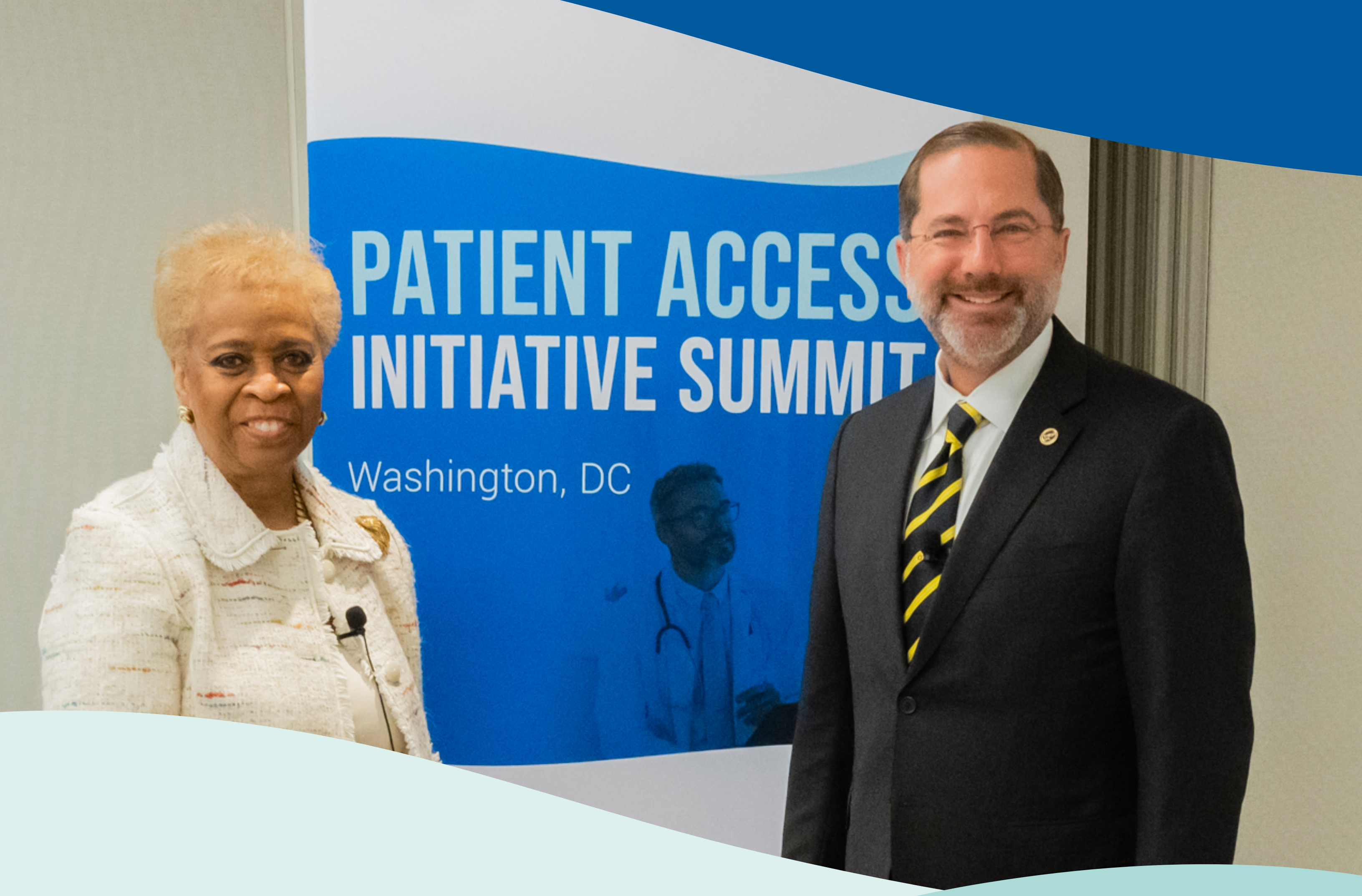

Stemming the Tide of Kidney Disease

Policy Recommendations for Early Diagnosis and Treatment

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Background

The American Kidney Fund (AKF) launched the Patient Access Initiative (PAI) in 2022 to better understand and address the unique health care issues faced by people living with kidney diseases, including people living with rare kidney diseases, their family members and their care partners. People with kidney disease, from those in early stages to those in end-stage kidney disease (ESKD), face unique challenges accessing appropriate treatments such as innovative therapies, dialysis and transplant. PAI is a multi-year effort that brings together stakeholders from across the kidney care continuum and industry leaders. AKF has hosted two PAI Summits in Washington, DC, with a third in-person Summit planned for 2025. Some of the key goals of the Summit are to identify opportunities to improve patient access to innovative and effective treatment choices, collect insights from patients and care partners about barriers they face and develop recommendations to inform policymaking.

> **AKF would like to express its gratitude to the kidney patients, care partners, health care professionals and other key stakeholders who collaborated with us to ensure continued innovation in kidney care.**

Introduction

The burden of chronic kidney disease (CKD) has grown rapidly in recent years and is now a public health crisis. One in seven Americans (35.5 million) are living with CKD and nine out of 10 people with the disease do not know they have it.[1] Too often, CKD causes a cardiovascular event such as heart attack or stroke before a person even progresses to kidney failure or ESKD. ESKD is a life-altering condition that requires dialysis or a kidney transplant for a patient to survive and significantly impacts quality of life, including one's ability to work or attend school. Today, 815,000 Americans are living with kidney failure and its enormous physical, emotional and financial burdens.[1]

To address this urgent public health crisis, AKF convened leading stakeholders from across the kidney care continuum for its second PAI Summit in November 2024. Key stakeholders in the kidney disease space, including patients, physicians, health care teams, biopharmaceutical and medical device companies and public policy experts discussed policy opportunities and innovations needed to improve early diagnosis and intervention in CKD.

This document summarizes PAI stakeholder recommendations to policymakers to address the kidney disease crisis in the United States in five key areas:

1. **PREVENTION, SCREENING AND DIAGNOSIS**
2. **THE CONNECTION BETWEEN CHRONIC KIDNEY DISEASE AND CARDIOVASCULAR DISEASE**
3. **KIDNEY HEALTH EDUCATION**
4. **COMPREHENSIVE COVERAGE**
5. **WORKFORCE DEVELOPMENT**

Kidneys play a critical role in keeping people healthy by removing waste and excess fluid from the body. Kidneys regulate calcium, potassium and phosphate levels in the blood, help produce red blood cells, regulate blood pressure and maintain bone health. However, when damage to the kidneys occurs, the body is not able to perform these vital functions, resulting in CKD.

The leading cause of CKD is diabetes. Other common causes of CKD include high blood pressure, genetic diseases, glomerular diseases and cystic diseases. These common conditions and other risk factors are often preventable, while other forms of kidney disease, including many of the over 150 rare kidney diseases, are genetic, hereditary and congenital. Thanks to recent U.S. Food and Drug Administration (FDA) approvals of new therapies, there are now treatments available that can slow disease progression to ESKD if CKD is diagnosed and treated early.

However, while advancements in screening, diagnosis and treatment have created new hope for patients living with kidney disease, barriers to optimal care remain and the excessive cost of treating kidney diseases continues to rise. Most people living with CKD do not receive a diagnosis until they have progressed to later, more costly and life-threatening stages of the disease. In fact, about 40% of people who end up on dialysis did not even know they had kidney disease.[2] This is partially due to the lack of symptoms of CKD in its early stages, as well as inconsistent screening for CKD in primary care and community health settings. As a result, ESKD accounts for $45 billion in direct health care spending each year, most of which is paid for by Medicare.[3] The high cost of ESKD also places a significant strain on the Medicaid program as many patients are dually eligible for both programs.[4] Further, CKD and ESKD disproportionately impact underserved populations with social risk factors, including rural populations and communities of color.[5]

Improving our nation's ability to prevent, detect, diagnose and treat CKD **"upstream"**—in early stages of the disease—is imperative to stem the tide of kidney disease. Prevention and early detection of the disease would save countless lives and would help to alleviate the enormous cost burden on our nation's health care system.

Prevention, Screening and Diagnosis

The Challenge

Screening, detecting, diagnosing and treating CKD in its early stages is key to reducing the significant burden of kidney failure. Unfortunately, limited awareness, coverage barriers and non-medical risk factors often delay diagnosis, leading to worse health outcomes for people living with or at risk for CKD.

Fortunately, kidney function can be assessed with simple and inexpensive tests.[6] If these tests are done regularly and patients are aware of their significance, they are armed with knowledge of their disease and risk factors, supporting earlier intervention that prevents or slows the progression of CKD. Further, understanding the cause of CKD is vital in helping patients and their health care providers determine a treatment plan, especially for people living with rare kidney diseases.

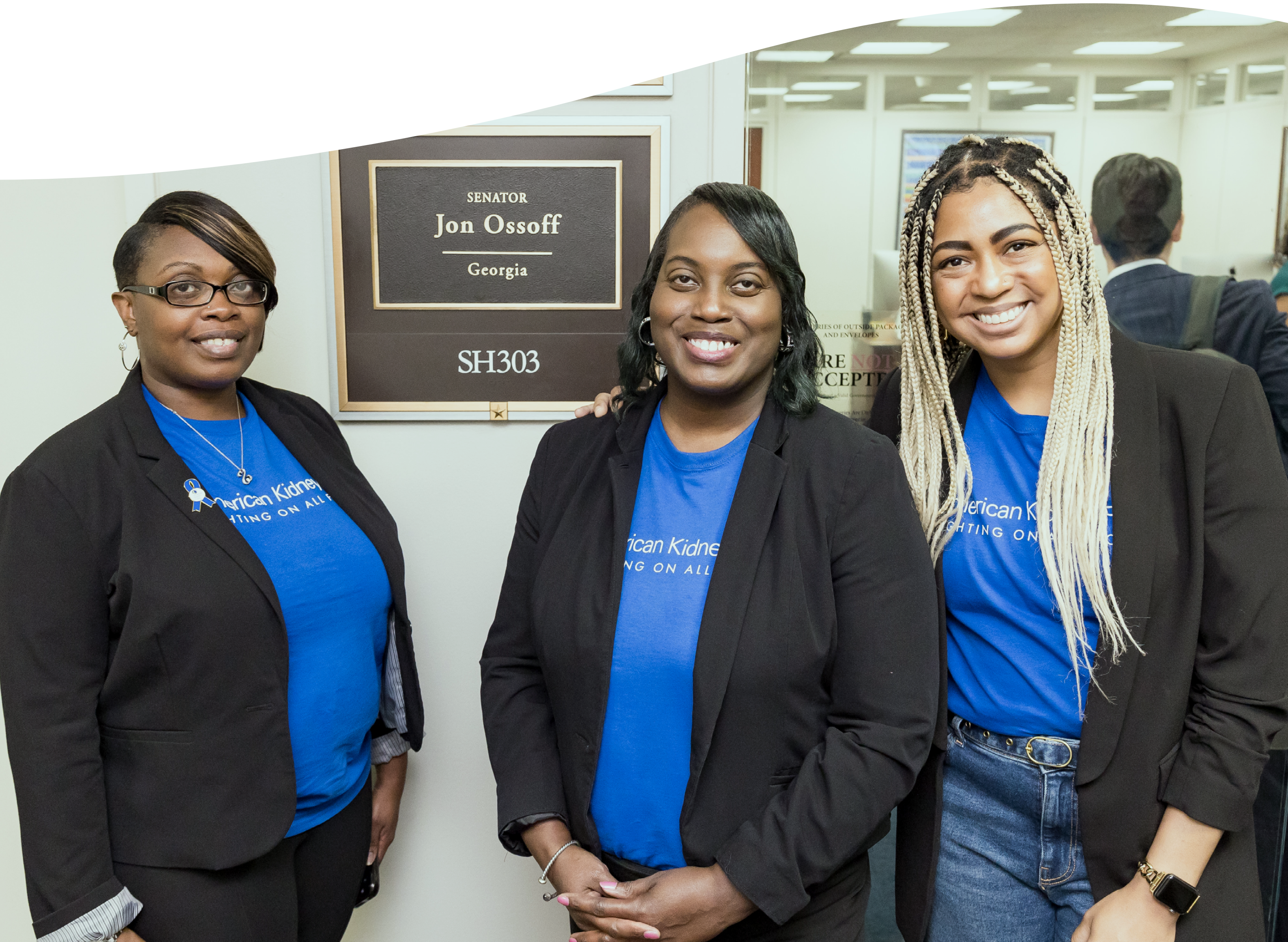
Policy Opportunities to Address this Challenge:

→ The U.S. Department of Health and Human Services (HHS) should create clear recommendations for kidney disease screening, including by:

- **Declaring a kidney public health emergency.** Recognizing kidney disease as a public health emergency (PHE) would grant federal public health agencies the flexibility to issue recommendations to prevent kidney disease through healthy lifestyle changes and routine screenings for people at risk of kidney disease, helping close the gap in undiagnosed patients.
    - PHE declarations provide access to funds for communities, researchers and physicians to address epidemics or health-related situations that lead to illness or death. For instance, the August 4, 2022 PHE on monkeypox arguably led to the containment of the disease in the U.S.[7]
    - The declaration of a PHE around the opioid crisis in 2017 addressed a rise in opioid overdose deaths by providing funds for public awareness, substance use disorder treatment and the widespread use of Naloxone.[8] After a significant increase in overdose deaths between 1999 and 2022, the death rate from opioid overdose decreased in 2023.[9]
    - A similar PHE declaration for kidney disease would provide federal assistance to address the growing number of people with CKD, halt progression of the disease to kidney failure and decrease the number of individuals who need dialysis.
- **Encouraging the United States Preventive Services Task Force (USPSTF) to issue a recommendation for routine CKD screening.** The USPSTF announced their research plan for developing a CKD screening recommendation in January 2023, yet a recommendation has not yet been released.[10] There is robust data available to support the benefits of preventive screening, especially in the populations most at risk for CKD, leading to earlier detection and improved outcomes. A USPSTF recommendation using existing research would provide clarity for health care providers and would increase the uptake of screening measures. This is important given that many private health plans are required to cover preventive services with a USPSTF rating of A or B without cost sharing.
- **Convening an HHS advisory committee on kidney health to issue recommendations on key issues, including prevention, screening and testing protocols (including for rare kidney diseases), treatments and patient and provider education.** Convening experts from across the kidney community to develop recommendations and protocols could provide a roadmap for kidney disease prevention and treatment.

The U.S. Congress should address the non-medical factors that increase the risk of CKD and associated complications, as well as enact safeguards for individuals who have undergone genetic testing. This can be accomplished by:

- **Reintroducing the Improving Social Determinants of Health Act (H.R. 7481, 118th Congress).** This bill would provide grants to disadvantaged areas to address social determinants of health and help prevent the occurrence of CKD and other associated chronic diseases. This bill should be reintroduced in the current Congress.
- **Enacting the CARING for Social Determinants Act (H.R. 1066, 118th Congress) and the Treat and Reduce Obesity Act (H.R. 4231/S. 1973, 119th Congress).** These bills would address important risk factors for CKD and increase the tools available to Medicare and Medicaid to address critical risk factors for CKD. The CARING for Social Determinants Act should be reintroduced in the current Congress.
- **Making updates to the Genetic Information Non-Discrimination Act to prohibit discrimination in life, long-term care, and disability insurance policies based on genetic information.** Many of the communities most impacted by kidney disease grapple with historic mistrust of the health care system. Enacting this safeguard, a proposal already being considered in some states, would promote greater patient confidence in genetic testing.



Recognizing the Connection Between Chronic Kidney Disease and Cardiovascular Disease

The Challenge

CKD is strongly linked to other serious health complications, such as high blood pressure and diabetes. In 2023, research from the American Heart Association (AHA) called attention to this link by classifying cardiovascular-kidney-metabolic (CKM) syndrome as its own condition.[11] While there is currently no cure for CKM, early treatment of CKM and its risk factors can slow or stop its progression and reduce the risk of other serious and costly health complications. Understanding that CKD is a major risk factor for cardiovascular disease is critical for physicians and patients, as cardiovascular disease is the number one cause of death in the U.S.

Policy Opportunities to Address this Challenge:

HHS should implement a population health approach to address kidney disease and its risk factors, including by:

- **Prioritizing CKM syndrome as part of Healthy People 2030.** As health care professionals now recognize the important link between cardiovascular, kidney and metabolic health, updating the goals of Healthy People 2030 would advance an integrated approach to improving health outcomes.
- **Creating an HHS advisory committee on cardiovascular-kidney-metabolic health.** Bringing together experts from across the kidney care and cardiac continuum such as AKF, the AHA, the American Diabetes Association (ADA), the American Society of Nephrology (ASN), the American Society of Pediatric Nephrology (ASPN) and the National Kidney Foundation (NKF), this advisory panel would:
    - Advance CKM syndrome research and treatment strategies;
    - Provide recommendations to clinicians on a multidisciplinary, team-based approach to care delivery that includes primary care physicians, nephrologists, cardiologists, renal dietitians and other specialists; and
    - Identify opportunities to strengthen coverage and reimbursement for the services provided by each member of a multidisciplinary health care team within federal programs.
- **Prioritizing National Institutes of Health (NIH) research on CKM syndrome and supporting policies that recognize CKM syndrome as a distinct diagnosis.** Organizations like the AHA have identified that the overlap of heart disease, kidney disease and diabetes often leads to worse outcomes for patients. These conditions require an integrated diagnosis and treatment plan, rather than treatment as isolated conditions, and should be treated as one "syndrome."
- **Convening experts from across the three disease states to:**
    - Explore the insurance coverage implications of treating and managing CKM syndrome as a discrete condition;
    - Work with the HHS Centers for Medicare & Medicaid Services (CMS) to address CKM-related reimbursement issues; and
    - Support interagency collaboration with private stakeholders (e.g., the NIH National Heart, Lung, and Blood Institute) and the NIH National Institute of Diabetes and Digestive and Kidney Diseases to develop clinical trial frameworks and treatment guidelines to approach CKM syndrome as a distinct disease.

Kidney Health Education

The Challenge

Up to 40% of patients who eventually require dialysis “crash” into it.[2] These patients were not previously aware of their kidney disease or that their kidneys were failing when they suddenly became ill and required dialysis immediately to survive. Research has shown that there are significant gaps in provider awareness of kidney disease risk factors, causes and emerging treatment options. There is also growing evidence that rare and genetic conditions account for a significantly greater share of CKD cases than was previously understood. These facts make increasing awareness of these conditions even more important.[12]

Educating patients on the need for prevention, screening and early treatment and equipping physicians with the tools they need to recognize, treat and support people living with kidney disease throughout their health care journey are critical to addressing the significant burden of CKD and ESKD.

Policy Opportunities to Address this Challenge:

The U.S. should fund public education programs to improve kidney health awareness and research by:

- **Protecting and increasing funding for the Chronic Disease Initiative of the Centers for Disease Control and Prevention (CDC).** Enhancing public education about the risk factors for CKD and the importance of early screening and intervention will address public awareness gaps of CKD and ensure that people at risk for the disease receive timely screening and treatment.
- **Providing HHS and CDC grant funding to support kidney disease community education programs.** Supporting education programming by nonprofit and community-based organizations is key to helping patients better understand and manage their kidney disease.
- **Enacting the New Era of Preventing End-Stage Kidney Disease Act (H.R. 1518, 119th Congress).** Despite their considerable health and financial burdens, rare kidney diseases have been historically under-researched and are often poorly understood.[13] This legislation would bring about significant positive changes in how we understand, treat and study rare kidney diseases, reducing their impact on people’s lives and reducing costs for patients and the health care system overall.

Comprehensive Coverage

The Challenge

Medicaid and Medicare are crucial for low-income and older Americans living with, or at risk for, CKD. Most ESKD costs have historically been borne by the federal government, as most people on dialysis are eligible for Medicare, regardless of age. Many of these patients are also dually eligible for Medicaid, increasing the costs of ESKD for states and the federal government. Given the recent passage of H.R. 1 (119th Congress), which cuts Medicaid by nearly $1 trillion, states will need to find even greater efficiencies in their Medicaid programs. Commercial payers also play a significant role in promoting access to early, high-quality kidney care for pediatric patients and working-age Americans.

Creating strong incentives for public and private payers to provide robust coverage for kidney care early in a patient's journey can help prevent or delay disease progression and save money. By one estimate, reducing progression to later stages of kidney disease could save Medicare up to $9 billion per year and could save commercial payers and employers an additional $2.8 billion annually.[14]

Policy Opportunities to Address this Challenge:

→ The U.S. Congress should expand coverage for screening and testing, and encourage upstream care in Medicare and private health insurance plans, including Affordable Care Act (ACA) and Employee Retirement Income Security Act plans, by enacting legislation that would:

- **Broaden Medicare coverage for comprehensive CKD screening during annual physicals and "Welcome to Medicare" visits.** Regular CKD screenings for Medicare-eligible individuals aged 65 or older would provide patients and primary care physicians with a baseline of kidney function and a yearly update to track decrease in function. Testing would allow for earlier intervention to avoid or delay kidney failure.
- **Expand the Medicare Kidney Disease Education benefit.** This benefit is currently only available to patients who have progressed to late-stage CKD (stage 4). Expanding access to these education sessions for patients in earlier stages of, or at risk for, CKD will equip patients to better manage their disease and prevent it from progressing. Along with this expansion, CMS should be directed to better market the availability of this benefit to Medicare beneficiaries.
- **Require coverage for CKD screening without cost sharing.** Like provisions previously included in the ACA for mammography, passing legislation to make routine screening and testing for CKD available to patients with no out-of-pocket cost would expand patient access and improve early detection of CKD.[15]
- **Establish a multi-payer Medicare Shared Savings model for CKD.** Preventing or delaying progression to ESKD would create significant savings for Medicare, but the program has limited ability to incentivize other payers to cover upstream kidney care. Legislation that gives CMS the authority to share these savings with commercial payers, state Medicaid programs and other health plans is a crucial step that would incentivize robust coverage of early screening, detection and treatment for CKD.
- **Prioritize patient-centered, outcomes-based quality measures to create incentives for comprehensive care.** Using the right quality measures in current and future CMS payment models would allow for more robust assessment of the effectiveness of these models and ensure that the models are creating incentives for providing the right care at the right time to the right patients, helping to improve health outcomes for patients with CKD.

Workforce Development

The Challenge

Workforce shortages across the nephrology field, including nephrologists, nephrology nurses, community health workers, the pediatric nephrology workforce and other allied health professionals, are contributing to delays in care for patients with CKD. It is estimated that there is currently just one nephrologist for every 2,000 patients with CKD, requiring providers to focus their time on patients with more advanced kidney disease.[16] To ensure people living with CKD receive the care they need, we must invest in and grow our nephrology workforce and provide incentives for entry into the field of nephrology.

Simultaneously, it is critical that we recognize the vital role that family care partners play in supplementing the direct care workforce and in helping patients with CKD manage their disease daily—particularly for those living with the life-altering impact of ESKD.

Policy Opportunities to Address this Challenge:

→ The U.S. Congress should invest in direct care workforce development by enacting legislation that would:

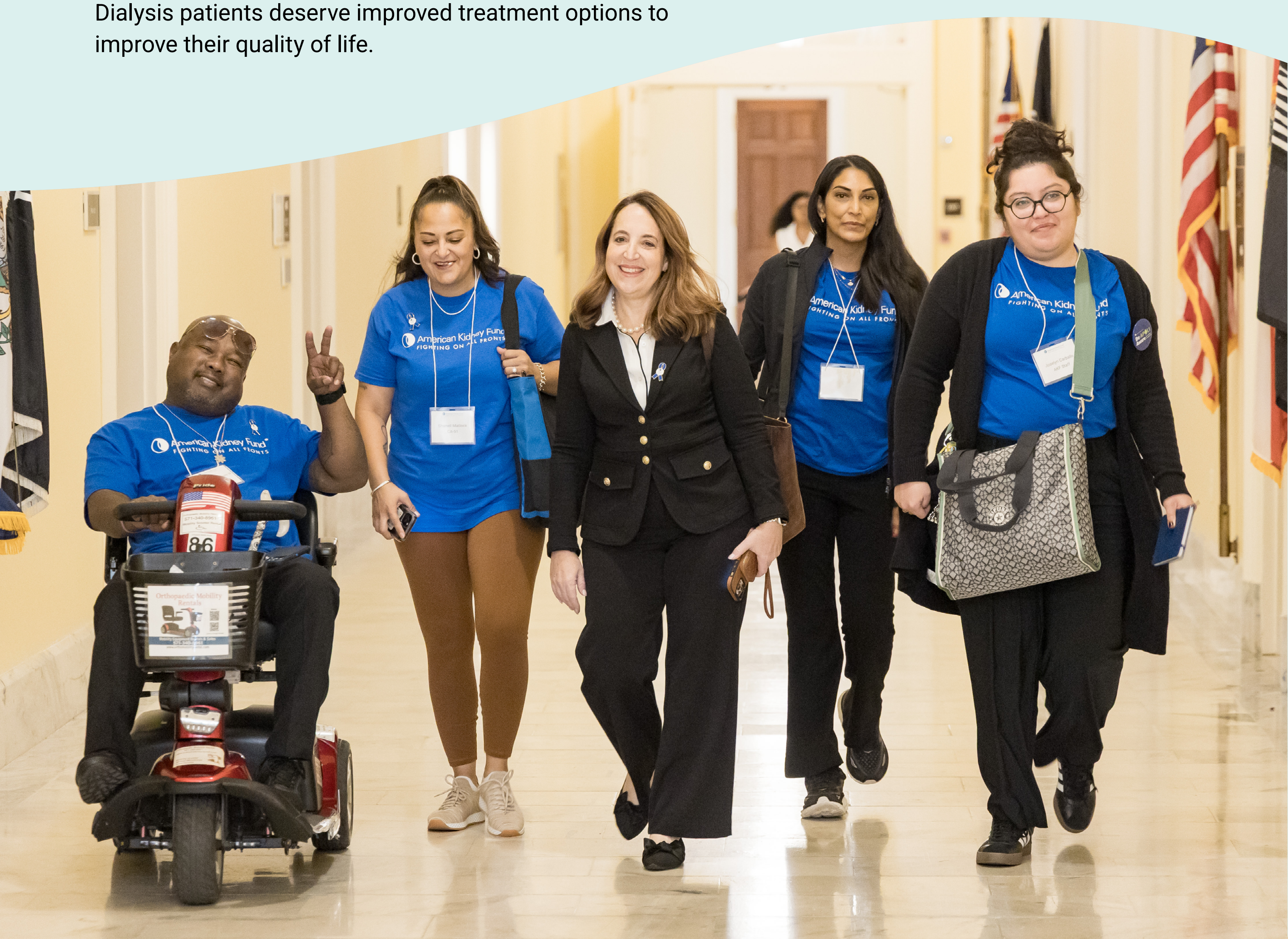
- **Create a targeted federal grant program to support education programs for adult and pediatric nephrologists, nephrology nurses, nephrology physician assistants (PAs), community health workers and other allied health professionals.** These education programs will train more specialized health care workers, reduce workforce shortages and improve care delivery. Additionally, HHS could direct medical schools to adhere to and update kidney disease educational standards through grant administration.
- **Include nephrologists as specialists who can receive loan repayment if they work in Federally Qualified Health Centers and other health professional shortage areas through the National Health Service Corps.** Increasing incentives for providers to work in underserved areas would directly increase the availability of care for populations that are most at risk for CKD.
- **Direct HHS to conduct research on the challenges faced by family care partners, particularly those caring for people living with ESKD.** HHS should support infrastructure to make care partner contributions more sustainable. Care partners play a key role in the care continuum, particularly in later stages of kidney disease. This research would provide the information needed to develop targeted policy interventions and ensure that family care partners can support their loved ones in a sustainable way.

Conclusion

We must take urgent action to address the public health crisis of kidney disease in the U.S. Known as a silent killer, kidney disease is increasing at alarming rates and taking a serious toll on patients, families, care partners, our nation's health care system, the federal budget and the national economy.

By focusing on upstream care, policymakers can help stem the tide of this devastating disease. We can improve the outlook for people with kidney disease if we advance targeted policy actions focused on prevention, screening and testing; improving care delivery; educating patients, care partners and providers; enhancing coverage; and bolstering the kidney care workforce.

In addition to the importance of upstream care, supporting innovation for later stages of CKD, including ESKD, is vital. There has been little change to dialysis treatment in the over 50 years since it has been in widespread use. Dialysis patients deserve improved treatment options to improve their quality of life.



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About the American Kidney Fund Patient Access Initiative Summit

The Patient Access Initiative Summit is part of the American Kidney Fund's ongoing effort to better understand and address health care access issues faced by the kidney patient community.

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