis facilities, home dialysis, and patients with acute kidney injury (AKI). Some of these disruptions are ongoing. In addition, it was difficult to get these patients to dialysis facilities and physician appointments early in the pandemic when access to basic transportation was disrupted. The economic vulnerabilities of the patient population also intensified during the pandemic, impacting access to needed health care services.

The expanded use of telemedicine from the public health emergency waivers was important for providing access to some of these needed health care services. Several important questions remain over how to incorporate telemedine as a permanent part of our health care system, but there is no question that enhanced telemedicine authorities should be incorporated into any future pandemic response.

Takeaways:

- Government officials need to protect supply lines and manufacturer capacity for medical products for all contingencies and significant disruptions like pandemics, widespread electrical grid failure, and cyberattacks, in addition to natural disasters.
- Congress should consider the value of vendor-managed inventories, as opposed to government stockpiles, in situations where vendors are best equipped to manage perishable products, such as dialysis disposables, and rapidly evolving technology platforms, such as dialysis machines. This will avoid expiration and obsolescence challenges.
- Officials need to ensure the needs of vulnerable patients such as those with CKD and ESRD are met during an emergency. These patients require therapy almost daily and are placed at risk by missing a single treatment. For this reason, it is critical to consider the portability of dialysis equipment. In addition, it is important to plan for emergencies where there are water source issues and power outages that would impact the ability to provide dialysis services.
- It is also important to consider how to quickly mobilize temporary dialysis delivery locations and ensure adequate support staff.
- Expanded telemedine authorities are crucial to providing access to important health care services when normal access to care is disrupted during a pandemic.

Patient Vulnerabilities

The pandemic exposed the unique vulnerabilities and disparities faced by patients with CKD and ESRD. As mentioned, there are significant economic vulnerabilities impacting patient access to care. These patients have a higher mortality, morbidity, and hospitalization rate. During the pandemic, they have had a higher exposure rate to COVID-19 due to the need to take dialysis, use public transportation, the fact that many live in multi-generational households, the reality that they have less access to information via broadband, and the fact that they disproportionately depend on foodbanks and community charity, which were overwhelmed in the early part of the pandemic.

Takeaways:

- Congress should focus on health disparities in all the policies they pursue.
- There is a need for more tailored outreach based on each specific community.
- Given the unique economic vulnerability of this patient population, Congress should consider flexible patient assistance grants when pandemics occur. Such assistance could flow to the Federal Emergency Management Agency (FEMA) and regional FEMA offices and could use pre-existing networks such as those of the America Kidney Fund to get the needed funds out to low-income patients.

Sincerely,

John Butler, Chairman