



January 6, 2022

The Unicode Consortium
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Dear Consortium Members

On behalf of the American Association of Kidney Patients (AAKP), the oldest and largest grassroots independent kidney patient organization in the nation, we respectfully submit our formal endorsement of a kidney emoji that will be presented to your organization for consideration by the kidney community. We understand and appreciate the tremendous volume of emoji requests the Unicode Consortium receives, but hope you consider this request within the context of other emoji approvals that have buoyed the confidence and activism of patient advocates and professionals in other health domains, including the brain and heart. We are honored to add our voice, as patient consumers, to the endorsements of many of our long-time professional medical and research allies in the United States and across the globe.

AAKP was founded in 1969 by six kidney dialysis patients who understood their lives had been saved by regular access to a novel and life-saving medical treatment. They felt a deep moral commitment that this treatment should be made available to every American experiencing kidney failure and as a bridge to kidney transplantation. Through their bravery and heroic grassroots phone and letter campaigns, decades before the advent of social media, these six patients and their allied medical professionals assembled a national policy advocacy campaign that changed medical history. Their efforts resulted in an opportunity for one of them to demonstrate their dialysis treatment in front of the U.S. House Ways and Means Committee in 1972. By 1973, based on the efforts of these same patients, and informed by what they had witnessed first-hand and heard directly from their kidney patient constituents, a bipartisan Congress acted in full coordination with the president to create the modern dialysis care program administered by the Centers for Medicare and Medicaid Services (CMS). AAKP understands the impact of effective national communications strategies and related technologies and we are proud of our legacy and contribution to creating modern dialysis care coverage for every American, a federal program that has saved well over a million lives since 1973.

As kidney patients and volunteer national advocacy leaders, we assure you our endorsement rests upon our expert understanding of the positive opportunities that exist to better unify and expand the impact of American and global kidney patient voices on public awareness and prevention efforts, public policy as well as ongoing research and clinical trials related to care innovation. An estimated 850 million people worldwide - including nearly 40 million in the United States – suffer from kidney diseases. Based on recently released research from the Netherlands that demonstrated COVID-19 impacts kidneys and generates scar tissues that can impact kidney function, we expect the number of kidney patients to sharply increase within the next several years.

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The Independent Voice of Kidney Patients Since 1969™

Kidney disease is both a healthcare and workforce issue and over half of those who are currently on dialysis in the U.S. crash into their care via the emergency room, the first place their kidney failure is detected. For a large percentage of these patients, awareness of kidney disease, knowledge of family history and a better understanding of the social determinants would have led to earlier interventions, better health outcomes and, ultimately, a longer life. We know first-hand the tremendous burden this disease has on individuals and families, and the severe toll it exacts through related co-morbidities, such as heart disease, painful treatments and disruptions to careers and economic security. At AAKP, we are passionate about saving lives and ending unnecessary human suffering across the world and we are convinced that dynamic and factual communications, peer-to-peer education and a broader public dialogue about the causes that lead to kidney disease can help bend the curve of this growing crisis.

We believe it is very important for the Unicode Consortium to understand that America, and the kidney community, is at a critical juncture and that there is tremendous momentum underway to address long-standing issues related to disparate levels of consumer care choice and timely access to prevention and treatment for kidney disease. These issues are at the heart of kidney-related poor health outcomes, high disability and unemployment rates and high morbidity rates – especially among minority communities. The national commitment to kidney disease treatment innovation and research is at an all-time high, and in the past ten years - across three presidential administrations, multiple Congresses and with the support of federal agencies including the Food and Drug Administration, the National Institutes of Health, the Centers for Medicare and Medicaid, the Department of Veterans Affairs and the Department of Defense – there has been a commitment and consensus to accelerate research and development of new diagnostics, devices and biologics to slow the progression of kidney disease, including rare diseases, and develop new technologies to save lives, including artificial implantable and wearable organs and xenotransplantation. These efforts have been aided by parallel federal, university research collaborative and private sector initiatives to harness kidney patient lived experience and social media data as Real-World Evidence and Patient Insight Data for use across new product development lifecycles and within regulatory and payment deliberations that are essential to bringing new technologies to patient consumer markets. AAKP is convinced that a kidney emoji will drive greater patient engagement and interaction with these transformative efforts both within the United States and across the globe.

In 2019, following President Obama's White House Summit on Organ Donation and President Trump's Executive Order on Advancing American Kidney Health, AAKP announced The Decade of the Kidney™, a global initiative to expand public awareness of kidney disease and patient involvement with industry and academic efforts related to research, clinical trials and treatment innovations. Also in 2019, we launched our first patient-lead and fully virtual *Global Summit on Kidney Disease Innovations*, in partnership with the George Washington University of School of Medicine and Health Sciences. The response among patients, families, professionals and researchers across the world has reaffirmed our belief that interest in fighting kidney disease transcends cultural and language barriers, as well as borders. In 2021, the Global Summit engaged over 20,000 patients and professionals across over 80 countries. Social media platforms have been an integral part of our strategy for the success of this free access summit and our ongoing international dialogue, as well as the international efforts of our kidney community allies. We are certain a kidney emoji will be met with an outpouring of support and tremendous utilization across the growing international consortium of patient consumers, advocates, media, medical professionals and policymakers working tirelessly to advance treatment innovations, organ donation and access to life-saving care.

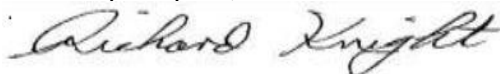
As professionals, together we have served under four presidential administrations, as staff under multiple Congresses, and in leadership roles in multiple non-profit and private sector enterprises. We have had specific responsibilities for the management of strategic communications and broad-based stakeholder strategies designed to accomplish complex, bipartisan public policy goals and impactful public awareness campaigns. We know the tremendous importance communication technologies have in determining the success or failure of any effort designed to accelerate engagement and swiftly convey complex concepts across broad, highly diverse audiences of grassroots leaders, professionals, policy-influencers and policymakers. A decision in favor of a kidney emoji by the Unicode Consortium will inject a new

communications tool into the national and global dialogue about kidney disease at the most opportune time we could ever imagine.

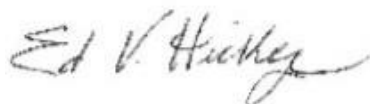
The work we and our members do at AAKP, as volunteer patients advocates, is fueled by the memories of family members and friends we have each lost to this terrible “silent killer” of a disease. On behalf of the millions of people who suffer from kidney disease, we appreciate your consideration of AAKP’s endorsement of a kidney emoji, and for your understanding that our motivation is pure and squarely on the side of those involved in the fight against this disease. At AAKP, we ask these questions everyday – *If Not Us, Who? If Not Now, When?* We believe the Unicode Consortium has an opportunity to make a profound impact in the fight against kidney disease and encourage you to seize this moment to do so.

If you have any questions, please feel free to contact us for additional information through AAKP’s Executive Director, Ms. Diana Clynes at 813-400-2391 or dclynes@aakp.org.

With deep respect,



Richard A. Knight
President
14-year kidney transplant recipient, 16-year kidney patient



Edward V. Hickey, III, USMC
Vice President
Chair, Veterans Health Initiative
10-year kidney disease patient; service-related disability



Paul T. Conway
Chair, Policy & Global Affairs and Immediate Past President
25-year kidney transplant patient; 41-year kidney patient