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MEDIA CONTACT:

Jennifer Rate
Marketing & Communications Manager

jrate@aakp.org

(813) 400-2394

COVID Pandemic Accelerates International Consortium of Kidney Patients Seeking Care Innovations

Argentine Kidney Patient Organization Joins with Largest American Kidney Organization

WASHINGTON, D.C. – The American Association of Kidney Patients (AAKP), the largest kidney patient organization in the USA, and the Argentina-based Asociacion Solidaria de Insuficientes Renales, (ASIR), today announced a formal partnership agreement designed to accelerate the growing worldwide consortium of kidney patient consumers and patient networks aligned to accelerate greater innovations and better health outcomes in kidney care. Both AAKP and ASIR are committed to driving medical innovation through more widespread utilization of kidney patient insight data and patient networks across the global kidney care ecosystem of researchers, clinical trial experts, innovators, companies, and government leaders. Kidney diseases impact over 850 million people worldwide and those living with chronic kidney disease, kidney failure, and organ transplants, as well as underlying chronic medical conditions often associated with kidney disease such as hypertension, diabetes, and heart disease, are among those at highest risk for COVID-19 infection and death.

The partnership was announced in conjunction with the [Third Annual Global Summit on Kidney Disease Innovations](#), founded by AAKP in full partnership with the George Washington University School of Medicine and Health Sciences in Washington, D.C. The Summit has grown into the largest patient-led and virtual kidney disease conference in the world. In 2020, the Summit engaged an audience of over 20,000 across seventy nations. Over the past year, AAKP has announced partnership agreements with patient advocacy organizations in the United Kingdom ([read here](#)), the Netherlands, the European Union ([read here](#)) and will be making multiple other announcements throughout 2021. In 2018, AAKP launched their *AAKP Global*™ operations to put an organized patient consumer voice at the decision table in policy matters related to innovation, access, regulations, and payment issues worldwide following AAKP's participation in a sobering United Nations event related to ethics, aging, and future patient care.

AAKP and ASIR are aligned in their missions of providing kidney patients with educational information related to their disease and treatment options, informing patients of new innovations and kidney research, and ensuring every patient has access to care options that fully align with patient goals and aspirations. ASIR has an impressive history of advocacy successes working with the National Congress of Argentina to pass current laws such as the Patient Rights and Duties Law of 2012, Law on Comprehensive Protection of Transplant People and Waiting List in 2015, and a new Transplant Law in 2017. AAKP and ASIR will partner together to further educate kidney patients on COVID-19 implications for kidney patients while preparing them to exercise greater influence on global kidney research, innovation, and advocacy

priorities. AAKP has a fifty-year history of policy engagement with the White House and U.S. Congress, numerous advocacy successes, and is heavily engaged with U.S. federal agency efforts to integrate patient insight data into regulatory and payment decisions ([read article](#)). AAKP is also working with the federal government, academia, and the medical industry to increase both inclusiveness and greater kidney patient involvement in clinical trials.

In a statement of support for the Third Annual Global Summit and the new AAKP partnership, Dr. Maria Eugenia Vivado Duran, President of the Argentina-based Asociación Solidaria de Insuficientes Renales of Buenos Aires, stated, "ASIR joins together with AAKP in support of the rights of the kidney patients and to share in efforts to further medical innovations that will better prevent and treat kidney diseases and improve the quality of life for kidney patients." Ms. Vivado Duran, a pediatrician and AAKP Global Ambassador, was diagnosed with kidney disease in 1979 during her second pregnancy. She was on hemodialysis for many years and sought out resources and support in her community, eventually working with ASIR and other national and international groups to defend rights of patients. In 2001, she received a kidney transplant from a deceased donor, allowing her to continue working for patients, educating the community, and enjoying her family. She has been President of ASIR for four consecutive terms and does everything in gratitude to her anonymous kidney donor.

Richard Knight ([read bio](#)), AAKP President and a 14-year kidney transplant recipient, stated, "For over five decades, AAKP has supported and networked with patients and researchers in this nation and across the world in the fight against kidney diseases. Today, we are honored to formally partner with ASIR to advance our shared agenda of patient-driven research and innovation, and together help expand the global consortium of patient advocates leading the fight against kidney diseases." Knight is a former legislative staff member in the United States Congress and liaison to the Congressional Black Caucus. He is a nationally known advocacy leader ([read article](#)).

Paul T. Conway ([read bio](#)), AAKP Chair of Policy and Global Affairs, Co-Chair of the Global Summit, and a 24-year kidney transplant recipient, stated, "Kidney patients in Argentina, like their counterparts here in the USA and around the globe, share the same desire for expanded patient consumer care choice, more inclusive clinical trials, and the greater use of their patient preference information in the development of new kidney drugs, devices, and diagnostics. As a partner to ASIR and an expanding number of patient networks worldwide, AAKP is fully committed to equipping patients and their medical professionals with the tools they need to better organize and more effectively advocate for innovation and improved treatments, no matter where they live." Conway has served in policy roles under four U.S. presidents and is a Patient Voice Editor for the Clinical Journal of the American Society of Nephrology (CJASN) ([read article](#)).

The Summit has also helped AAKP boost [The Decade of the Kidney™](#), an AAKP global initiative ([read article](#)) launched in 2019 for the 2020-2030 decade to help U.S. and global policy-makers address the devastating human and societal costs of kidney diseases. Kidney patient consumers across the globe are demanding an end to outdated, status quo dialysis and its staggeringly high mortality rates and more solutions aimed at detecting, preventing, and treating kidney disease earlier and in ways that improve quality of life and mobility decrease dependency. They have been joined by allies including academic and medical researchers, clinical trial designers, innovators, capital market investors, companies, non-governmental and faith-based organizations, and governmental leaders.

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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 innovations. 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-funded 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 FMLA 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 Instagram, and visit the AAKP website at www.aakp.org.

About the Asociacion Solidaria de Insuficientes Renales (ASIR):

ASIR is a non-profit association formed by patients in pre-dialysis, peritoneal dialysis, hemodialysis, transplanted, family, friends, and all people in solidarity with our cause. Our primary objectives are to inform about all existing alternative therapies that offer the possibility of choosing and adopting the one that you consider most in line with your lifestyle. As well as everything concerning the problems of a kidney patient. We started ASIR, believing that all people need other people, that alone the road is harder and together you can grow more and fight better. Meet with us, present your doubts, your concerns, your fears, your hopes. For more information, visit <http://www.asirargentina.com.ar/>.