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SURVEY: AS KIDNEY PATIENTS AWAIT COVID VACCINES, THEIR QUESTIONS MOUNT

Top U.S. Kidney Patient Group Releases COVID-19 Patient Insights
Hosts Medical Expert Webinar to Answer Patient Questions, Boost Vaccination

Tampa, FL: Today, the American Association of Kidney Patients (AAKP), the nation’s largest independent kidney patient organization and a global champion for patient care choice and treatment innovation, released the results of a patient membership survey, Kidney Patients and the COVID-19 Vaccine. AAKP Flash Surveys are conducted under AAKP’s Center for Patient Research and Education, which provides key kidney community insights to elected and appointed federal and state policymakers through patient survey and polling data. The Center also coordinates kidney patient engagement in medical research, clinical trials, and patient inclusion on key federal agency policy panels.

Kidney patients, many of whom depend upon life-sustaining dialysis care or are living with an organ transplant and taking immunosuppressive medications, manage multiple chronic conditions and multiple comorbidities and are listed by the Centers for Disease Control and Prevention (CDC) as being at high-risk for COVID-19. Since kidney disease impacts minorities disproportionately, COVID-19 has had an increased impact among both minority and kidney patient communities.

The survey provided top patient questions about the COVID-19 vaccine as well as key insights. Results showed that 85 percent of responding kidney patients had not received the COVID-19 vaccine and that nearly 75 percent indicated they planned to get it when it was available because the benefits outweigh the risks. Patients indicating they did not plan to get the vaccine raised a wide range of concerns and questions, but the primary reason cited was a concern about safety. However, among those indicating they did not plan to take the vaccine, over half would take it if their healthcare team proactively engaged them and communicated it as a recommendation.

“AAKP is fully committed to addressing kidney patient concerns related to COVID-19 including their risk of infection and the safety of vaccines,” stated Richard Knight, AAKP President. “As AAKP demonstrated throughout 2020, we are committed to arming patients with the information they need to make intelligent decisions about their own care, in full coordination and with the advice of their respective medical providers. AAKP will continue to monitor patient concerns during 2021 to assess patient reactions to the constantly changing vaccination decisions and choices facing kidney patients.”

AAKP utilized survey insights to launch their inaugural 2021 COVID-19 national medical expert Healthline Webinar (Watch Now OnDemand) featuring kidney care and kidney transplant experts from the American Board of Internal Medicine (ABIM) as well as the American Society of Transplant Surgeons (ASTS). The webinar provided answers to key patient concerns about vaccine safety, armed patients with questions to ask their medical providers, and included information on recent COVID-19 virus mutations and the ongoing health and economic impacts of the virus. Speakers included Dr. Deidra Crews, Associate Professor of Medicine in the Division of Nephrology and Associate Vice Chair for Diversity and Inclusion in the Department of Medicine.
at the Johns Hopkins University School of Medicine, and a member of the ABIM Nephrology Specialty Board; Dr. Michael Alan Rees, ASTS, transplant surgeon and professor at the University of Toledo Health Science Campus, Departments of Urology and Pathology, and 2021 AAKP Medal of Excellence awardee; Richard Knight, AAKP President, Advisory Council member of the National Institutes of Health (NIH) National Diabetes and Digestive and Kidney Diseases (NIDDK), and a current transplant recipient; Paul T. Conway, AAKP Chair of Policy and Global Affairs, member of the ABIM Nephrology Specialty Board, and a current transplant recipient; and Dale Rogers, AAKP National Board of Directors Member, AAKP National Ambassador, and a current transplant recipient. Patient participants in the webinar each received the 2020 President’s Volunteer Service Award (PVSA), a national non-partisan program created in 2003 for community-based volunteers working on some of the nation’s toughest problems. AAKP’s 2020 PVSA awardees were recognized for their efforts to educate the kidney patient community on the personal and public health risks associated with the COVID-19 pandemic.

“AAKP’s educational programming has a massive level of engagement throughout the kidney patient community because of its unique blend of medical expert opinions and peer-to-peer viewpoints” stated Edward V. Hickey, III, USMC, AAKP Vice President and Chair of the AAKP Veterans Health Initiative. “A central tenet of AAKP’s Decade of the Kidney™ initiative is the principle that kidney patients must be equal partners in all decisions that impact their own healthcare and economic security. The COVID-19 pandemic has brought the importance of this principle to the immediate forefront of kidney care and AAKP will continue to be aggressive advocates for patient inclusion and legal rights in all care decisions.”

The recent AAKP Flash Survey, conducted between January 12 and 17, 2021, involved over 700 patients and revealed the following patient insights:

- 85 percent of respondents had not received a COVID-19 vaccination at time of survey completion.
- 74 percent of respondents who have not received a COVID-19 vaccine indicated they did plan to get the vaccine when available.
- 78 percent of individuals who have not received a COVID-19 vaccine shared what makes them comfortable receiving the vaccine, when available to them, is their belief that the benefits outweighed any potential risk/side effect.
- 70 percent of individuals who do not plan to get the COVID-19 vaccine cite being unsure how safe and effective the vaccine was for them (kidney patient) as their main reason for not wanting the vaccination. Of these individuals, they equally indicated the following would make them more comfortable receiving the vaccine:
  - 57 percent - If their physician/healthcare team recommended the vaccine.
  - 53 percent - If they were provided with more information/education on the risks/benefits.
  - 46 percent - If they knew of other individuals with kidney disease who already had or planned to receive the vaccine.

The top kidney patient questions identified in the AAKP Flash Survey were:

1. Are the current vaccinations safe for chronic kidney disease and dialysis patients, what are the side effects, and how common are allergic reactions? Is one type of vaccine recommended for one group of patients versus others?
2. I am scheduled to receive a living donor transplant soon. Should I go ahead and get the first dose of the vaccine or wait until after my surgery? Also, what are the short-term and long-term impacts of the vaccine on transplanted kidneys or kidney transplants with impaired function?
3. What is the safest location for kidney patients to access vaccines - their doctor’s office, other medical facilities, or their local pharmacy? Will dialysis centers provide vaccines?
4. Are kidney patients who are 65 and older and have comorbidities also recommended to get the vaccination? Have there been any issues or concerns discovered?
5. Will vaccinations change current protective measures recommended by the CDC, i.e., the use of masks, social distancing, and isolation?
“In an era when truth and fact about COVID-19 and related vaccines are often overshadowed by misleading rhetoric and inaccuracy, it is critical that high-risk patients and their caregivers have timely access to accurate and factual information,” stated Paul T. Conway, AAKP Chair of Policy and Global Affairs. “AAKP is grateful to the credentialed and board certified frontline medical experts who understand COVID-19 and vaccines and who selflessly educate patients on how to protect their own lives as well as the lives of those they love and interact with on a regular basis.” Conway also serves as the AAKP liaison to the Health Infection Control Practices Advisory Committee (HICPAC) of the CDC.

A previous AAKP Flash Survey, conducted between November 4 and 10, 2020, involved nearly 800 patients and indicated the following key insights:

- 79 percent of respondents did receive a seasonal flu vaccine.
- 78 percent of respondents are more concerned about the risks of COVID-19 now than compared to March 2020.
- 73 percent of respondents indicated they would be more willing to take the COVID-19 vaccine if they knew kidney patients were involved in clinical trials and a vaccine was declared safe for kidney patients.
- 65 percent of respondents indicated that they are very concerned that over the next 3 to 4 months, the flu and COVID-19 will pose a great risk to the most vulnerable, including those with underlying chronic conditions such as kidney diseases, heart disease, and diabetes.
- 44 percent of respondents shared that a member of their family or close circle of friends has been infected by the COVID-19 virus.
- 39 percent of respondents share that a member of their immediate family has experienced a job layoff or job loss due to the economic impact of COVID-19.
- Nearly a third of respondents indicated they are interested in participating in COVID-19 clinical trials—if asked.

For more information or to view all AAKP HealthLine COVID-19 webinars, click here. To visit the AAKP Coronavirus Resource page, visit bit.ly/AAKPCOVID19Resources.

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**About the American Association of Kidney Patients (AAKP):** Established in 1969, AAKP maintains a national and global network of patient advocates, kidney researchers, medical innovation leaders, and policy influencers. 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 (ESRD), which has saved over a million lives through modern dialysis coverage as administered by the Centers for Medicare and Medicaid Assistance. For more information, visit www.aakp.org. Follow AAKP on social media: @kidneypatient on Facebook, and @kidneypatients on Twitter.