



American Association of Kidney Patients
aakp.org

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Kidney Patients Raise National Health Alert on Phosphorus

First National Phosphorus Awareness Day is April 5, 2024

Medicare Phosphorus Drug Proposal Undermines Kidney Health Goals

Washington, D.C.: The American Association of Kidney Patients (AAKP), the oldest and largest independent kidney patient consumer organization in the U.S., is raising public awareness on April 5, National Phosphorus Awareness Day, about the devastating impacts of unmanaged phosphorus levels in individuals with advanced chronic kidney disease (CKD).

Through AAKP's Center for Patient Research and Education, the Association will launch a grassroots education effort via its sophisticated national social media and email marketing platforms to educate millions of at-risk Americans and their families on the importance of managing their phosphorus intake and levels.

Kidney patients are at an increased risk for high phosphorus (termed hyperphosphatemia) due to their decreased kidney function and an inability to excrete excess nutrients, including phosphorus. Among these patients, phosphorus can accumulate to toxic levels.

Hyperphosphatemia often has no symptoms, and if undetected, can increase the risk of seizures, stroke, heart attack, and even death. Approximately [80% of patients on dialysis](#) require phosphate-lowering therapy on top of a [modified, low phosphorus diet](#).

Hyperphosphatemia is defined as a serum phosphorus level higher than 4.5 mg/dL. To reinforce the 4.5 mg/dL marker, AAKP is marking April 5 (4/5/2024) the ideal target for the first National Phosphorus Awareness Day.

In 2019, AAKP launched the [Decade of the Kidney™](#) to organize greater public awareness of kidney-related issues and the overwhelming unmet patient needs for greater investments and innovations in new kidney drugs, diagnostics, and devices that can help transcend outdated, high-mortality status quo kidney care. Kidney patients are medically complex and typically

manage multiple co-related health conditions including [hyperphosphatemia](#), [hyperkalemia](#), [CKD associated pruritis \(CKD-aP\)](#), and [more](#).

The national, bipartisan policy consensus for addressing kidney disease, established under multiple presidential administrations and multiple Congresses, prioritizes greater disease prevention, upstream disease detection and earlier intervention, better care management, and avoidance of preventable kidney failure and the need for organ transplants and/or dialysis. In 2018, AAKP launched the first and largest non-partisan voter education and registration effort, [KidneyVoter™](#), in the kidney community. AAKP plans to engage and mobilize over 500,000 [KidneyVoters™](#) in 2024 to make certain issues impacting the lives and livelihoods of kidney patients are not overlooked by candidates and elected leaders.

AAKP is working closely with advocates, the media, and federal appointed and elected officials in the Executive Branch and Congress to drive commonsense reforms in national kidney care policy and practice. More than 37 million Americans are living with kidney diseases, more than 800,000 have kidney failure and need dialysis or a transplant to live, and nearly 90,000 are awaiting a kidney transplant. The costs of kidney care to the American taxpayer and health system exceed \$100 billion dollars a year. AAKP has also targeted Government Determinants of Health (GDoH), regulatory and payment actions the federal government knowingly or unwittingly take, that negatively impacts timely patient access to new therapies, as a key barrier to improved kidney patient health outcomes and lower mortality rates.

AAKP President Edward V. Hickey, III stated, “AAKP strongly believes that physicians and patients must have choice and access to the right treatment at the right time for the right patient, especially when it comes to managing phosphorus and avoidable catastrophic health events. Our inaugural phosphorus campaign puts a laser on a Government Determinant of Health the Centers for Medicare and Medicaid Services (CMS) has created by their proposed rule to shift vital oral treatments, including phosphate lowering therapies (PLTs), into the End Stage Renal Disease (ESRD) Medicare Prospective Payment System (“bundle”) starting January 1, 2025. The kidney bundled payment is a relic of the decades-old, pre-innovation mindset that prioritized drug access restrictions and short-term cost controls over long-term patient outcomes and taxpayer savings. We encourage all kidney patients and professionals to immediately call their elected leaders and demand that CMS abandon their proposed rule, recommit themselves to improved kidney patient health, and stop interfering with phosphorus management therapies.” [Hickey](#) is a U.S. Marine Corps Veteran, Chair of AAKP’s [Veterans Health Initiative](#), and has a professional background that includes senior posts on Capitol Hill and in two presidential administrations.

Kidney patients and all people of goodwill involved in the fight to improve kidney health are making their voices heard by contacting their U.S. Senators and asking them to support a companion U.S. Senate bill to [The Kidney PATIENT Act \(H.R. 5074\)](#) in the U.S. House of Representatives. The Kidney PATIENT Act would instruct CMS to delay adding PLTs to the ESRD bundle until 2033 or until the Food and Drug Administration (FDA) approves an intravenous (IV) treatment for lowering phosphate. AAKP national patient advocates, in close

alliance with other patients and medical professionals, gained strong bipartisan support for The Kidney PATIENT Act last month in markup sessions of both the U.S. House Ways and Means Committee as well as the U.S. House Energy and Commerce Committee.

“Based on AAKP’s overwhelming success leading [National High Potassium Awareness Day](#) (May 1) and [National Itch Day](#) (June 3) through our highly effective “[Are You O-K+](#)” and “[Stop the Itch](#)” campaigns, AAKP is well-prepared to lead another national kidney health education campaign. On April 5, National Phosphorus Awareness Day will further support individuals affected by kidney disease and empower them to stay on top of their care and remain strong.” stated Diana Clynes, AAKP’s Executive Director.

Access more phosphorus resources including AAKP’s [Nutrition Counter](#) and [Understanding the Food Nutrition Facts Label](#) brochures, all seven editions of *AAKP Delicious!* kidney-friendly recipes, and our latest webinar on [The Essential Role of Diet in Kidney Health](#).

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Since 1969, The American Association of Kidney Patients has been a patient-led organization driving policy discussions on kidney patient care choice and medical innovation. Over the past decade, AAKP patient advocates have helped advance lifetime transplant drug coverage for kidney transplant recipients (2020); the Presidential *Executive Order on Advancing American Kidney Health* (2019); new job protections for living organ donors under the Family Medical Leave Act (FMLA) via the U.S. Department of Labor (2018); and Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013). Follow AAKP on social media at [@kidneypatient](#) on Facebook, [@kidneypatients](#) on X, and [@kidneypatients](#) on Instagram, and visit www.aakp.org for more information.