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Kidney Patients Issue National Health Alert on High Potassium

May 1 is 5th Annual National High Potassium Awareness Day

Alert Comes as FDA Advances Potassium-Based Salt Substitutes and Ignores Kidney Community Concerns About Known Risks to Vulnerable People

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 May 1, National High Potassium Awareness Day, about the devastating impacts of unmanaged potassium levels in individuals with chronic kidney disease (CKD). Nearly three million Americans with CKD and/or heart failure live with high potassium levels.

Many people with CKD, including those with kidney failure, cannot properly excrete potassium. When a high amount of potassium is consumed, including through the consumption of artificially added potassium (e.g. salt substitutes), it accumulates in the person's body. This elevated level of potassium, medically known as hyperkalemia, can cause cardiac arrhythmias and sudden cardiac death. Immediate medical attention is required if a person experiences hyperkalemia.

In 2020, AAKP launched National High Potassium Awareness Day to raise awareness of high potassium, hyperkalemia, and related serious medical consequences among highly vulnerable people. May 1, 2024, marks AAKP's fifth annual "Are You O-K+" campaign, which is managed through AAKP's Center for Patient Research and Education. The "Are You O-K+" campaign utilizes the scientific symbol of potassium, "K+," with a popular message, "Are You Ok," to encourage individuals with kidney diseases to know their potassium level. A potassium of 5.1 mEq/L and higher may indicate hyperkalemia, making May 1 (5.1) the key time for this annual awareness day. The campaign utilizes AAKP's highly sophisticated and integrated digital platforms and grassroots networks to reach and educate millions of at-risk Americans and their families on the importance of managing potassium intake and levels.

In addition to the educational components of this year's campaign, AAKP is activating its

Action Center to mobilize patients, and all people of goodwill concerned about kidney health, to contact their Congressional representatives and the U.S Food and Drug Administration (FDA) Commissioner Dr. Robert M. Califf to express their immediate concerns with the FDA Proposed Rule that would permit the use of potassium-based salt substitutes in foods for which salt is a required or optional ingredient.

During the open comment period for the FDA proposed rule, the AAKP, Academy for Nutrition and Dietetics (AND), and the National Kidney Foundation (NKF) submitted a joint letter respectfully urging the FDA to reconsider the proposed rule and focus on safer and more effective ways to reduce sodium intake for the greater population. Given the very high estimates of those who are unaware they have compromised kidney function, and the clinical consequences of hyperkalemia, adding "hidden potassium" in the form of potassium chloride substitutes to the American diet is a risk that should not be taken. Further, kidney disease disproportionately affects Black Americans as well as other minority populations and those with lower income status and food insecurity.² Therefore, the risks associated with the adoption of potassium-based salt substitutes would likely exacerbate negative health outcomes among populations that already face significant and historical risks.

AAKP President Edward V. Hickey, III stated, "AAKP and allied kidney health organizations work diligently to educate patients and professionals on the dangers of high potassium and the impact adverse events can have on people, the healthcare system, and taxpayers. We strongly encourage the FDA to demonstrate greater leadership and proactively engage the kidney stakeholder community before any new policy allowing potassium-based salt substitutes is finalized. Government Determinants of Health (GDoH) occur when agencies knowingly or unwittingly take actions that harm patients and, in this case, the FDA is fully aware of the risks their proposed action will have among Americans with poor kidney health." 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.

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. 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 targeted Government Determinants of Health (GDoH) as a key risk factor for Americans trying to manage kidney disease and avoid kidney failure. GDoH occurs when federal healthcare agencies lose sight of their primary duty to safeguard the vulnerable populations they serve and instead of acting as a problem solver, government itself becomes a barrier to improved clinical outcomes and an exacerbator of health disparity.

In 2018, AAKP launched the first and largest non-partisan voter education and registration

effort, <u>KidneyVoter™</u>, in the kidney community. AAKP plans to engage and mobilize over 500,000 <u>KidneyVoters™</u> in 2024 to make certain issues impacting the lives and livelihoods of kidney patients are not overlooked by candidates and elected leaders.

To support this year's National High Potassium Awareness Day, kidney advocates and others of goodwill can engage in the following efforts: send a letter to FDA Commissioner Dr. Robert M. Califf and Congressional leaders through AAKP's Action Center in opposition of the proposed salt-substitute rule; register for this year's "Are You O-K+" virtual event held on May 1 from 1:00-2:00 p.m.ET at https://www.surveymonkey.com/r/AreYouOK2024; and visit www.areyouok.org to access educational resources about high potassium and kidney disease, patient stories, and additional AAKP materials including AAKP's Nutrition Counter and Understanding the Food Nutrition Facts Label brochures, all seven editions of AKKP Delicious! kidney-friendly recipes, and our latest webinar on thtps://www.surveymonkey.com/r/AreYouOK2024; and visit Wurition Counter and additional AAKP materials including AAKP's Nutrition Counter and Understanding the Food Nutrition Facts Label brochures, all seven editions of AKKP Delicious! kidney-friendly recipes, and our latest webinar on thtps://www.surveymonkey.com/r/AreYouOK2024; and visit Wurition Counter and Understanding the Food Nutrition Facts Label brochures, all seven editions of https://www.surveymonkey.com/r/AreYouOK2024

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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.

¹ American Association of Kidney Patients. (2023, January 12). Hyperkalemia. Retrieved July 21, 2023, from https://aakp.org/center-for-patient-research-and-education/hyperkalemia/

² National Kidney Foundation. (2023, March 8). Minorities and Kidney Disease. Retrieved July 21, 2023, from https://www.kidney.org/atoz/content/minorities-KD