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U.S. AND INTERNATIONAL KIDNEY PATIENTS ALLY TO PUSH RESEARCH AND INNOVATION

Largest American Kidney Patient Group Partners with UK Based Renal Patient Support Group

Kidney Patient Networks Signal Widening Support for International Kidney Consortium

WASHINGTON, D.C. – The American Association of Kidney Patients (AAKP) and the Renal Patient Support Group (RPSG), based in the United Kingdom (UK), today announced a partnership to accelerate links among kidney patients worldwide to elevate patient insights among an international network of researchers, clinical trial experts, innovators, companies, and government leaders. AAKP launched their Global Ambassador strategic initiative in 2019 to accelerate global patient networking and to increase interest for an international kidney innovation consortium as a part of <u>The Decade of the Kidney</u>[™].

The announcement came during the 2020 Virtual Global Summit on Kidney Disease Innovation, a collaborative event between AAKP and the George Washington University School of Medicine & Health Sciences (GW SMHS). The Global Summit, featuring international experts on coronavirus and kidney innovation, is being hosted virtually July 16-17, 2020. Thousands of viewers in over 65 countries participated the first day of the Summit, exceeding the 2019 Inaugural Global Summit. To view the 2020 Summit agenda or to register, go to https://aakp.org/programs-and-events/2nd-annual-global-summit-global-kidney-innovations-expanding-patient-choices-outcomes/.

AAKP and RPSG share joint strengths in their diverse and global memberships and highly sophisticated social media and online communication platforms. Both organizations have a shared agenda to increase kidney patient care choice and the inclusion of patient preference information (PPI) and evidence in the development of new kidney drugs, diagnostics, and devices. The RPSG has an international membership, including, but not limited to, the United Kingdom, United States of America, Egypt, India, Canada, Saudi Arabia, Ireland, and Australia.

Richard Knight, AAKP President and a 14-year kidney transplant recipient, stated, "Over the course of our 50 history, AAKP has supported and networked with patients and researchers across the globe.

Today, we are honored to formally partner with the RPSG to advance our shared agenda of patientdriven research and innovation, and to prepare patient networks for a global consortium to fight 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. <u>http://bit.ly/KnightPV</u>

Shahid Muhammad, Academic and Chartered Scientist from the University of the West of England (UWE), Bristol UK, and former Co-Founder of RPSG, stated, "It is fantastic to see best practice grow through the work of the RPSG strengthening Evidence-Based Practice surrounding kidney care internationally. It is fantastic news to see that the more recent partnership is going ahead with the AAKP, prompting robust UK and USA efforts. I am pleased to see that the RPSG has progressed and has expanded its partnership portfolio over time." Mr. Muhammad served as an International Expert Speaker and lectured on Clinical Trials in Kidney Disease: International Perspective on Patient Engagement during the first day of the 2020 Virtual Global Summit.

John and Vicky Gardner, Co-founders of the RPSG stated, "Over the past decade, the RPSG has been an international Evidence-Based Support Group, collaborating and raising kidney disease awareness. It is now with great pleasure to announce that the Renal Patient Support Group (RPSG) and the American Association for Kidney Patients (AAKP) are partnering to further increase healthcare transparency and raise education awareness for ALL those going through kidney disease. This UK and USA partnership will be at the forefront."

Paul T. Conway, AAKP Chair of Policy and Global Affairs and a 20-year kidney transplant recipient, stated, "Kidney patients worldwide have a shared the agenda for expanded patient consumer care choice, fully representative clinical trials, and a greater valuation of patient preference information in the development of new kidney drugs, devices, and diagnostics. We are committed to equipping patients and their medical professionals, regardless of where they live or the political system under which they live, with the tools they need to organize and freely advocate for innovation and improved treatments." Conway has served in policy roles under three U.S. presidents and is a Patient Editor for the Clinical Journal of the American Society of Nephrology (CJASN) (https://cjasn.asnjournals.org/content/15/7/907).

AAKP Global Ambassador Vasundhara Raghavan (Dubai, United Arab Emirates) and AAKP National Ambassador Meshia Adams (USA) represent the RPSG team as Research and Administrators. AAKP Global Ambassador Vasundhara Raghavan will provide a patient perspective on Patient-Driven Transformations in Global Care and Care Delivery during the 2020 Virtual Global Summit.

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About the American Association of Kidney Patients (AAKP): The AAKP is a strong global advocate for kidney patient consumer care choice and treatment innovation. From 1969-1973, AAKP patients led the effort in the U.S. Congress, alongside senior White House officials, to establish the End Stage Renal Disease Program, which has saved over a million U.S. lives through modern dialysis coverage. In 2019, AAKP announced the start of the <u>Decade of the Kidney</u>[™] upon the signing of the White House *Executive Order on Advancing American Kidney Health Initiative*. Since 2018, AAKP has conducted the

largest virtual kidney voter registration drive in America, the <u>"I am a Kidney Voter" campaign.</u> AAKP builds policy consensus for early disease detection; increased kidney transplantation and pre-emptive transplantation; and protection of the patient/physician relationship. For more information, visit <u>www.aakp.org</u>. Follow AAKP on social media at <u>@kidneypatient on Facebook</u> and <u>@kidneypatients on Twitter</u>.

About the Renal Patient Support Group (RPSG): The RPSG was founded in 2009 by two renal patients and one caregiver to help raise Chronic Kidney Disease (CKD) awareness on a wider scale. The RPSG is an Evidence-Based support group and defined as a 'place' where awareness and research meet. The RPSG was short-listed as Advancing Healthcare Awards (2018) finalists. The RPSG was also short-listed for an Impact and Innovation Award (2018). For more information, visit <u>www.rpsg.org.uk.</u>