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MEDIA CONTACT:
Jennifer Rate
Marketing and Communications Manager
(813) 400-2394
jrate@aakp.org

KIDNEY PATIENTS MOBILIZE FOR GREATER DISEASE RESEARCH AND INNOVATION

The Decade of the Kidney™ Includes New Therapies, Home Dialysis, and Artificial Organs

WASHINGTON, D.C. – The American Association of Kidney Patients (AAKP), the largest independent kidney patient organization in the nation, recently hosted its 46th Annual National Patient Meeting, a virtual experience that broke all previous attendance records and engaged kidney patients across the United States and over 25 countries. A total of 60 national and international expert speakers participated, including patient advocates, [patient experts](#), and other top influencers drawn from key sectors, including government, medicine, academia, research centers, and industry. Throughout the meeting, kidney patients and their allies supported innovations in kidney care by contributing their unique and highly valuable [patient insights](#). Further, participants could construct their own "after hours" session from over 45 webinars and sessions on issues including clinical trials and diversity, home dialysis therapies, COVID-19, veterans, and diabetic kidney disease. The event agenda and all general, breakout, and training sessions from the 2021 Patient Meeting are available OnDemand through the [AAKP website](#) and [AAKP YouTube Channel](#).

AAKP is nationally and internationally known for its aggressive advocacy on behalf of kidney patient consumers and their right to treatment care choice in consultation with the doctors they choose to care for them. The Association defines high-quality kidney care as timely patient access, without interference, to prevention and treatment innovations that empower patients to remain healthy, independent, and able to pursue their life goals and aspirations, including meaningful work and a career, homeownership, starting and supporting a family, and secure retirement.

The event highlighted the latest in kidney research and treatment innovations, including advancements in home therapies; the future of organ transplantation; rare and genetic conditions that cause kidney disease; advancements in diabetic kidney disease (DKD) and acute kidney injury (AKI); and discussions related to the incorporation of artificial intelligence and machine learning in the diagnosis, care, and treatment of kidney diseases. In 2015, AAKP established its Center for Patient Research and Education to service requests for patient participants, data insights, and data analysis as more innovation leaders, entrepreneurs, investors, and companies move into the kidney space to pioneer new care and treatment solutions for the deadly disease. AAKP's database and deep reach within the patient community helped put kidney patients at the center of government and industry-led research initiatives, technical evaluation panels, advisory committees, market analysis, policy roundtables, and clinical trials.

During the opening session, Fokko Wieringa, Principal Scientist for IMEC of the Netherlands, and Henning Søndergaard, a home dialysis patient and psychologist affiliated with the Danish Kidney Foundation, commented on the lack of innovation in modern kidney dialysis. Søndergaard described dialysis by stating, "It is the same technology as they were using 50 years ago. It blows my mind. If the innovation in consumer electronics had been like the same for dialysis machines, my laptop or my cell phone, for that matter, would be the size of four New York City Blocks." Søndergaard is a member of the "Breakthrough Innovation" Work Group of the European Kidney Health Alliance (EKHA) and collaborates closely with Fokko Wieringa and other top European scientific,

medical, and private sector experts on breakthrough kidney therapies, including efforts to develop an artificial kidney. As part of their global efforts, AAKP announced a formal partnership with EKHA and the European Kidney Patient Federation (EKPF) on [World Kidney Day 2021](#), designed to accelerate the growing international network of patient consumers demanding greater kidney care innovation, including artificial wearable and implantable kidneys.

In 2019, AAKP declared 2020-2030 [The Decade of the Kidney™](#) to prioritize investments in kidney disease research and to support the development of new diagnostics, devices, and biologics to combat the disease, which impacts nearly 40 million Americans, including 400,000 on dialysis and over 100,000 waiting for a kidney transplant. Since 2018, AAKP has organized the largest non-partisan voter registration drive within the kidney stakeholder community, [KidneyVoters™](#), which aims to identify 500,000 KidneyVoters™ by 2024. Both [The Decade of the Kidney™](#) and [KidneyVoters™](#) efforts are designed to encourage elected and appointed leaders nationwide that kidney patients and their families expect major changes to status quo kidney care, which is currently characterized by outdated technologies, in-center kidney care, and high mortality rates.

Three winners of the 2021 KidneyX prize, the internationally known kidney treatment innovation competition that is a partnership between the American Society of Nephrology and the U.S. Department of Health and Human Services, were included in the AAKP meeting program. The KidneyX speakers were **Shuvo Roy, PhD**, Technical Director, The Kidney Project, and Professor at the Departments of Bioengineering and Therapeutic Sciences and Surgery, the University of California San Francisco; **David K.C. Cooper, MD, PhD**, co-director, Xenotransplantation Program, University of Alabama, Birmingham School of Medicine; and **Dr. Fokko Wieringa, PhD**, also affiliated with both the Dutch Kidney Foundation and The Kidney Health Initiative.

The event included sessions focused on [COVID-19](#) and kidney patient updates, including the latest information on the impact of the Delta variant and third dose vaccinations provided by [Robert Montgomery, MD, DPhil, FACS](#), **heart transplant patient** and Chair of the Department of Surgery, Director of the NYU Langone Transplant Institute. Dr. Montgomery has won international attention for his recent successful experiment with xenotransplantation and will be participating in a free November 11, 2021, AAKP webinar on the topic “Innovation in Transplantation: Xenotransplantation” ([click here to register](#)). Federal agency officials participating in the program included **Paul Palevsky, MD**, Deputy Director of the U.S. Department of Veterans Affairs Kidney Disease and Dialysis Program, Professor of Medicine, University of Pittsburgh School of Medicine, and the President of the National Kidney Foundation; **Ivonne H. Schulman, MD**, Program Director, Translational and Clinical Studies of Acute Kidney Injury, National Institutes of Health (NIH), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), Division of Kidney, Urologic and Hematologic Diseases (KUH); **Matt Diamond, MD, PhD, CMO**, Digital Health Center of Excellence, U.S. Food and Drug Administration; and **Shannon Novosad, MD, MPH, LCDR**, Medical Officer, Division of Healthcare Quality Promotion, Centers for Disease Control and Prevention (CDC).

The meeting also provided kidney patients, families, and kidney medical professionals with 12 practical advocacy skill and technology training sessions through AAKP's [Center for Patient Engagement and Advocacy](#). The Center, founded in 2015, has expanded AAKP's national grassroots impact on policy and legislative issues in Congress and all 50 states by training patient advocates in policy analysis and grassroots tactics. The 2021 skill training sessions included: “How To Be an Effective Participant in Clinical Trials and Research Efforts” by **Scott Toner**, President and Founder, BridgeView Strategies; “Training for Organizing Patients and Families under AAKP's KidneyVoter™ Voter Registration Program” by **Erin Kahle, MPA, CNP**, AAKP's Director of Patient Insights, Data Analytics, and Advocacy; “Practical Steps in Sharing YOUR Story to Support Finding a Living Organ Donor” by **Risa Simon**, AAKP Ambassador, Founder, TransplantFirst Academy, and a preemptive transplant recipient; “Top Ten Things to Know to be Effective on Camera – From Zoom to Media Interviews” by **Jonathan St. John**, Owner and Senior Editor, Briar Patch Media, LLC, and AAKP's national strategic media partner; and “How to be Effective with Video on Social Media” by **Jennifer Rate**, AAKP's Marketing and Communications Manager. These skill sessions complimented eight skill sessions AAKP conducted during 2020 that are widely shared among patient advocates and available [here](#). Since 2018, AAKP has conducted the first and largest non-partisan kidney patient and family voter registration effort, [KidneyVoters™](#), and aims to mobilize 500,000 KidneyVoters™ by 2024.

AAKP President Richard Knight, a former hemodialysis patient and current 14-year transplant recipient, stated, “For over 50 years, AAKP patient volunteers united alongside kidney professionals have led the fight for greater innovation in kidney medicine by organizing grassroots support for more investments in kidney research, product

development, and policy. As staunch believers in the power of individuals and private sector partners to develop care solutions, we appreciate our expanding base of individual donors and major sponsors, whose support was used to provide substantive educational programming and advocacy skill training." [Knight](#) is a small business consultant and business strategy instructor at Bowie State University (BSU) and a former Congressional staff member and liaison to the Congressional Black Caucus. [Read Richard Knight's day two closing remarks.](#)

AAKP thanks the 2021 National Patient Meeting Sponsors for their generous support that allowed the AAKP to host this year's virtual meeting and waive the cost of registration, providing full access of this event to everyone. Platinum Sponsors included Baxter International, Becton Dickson and Company, CareDx, Horizon Therapeutics, Medtronic, Natera, Otsuka Pharmaceuticals, and Sanofi Genzyme. Gold Sponsors included Akebia Therapeutics, Amgen, AstraZeneca, and Novartis. Silver sponsors included Travere Therapeutics and Vifor Pharma. Bronze Sponsors included Aurinia Pharmaceuticals, Bayer Pharmaceuticals, CVS Kidney Care, Reata Pharmaceuticals, and Vertex Pharmaceuticals. Patron Sponsors included Humacyte, Outset Medical, and Palladio Biosciences.

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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 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, [@kidneypatients](#) on Twitter, and [@kidneypatients](#) on Instagram, and visit www.aakp.org for more information.