

## American Society of Nephrology Statement for the Record U.S. Senate Committee on Finance The President's 2026 Health Care Agenda September 4, 2025

On behalf of the more than 37 million Americans living with kidney diseases and the 22,000 nephrologists, scientists, and other kidney health professionals represented by the American Society of Nephrology (ASN), thank you for today's hearing and markup on President Donald J. Trump's health care agenda for 2026.

Kidney diseases are characterized by the gradual loss of kidney function, affecting approximately one in seven U.S. adults, and the prevalence of kidney diseases is rising. Kidney diseases pose an increasing public health crisis resulting in considerable morbidity and growing expenditures. The Medicare program spends more than \$150 billion each year managing kidney diseases, including \$50 billion alone to treat Americans with kidney failure.

The United States must reduce the burden of kidney diseases on individuals, their families, and the health care system while providing clinicians and patients with the resources necessary for people living with kidney diseases to achieve the best possible health outcomes. Consistent with President Trump's Executive Order on Advancing American Kidney Health in 2019, this goal aligns with the Trump Administration's chronic disease prevention efforts to Make America Healthy Again (MAHA). On behalf of Americans with kidney diseases, ASN urges the U.S. Senate to:

- I. Preserve confidence and access to historically safe and effective vaccines as well maintain trust in medical professionals.
- II. Continue necessary funding for scientific research that has made the United States the world's unquestioned leader in research and innovation.
- III. Improve data integrity and transparency, including a strong and accessible U.S. Renal Data System.

## I. Preserving Confidence and Access to Vaccines as well as Maintaining Trust in Medical Professionals

ASN opposes proposals and actions to dismantle or defund critical public health agencies, such as the Centers for Disease Control and Prevention (CDC), and committees, such as the Advisory Committee on Immunization Practices (ACIP), which provides guidance on vaccine use to CDC. Vaccination is critical to the health of Americans living with kidney diseases who are at a higher risk of acquiring preventable infectious diseases like influenza or COVID-19 and are at higher risk of mortality from these illnesses.

Unclear guidance on vaccination jeopardizes centuries of scientific progress and threatens the health of all Americans, particularly those living with kidney diseases. The development and implementation of COVID vaccines in less than one year during the COVID pandemic was a tremendous success, and vaccination of people with kidney diseases as well as their health care professionals and close contacts saved lives. As the national public health agency for the United States, CDC has provided decades of scientific progress, guidance, and protection for all Americans.

Preserving CDC, respecting expert panels like ACIP, and supporting the trust placed in our medical professionals is a moral obligation and public health imperative. As the organization that represents the nation's doctors caring for people living with kidney diseases, ASN believes in the value of vaccinations for these individuals and for their health care professionals who should have access to and adequate coverage for these vaccines. ASN implores you to value the clinician-patient relationship and to support the patient-centered decisions that clinicians make collaboratively with their patients in guiding medical care.

People with kidney diseases—including those on dialysis and those with a kidney transplant—often have weakened immune systems and are more susceptible to severe infections. Often, they spend prolonged periods of time near other patients and health care workers, such as during four-hour long hemodialysis treatments three times per week. These individuals should be protected against infections that are preventable by the vaccination of others. Americans living with kidney diseases and the health professionals who care for them urge the Trump Administration to renew and strengthen its dedication "to advancing American kidney health."

## II. Continuing Necessary Funding for Scientific Research that Has Made the United States the World's Unquestioned Leader in Research and Innovation

ASN opposes the recently implemented National Institutes of Health (NIH) policy requiring that 50% of funding for competing grant awards be committed up front. This change raises profound concerns about its unintended consequences for the kidney research community, particularly for investigators applying to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). By requiring NIH to obligate such a large portion of funding in the first year—rather than spreading costs over the life of the grant—this policy significantly reduces the likelihood of supporting both overall NIH research and NIDDK-specific proposals, particularly those from early-stage investigators. At a moment when scientific advances are poised to transform kidney care for the first time in decades, this abrupt shift threatens to stall progress at a critical inflection point.

Because this policy drastically increases the immediate cost of each new grant, NIH will fund fewer grants overall—even those with highly competitive scores (that would have been funded previously). Investigators are already reporting greater difficulty securing support for meritorious applications, especially those led by early career scientists and researchers at institutions with fewer resources.

ASN is alarmed that NIH is shrinking the share of applications funded, with some Institutes cutting paylines by more than one-half. For example, the National Cancer Institute projects a drop from about 9% to just 4% of applications funded. While precise projections for NIDDK remain uncertain, current estimates suggest that its payline could drop by 50% in Fiscal Year (FY) 2025—markedly reducing the number of funded studies.

While recognizing the Trump Administration's commitment to reducing federal spending, ASN asserts that sudden policy shifts jeopardize critical research—which is the envy of the world—and impede institutes like NIDDK from planning and executing their missions. ASN urges Congress to work closely with NIH to ensure timely release of appropriated funds and to sustain medical research throughout FY 2025, 2026, and beyond. Abrupt changes not only disorient established researchers and discourage new investigators from pursuing careers in research but also threaten continuity of critical studies across disease areas. These constraints could cause long-term erosion of the scientific workforce, slow innovation, and diminish public health outcomes—effects that may take years to emerge but will be extraordinarily difficult to reverse once underway.

ASN strongly commends the efforts of the House Appropriations Committee and Labor, Health and Human Services, Education Appropriations Subcommittee to safeguard medical research funding in its FY 2026 spending bill against funding cuts, and for including a \$20 million increase for NIDDK. However, the proposed funding bill does include a 6% cut to the HHS, a significant \$1.7 billion cut to CDC, a \$456 million cut to the NIH coupled with drastic restructuring, and the elimination of the Agency for Healthcare Research and Quality. ASN urges the Senate to work closely with its colleagues in the House to recognize medical research as a national priority and to advance a bipartisan spending bill for FY 2026 that provides sustained, necessary funding for kidney research.

## III. Improving data integrity and transparency, including a strong and accessible U.S. Renal Data System

The U.S. Renal Data System (USRDS) is a vital resource for researchers, clinicians, policymakers, and advocates, supplying the evidence necessary to conduct studies, shape policy decisions, and improve clinical care. Form CMS-2728 provides data for the USRDS, a congressionally mandated surveillance system that tracks incidence, prevalence, treatment modalities (dialysis and transplant), costs, outcomes, and disparities for Ameircans living with kidney diseases.

ASN opposes the Centers for Medicare & Medicaid Services (CMS's) recent decision to remove race and ethnicity questions from Form CMS-2728, the End-Stage Renal Disease (ESRD) Medical Evidence Report that feeds information directly to the USRDS database. The removal of the race and ethnicity fields will severely limit the ability of the USRDS to conduct demographic analyses of kidney diseases, hindering public health research and the development of targeted interventions to improve kidney health outcomes for all Americans.

ASN has additional suggestions to improve data integrity and transparency. Starting as early as 2026, CMS will end the physical delivery of key health care data and instead require researchers to access all CMS Research Identifiable File (RIF) data through the Chronic Conditions Warehouse Virtual Research Data Center (CCW VRDC), citing the need to modernize data systems. ASN opposes this change.

Under the current system, researchers receiving physical extracts pay a large upfront fee but may reuse those extracts for a modest per-project cost. By contrast, VRDC users face substantial recurring fees for each project and user seat. This significant increase in cost is likely to slow or prevent important kidney research; limit the ability of research teams to expand or collaborate; and reduce the volume of studies examining kidney disease incidence, treatment patterns, disparities, and outcomes.

The shift also risks fragmenting long-standing datasets that have been essential for evaluating care quality, informing policy, and driving clinical innovation in the kidney community. ASN recommends continuing access to these data sets through prior mechanisms to allow ongoing quality improvement projects, research efforts, and subsequent improvements in patient care.

The MAHA initiative emphasizes prevention, early detection, and effective management of chronic conditions, all of which rely on timely, comprehensive, and accessible data. By limiting the ability of researchers to evaluate care quality and develop evidence-based interventions, these policy changes threaten to slow progress in reducing the burden of kidney diseases, hinder efforts to improve outcomes for high-risk populations, and impede the development of strategies that could prevent progression kidney diseases to kidney failure. CMS must ensure that modernization efforts strengthen rather than weaken access to the data necessary to achieve these critical public health goals.

In closing, ASN urges HHS to collaborate with medical societies, as occurred during the first Trump Administration. Together, we can ensure optimal health and health care of all Americans, including the more than 37 million Americans living with kidney diseases.

Again, thank you for holding today's hearing and markup.

Sincerely,

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President