



October 3, 2022

Secretary Xavier Becerra
U.S. Department of Health and Human Services
Office for Civil Rights
Attention: Section 1557 NPRM (RIN 0945-AA17)
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: RIN Number 0945-AA17: Nondiscrimination in Health Programs and Activities Proposed Rule

Dear Secretary Becerra:

On behalf of Kidney Care Partners (KCP), I would like to thank you for providing us with the opportunity to comment on the “Nondiscrimination in Health Programs and Activities” proposed rule (Proposed Rule). KCP is a non-profit, non-partisan coalition of more than 30 organizations comprising patients, physicians, nurses, dialysis professionals, researchers, therapeutic innovators, transplant coordinators, and manufacturers dedicated to working together to improve the quality of care for individuals living with kidney disease.

Our members who are battling on the frontlines of the COVID-19 pandemic to provide access to high quality care for patients with kidney disease/kidney failure applaud the Office for Civil Rights (OCR) its efforts during the pandemic to ensure that individuals with kidney failure receiving dialysis, whom federal law defines as “disabled,” are treated with the dignity and respect. The challenges these individuals face often stem from disparities in the health care system linked to their race and/or ethnicity. The Centers for Medicare & Medicaid Services has recognized and data from the United States Renal Data System (USRDS) indicates that those “receiving renal dialysis services are disproportionately young, male, disabled, Black/African-American, low income as measured by dually eligible Medicare and Medicaid status, and reside in an urban setting.”¹

We are pleased that OCR/HHS once again is proposing policies to support individuals with disabilities in the Proposed Rule. Given our members’ experience during the pandemic, as well as the historic discriminatory actions undertaken by some private insurers even prior to the pandemic, KCP asks that the final rule expressly describe the protections that apply to individuals with kidney failure.

¹87 Fed. Reg. 38464, 38524 (June 28, 2022).

First, we recommend that OCR reaffirm that individuals with kidney failure (also known as End Stage Renal Disease (ESRD)) who require dialysis are classified as disabled, consistent with other federal laws. As such, the protections that OCR provides to those individuals who are disabled also apply to those individuals with kidney failure. These protections include prohibitions against discriminating against these individuals directly or indirectly. This clarification is important because dialysis patients have had an extremely difficult time obtaining relief when health plans discriminate against them. Given the Administration's commitment to address racial and ethnic disparities in the delivery of health care, the applicability of the Section 1557 protections to this group of people becomes even more important.

Second, we reiterate our previous recommendation that OCR take a more proactive role in enforcing Section 1557 to protect individuals against discriminatory policies and actions of insurers.

I. KCP Recommends that OCR Clarify in the Final Rule that Individuals with Kidney Failure Requiring Dialysis are Protected by the Antidiscrimination Provisions.

OCR should reaffirm that the protections of Section 1557 extend to individuals whose lives are dependent on dialysis treatments at least three times per week. The Rehabilitation Acts of 1973 and 1993 recognize that individuals receiving dialysis because of kidney failure are disabled and, therefore, protects them against being turned down for a job or promotion or being fired because of their disability if they can do the assigned job. Given OCR's reliance upon the definitions of the Americans with Disabilities Act (ADA) and the Rehabilitation Acts, we believe that the protections against discrimination of Section 1557 also apply to dialysis-dependent individuals, *i.e.* those with kidney failure. We ask that OCR/HHS specifically reference this group of individuals in the final rule to avoid any confusion about the applicability of the protections to this group of individuals.

Providing this clarification is extremely important because State-based Marketplaces have approved plans that discriminate against individuals with kidney failure who require dialysis treatments. KCP has raised concerns in previous years about plans that adopt policies that result in individuals being forced to enroll in Medicare after a diagnosis of kidney failure. Some plans raise co-insurance costs on services that only dialysis patients require. Other plans refuse to accept charitable assistance for individuals who require dialysis, even though the plans continue to accept it for patients with other chronic conditions. More recently, our members report that some plans apply "utilization management techniques" that seek to justify denying or restricting medically necessary services that only dialysis patients receive. We have even seen some plans try to apply prior authorization for dialysis treatments themselves.

These are only a few examples of the problems individuals with kidney failure who require dialysis treatments have shared. We ask that OCR/HHS in the final rule make clear that any of these policies when applied in a manner that directly or indirectly result in a restriction of access to medically necessary dialysis services or result in an enrollee losing primary coverage with their plan constitute discrimination and are inconsistent with the requirements of Section 1557.

It is also important that the Sections 1557 protections apply to all insurers. We ask that OCR/HHS not finalize the proposed exemption for employer liability and clarify that the protections apply to group health plans, including self-funded plans.

Individuals with kidney failure who rely upon dialysis treatments should be allowed to retain their choice of plans. There are many reasons an individual may prefer their current plan over Medicare. These reasons include: potentially lower premiums, deductibles, and copayments, as well as different benefits that may not be available to them under the Medicare program. Switching to the Medicare program may also negatively impact their family members. For example, the costs an individual would incur as a Medicare beneficiary would not count against the Marketplace plan deductible of the family, increasing the overall cost of health insurance for them all.

Therefore, KCP encourages OCR to reaffirm and clarify the protections of Section 1557 for individuals with kidney failure who require dialysis treatments.

II. KCP Recommends that OCR Take Greater Action to End Discrimination against Individuals with Kidney Failure.

In addition to clarifying the applicability of the protections to individuals with kidney failure who require dialysis treatments, KCP also recommends that OCR take a more proactive role in ensuring that insurers do not discriminate against these individuals. We also believe that OCR should augment its current enforcement activities by establishing a process by which individuals who believe they have been discriminated against because of their disability can more easily file a complaint with OCR. In addition, OCR should clarify that providers caring for disabled individuals and relatives of such individuals may have the ability to bring a civil rights action in appropriate cases, such as where the provider or relative is themselves harmed by the plan's discriminatory conduct.

III. Conclusion

KCP appreciates the opportunity to review and provide comments on the Proposed Rule. As OCR/HHS finalizes these provisions, we ask that the final rule

Secretary Xavier Becerra

October 3, 2022

Page 4 of 5

clearly state that: (1) individuals with kidney failure requiring dialysis are individuals with disabilities and the protections against discrimination apply to them; and (2) that OCR increase its efforts to enforce Section 1557 to protect individuals with kidney failure, who are disproportionately black and brown, low-income, and disabled. We welcome the opportunity to discuss our comments with you. Please do not hesitate to contact Kathy Lester at (202) 534-1773 or klester@lesterhealthlaw.com if you have any questions.

Sincerely,

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

John Butler
Chairman

Appendix: KCP Members

Akebia Therapeutics
American Kidney Fund
American Nephrology Nurses' Association
American Society of Nephrology
American Society of Pediatric Nephrology
Ardelyx
AstraZeneca
Atlantic Dialysis
Baxter
Cara Therapeutics
Centers for Dialysis Care
Cormedix
DaVita
Dialysis Patient Citizens
DialyzeDirect
Dialysis Vascular Access Coalition
Fresenius Medical Care
Greenfield Health Systems
Kidney Care Council
NATCO
Nephrology Nursing Certification Commission
Otsuka
ProKidney
Renal Healthcare Association
Renal Physicians Association
Renal Support Network
Rockwell Medical
Rogosin Institute
Satellite Healthcare
U.S. Renal Care
Vertex
Vifor Pharma