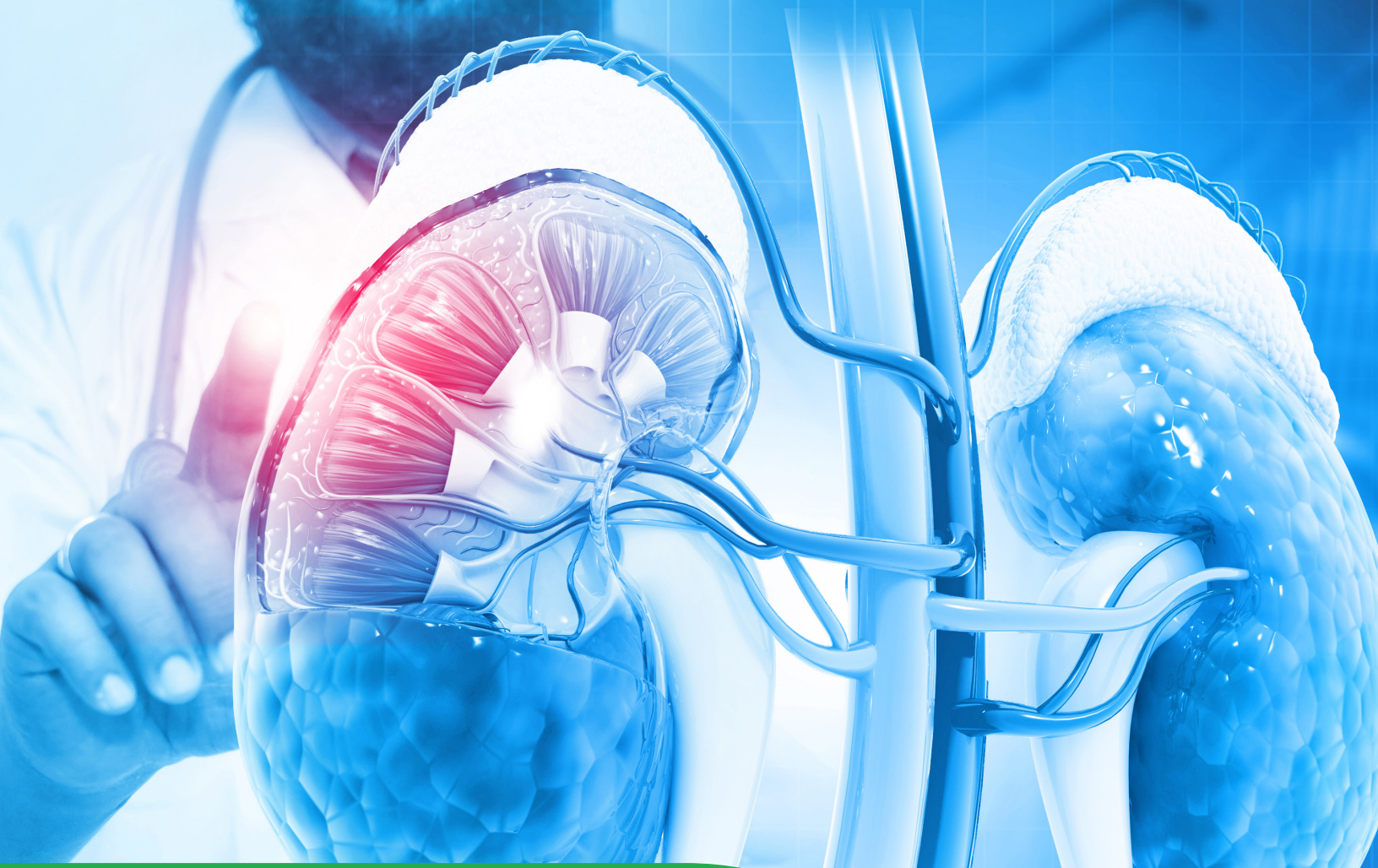

Transforming Kidney Health Research

A Research Agenda for the Future

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Foreword by Dr. Parikh , MD, FASN

Kidney diseases kill more Americans every year than most cancers—yet it receives only a fraction of the research investment. More than 37 million people in the United States live with kidney diseases, and an additional 86 million are at risk due to diabetes, hypertension, and obesity. Each year, over 100,000 Americans progress to kidney failure, requiring dialysis or transplantation to survive. For too many, those treatments fall short: nearly 60 percent of patients who begin dialysis will die within five years.

The economic burden is equally profound. Through Medicare, American taxpayers spend more than $150 billion annually on care for kidney diseases, representing nearly two percent of the federal budget. Dialysis and transplantation alone account for approximately $50 billion each year (1). Beyond these federal expenditures, the hidden costs to families and communities are immense: loss of income, lost productivity, reliance on disability benefits, and the daily sacrifices made by caregivers.

Kidney diseases are a silent epidemic that spares no group. Unlike heart disease or stroke, it offers few warning signs; nine out of 10 people with kidney diseases are unaware of their condition until it's often too late. It affects premature infants, as well as older adults, coal miners, farmers, and office workers in major cities. While personal wealth cannot shield individuals from genetic forms of kidney diseases, poverty, poor nutrition, and limited access to preventive care accelerate its impact. Kidney diseases worsen existing health inequities and threaten the stability of families and communities across the nation.

During his first term, President Donald J. Trump signed the Executive Order on Advancing American Kidney Health (2). Since this landmark action, the federal government has started to prioritize and improve kidney health through policy and law. Examples include the 2024 ESRD (End Stage Renal Disease) Quality Incentive Program from the Centers for Medicare & Medicaid Services (CMS), the Health Resources and Services Administration's Organ Transplantation Affinity Group and Modernization Initiatives, and several new laws passed by Congress, including most recently the Securing the US Organ Procurement and Transplantation Network Act [Public Law 118-14] (3).

These important steps may help, but a century-long underinvestment in kidney research has stalled our search for breakthroughs (4). Today, the United States spends roughly $17 per patient per year on kidney research — a fraction of the per-patient investments made in cancer (5). This imbalance has stalled progress, leaving dialysis as the default therapy for kidney failure despite its debilitating impact and poor survival outcomes.

The Transforming Kidney Health Research (TKHR) Panel convened in 2024 to address this urgent gap. Representing patients, clinicians, researchers, and policy experts, the Panel has developed a comprehensive roadmap for the future of kidney health research. This report outlines that roadmap — a coordinated, evidence-based plan to accelerate the discovery of earlier diagnostics, more effective treatments, and ultimately, cures. The panel's recommendations will transform the lives of millions of Americans living with kidney diseases, improve the outlook for people living with kidney failure, and help address concerns about federal spending, especially the long-term viability of the Medicare program.

The choice before the nation is clear. Strategic investment in kidney research offers the opportunity to save lives, reduce disparities, strengthen the workforce, and safeguard the nation's fiscal health. The path forward is well defined. What is needed now is the resolve to act.

Samir M. Parikh, MD, FASN
Chair of the Transforming Kidney Health Research Panel
President-Elect of the American Society of Nephrology

1. *US Renal Data System. 2023 USRDS Annual Report: Epidemiology of Kidney Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Bethesda, MD. 2023. https://usrds-adr.niddk.nih.gov/2023/end-stage-renal-disease/9-healthcare-expenditures-for-persons-with-esrd*
2. *Federal Register. Executive Order on Advancing American Kidney Health. Exec Order No. 13,879, 84 FR 33817 (2019). https://www.federalregister.gov/documents/2019/07/15/2019-15159/advancing-american-kidney-health. Accessed February 20, 2025.Securing the U.S. Organ Procurement and Transplantation Network Act, Public Law 118–14, 137 STAT.69(2023). https://www.congress.gov/118/plaws/publ14/PLAW-118publ14.pdf.*
3. *US Government Accountability Office (2017). National Institutes of Health: Kidney Disease Research Funding and Priority Setting (GAO Publication No. 17-121). Washington, D.C.: U.S. Government Printing Office. Retrieved from https://www.gao.gov/products/gao-17-121*
4. *National Institutes of Health. Research Portfolio Online Reporting Tools. Estimates of Funding for Various Research, Condition, and Disease Categories. May 14, 2024. https://report.nih.gov/funding/categorical-spending#/*
5. *National Institutes of Health. Research Portfolio Online Reporting Tools. Estimates of Funding for Various Research, Condition, and Disease Categories. May 14, 2024. https://report.nih.gov/funding/categorical-spending#/*

Executive Summary

Today, patients and health professionals are "managing" kidney diseases. We are managing chronic conditions that contribute to the progression of kidney diseases, such as diabetes, heart disease, and obesity. We are managing the onslaught of acute kidney injury in our hospitals. We are managing kidney failure with dialysis. Even as emerging therapies enable better management, this report from the Transforming Kidney Health Research (TKHR) Panel boldly envisions a future without kidney failure. A future for kidney care that focuses on early detection and prevention, and transplantation and cures for kidney diseases that obviate the need for dialysis.

Navigating these tracks—better chronic disease management, more transplantation, and a proliferation of new therapies and cures—is vital to improving kidney health in the US. Achieving this vision will take new investments in kidney research, analogous to the federal appropriations that have transformed cancer and HIV care in our lifetimes. Unlike cancer or HIV/AIDS, research investment in kidney health can directly save the US government money because Medicare predominantly covers dialysis, regardless of age.

With 37 million Americans affected and $150 billion spent annually on Americans with kidney diseases, this report targets a common, costly, and debilitating set of conditions. The returns on investment are therefore multiple and historic. Eliminating the need for dialysis will dramatically improve patients' lives, freeing them of the burden of hours-long dialysis sessions multiple times per week. This investment will not only reduce future federal health care and disability expenditures, but it will also alleviate demands on caregivers and decrease dependency on public assistance programs by enabling patients to re-engage in the workforce. Investments now will foster future economic productivity and prosperity.

The TKHR Panel envisions a future in which most patients never develop progressive kidney diseases as a result of advances in preventive care. For those who do develop a progressive disease, this report describes bold research priorities that will lead to breakthrough cures. Finally, among those patients for whom a cure remains elusive, we envision transplantation and a future free of the burdens that come with today's heavy immune-suppressing medicines.

To achieve a future without kidney failure, the TKHR Panel has outlined a plan of action in the second half of this report. The report identifies opportunities to leverage AI and the genomics revolution to diagnose kidney diseases, deploy cutting-edge technologies like CRISPR-Cas9 and designer approaches to cure genetic kidney diseases, and accelerate innovations that increase the supply of kidneys for transplant, help them last longer, and help people living with kidney diseases live fuller lives unburdened by disease. A few key highlights from the TKHR recommendations include:

- Developing new screening tools and platforms using molecules and liquid biopsies, and by harnessing AI and electronic health records.
- Utilizing existing and developing new data sources to identify causes of all the different kidney diseases, including genetics, nutritional factors, and interactions with other organ systems, to understand and treat all kidney diseases better.
- Discarding fewer kidneys by developing innovative strategies for salvaging, rejuvenating, and transporting donor kidneys.
- Develop new monitoring and risk prediction tools to tailor dialysis prescriptions better.
- Invest in the development of the kidney research workforce by providing increasing training opportunities in extramural research.

The TKHR Panel's vision is to focus on keeping patients healthy and free of kidney diseases and ultimately eliminating kidney failure and the need for dialysis by drastically increasing US investment in kidney research to fund breakthrough discoveries and innovative therapies. Achieving the bold vision outlined by the TKHR Panel will require substantial investments from private and public funders in the research necessary to facilitate this new research ecosystem. However, the return on investment in improving lives and saving public dollars is enormous.

Introduction

More than 37 million Americans have kidney diseases—roughly one in seven US adults—and that number is expected to grow (6). Kidney diseases are common, have multiple causes, and can affect anyone at any stage of life:

- Every American is at risk for acute kidney injury, including people experiencing other serious conditions such as heart failure or cancer. Acute kidney injury is a frequent complication of severe respiratory infection and major surgery. Many of the medicines we use in the hospital setting can harm the kidney. Acute kidney injury is a major risk factor for future, irreversible kidney diseases.
- Two of the most common chronic diagnoses across all US communities—high blood pressure and diabetes—are also the most common causes of kidney diseases and cause or contribute to 2 of 3 new cases of kidney failure.
- While diabetes and hypertension are major causes, over half of all kidney diseases in the world arise from rare causes, both genetic and acquired.
- Over 90,000 people are waiting for a kidney transplant in the United States, but there are not enough organs to help all those in need. Alternatives, such as xenotransplantation, are underdeveloped due to poor funding.
- The most common reason for childhood kidney diseases is a congenital kidney anomaly. Babies born with congenital kidney anomalies often must start dialysis in early life before they grow enough to receive a transplant. Dialysis exposure in childhood reduces life expectancy by decades. Even children who receive a transplant in childhood often require multiple transplants over their lives, with each succeeding one becoming harder to match and resulting in more complications.
- Preeclampsia can strike otherwise healthy pregnant women, necessitating pre-term delivery that can put both the mother and baby at risk for permanent kidney damage. A history of preeclampsia is a major unrecognized risk factor for progressive kidney diseases.
- The most common inherited disease in the world, sickle cell disease, leads to early kidney failure, amplifying the damage caused by abnormal red blood cells to every other major organ. It is most common among individuals of African or Asian ancestry.
- Another common genetic disorder, polycystic kidney disease (PKD), is the mirror image of sickle cell disease, striking multiple family members in every generation and not discriminating by race.
- The prevalence of kidney diseases is expected to grow in the US as the population continues to age and become more obese.

Societal factors worsen the pervasive biological contributors to kidney diseases: lack of access to good nutrition, preventive care, and other essential determinants of health. Approximately one-third of individuals with kidney failure come from zip codes with high levels of poverty and/or potential reduced access to care, affecting rural and urban communities alike.

Despite how many people are affected, nine in ten individuals living with kidney diseases are unaware they have kidney issues until it is too late, and dialysis becomes necessary. Over 50% of patients start dialysis in the emergency room. Kidney diseases accelerate the course of many other common diseases, increasing the risk of heart failure, stroke, and death. The lack of awareness leads to delayed and often suboptimal care and missed opportunities to prevent kidney failure. About 800,000 people in the United States live with kidney failure, the end stage of kidney diseases, at which point the kidney can no longer clear toxins from the blood and balance its chemistry. More than two-thirds of these people living with kidney failure are on dialysis (1).

1. *US Renal Data System. 2023 USRDS Annual Report: Epidemiology of Kidney Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Bethesda, MD. 2023. https://usrds-adr.niddk.nih.gov/2023/end-stage-renal-disease/9-healthcare-expenditures-for-persons-with-esrd*
6. *Centers for Disease Control and Prevention. Chronic Kidney Disease in the United States, 2023. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2023*

Dialysis becomes the only treatment option for too many patients with kidney failure. It most often requires four-hour sessions three times a week, which most patients receive in dialysis centers. Only one in four Americans on dialysis works: their grueling dialysis schedule or debilitating side effects like fatigue and frequent hospitalizations often make productive economic activity impossible (7).

Many patients on dialysis rely on Social Security benefits for support. Their care partners also often shoulder the heavy burden of driving them to and from dialysis treatments, which can affect their own ability to work. Only about 14% of patients with kidney failure in the United States currently receive home dialysis, which can reduce the burden associated with frequent in-center care and improve health outcomes. Home dialysis is underused partly due to care partner burden, patient fear, and the need for space to store supplies. By comparison, more than 20% of patients in Canada, Mexico, and Australia currently receive home dialysis (8).

Fewer than one-third of patients with kidney failure receive a kidney transplant, which is considered the optimal therapy. In the United States, about 100,000 people are currently on the waitlist for a kidney, and only about one-half of these Americans will receive a transplant within five years, while many die on the wait list. Despite the dire need for more transplants, about one-third of potential donor kidneys are discarded due to a combination of burdensome policies and a lack of innovation around approaches to salvage these kidneys.

Financial Burden and Progress in Federal Kidney Policy

The direct financial costs of kidney care in the US today are simply staggering. Patients with kidney failure account for about 1% of Medicare beneficiaries, but their care accounts for nearly 6% of Medicare's budget. Annually, Medicare pays about $150 billion for the care of people living with kidney diseases, of which $50 billion is allocated for kidney failure care alone, as Medicare currently pays about $100,000 per patient on dialysis annually (1). Disability is common among people living with kidney diseases and exerts multiplicative harms—to the patients themselves, to the care partners who come under persistent stress and lose economically productive time, to the coffers of Social Security as many become reliant on its supplemental income, to the lost income tax base that patients and their care partners might otherwise have generated.

The devastating personal and collective toll of kidney diseases on the United States has captured bipartisan and bicameral support for policy solutions. Congress created Medicare's End-Stage Renal Disease (ESRD) program to ensure that every American had access to dialysis care in 1972 and has enacted several other important pieces of legislation since then. The 21st Century Cures Act extended access to private Medicare Advantage plans to patients with kidney failure in 2021, giving them additional coverage options beyond traditional Medicare. The Congressional Kidney Caucus has also proposed a raft of legislation, including bills to protect access for kidney donors and patients with kidney diseases to employer-based insurance for 30 months during their transition to Medicare coverage. The Centers for Medicare and Medicaid Services (CMS) has created several quality-based payment models for kidney care, including the ESRD Treatment Choices and Kidney Care Choices models.

7. *American Kidney Fund. Returning to Work. January 30, 2022. https://www.kidneyfund.org/living-kidney-disease/balancing-work-family-travel/returning-work. Accessed February 20, 2025.*
8. *Wilke M. Home dialysis-an international perspective. NDT Plus. 2011. Dec;4(Suppl3):iii4-ii6. Doi:10.1093/ndtplus/sfr129.*

Against this backdrop of policy and legislation stretching to the 1970s, the Executive Order on Advancing American Kidney Health (AAKH), signed in 2019, by President Trump marked a major inflection point. The executive order articulated bold goals designed to stoke the transformation of kidney care in the United States within a decade, including the following:

- Reduce the number of Americans developing kidney failure by 25% by 2030.
- Ensure that 80% of new patients with kidney failure can receive home dialysis or transplants by 2025.
- Double the number of kidneys available for transplant by 2030.

Since the executive order, the executive branch has launched numerous efforts to reach these goals. The Health Resources and Services Administration launched a historic effort to modernize the Organ Procurement and Transplantation Network (OPTN) and encourage innovation and competition in the organ transplant system in the US. The Center for Medicare & Medicaid Innovation launched the Increasing Organ Transplant Access model on July 1, 2025, a mandatory value-based payment model designed to incentivize transplant centers to increase transplants and reduce discards of donor organs.

The policy efforts are important, but they are directed at the final common destination of kidney diseases, i.e. kidney failure, and have been stymied by a lack of innovation, leaving people living with kidney diseases stuck with outdated care. To reduce costs, transform lives, and achieve the goals of AAKH, we must move upstream toward prevention and cures even as we continue to incentivize innovation in transplantation. This document articulates an ambitious research agenda coordinated across the federal government and the private sector to develop better prevention strategies, cures for kidney diseases, and breakthroughs in kidney transplantation.

Return on Investment

Despite the enormous economic and personal toll of kidney diseases in the United States, kidney research has been severely underfunded by both private and public funders. A US Government Accountability Office (GAO) report found that, in 2016, only $13.94 was spent on research per person living with kidney diseases compared with $2500 per patient with HIV/AIDS, $372 per patient with cancer, and $133.30 per patient with heart disease (4). Kidney research funding has remained stagnant since then, with just more than $17 spent in 2023 per person living with kidney diseases (5).

Disease	Disease Prevalence in 2023	Fiscal Year 2023 NIH Spending	NIH Spending Per Patient
HIV/AIDS	1,200,000	$3,647,800,661	$3,039.83
Alzheimer's	6,700,000	$2,873,365,379	$428.86
Cancer	18,000,000	$6,990,956,516	$388.38
Kidney Diseases	37,000,000	$645,619,036	$17.44

4. *US Government Accountability Office (2017). National Institutes of Health: Kidney Disease Research Funding and Priority Setting (GAO Publication No. 17-121). Washington, D.C.: U.S. Government Printing Office. Retrieved from https://www.gao.gov/products/gao-17-121*
5. *National Institutes of Health. Research Portfolio Online Reporting Tools. Estimates of Funding for Various Research, Condition, and Disease Categories. May 14, 2024. https://report.nih.gov/funding/categorical-spending#/*

Federal research appropriations have a long track record of fostering medical breakthroughs. Major increases in investment in cardiovascular disease, cancer, HIV/AIDS, Alzheimer's disease, and Type 1 diabetes have yielded transformational advances in care.

According to the American Cancer Society's 2025 report, the overall cancer mortality rate in the US has declined by 34% from 1991 to 2022, averting nearly 4.5 million deaths. Age-adjusted death rates for heart disease have shown a steady decline since the mid-1960s, and although the rate of decline slowed to 0.7% each year from 2011 to 2019, the overall trend remained downward (9). These improvements are the result of advances in prevention, diagnosis, and treatment—many stemming from NIH-supported research.

Notably, the development of immune checkpoint inhibitors for cancer treatment, such as pembrolizumab (Keytruda), was based on foundational NIH-funded research into T-cell biology, and significantly improved survival rates in cancers like melanoma and non-small cell lung cancer. Additionally, NIH-supported genomic studies have led to targeted therapies, such as trastuzumab (Herceptin) for HER2-positive breast cancer, transforming outcomes for patients with this aggressive cancer subtype.

Beyond treatments, NIH investment has facilitated crucial advancements in prevention and early detection. The Framingham Heart Study's identification of cardiovascular disease (CVD) risk factors has informed public health strategies (10). And the Lipid Research Clinics Coronary Primary Prevention Trial established the role of high cholesterol in heart disease (11) and laid the groundwork for the development of statins, which are now widely used to reduce cardiovascular risk. In cancer prevention, the introduction of the human papillomavirus (HPV) vaccine, supported by NIH research, has resulted in a 65% drop in cervical cancer rates among women in their early 20s from 2012 through 2019 (12).

A similarly bold research plan, issued in 1999 by the Diabetes Research Working Group, resulted in an additional $3.5 billion in annual funding for Type 1 diabetes research since 1998, and a consequent transformation of health outcomes for those with the condition through novel technologies, new drug therapies, and better screening (13). Notably, these federal investments spurred scientific advances that the private sector, then successfully deployed commercially. The artificial pancreas—composed of continuous glucose monitoring connected to dynamic insulin infusion—is a reality today for thousands of patients with Type 1 diabetes that was made possible by targeted federal research investment.

These public health gains underscore the profound return on investment from NIH-funded research and highlight the critical opportunity that renewed federal support for research on kidney diseases can drive future medical advances in prevention, diagnosis, and treatment.

Achieving similar gains in kidney research will take vision, courage, and out-of-the-box funding solutions. For example, the 21st Century Cures Act set aside funding for Alzheimer's disease. Congress also funds Type 1 diabetes research through mandatory appropriations to help meet patient needs.

This report outlines the tremendous opportunities for policymakers to make smart investments in kidney research that could prevent disease, prolong and improve patients' lives, and reduce the fiscal burden of kidney diseases on the federal health and disability budgets. The return on investment is potentially enormous. For example, spending just $1.8 billion per year over the next 10 years to develop scalable cures for kidney diseases that negate the need for dialysis would pay for itself within two weeks of Medicare spending for dialysis.

9. *Centers for Disease Control and Prevention. State Declines in Heart Disease Mortality in the United States, 2000–2019. Atlanta, Georgia: US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics 2021. https://www.cdc.gov/nchs/data/databriefs/db425.pdf*
10. *Framingham Heart Study: Three Generations of Dedication. https://www.framinghamheartstudy.org/fhs-about/. Accessed August 27, 2025.*
11. *National Heart Lung and Blood Institute. Lipid Research Clinics (LRC) Coronary Primary Prevention Trial (CPPT). Biologic Specimen and Data Repository Information Coordinating Center. 2020. https://biolincc.nhlbi.nih.gov/studies/lrccppt/. Accessed August 27, 2025.*
12. *Siegel RL, Miller KD, Wagle NS, Jemal A. Cancer statistics, 2023. CA Cancer J Clin. 2023 Jan;73(1):17-48. doi: 10.3322/caac.21763. PMID: 36633525.*
13. *United States Government Publishing Office. Hearing before the Committee on Governmental Affairs of the United States Senate. Conquering Diabetes: Are We Taking Full Advantage of the Scientific Opportunities for Research? October 14, 199. https://www.govinfo.gov/content/pkg/CHRG-106shrg61160/pdf/CHRG-106shrg61160.pdf. Accessed April 25, 2025.*

Part II: A Vision for Change—Eliminating Kidney Failure

The time is now. American science is poised to achieve medical breakthroughs that will improve the lives of 37 million Americans living with kidney diseases and provide hope for the nearly one billion people around the world suffering from kidney diseases. Emerging therapies like glucagon-like peptide-1 receptor agonists (GLP1s) and sodium-glucose cotransporter-2 inhibitors (SGLT2s) are based on discoveries first made in US laboratories. These accomplishments would not have been possible without the tremendous investments made by American taxpayers, private industry, and investors. These medicines have now been shown to slow the progression of kidney diseases. Targeted research is now needed to tell us who should receive these medicines, how they should be taken, and how long they can forestall the need for dialysis or transplantation. The hope and promise for kidney patients, taxpayers, and American society is a cause for celebration and optimism.

Slowing the course of chronic disease with these and other medicines is a critical step in the right direction, but curing kidney diseases is the shared American vision and national consensus policy. Researchers in the United States may now be able to shrink the kidneys back to normal size for those living with polycystic kidney disease. A recently approved cell therapy gives hope for a "one-and-done" treatment that will cure patients with sickle cell disease. A simple injection once every six months can indefinitely forestall the need for a combined liver-kidney transplant. Such designer medicines hold unprecedented promise to transform the entire landscape for Americans living with kidney diseases.

Below, we present a roadmap for research and policy that will transform kidney diseases, save more lives, reduce Medicare expenditures, and restore the health and economic contributions of millions of Americans. Within each section, we proposed a series of recommendations for consideration and discussion.

The sections are organized into the following:

Spotting the Silent Killer

Only 10% of patients living with kidney diseases are aware of their condition. Many do not learn of their condition until they crash into kidney failure and require dialysis to survive. Over 50% of patients start dialysis in the emergency room. Early identification is pivotal both for primary prevention and for preventing the progression of kidney diseases.

The TKHR Panel envisions a robust and proactive approach to kidney health. Instead of waiting for patients to crash into kidney failure, primary care professionals would routinely assess kidney health like they do blood pressure during annual physicals. The research base to support this recommendation can be built through pragmatic studies. Pharmacies would provide inexpensive tests that at-risk patients can use to monitor their own kidney health. Kidney health screenings could be routinely offered alongside blood pressure and cholesterol checks during community health events.

Artificial intelligence (AI) would be deployed along with other cutting-edge technology to proactively identify high-risk patients and to flag individuals with progressive kidney diseases to ensure timely referral for transplant, time to find a living donor, or time to get on a waitlist for a deceased donor kidney.

Today, health clinics in Albertson's grocery stores are offering AI-driven screening for diabetic retinopathy for patients at risk (14). Smartphone technologies can detect eye changes, and finger sensors can suggest a need for cardiovascular testing. AI-powered algorithms could also scour people's electronic medical records and help flag individuals for further screening or referral to specialist care. Investigators nationwide are testing similar algorithms to identify and improve the care of patients with acute kidney injury in the intensive care unit. Further development of screening tools and algorithms that can proactively spot this silent killer could spark a revolution in care.

Recommendations

- Develop new screening tools and platforms that harness the power of molecules and liquid biopsies, AI and electronic health records data, novel imaging and radiopharmaceuticals, and point of care testing and mobile devices.
- Improve evaluation of patients by creating new and expanding existing clinical trials networks, developing combinatorial approaches (e.g., AI and geospatial approaches to identify high-risk patient populations) and applications across the lifespan from prenatal care onward.
- Enhance care implementation among populations by supporting large pragmatic health system studies and decentralized community-based screening, remote and point-of-care testing (via apps and mobile devices), akin to blood pressure machines which are widely available for at home and in community use.

14. *Review of Optometry. Supermarkets Embrace AI Exams for Diabetic Retinopathy. December 19, 2018. https://www.reviewofoptometry.com/news/article/supermarkets-embrace-ai-exams-for-diabetic-retinopathy. Accessed February 20, 2025.*

Finding Causes and Creating Cures

Identifying the specific cause of a patient's kidney disease is also critical. One in four Americans with kidney diseases carries a change in a single gene that contributes to their condition. At the same time, most patients with kidney diseases have multiple genetic or environmental contributors that alter the gene's effects.

Knowing the exact cause is vital to providing appropriate and effective therapy. Genetic diseases are amenable to "one-shot" genetic cures or genetic therapies that precisely target the underlying problem. Even for more complex conditions involving many genes and environmental risk factors, our ability to identify genetic contributors to an individual's kidney disease could facilitate risk assessment and future precision therapies.

Several large datasets on kidney diseases could rapidly yield new insights, but a lack of coordination and infrastructure has left this valuable data siloed. Linking large data sets like the National Institute of Diabetes and Digestive and Kidney Diseases' (NIDDK's) Kidney Precision Medicine Project (KPMP), which provides a single cell map of the kidney; National Heart, Lung, and Blood Institute's (NHLBI's) Trans-Omics for Precision Medicine (TOPMed), which has 180,000 whole genome sequences from 85 studies; NIDDK's CKD Consortium; and patient records from electronic health records systems, commercial laboratories data, or the US Renal Data System (USRDS) could help.

Recommendations

- Identify new causes of kidney diseases, including genes, epigenetics, and multi-omics, pollutants and environmental risk factors, nutrition and diet, and interactions with other organ systems (hypertension and diabetes) through electronic health record integration (e.g., PheWAS), developing better disease models (including large animal models), and identifying measurable and mechanistic biomarkers.
- Develop new diagnostics, medicines, and other interventions that target small molecules, biologics, gene and cell therapies, lipid, viral, and other targeting strategies, and one-time interventions (i.e., catheter-based, surgical).
- Support effective implementation across populations through public-private partnerships to build patient groups for rare disease trials, and support venture funds for catalytic investments and identify applications across the lifespan from prenatal care onward.
- Fund infrastructure to advance research and development fully through to implementation by supporting clinical trials networks for rare and common kidney diseases, developing registries and biobanks (particularly for rare kidney diseases), furthering data sciences and cloud-based computing to unite data streams spanning genomics and multi-omics through electronic health records and national registries (e.g., USRDS), and by developing pathways for multi-agent and multi-disciplinary care for acute kidney injury and kidney diseases.
- Address barriers to accessing and connecting the USRDS to other data sets and move the USRDS from NIH to CMS.
- Establish an NIH or FDA policy that all cardiovascular disease and diabetes trials appropriately assess kidney diseases and encourage TOPMed to prioritize integration of kidney diseases.
- Invest in research on optimal regulatory endpoints and approval pathways with the FDA.

Transforming Transplantation

Since the first human kidney transplant in 1954, transplantation has dramatically extended and improved patients' lives. Improved immunosuppressant medicines in the past two decades have extended the lives of donated kidneys to a decade or more for recipients of living donor kidneys and about seven to ten years for recipients of deceased donor kidneys. But progress has stalled. There is a need to extend the lifespan of donated kidneys and to improve the side effect profile of immunosuppressant medicine. Therapies cause life-threatening infections, cancer, and paradoxically, kidney diseases in the kidney graft.

Demand for transplants far exceeds available organs. Access to living donor organs is often limited by donors' concerns about long-term health impact or the financial costs associated with donating. As many as one-third of deceased donor organs go to waste, either because the organ is deemed unusable by the transplant center or a match with a suitable donor is not made in time. Additionally, some patients have health or other challenges that make them unsuitable transplant candidates. But innovations that could expand organ access, refurbish donor kidneys, and improve immunosuppression are within reach.

Xenotransplantation has seen rapid progress from research in primates to preliminary studies in which genetically edited pig kidneys have lasted several months in human recipients. Improvements in perfusion technology and advances in immunology also have the potential to extend the lifespan of donated kidneys and to improve the transplant recipient's quality of life.

Recommendations

- Improve preparation for both the donor and the recipient by identifying single-kidney health risks and risk mitigation levers, developing innovative methods to evaluate donors (e.g., kidney stress tests), producing new pre-transplant strategies to prevent rejection (e.g., desensitization), augmenting donor remnant kidney (e.g., local growth factor and stem cell strategies), and identifying psychological and social preparation strategies for donors, recipients and families.
- Discard fewer kidneys by researching salvage and rejuvenation strategies (e.g., scaffolds and organoids) and developing innovative transport strategies.
- Improve life with a transplant by developing medicines that are less kidney-toxic to help all solid organ transplant patients, improving screening and monitoring tolls for graft health (i.e., liquid biopsies, imaging, cellular and molecular markets, multi-omics), developing tools and assays to titrate pharmacodynamics of immune suppression, extending graft half-life through new care protocols and pathways (i.e., GLP1ra), developing new medicines and cell therapies to achieve organ tolerance, and identifying new strategies to reduce chronic complications including infection, cancer, CVD risk, bone disease, and kidney diseases from medications or recurrence.
- Accelerate the promise of xenograft transplantation by reducing porcine viral DNA sequences, reducing cross-species barriers (e.g., thymokidney) through innovative strategies, and advancing toward a personalized xenokidney (e.g., engraftment of recipient resident immune cells into future donor animals) and supporting vaccine research against porcine diseases.
- Initiate a homograft discovery effort by researching organoids and acellular scaffolds, and bioengineered and printed kidney tissues.
- Support implementation among patient populations by funding Center for Medicare & Medicaid Innovation models that support transplantation as a primary and pre-emptive option for people with advancing kidney diseases, researching policy frameworks to increase organ availability in rural settings, developing ethical frameworks for allo-, xeno-, and homograft transplantation, and supporting cost-effectiveness research to incentivize donors, dialysis organizations, and health systems.
- Fund infrastructure to advance research and development fully through to implementation by supporting clinical trials networks, developing registries and biobanks, and furthering data sciences and cloud-based computing to unite data streams spanning genomics and multi-omics through electronic health records and national registries (i.e., Scientific Registry of Transplant Recipients).
- Invest in research on optimal regulatory endpoints and approval pathways with the FDA.

Reimagining Dialysis

Dr. Willem Kolff is credited with the first tests of hemodialysis starting in the 1940s. Whereas many of his first patients died from the therapy, progressive improvements now enable dialysis to be a critical life-extending option. Nonetheless, about 60% of dialysis patients die within five years of initiating treatment. Better dialysis is needed both as a bridge to transplant for individuals who need temporary kidney support and for those who are not candidates.

Numerous public and private sector efforts are underway to foster long-overdue innovation. Home dialysis machines are becoming smaller, more portable, and work is underway to dramatically reduce their water and dialysate use. Artificial, wearable, and implantable kidneys in development by researchers at public and private institutions are close to a breakthrough, and modest investments could deliver a device within five years.

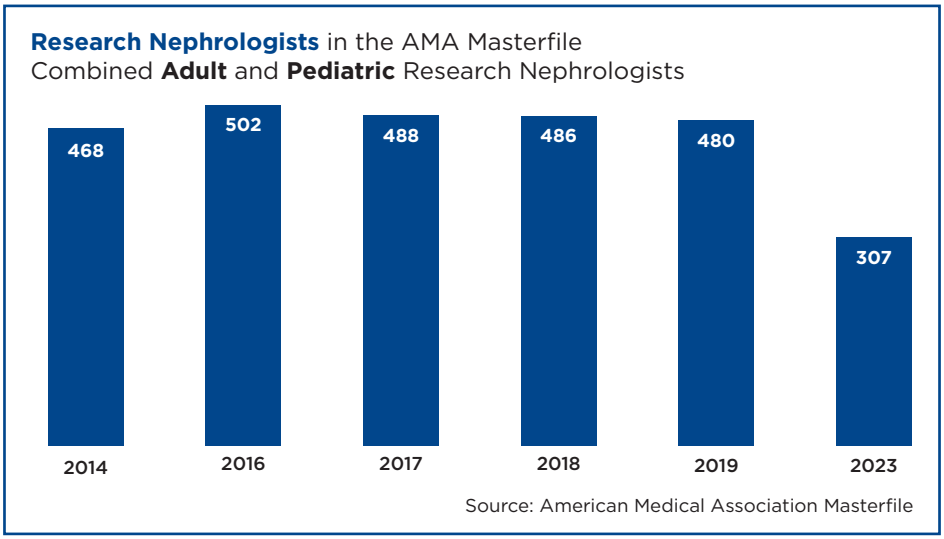
Recommendations

- Prioritize dialysis innovation by developing new monitoring and risk prediction tools to tailor dialysis therapy, identifying risk factors for CVD, bone disease, brain health, and infections, advancing dialysis vascular and peritoneal access to reduce infection and failure, expanding robot assistance for home modalities, and developing novel methods to clear toxins (i.e., adsorption).
- Support implementation among populations by funding the Center for Medicare & Medicaid Innovation models that incentivize clinical trial enrollment and full data-sharing and support cost-effectiveness research that incentivizes dialysis organizations and health systems to increase quality of care and improve patient outcomes.
- Fund infrastructure to advance research and development fully to implementation by supporting clinical trials networks and biobanks, and furthering data sciences and cloud-based computing to unite data streams spanning genomics and multi-omics through electronic health records and national registries (i.e., USRDS).
- Develop sustainable strategies for water usage in dialysis treatment.
- Invest in research on optimal regulatory endpoints and approval pathways with the FDA.

Reviving the Research Workforce

An ongoing workforce crisis has contributed to the lack of access to kidney care and innovation. Despite tremendous opportunities to improve care, the field has struggled to recruit kidney care professionals, physician-scientists, and PhD scientists due to the lack of research funding, resulting in a dearth of innovative therapies and a stagnant care paradigm.

The combined number of MD, PhD, and MD/PhD research nephrologists studying adult and pediatric kidney diseases has fallen steadily over the past decade, peaking at 500 researchers in 2016 before dropping to just 307 researchers in 2023 (15).



Zero fellows in 2024 indicated that they would pursue research in the next academic year, continuing an ongoing decline. Poor funding has diminished interest in kidney research careers. The number of doctoral-level researchers entering the field has steadily dropped from 35 per year in 2017-2018 to 10 in 2019-2021 to none in 2024 (16). This shortfall in emerging talent has contributed to the under-representation of kidney projects in the national portfolio of high-impact research. For example, we are not aware of any kidney research represented in the NIH Director's common fund programs. Kidney research is similarly poorly represented in prestigious philanthropic research portfolios, including the Howard Hughes Medical Institute and the Bill and Melinda Gates Foundation. Because almost three-quarters of grant applications to the NIH are submitted by PhD researchers, persistent NIH under-funding of kidney science has eroded the entire ecosystem that supports innovation in kidney health.

A complex mix of factors is contributing to this kidney research workforce crisis. Few young physician-scientists or researchers are enthusiastic about working in a field where most of the clinical-grade technology was invented from the 1940s to the 1960s. Many young investigators instead gravitate toward fields with more robust funding and more innovation, seeing more opportunities to build sustainable careers and improve the lives of patients. Increasing funding for kidney research will help attract more research talent and dramatically increase the discovery rate.

15. *American Medical Association. AMA Physician Masterfile. Available from: https://www.ama-assn.org/practice-management/masterfile/ama-physician-masterfile.*
16. *ASN. Pivert KA et al. 2024 ASN Nephrology Fellow Survey. October 14, 2024. https://data.asn-online.org/posts/2024_fellow_survey/. A. Accessed April 25, 2025.*

As a result of the shortage of PhD researchers, nephrologists are often the ones leading the research on kidney diseases. Though the field has a talented cohort of physician researchers, there are too few. The workforce struggle even extends to clinical nephrology: most US trainees now opt for better-paying specialties to help pay for medical school educational debt that can exceed hundreds of thousands of dollars. As a result, the field relies heavily on nephrologists trained in other countries. These internationally trained medical graduates comprise half of all US nephrologists. These individuals may face visa and other hurdles that make filling critical gaps in the US nephrology workforce harder.

The tremendous opportunities to revolutionize kidney care could attract enormous talent to help fill the vacuum—but only if there is adequate investment in kidney research to support stable careers. Reversing the trend will also take more upstream recruiting to ensure that internal medicine and pediatrics residents, medical students, and even undergraduates see the tremendous opportunity to make a difference in the lives of millions of people living with kidney diseases through a career in nephrology. Critically, we need to lure promising researchers from other fields to make their mark in a field desperate for innovation. Building sustainable career paths for researchers in nephrology, as individual investigators and as members of larger consortia, is vital.

However, adequate kidney research funding is needed to ensure that researchers can build a sustainable career in the field. Currently, future scientists are discouraged from pursuing careers in kidney research because related fields, such as cardiovascular diseases, diabetes, and cancer, receive so much private and public research funding. Furthermore, kidney research is spread across several federal agencies, including but not limited to the National Institutes of Health (the National Institute of Diabetes and Digestive and Kidney Diseases in particular), the Advanced Research Projects Agency for Health (connected to NIH), and the Department of Veterans Affairs. Decisions made by payors and regulators, like the Centers for Medicare and Medicaid Services and the Food and Drug Administration, also play a role in how the field prioritizes scientific areas of opportunity. Nongovernmental organizations that may receive federal funding for research also contribute, like the Patient-Centered Outcomes Research Institute and professional foundations.

To execute the ambitious agenda outlined in this report, there is a need for more coordination, collaboration, and a commitment to building a robust kidney research workforce.

Recommendations

- Establish a National Kidney Institute at NIH to elevate and prioritize kidney research by developing Kidney Research Centers of Excellence and increasing requests for applications focused on attracting researchers from outside the kidney field.
- Promote public-private partnerships to engage in more cross-collaboration and research partnerships across institutions in the same geographic areas to leverage the strengths of different teams and statistical and analytical support, while collaborating with academic centers to optimize and reduce disparities in indirect costs.
- Conduct a GAO analysis of federal support for research training to understand how the research workforce (MDs, PhDs, and MD/PhDs) in each specialty is supported. Use the results of this GAO report to guide a task force charged with identifying and recommending the best ways to rebuild the nephrology research workforce.
- Support early exposure programs for high school students, undergraduates, and medical students to learn about nephrology and research careers.

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Thank you

ASN would like to thank its community partners for their contributions to the Transforming Kidney Health Research Panel's Report and steadfast dedication to improving the lives of the 37 million Americans living with kidney diseases.

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