

## American Kidney Fund Policy Agenda 2023

The American Kidney Fund (AKF) fights kidney disease on all fronts as the nation's leading kidney nonprofit. AKF works on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease—from prevention through post-transplant living. With programs of prevention, early detection, financial support, disease management, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF. AKF is one of the nation's top-rated nonprofits, investing 97 cents of every donated dollar in programs, and holds the highest 4-Star rating from Charity Navigator and the Platinum Seal of Transparency from GuideStar.

We are a strong and independent voice advocating for policies that improve access to health care and that strengthen quality of care for Americans living with kidney disease. We work with Congress, the Administration, federal agencies and state governments to make kidney disease a national priority.

AKF partners with many other advocacy groups to achieve policy priorities. In many instances, AKF will advocate for policies directly; in other cases, we will support the efforts of other advocacy organizations.

The following are AKF's policy agenda for 2023.

### Addressing health disparities and advancing health equity

**The issue:** *There are longstanding health disparities in the U.S.—differences in health outcomes and health care among groups of people related to their race, ethnicity, age, disability, gender, geographic location, socioeconomic status and sexual orientation. Kidney failure (end-stage renal disease or ESRD) disproportionately impacts minority populations: Black Americans make up just 13 percent of the U.S. population, but they account for 35 percent of Americans with kidney failure and are 3.4 times more likely than white Americans to develop kidney failure. Native Americans are 1.9 times, and Asian Americans are 1.3 times, more likely than white Americans to develop kidney failure. People of Hispanic ethnicity are 1.5 times more likely to develop kidney failure than non-Hispanics.*

To address health disparities and advance health equity so that all individuals have the opportunity to be as healthy as possible, AKF advocates for policies that will:

- Address the social determinants of health (SDOH), which are the social, economic and environmental conditions that affect health and wellbeing and are significant contributors to health disparities. SDOH include income level, educational and job opportunities, access to housing and utility services, workplace safety, gender inequity,

racial segregation, food insecurity, early childhood experiences, and exposure to violence and pollution.

- Ensure equitable access to affordable and comprehensive health insurance coverage.
- Enforce federal protections against discrimination in the provision and administration of health insurance coverage, including discriminatory benefit design.
- Improve the health care delivery system to make it more equitable, accessible and inclusive, and to ensure high quality care across demographics and geographic regions, including rural and urban areas.
- Conduct research on kidney disease in communities of color, rural communities and underserved communities. Particularly, we support the CARE for All Kidneys Act, federal legislation introduced in the previous Congress that aims to improve kidney disease research, prevention, surveillance, and treatment in minority populations and rural and underserved communities.
- Ensure equitable access to all ESRD treatment modalities, including transplantation and home dialysis, across racial, ethnic, and socioeconomic populations and geographic regions to support treatment choice that is clinically appropriate for a person's health needs and their individual circumstances.
- Improve diversity in clinical trials to ensure participants are reflective of the populations that are most impacted by specific diseases and conditions.
- Mandate that insurers must accept health insurance premiums from charities, as these programs help communities of color who are more likely to be uninsured.
- Promote the diversification of the health care workforce and ensure proper training for health professionals to recognize and address implicit and conscious bias and to provide culturally appropriate care.

## Encouraging organ donation and supporting kidney transplants

***The issue:*** *Kidney transplantation is considered the best treatment option for people facing kidney failure because it can increase their chances of living a longer, healthier life. However, the number of people on the organ transplant waiting list is great—about 105,000 Americans are on the list, with 86 percent of those in need of a kidney. Many will die before they receive one because of the dire shortage of kidneys for transplant.*

To encourage organ donation and increase kidney transplants, AKF supports:

- Federal legislation, such as the Living Donor Protection Act, that would encourage organ donation and protect living organ donors from discrimination when seeking life, disability and long-term care insurance. It would also codify that living organ donors may use Family and Medical Leave time to recover from donation surgery and maintain job security.
- State legislation that provides tax breaks to living donors and employers who provide paid leave, as well as state legislation that mirrors the federal Living Donor Protection Act.

- Legislation and regulatory actions to improve the organ transplant ecosystem and align policies across all stakeholders, including providers, dialysis facilities, organ procurement organizations and transplant centers.
- Appropriate implementation of extended Medicare coverage of immunosuppressive drugs for kidney transplant recipients.

## Improving early detection of kidney disease and addressing the unknown causes of kidney disease

**The issue:** *Although 37 million Americans are living with chronic kidney disease (CKD), most of them do not know it because it has no symptoms in the early stages. Millions more individuals are at risk of developing kidney disease and are not aware of their risks. Anyone can get kidney disease, but some people are more at risk than others. Diabetes and high blood pressure are the most common causes of kidney disease. Having a family history of kidney disease, being over age 60 and being of a certain race or ethnicity can also increase an individual's risk for kidney disease. However, for a number of people living with kidney disease, the cause of their kidney disease is unknown. Identifying the root cause of a person's kidney disease, both early in the disease and as a life-preserving necessity, is important for making crucial treatment decisions.*

To improve the early detection of kidney disease and address the unknown causes of kidney disease, AKF supports policies that would:

- Expand the use of CKD screening to diagnose CKD in individuals as early as possible so they can begin to manage their disease and slow its progression, which could lead to better health outcomes for populations disproportionately impacted by kidney disease. As an important first step, we encourage the U.S. Preventive Services Task Force to reconsider making a recommendation for CKD screening.
- Increase access and expand coverage of genetic testing and counseling, particularly in public programs, for people living with kidney disease, which will help provide answers to patients seeking to understand the cause of their kidney disease. Having a clear diagnosis and identifying the root cause of a person's kidney disease will help patients and providers develop appropriate treatment plans that are tailored to the patient's specific needs. A clear diagnosis also allows people living with kidney disease to be informed of any genetic based susceptibility for family members.
- Establish national genetic testing and counseling standards for kidney disease through stakeholder collaboration and a consensus-driven, iterative process. Establishing national standards and cohesive guidelines will help ensure high quality care is consistently provided to all people living with kidney disease.
- Increase awareness and resources for rare kidney disease to improve clinical research, provider training, diagnosis, prevention, and treatment of rare kidney disease. Certain rare kidney diseases do not have any approved treatments and inevitably lead to kidney failure. Rare kidney diseases also disproportionately affect communities of color, particularly Black Americans. More resources are needed to improve early diagnosis,

better understand ways to slow the progression of rare kidney disease and improve treatments for rare kidney disease.

### Ensuring adequate funding for kidney research and promoting innovation

**The issue:** *Kidney disease affects 37 million Americans—far more than many other diseases. Yet federally funded research for kidney disease has lagged compared with many other diseases. This has slowed innovation in the diagnosis and treatment of a disease that is the fastest-growing noncommunicable disease in the United States.*

To address the underfunding of kidney disease research, AKF supports efforts to:

- Increase appropriations funding for the National Institute of Diabetes, Digestive and Kidney Disease (NIDDK), which is a part of the National Institutes of Health (NIH). NIDDK conducts and supports medical research and research training and disseminates science-based information on kidney diseases.
- Increase funding for the Centers for Disease Control and Prevention’s (CDC) Chronic Kidney Disease Initiative, which is designed to provide public health strategies for promoting kidney health.
- Increase funding for KidneyX, the Kidney Innovation Accelerator Program, a public-private partnership to accelerate innovation in preventing, diagnosing and treating kidney diseases.

### Fighting insurance discrimination against people on dialysis

**The issue:** *Health insurers systematically discriminate against low-income people living with ESRD who rely on charitable assistance to afford their health insurance premiums and access the health care they need to stay alive. Over the years, many insurance carriers have refused charitable premium assistance payments from AKF on behalf of people living with ESRD. These people living with ESRD, who are disproportionately members of racial and ethnic minorities, depend on AKF’s federally-approved, 100% needs-based Health Insurance Premium Program (HIPPP) to afford the premiums for their Medicare Part B, Medigap, Medicare Advantage, employer group health, COBRA and other commercial plans, including Qualified Health Plans (QHPs).*

To protect access to health coverage and protect low-income people living with ESRD from insurance discrimination, AKF supports:

- Federal and state regulation that would ensure insurance carriers accept charitable payments on behalf of people living with ESRD.
- Federal and state legislation that would protect patient access to coverage by requiring insurance companies to accept payments from nonprofit charitable organizations like AKF.

## Supporting Medigap reform

**The issue:** Most people with ESRD are eligible for Medicare even if they are under 65. But 19 states do not require health insurers to offer private supplemental Medigap plans to these younger Medicare beneficiaries. Without Medigap, ESRD Medicare beneficiaries face daunting out-of-pocket expenses for the 20% of medical care not covered by Medicare Part B and that is not subject to an out-of-pocket cap. Additionally, ESRD Medicare beneficiaries are required to have supplemental insurance in order to be added to the kidney transplant waiting list, as Medicare alone is not considered full coverage by transplant centers across the nation. Without access to Medigap plans, many ESRD Medicare beneficiaries under 65 cannot access kidney transplantation.

To protect people living with ESRD who do not have access to Medigap, AKF supports:

- Federal legislation that would ensure guaranteed availability of Medigap supplemental insurance to all Medicare ESRD beneficiaries, regardless of age.
- State legislation that would require insurance companies that offer Medigap coverage to make it available to Medicare ESRD beneficiaries under 65 and that would place limits on the premiums charged to Medicare ESRD beneficiaries so that Medigap is affordable.

## Ensuring access to high quality, patient-centered care for Medicare beneficiaries with kidney disease

**The issue:** As the Medicare benefit continues to evolve for ESRD beneficiaries and people with earlier stages of chronic kidney disease, access to coverage options, supporting patient choice in treatment options, supporting innovation, and improving care quality and patient education must be at the center.

To ensure access to high quality, patient-centered care for Medicare beneficiaries with kidney disease, AKF supports policies that would:

- Include coverage of kidney disease screening in the Medicare wellness visit.
- Expand access to the Medicare Kidney Disease Education benefit, which provides education to patients on how to take the best possible care of their kidneys and the information they need to make informed decisions about their care.
- Ensure the long-term adoption of innovative treatments in the Medicare ESRD Prospective Payment System (PPS), particularly innovative drugs, equipment and supplies that have been made available to beneficiaries through the transitional drug add-on payment adjustment (TDAPA) and the transitional add-on payment adjustment for new and innovative equipment and supplies (TPNIES).
- Ensure Medicare ESRD beneficiaries who want to enroll in a Medicare Advantage (MA) plan have access to needed services, treatments, and providers. Particularly, federal policies should ensure MA enrollees with ESRD have access to adequate provider networks; access to innovative drugs and devices that are available to ESRD

beneficiaries in traditional Medicare; and that MA enrollees do not encounter access barriers to necessary treatments due to burdensome prior authorization requirements.

- Implement certain telehealth flexibilities for Medicare beneficiaries, such as amending geographic and originating site requirements, while preserving patient choice and ensuring telehealth is used as a clinically appropriate supplement to accessing in-person care.
- Ensure mandatory payment models such as the ESRD Treatment Choices (ETC) Model and voluntary Kidney Care Choices payment models preserve or enhance the quality of care and the patient experience and supports a patient in choosing a modality that is clinically appropriate for their health needs.
- Ensure quality measurement that has the patient perspective in mind, and that furthers the goals of improving patient care, experience and outcomes.

## Protecting and enhancing access to health coverage under the Affordable Care Act, Medicaid, and employer-sponsored insurance

**The issue:** *The elimination of preexisting condition exclusions for health insurance under the Affordable Care Act (ACA) has enabled people with chronic diseases, including kidney disease, to enroll in private commercial health plans that provide comprehensive coverage. Medicaid, which provides health coverage for one in five low-income individuals, plays a vital role in helping enrollees prevent and manage chronic conditions such as chronic kidney disease and its leading causes, diabetes and hypertension. However, administrative actions over the last several years and the COVID-19 pandemic has jeopardized access to affordable, comprehensive coverage for many Americans.*

To protect and enhance access to affordable, comprehensive coverage for people with chronic conditions such as kidney disease, AKF supports policies that would:

- Rescind regulations that have led to the expansion of less comprehensive insurance options, such as association health plans and short-term limited duration plans, which are exempt from covering the essential health benefits or can deny or limit coverage for people with preexisting conditions.
- Ensure the integrity of the ACA essential health benefit (EHB) requirements to safeguard patient access to comprehensive benefits and lifesaving services and treatments such as chronic kidney disease management, dialysis treatment, and kidney transplantation.
- Ensure strong network adequacy standards for qualified health plans on the ACA Marketplace, which is critical for advancing health equity and enhancing patient access to quality, affordable care.
- Strengthen the ACA Marketplace by funding reinsurance programs, cost-sharing reduction payments, ACA enrollment outreach and education activities, and expanding eligibility for cost-sharing reduction subsidies and advanced premium tax credits beyond the current income thresholds. Particularly, we support making permanent the enhanced ACA premium tax credits that have been available to individuals and families since 2021.



- Uphold the core statutory objective of the Medicaid program, which is “to furnish medical assistance [to individuals] whose income and resources are insufficient to meet the cost of necessary medical services.”
- Address the coverage gap for individuals who are ineligible for Medicaid because they live in states that did not expand Medicaid coverage under the ACA but are also ineligible for ACA premium tax credits because they have incomes below poverty.
- Enhance federal Medicaid funding by automatically increasing federal support to state Medicaid programs during economic downturns and link Federal Medical Assistance Percentage (FMAP) adjustments to state unemployment levels.

### Ensuring equity in the COVID-19 pandemic response

**The issue:** *People with ESRD have experienced a disproportionate impact from COVID-19. Data from the Centers for Medicare and Medicaid Services (CMS) showed that at the end of 2021, Medicare beneficiaries with ESRD had the highest rate of hospitalization among all Medicare beneficiaries—a rate more than five times higher than the hospitalization rate for Medicare beneficiaries generally. The situation is even more dire for communities of color, who are disproportionately impacted by ESRD and are experiencing higher rates of COVID-19 infection, hospitalization and deaths.*

To ensure equity in the COVID-19 pandemic response, AKF advocates for policies that would:

- Improve the public health data infrastructure to modernize reporting on COVID-19 and other diseases and conditions, and to improve the collection and reporting of race and ethnicity data.
- Ensure equitable access to COVID-19 testing, treatment and vaccines for high-risk populations, including communities of color, underserved populations, and people with ESRD who are on dialysis or have a kidney transplant.
- Prioritize COVID-19 vaccine education, outreach, and access to high-risk populations who have been disproportionately affected by COVID-19, particularly communities of color and underserved populations who have also experienced medical discrimination and may have higher levels of mistrust in the health care system.

### Protecting patient access to needed medications; supporting lower prescription drug costs

**The issue:** *Access to medically appropriate prescription drugs for people living with kidney disease must be preserved amid federal efforts to address the rising cost of prescription drugs. People with chronic kidney disease, kidney failure and kidney transplants rely on prescription drugs to manage their kidney disease and comorbidities. People need access to medically-appropriate prescription drugs that are effective and right for their individual situation, and they must be able to afford them.*

To protect patient access to needed medications, avoid disruptions to stable drug regimens, and support lower prescription drug costs for patients, AKF supports:

- Appropriate implementation of the restructuring of the Medicare Part D benefit, particularly the expansion of the Part D low-income subsidy (LIS) and implementation of a true out-of-pocket cap for beneficiaries with a smoothing mechanism.
- Policies that would result in lower drug costs and lower out-of-pocket costs for patients, including policies that protect a patient’s ability to use drug copay assistance to afford needed medications, and to have that assistance count towards their annual deductible and out-of-pocket spending cap.
- efforts to drive greater innovation in kidney care and to encourage the development of new products that can improve the treatment of kidney disease, specifically the transitional drug add-on payment adjustment (TDAPA) and the transitional add-on payment adjustment for new and innovative equipment and supplies (TPNIES)
- Efforts that encourage the introduction and availability of generic prescription drugs and biosimilars, while maintaining effective safeguards to ensure that patients for whom generic substitution is not medically appropriate still have access to branded drugs that are part of their stable drug regimen. AKF supports maintaining patient access to prescription drugs in the Medicare Part D program as it relates to the six categories and classes of drugs of clinical concern (the six protected classes), which includes immunosuppressive drugs for treatment of transplant rejection.

### Utilizing nutrition as a way to prevent and manage chronic diseases

**The issue:** *Dietary interventions have been shown to be successful in managing and improving symptoms of chronic diseases such as heart disease, diabetes, and kidney disease.<sup>1,2</sup> Nutritious food promotes good health. Access to fresh fruits, vegetables, and lean proteins can provide families and children alternatives to processed foods that have been linked to obesity, metabolic disease and low levels of HDL (high-density lipoprotein or “good” cholesterol).<sup>3</sup>*

As part of prevention and management of kidney disease, AKF supports:

- Expanding current Medicare coverage for medical nutrition therapy (MNT), which is nutrition related diagnostic, therapeutic and counseling services provided by a registered dietitian nutritionist. This intervention has been found cost-effective and successful for preventing and managing chronic illnesses.<sup>4</sup> Medicare currently covers MNT for people with diabetes or a renal disease. AKF supports expanding MNT under Medicare to include prediabetes, hypertension, and other illnesses that can be improved with nutrition.
- Improving access to non-processed groceries, such as initiatives to encourage the development of grocery stores that carry fresh fruit and vegetables in “food deserts,”

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6412662/>

<sup>2</sup> <https://www.ingentaconnect.com/content/wk/mnh/2015/00000024/00000006/art00007>

<sup>3</sup> <https://www.cambridge.org/core/journals/british-journal-of-nutrition/article/consumption-of-ultraprocessed-foods-and-health-status-a-systematic-review-and-metaanalysis/FDCA00C0C747AA36E1860BBF69A62704>

<sup>4</sup> <https://www.anddeal.org/topic.cfm?cat=4085>



and tax credits and grants for businesses who serve low-income urban and rural areas. The U.S. Department of Agriculture defines a food desert as “a low-income tract where a substantial number or substantial share of residents does not have easy access to a supermarket or large grocery store.”

- Enhancing policies that provide free delivery of groceries to people who live in “food deserts.” Low-income people on dialysis and those with CKD, diabetes, pre-diabetes, or hypertension who live in food deserts would benefit from having nutritious food delivered. The 2018 Farm Bill included a national Online Purchase Pilot which provided SNAP beneficiaries’ access to grocery delivery services. In urban areas, 5.9% were “non-deliverable.” In rural areas, 69.5% were “non-deliverable.”<sup>5</sup>

### Addressing the impact of climate change on people with kidney disease

**The issue:** *Climate change poses a current and increasing threat to people’s health, especially for people living with kidney disease or other chronic conditions. Rising surface temperatures, more frequent extreme weather events and heat waves, increased flooding, and other effects from climate change have a significant impact on health outcomes. Studies have indicated that extreme heat and heat-related illness can lead to acute kidney injury (AKI). For people with CKD or ESRD, extreme heat events can exacerbate their kidney disease and increase their risk of hospitalization. More frequent and more intense weather events that result in flooding, power outages and infrastructure and property damage can disrupt the care of people on dialysis, who may miss their dialysis treatments and increase their risk of adverse health events.*

To address the impact of climate change on health, especially the health of people living with kidney disease, AKF supports:

- Federal efforts to work collaboratively with state, tribal, local, and territorial governments, community-based organizations, business and industry, and other stakeholders to address the health impacts of climate change.
- The development of strategies, programs and actions plans for federal and local agencies to prepare for and respond to the public health effects of climate change.
- Providing adequate resources to respond to the health impacts of climate change.
- Promoting and elevating the patient voice as stakeholders work to address the impact of climate change on people’s health.

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<sup>5</sup> <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2756107>