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U.S. and EU Kidney Groups Align for Global Innovation Consortium

World Kidney Day Announcement Precedes Virtual Patient-Led Global Summit

WASHINGTON, D.C. – The American Association of Kidney Patients (AAKP), the largest U.S. kidney patient organization, today joined the European Kidney Patients' Federation (EKPF) and the European Kidney Health Alliance (EKHA) in a new collaboration designed to expand the role of kidney patient consumers as central influencers in policy deliberations related to kidney research investments, more inclusive clinical trials, accelerated innovations, and improved health outcomes.

The collaborative effort will boost [The Decade of the Kidney™](#) an AAKP global initiative, launched in 2019 for the 2020-2030 decade, to support a patient-led international consortium to drive kidney disease as a global health priority and to better align governmental regulatory and payment policies so that barriers blocking rapid entry of treatment innovations into consumer markets are removed. Internationally, kidney patients are equal partners in breakthrough efforts related to, artificial implantable organs and wearable kidney devices; improved diagnostics for disease detection, precision medicine and new biologics that slow or stop disease progression. The AAKP, EKPF, and EKHA announcement comes as the unique value of kidney patient insights ([Read articles: CJASN Legitimization and Incorporation of Patient Preferences and CJASN Overview of Various Components of the Science of Patient Input](#)) has gained traction among U.S. and global policy-makers and a rapidly expanding international network of experts dedicated to addressing the devastating human and societal costs of kidney diseases that impact over 850 million people world-wide. Kidney patient consumers are demanding an end to outdated, status quo dialysis and its staggeringly high mortality rates. They have been joined by allies including academic and medical researchers, clinical trial designers, innovators and capital market investors, companies, non-governmental and faith-based organizations, and governmental leaders. In October 2020, EKPF released a [manifesto](#) stating, "Patients must be involved in kidney health policy."

Daniel Gallego, President of the European Kidney Patients' Federation stated, "We are more than happy that the AAKP reached out to us to support the collaboration of Kidney Patients Worldwide to really give a push for innovation and new therapies that will enhance the quality of life of kidney patients, contributing to expand our daily life activities. EKPF strongly believes, that in creating these therapies, patients should be included and in the driver's seat to reach next level treatments. Together we can create and extend a platform that is responsible for the long overdue innovation that Kidney Patients are waiting for." Gallego has been undergoing home hemodialysis for the past 25 years and previously received a kidney transplant. In addition to the above-mentioned priorities

of EKPF, Gallego stated how the COVID-19 pandemic impacted their work, prioritizing safety in dialysis units, and questions about vaccines.

Raymond Vanholder, President of the European Kidney Health Alliance stated, “Collaboration for improvement of kidney therapies can really cause benefit by moving boundaries. We are delighted with the expansion of our international collaboration by teaming up with AAKP. At EKHA, we strongly believe in the empowerment of patients to enhance the quality of life where possible. We therefore adopted their ‘*Decade of the Kidney*™’ initiative to create awareness for the unmet needs of kidney patients. An important part of this collaboration will consist of setting the political agenda at the level of EU and USA to push for real innovative therapies and corresponding funding to realize them.”

AAKP launched *AAKP Global*™ operations following participation in a 2018 policy discussion related to ethics, aging, and future patient care held at the United Nations. In 2019, AAKP announced its Global Patient Ambassador program and, in partnership with The George Washington School of Medicine and Health Sciences, began the virtual [Global Summit on Kidney Disease Innovations](#). The Summit has evolved into the largest kidney patient-led international event, with over 70 countries and 20,000 people engaged in 2020 ([read press release](#)), including thousands of patients and professionals across the European Union.

AAKP President Richard Knight, a former dialysis patient and 14-year kidney transplant recipient, stated, "Over the course of our 50-year history, AAKP has supported and networked with patients, medical professionals, and researchers across the globe. Today, we are honored to formally partner with some of the most respected kidney patient and professional organizations in the European Union in our shared vision for improving and extending the lives of those who suffer from kidney diseases. Patients and patient-led networks are a key source for the insights and data necessary for innovation leaders, and our voices, united worldwide, are having a growing influence among the elected and appointed leaders responsible for improving patient health outcomes." Knight ([read bio](#)) is a former staff member in the United States Congress and served as a liaison to the U.S. Congressional Black Caucus and is involved in multiple U.S government kidney policy initiatives.

Paul T. Conway, AAKP Chair of Policy and Global Affairs, also a former dialysis patient and a 23-year kidney transplant recipient stated, "This growing global consortium, led by kidney patients, will positively impact government policies and speed a new generation of life-extending and life-saving kidney treatments into consumer markets. Further, the technologies under development have the potential to save lives and livelihoods outside current infrastructure limitations affecting patients in many countries. Our aim is to reverse the growing global rate of kidney diseases and positively impact individuals and economies based on ideals and policies similar to those underlying the highly successful 2003 President’s Emergency Plan for AIDS Relief (PEPFAR)." Conway ([read bio](#)), is former Chief of Staff of the U.S. Department of Labor, has served under three American presidents and is a Patient Voice Editor for *The Clinical Journal of the American Society of Nephrology (CJASN)* ([read CJASN Patient Voice article](#)).

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About the European Kidney Patients’ Federation (EKPF):

The European Kidney Patients’ Federation is a consortium of over 25 nations and represents over 75 million people with kidney health conditions across Europe. The foundation of the EKPF’s activities is the health and well-being of patients with Chronic Kidney Disease (CKD) and their

careers. Those on dialysis treatment and kidney transplant recipients make up the vast majority of patients, but EKPF also includes those in the early stages of kidney disease who are sometimes called pre-dialysis patients. Part of EKPF's mission is to promote early detection of kidney disease. For more information, visit <https://ekpf.eu/>.

About the European Kidney Health Alliance (EKHA):

EKHA is a common effort by stakeholders to propose solutions for the challenges of Chronic Kidney Disease in Europe through effective prevention and a more efficient care pathway intended to facilitate the provision of appropriate and affordable treatment to all Europeans equally, while promoting the highest quality of care. EKHA works on the principle that the issue of kidney health and disease must be considered at the European level and that both the European Commission and European Parliament have vital roles to play in assisting national governments with these challenges. For more information visit <http://ekha.eu/about-us/>.

About the American Association of Kidney Patients (AAKP):

Since 1969, AAKP has been a patient-led organization driving policy discussions on kidney patient consumer care choice and treatment innovation. By 1973, AAKP patients had collaborated with the U.S. Congress and White House to begin American dialysis coverage for any person suffering kidney failure, a taxpayer effort that has saved over one million lives. In 2018, AAKP established the largest U.S. kidney voter registration program *KidneyVoters*[™]. Over the past decade, AAKP patients have helped gain lifetime transplant drug coverage for kidney transplant recipients (2020); new patient-centered policies via the White House *Executive Order on Advancing American Kidney Health* (2019); new job protections for living organ donors from 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 and [@kidneypatients on Twitter](#) and visit at www.aakp.org.