

AAKP Press Release: New CDC Respiratory Guidance Ignores Kidney Patient Concerns

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FOR IMMEDIATE RELEASE

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New CDC Respiratory Guidance Ignores Kidney Patient Concerns

HHS and CDC Omission Labeled a Government Determinant of Health

Serious Questions Build Over Inconsistent HHS Approach to Kidney Health

Washington, D.C.: Today, the American Association of Kidney Patients (AAKP), the largest and oldest independent kidney patient organization in the nation, issued an **Official Statement** (appears below) in response to the Center for Disease Prevention and Control's (CDC) new Respiratory Virus Guidance, publicly announced on March 1, 2024. The CDC announcement occurred on the first day of National Kidney Month. March traditionally unites kidney stakeholders and people of goodwill in efforts to raise awareness of kidney diseases, address ongoing unmet patient needs, and advocate for removal of federal regulatory and payment barriers that impede access to, and development of, new kidney diagnostics, drugs, and devices.

AAKP is calling out CDC leadership, as well as appointed leaders at the U.S. Department of Health and Human Services (HHS), for their failure to specifically highlight the documented, higher risks of severe COVID illness,

hospitalization, and death among immunosuppressed kidney transplant recipients and immunocompromised chronic kidney disease (CKD) and dialysis patients. The unique vulnerabilities of kidney patients, who often manage multiple co-morbidities including diabetes and hypertension, were not specifically mentioned during the CDC's March 1st policy announcement, despite AAKP's request these concerns not be ignored. Over the past year, AAKP has pushed CDC and HHS officials to demonstrate stronger leadership and to do a better job of including the unique medical circumstances and needs of vulnerable kidney patients in HHS agency decisions and public communications. An estimated 37 million Americans have kidney disease. The disease [disproportionately impacts](#) minority Americans, many of whom are from historically underserved communities and are Medicare beneficiaries. [Mortality rates among kidney patients](#) occurred at historic levels at the start of the COVID pandemic, [devastated the kidney patient community](#) and families, and this community's [ongoing risks remain a strategic concern](#) among patient advocates and allied kidney professionals.

On May 10, 2023, when White House and HHS officials announced the end of the COVID-19 Public Health Emergency, AAKP issued a statement entitled [“Don't Forget Kidney Patients – Their Vulnerabilities Remain.”](#) Throughout 2023, AAKP issued concerns about ongoing safety and infection threats to kidney patients in healthcare settings as the CDC's [Health Infection Control Practices Advisory Committee](#) deliberated new, draft CDC infection control guidelines. AAKP also raised kidney patient health and safety concerns to CDC officials in stakeholder briefings prior to the March 1, 2024, CDC Respiratory Virus Guidance announcement.

CDC and HHS officials have expert knowledge of the evidence documenting the ongoing risks and potential negative consequences of COVID among people with kidney transplants, on dialysis or living with chronic kidney disease. The [CDC's official website](#) cites that people with these underlying medical conditions are associated with higher risks for severe COVID infection. Among kidney transplant recipients, [COVID-19 vaccines have limited efficacy](#) due to the lifetime, immunosuppressive drug regimens these patients depend upon to maintain their organs. New COVID treatments that help prevent more severe COVID infections and reduce hospitalizations are often not used for transplant patients due to serious concerns over safety and incompatibility.

CDC's failure to effectively engage stakeholders in policy development and communications has led to other recent controversies. The agency has been under public and media scrutiny related to the management of the HICPAC and charges over a lack of transparency, failure to engage a broad-range of scientific experts, and selective use of evidence to develop new, [draft infection control guidelines](#) for health facilities, including hospitals ([Read FORBES article](#) / [Read FORBES article](#)). The CDC has received thousands of comments from medical professionals, patients, professional societies, and consumer interest organizations related to HICPAC and the concerns continue to [impact agency credibility](#) among key stakeholders. AAKP expressed its own concerns related CDC and HICPAC stakeholder engagement and

communications, in its official role as HICPAC liaison organization, during [2023 HICPAC meetings](#) (Read AAKP comments before HICPAC, [June 8-9, 2023 see transcript, pages 55-56](#), and [November 2-3, 2023, see transcript page 95](#)). AAKP has strongly recommended CDC consider more inclusive stakeholder engagement models, including those utilized by the U.S. Department of Veteran Affairs (VA) and the U.S. Food and Drug Administration's (FDA) Center for Devices and Radiological Health (CDRH).

AAKP has a decades-long association with the CDC on issues related to public health and disease prevention. In 2016, AAKP, along with allied kidney medical professional associations, was a founding member of the [CDC's Making Dialysis Safer Coalition](#). AAKP has been a frontline partner in CDC's efforts to prevent infections among kidney patients in healthcare settings, including health acquired infections (HAIs) and catheter-related bloodstream infections (CRBSIs). At the start of the COVID-19 pandemic, and over the past several years, AAKP worked closely with CDC career officials to encourage greater awareness and protection from the virus, especially among immunocompromised dialysis patients and immunosuppressed kidney transplant patients, through joint webinars ([March 24, 2021](#); [March 27, 2020](#); [August 20, 2020](#)) and presentations ([September 21, 2020](#); [September 20, 2023](#)) and [awareness campaigns](#). AAKP is currently engaged in efforts to raise awareness and patient engagement within CDC's [Chronic Kidney Disease Surveillance](#) initiative.

AAKP has a 50-year history of fighting for greater patient care choice, full access to care innovations, and disability rights. Since 2018, AAKP has conducted the largest national voter registration and mobilization initiative in the kidney space, titled [KidneyVoters™](#) which engages a broad-based coalition of kidney patients, organ donors, professional medical stakeholders and industry on issues impacting patient outcomes. AAKP mobilizes [KidneyVoters™](#) to hold elected and appointed leaders accountable for commitments to patients and support of policies that help transcend high mortality, status quo kidney care.

AAKP STATEMENT

The American Association of Kidney Patients (AAKP), the nation's largest and oldest independent kidney patient organization in the nation, is deeply concerned about the Center for Disease Prevention Control's (CDC) [Respiratory Virus Guidelines](#), including for COVID, announced on March 1, 2024. We believe these guidelines fail to adequately address the ongoing vulnerability of immunocompromised and immunosuppressed individuals and their unique needs, including people with chronic kidney disease (CKD), end stage renal disease (ESRD), and people undergoing kidney failure treatment through dialysis or a kidney transplant.

AAKP recognizes the tremendous achievements the nation has made to address COVID, and we celebrate every life that has been saved through new innovations including vaccines and treatments that help prevent severe

infection, hospitalization, and death. And, we will never forget all the innocent people who lost their lives to COVID, the impact on their families and friends, and all who are currently hospitalized suffering from long-COVID. The reality is, the threat of severe infection and death remains for many vulnerable Americans and their families, especially those impacted by kidney diseases. For many, the CDC's highly scripted narrative of being "in a better place," does not apply. Instead, these individuals' lives and livelihoods still require constant vigilance, and their day-to-day existence is marked by medical and financial burdens, isolation, and loneliness.

The current guidelines ignore these concerns and fail to provide sufficient protection or support for this particularly high-risk group of people. This failure is deeply troubling, especially in light of the federal data available to senior appointed leaders at the CDC and the U.S. Department of Health and Human Services (HHS). The guidelines do not address the unique needs of immunocompromised and immunosuppressed individuals. These individuals face a significantly higher risk of severe illness or death if they contract COVID and vaccinations afford unreliable protection¹, yet the guidelines do not offer clear and specific recommendations tailored to their individual circumstances. This omission is a disservice to those who have fought to stay healthy over the past four years and remain in a precarious position due to their compromised health. And, it is disservice to future patients who will undergo dialysis treatments and/or secure a life-saving kidney transplant.

The CDC's failure to address the vulnerability of immunocompromised and immunosuppressed individuals is particularly egregious given the growing body of evidence demonstrating the heightened risk this group faces when it comes to COVID. The propensity of the virus to be spread by infected but otherwise healthy individuals², along with the suboptimal efficacy of the updated booster to prevent hospitalizations in the general adult population³, are of great concern. Studies continue to show that immunocompromised and immunosuppressed individuals are more likely to experience severe complications if infected with the virus and yet the guidelines do not offer the level of protection necessary to mitigate this heightened risk.

The lack of specific guidance for the vulnerable kidney population sends a message that their health and safety are not a priority. This neglect is simply unacceptable and AAKP views it as a negative Government Determinant of Health (GDoH). The CDC has a moral, ethical, and legal responsibility to protect the health of all individuals, including those who are immunocompromised and immunosuppressed, and the current guidelines fall short of fulfilling this serious duty. Americans expect the CDC to put forward reliable science and substance, not surrogates and scripts that deliberately omit the concerns of the most vulnerable people in our society.

It is imperative that the CDC revise its guidelines to explicitly address the needs of immunocompromised and immunosuppressed individuals. This should include clear and specific recommendations for reducing the risk of exposure, as well as clear guidelines for accessing and receiving vaccines and other safe, preventative measures. Additionally, there should be targeted

guidance for employers, healthcare providers, and the general public on how to support and protect immunocompromised and immunosuppressed individuals in their workplaces and communities.

The American people are fair, deeply empathetic, and generous toward people and their families who live with difficult medical circumstances. But the American people deserve clear and timely information to inform their understanding, and the CDC has failed to provide America with a complete picture on where they stand in regard to COVID and ongoing risks to fellow Americans. It is essential that the CDC rectifies this error immediately and demonstrates its commitment to protecting all individuals, especially those who are most vulnerable.

The time is now for the CDC to fulfill its duty and take decisive action and rectify the shortcomings of the new Respiratory Virus Guidelines. The lives of kidney patients and millions of other vulnerable Americans are at stake.

CDC's ongoing silence and failure to adequately address the concerns of kidney patients and protect immunocompromised and immunosuppressed individuals is unacceptable policy.

References:

- 1) Evans RA, Dube S, Lu Y, et al. Impact of COVID-19 on immunocompromised populations during the Omicron era: insights from the observational population-based INFORM study. *Lancet Reg Health Eur*. 2023;35:100747. Published 2023 Oct 13. doi:10.1016/j.lanepe.2023.100747. [https://www.thelancet.com/journals/lanep/article/PIIS2666-7762\(23\)00166-7/fulltext](https://www.thelancet.com/journals/lanep/article/PIIS2666-7762(23)00166-7/fulltext)
- 2) Boyton, R.J., Altmann, D.M. The immunology of asymptomatic SARS-CoV-2 infection: what are the key questions?. *Nat Rev Immunol* **21**, 762–768 (2021). <https://doi.org/10.1038/s41577-021-00631-x>
- 3) DeCuir J, Payne AB, Self WH, et al. Interim Effectiveness of Updated 2023-2024 (Monovalent XBB.1.5) COVID-19 Vaccines Against COVID-19-Associated Emergency Department and Urgent Care Encounters and Hospitalization Among Immunocompetent Adults Aged ≥18 Years - VISION and IVY Networks, September 2023-January 2024. *MMWR Morb Mortal Wkly Rep*. 2024;73(8):180-188. Published 2024 Feb 29. doi:10.15585/mmwr.mm7308a5. <https://www.cdc.gov/mmwr/volumes/73/wr/mm7308a5.htm>

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Since 1969, The American Association of Kidney Patients has been a patient-led organization driving policy discussions on kidney patient care choice and medical innovation. Over the past decade, AAKP patient advocates have helped advance lifetime transplant drug coverage for kidney transplant recipients (2020); the presidential Executive Order on Advancing American Kidney Health (2019); new job protections for living organ donors under the

Family Medical Leave Act (FMLA) via 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 X, and [@kidneypatients](#) on Instagram, and visit www.aakp.org for more information.

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