January 17, 2024

The Honorable Charles E. Schumer
Majority Leader, U.S. Senate
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Mitch McConnell
Minority Leader, U.S. Senate
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Mike Johnson
Speaker, U.S. House of Representatives
568 Cannon House Office Building
Washington, DC 20510

The Honorable Hakeem S. Jeffries
 Minority Leader, U.S. House of Representatives
2433 Rayburn House Office Building
Washington, DC 20510

Dear Congressional Leaders:

We, the undersigned organizations representing tens of millions of American patients, consumers, and seniors, write to you with an urgent plea regarding the upcoming Continuing Resolution, scheduled for March. We respectfully request the inclusion of date-change language to delay integrating oral-only Phosphate Lowering Therapies (PLTs) into the End Stage Renal Disease (ESRD) payment bundle by one year, until January 1, 2026, in Section 204 of the Stephen Beck Jr. Achieving a Better Life Experience (ABLE) Act of 2014.

Today, many Americans suffering from kidney failure rely on medicines known as PLTs. Patients on dialysis are prone to having high levels of phosphate in their blood, which can heighten the risk for heart attack or stroke if left untreated. Patients currently have access to these drugs, but that would change under the Center for Medicare and Medicaid Services’ (CMS) plan to add PLTs to the ESRD payment bundle by 2025.

Wedging these treatments into a limited payment bundle where they will compete with other treatments for coverage means some patients will inevitably have less access to these drugs that reduce their risk of death. It’s an unnecessary and ill-conceived step, and will degrade the health care options available to patients already struggling with serious disease.

This is also a health equity issue. A disproportionate number of patients experiencing ESRD are minorities and live in rural and low-income communities. Black, Hispanic, and Native
Americans have significantly higher rates of ESRD. Transferring coverage of PLTs into the ESRD bundle will only exacerbate the health disparities that already exist in our society.

Congressional action has previously upheld accessible coverage for PLTs, and it is essential that Congress act again. We firmly believe the only long-term solution to minimize patient risk is the passage of the Kidney PATIENT Act of 2023 (H.R. 5074). The Kidney PATIENT Act would instruct CMS to delay adding PLTs to the ESRD bundle until 2033 or until the Food and Drug Administration approves an intravenous treatment for lowering phosphate.

In the short-term, however, delaying the inclusion of oral-only PLTs in the ESRD bundle by one-year as part of the March Continuing Resolution is a critical step to ensure patient safety and equitable access.

Thank you for your dedication to this important issue. We appreciate your consideration in making this temporary delay a reality as we continue to advocate for the Kidney PATIENT Act’s comprehensive solutions.

Sincerely,

National Minority Quality Forum Action Network
A. Philip Randolph Institute
Advocates for Responsible Care
Alliance for Aging Research
American Health Care Association
American Kidney Fund
American Society for Nephrology
American Society of Consultant Pharmacists’
Antioch South Baptist Church (Atlanta, GA) - Pastor Marvin Gordon, Senior Pastor
Arizona Blood Alliance
Arizona Chronic Care Together Coalition
Atlanta Black Nurses Association
Bethesda Baptist Church
Breaking the Sickle Cell Cycle Foundation
California Chronic Care Coalition
Calvary Temple Baptist Church (Atlanta, GA) - Pastor J. O. Jackson, Senior Pastor
Center for Patient Advocacy Leaders (CPALs)
Coalition for Cultural Change
Cornerstone Community Baptist Church (Atlanta, GA) - Pastor W. J. Lawson, Senior Pastor
Crown of Glory Baptist Church (Atlanta, GA) - Pastor Joshua McKinsey, Senior Pastor
Dialysis Patient Citizens
Eastern Shore of Maryland Sickle Cell Disease Association
Faith Advisory Council for Community Transformation
Fellowship Baptist Church - Pastor Stanley Smith, Senior Pastor
Gerontological Society of America
HEAL Collaborative
Healthy Women
iAdvocate
Kidney Care Partners
Latino Connection
Looms for Lupus
Lupus and Allied Diseases Association, Inc.
MassBio
Millennium Man Ministries
MTS Sickle Cell Foundation
National Association of Nutrition and Aging Services Programs
National Center for Assisted Living
National Consumers League
National Grange
National Kidney Foundation
Northwest Kidney Council
Partnership to Fight Chronic Disease
Redmoon Project
Renal Healthcare Association
Renal Physicians Association
Renal Support Network
RetireSafe
Ruby A. Neeson Diabetes Awareness Foundation
Rx in Reach Coalition
Sickle Cell/Thalassemia Patients Network
Texas Kidney Foundation