

# Health Equity in Kidney in Disease

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**National Health Council Health Equity  
Lunch and Learn**

 American Kidney Fund®  
FIGHTING ON ALL FRONTS

# Holly Bode

Vice President of Government Affairs

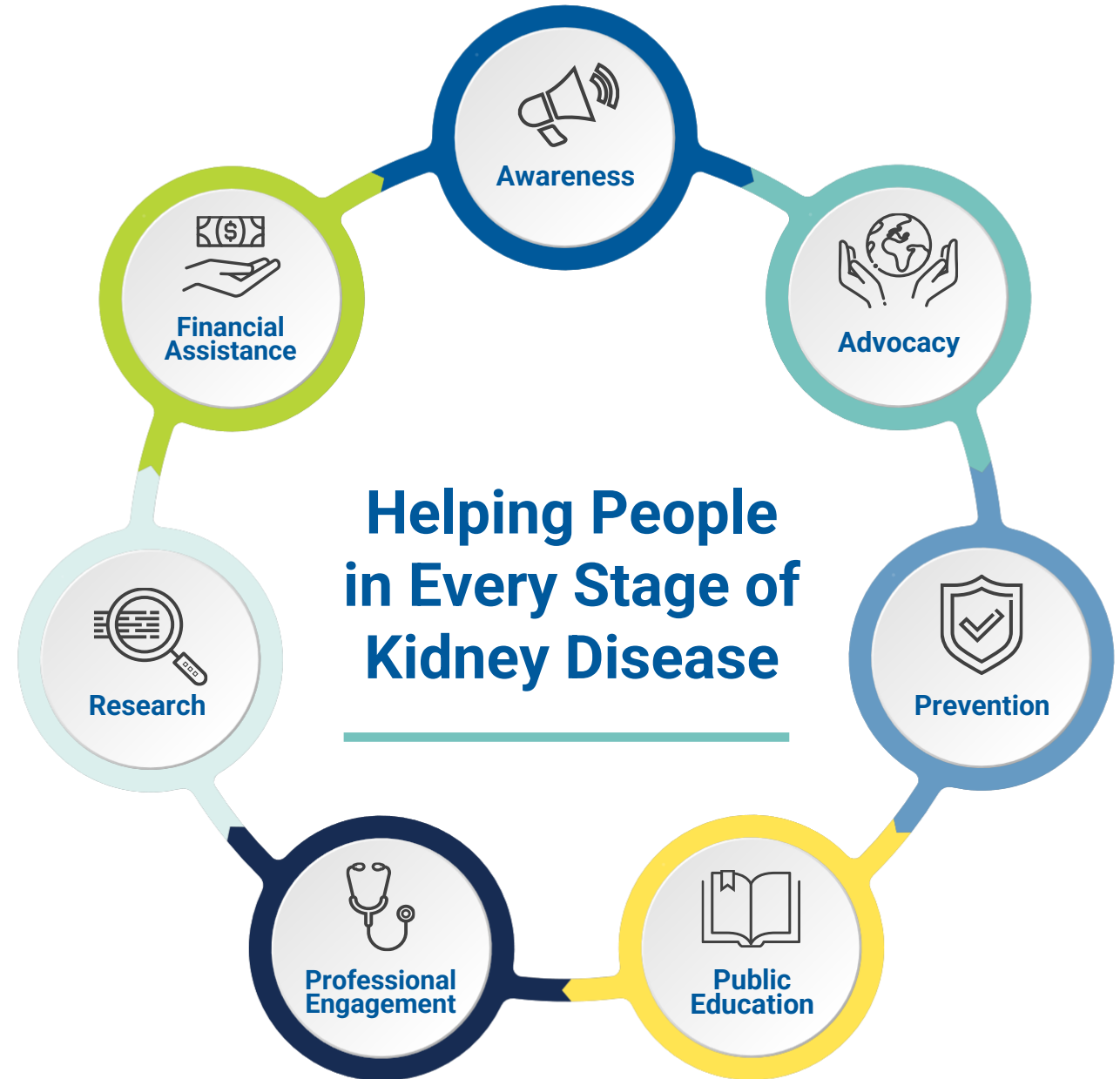
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# Melanie Paris, MA, MPH

Senior Director of Strategic  
Partnerships and Kidney Disease  
Education

# Fighting On All Fronts

- Awareness
- Advocacy
- Prevention
- Public Education
- Professional Engagement
- Research
- Financial Assistance



# What Do You Know About Kidney Disease?

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Let's see...

# What do you know about kidney disease?

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How many Americans are currently living with kidney disease?

- A. 10-15 million
- B. 35-37 million
- C. 20-25 million

Correct answer: B. 35-37 million Americans are living with kidney disease. Because progresses gradually, symptoms are often “silent”. **9 out of 10 do not know they have it.**

# What do you know about kidney disease?

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What are the top two causes of kidney disease?

- A. Diabetes**
- B. Drug abuse**
- C. Excessive alcohol**
- D. Smoking**
- E. Hypertension**

**Correct answer: A and E.**

# What do you know about kidney disease?

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What is the incidence rate of kidney failure among Black Americans compared to White individuals?

- A. Similar rates
- B. 1 to 2-fold higher
- C. 2 to 4-fold higher
- D. 5 to 6-fold higher

Correct Answer: **C) 2 to 4-fold higher**

# What do you know about kidney disease?

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How likely are Black Americans to be referred for kidney transplants compared to other populations?

**A. 10% less likely**

**B. 25% less likely**

**C. 50% less likely**

**D. 75% less likely**

**Correct Answer: B. 25% less likely**



# What do you know about kidney disease?

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Black Americans comprise approximately 12% and Hispanics 16%, respectively, of the U.S. population, but only account for \_\_\_% of participants in clinical trials.

**A. 1%**

**B. 5%**

**C. 9%**

**D. 7%**

**Correct answer: A. 1%**

# AKF and Health Equity

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Priority since our founding in 1971

# American Kidney Fund Health Equity Coalition

**Association of Black Cardiologists** (Neicey Johnson, RN, JD-Senior Director of Programs)

**American Diabetes Association** (Joshua Martinez, MPA, Director of Health Equity and Community Engagement)

**American Nephrology Nurses Association** (Nikeyia Davis, MBA-HCM, MSN, APRN, AGPCNP-C, CNN, Vice Chair of Diversity, Equity, and Inclusion Committee)

**Ashte Collins, MD** (George Washington University Department of Nephrology)

**Chi Eta Phi Sorority, Inc.** (Stacey Johnson, DNP, MSN, National Secretary)

**Home Dialyzers United** (Nicole Jefferson, President and kidney disease patient)

**Renal Physicians Association** (Adonia Calhoun Groom, CAE, CMP, Executive Director)

**National Health Council** ([Omar Escontrías, Dr.P.H., M.P.H., Vice President, Research, Education & Programs](#))

**Crystal Scott** (AKF Ambassador)

**Elaine Ku, MD** (Associate Professor and Director of Nephrology Transition Clinic, University of California San Francisco)

**Anika Lucas, MD** (Nephrology Fellow, Duke University and Fellow, AKF Clinical Scientist in Nephrology Fellowship)

**Deena Adimoolam, MD** (Internist and Endocrinologist, Mt. Sinai Hospital)

**National Hispanic Medical Association** (Elena Rios, MD, President & CEO)

**National Medical Association** (Randall Maxey, MD, Past President and Past Chairman of the Board)

**National Minority Organ Tissue Transplant Education Program** (Velma Scantlebury-White, MD; Professor of Surgery at TCU and UNTHSC; Medical Director)

**National Minority Health Association** (Burgess Harrison, Executive Director & Sara Moore, Chief Operating Officer)

**NephCure** (Maurice Madden, Director of Stakeholder Management)

**Rachel Perlman, MD** (Clinical Associate Professor, Nephrology and Internal Medicine-University of Michigan)

**Leigh-Ann Williams, MPH, MS** (AKF Ambassador & Research fellow, Dillard University)

# KIDNEY HEALTH FOR ALL™

## 2024 Accomplishments

### Prevention & Disease Management

- National Media Campaign
- Kidney Health Coach grassroots grant program
- In-person Advocacy Trainings
- Patient Journey Mapping Project
- 2 professional webinars on disparities in CKD identification, management
- AMKD National Awareness Day
- Grassroots Conference attendance

### Diversity in Clinical Trials

- Clinical trial awareness through KAW and other platforms
- Partnership with a grassroots organization to broaden reach
- Active in clinical trial coalitions such as PALADIN

### Transplant Access

- Distribute transplant toolkit via exhibits, transplant centers and to those receiving AKF charitable assistance
- Expand toolkit resources
- Active member of the National Multicultural Action Group (NMAG)
- Poster at NKF Spring Clinicals on effect of HIPP in reducing transplant disparities

### Home Dialysis

- 3rd annual Dialysis at Home Summit
- Dissemination of home dialysis decision aid, evaluation of user feedback

#### Presenting Sponsors



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# KIDNEY HEALTH FOR ALL™

## 2025 Activities

### Prevention & Disease Management

Building awareness of diabetes and high blood pressure, which are the top causes of kidney disease. Emphasizing the importance of testing in high-risk communities.

- Kidney Health Coach community grants
- Grassroots advocacy engagements in highly-impacted areas
- Exhibiting, presenting and participating at community events such as Black Greek organizations, faith-based organizations and related professional associations (ex. National Association of Black Social Workers)

### Diversity in Clinical Trials

Recruiting a more diverse pool of participants to reflect the populations the medications will treat.

- Expansion of patient content on Kidney Health for All website
- Professional outreach to community physicians and allied healthcare workers



**Everyone deserves their best kidney health.** However, health disparities in kidney care — especially in people of color — are a serious barrier to receiving the care that all people need and deserve.

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# KIDNEY HEALTH FOR ALL™

## 2025 Activities

### Home Dialysis

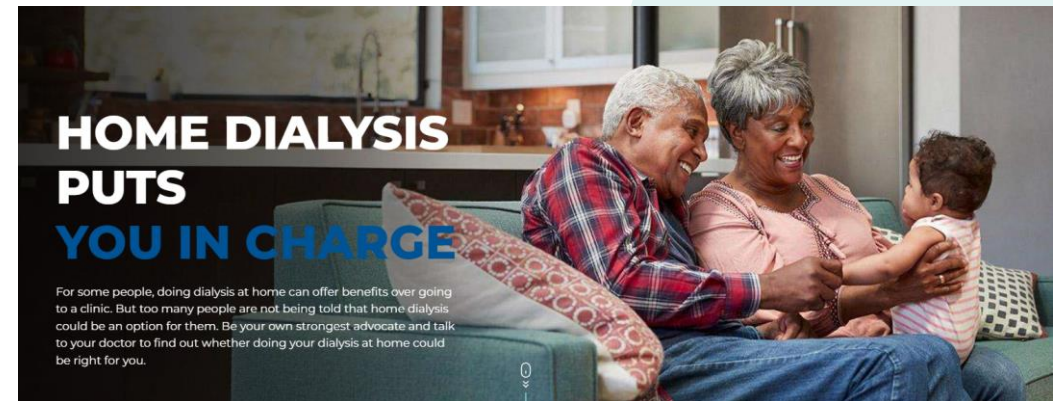
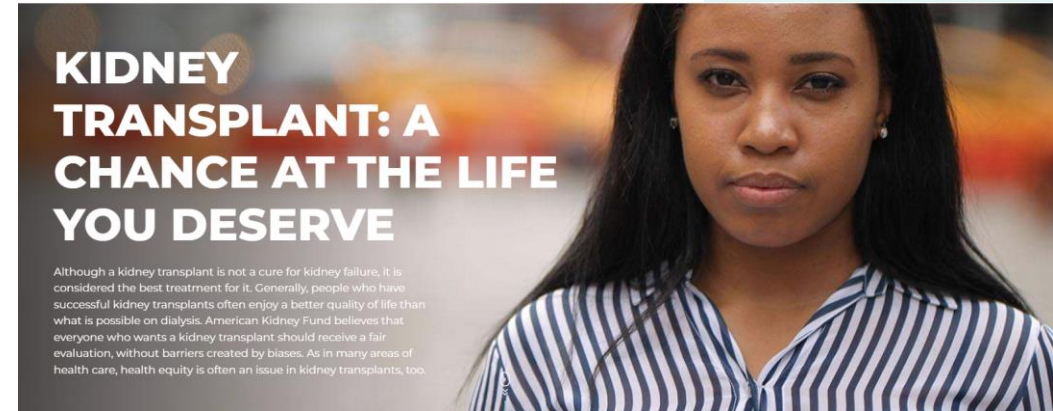
Increasing understanding and adoption of home dialysis, which can result in better health outcomes.

- 4th Annual Dialysis at Home Event
- Dissemination of our Home Dialysis Decision Aid

### Transplant Access

Removing barriers to transplant, so that everyone has equal access to lifesaving transplant.

- Dissemination of Your Guide to Kidney Transplant
- Creation of a Post-Transplant Guide
- Adding content and outreach strategies for organ and tissue donation



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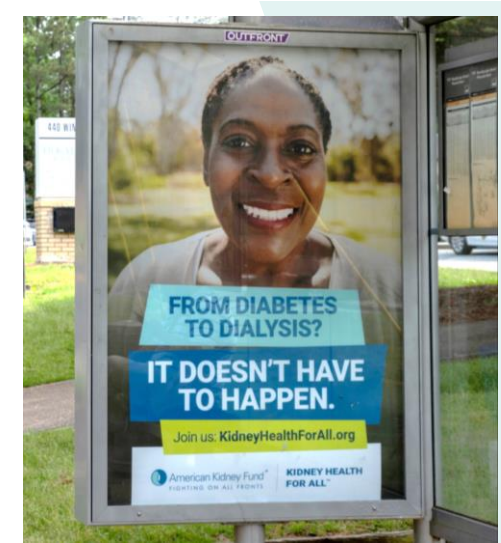


# KIDNEY HEALTH FOR ALL™

## National Media Campaign

Last April, AKF launched a nationwide media campaign in English and Spanish with the goal of reaching populations of color with prevention and awareness messaging. All campaign tactics to-date have exceeded estimated performance projections.

- **TV, Streaming & Radio PSAs:** Distributed nationwide to platforms including Amazon video, YouTube, Warner, Viacom, Univision, Telemundo. Achieved over \$1 million milestone in est. donated media and generated nearly 18 million est. impressions.
- **Out-of-Home Placements:** In 2024 we were in 8 markets with high rates of kidney disease, including billboards, bus shelter and interior bus ads. Delivered over 42 million est. impressions. We will add 8 new markets in 2025.
- **In-Doctor's Office Campaign:** Video PSAs running in primary care offices in markets with high rates. Culminated in nearly 3 million estimated impressions.
- **Digital Media Campaign:** Digital ads and user generated videos driving traffic to KidneyHealthForAll.org. Generated 4 million estimated impressions and over delivered over 40,000 individuals to KHFA.org



# APOL-1 Kidney Disease Awareness Day

April 29, 2025

This past April 30th, AKF celebrated the first-ever APOL1-Mediated Kidney Disease (AMKD) Awareness Day. Leveraging earned and paid media and grassroots partnerships, we sparked a national conversation about AMKD and how communities can better understand their risk.

## 2024 Campaign Highlights

- Panel session at National Minority Quality Forum Leadership Summit
- Policy roundtable and reception on Capitol Hill with Alonzo Mourning; House Resolution to support the designation of AMKD Day
- State Proclamations, securing 13 of 31 states submitted
- Boston Red Sox Ceremonial First Pitch
- Satellite Media Tour with 24 interviews and article on AMKD with 1,279 placements
- People Magazine feature
- Social media influencer campaign, with 2.6M reach of #APOL1Aware hashtag
- 25 Official Awareness Day Partners



VIRTUAL Q&A | APRIL 26 | 12PM ET  
**Understanding APOL1-Mediated Kidney Disease (AMKD):**  
One Man's Journey with a Genetic Cause of Kidney Disease



Woman, 20, Recalls 'Morbid' Kidney Disease Disrupting Her Life: 'I Couldn't Be a Normal Teenager' (Exclusive)  
Enmoni McConnell-Bent, 20, opens up to PEOPLE about being diagnosed with a genetic kidney disease and marking the nation's first AMKD Awareness Day  
By Vanessa Rittenberg Published on April 30, 2024 09:00AM EDT

2024 CORPORATE SPONSORS





# Kidney Health Coach



- Free, community health education program that trains participants to become health educators and educate others about kidney disease
- Continuing education credits are available for allied healthcare professionals
- Prevent CKD and kidney failure through education and reach people in their communities across the United States, tribes, and territories
- Over 6,500 Kidney Health Coaches worldwide (up from 967 coaches in 2018)

## KHC Health Equity Grants

- One-year grants to help organizations and individuals overcome financial barriers to implementing KHC programs and spread CKD awareness and education to at-risk populations
- 40 coaches and 8 community organizations will receive \$100,000 in 2025



# Unknown Causes of Kidney Disease Project

2024 Activities

The Unknown Causes of Kidney Disease Project seeks to improve understanding of how undiagnosed or misdiagnosed causes of kidney disease directly impact patient care and outcomes.

## 5th Annual National Summit

- Nearly 100 medical and industry leaders with patient advocates in Washington, D.C.

## Know Your Cause Website

- Launched May 2024

## Healthcare Professionals Working Group

- Creating a plan to reach community nephrologists with our key messages on identifying the cause of kidney disease

## Patients and Caregivers Working Group

- Creating a plan to engage with those at the grassroots level who may not see our digital efforts

## Public Policy Working Group

- Rare Disease Fly-in on Capitol Hill to coincide with Summit
- Supporting Access to Genetic Counselor Services Act (H.R. 2144/S. 1450) and New Era of End Stage Kidney Disease legislation



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### Leadership Sponsors



### Champion Sponsors



# Know Your Kidneys

## Bridging the Gap from Diagnosis to Causality

### Know Your Kidneys

- Overall CKD awareness learning more about kidney disease and prevention
- Interactive Know Your Numbers tool stressing the importance of uACR and eGFR tests

### Know Your Cause

- For patients who don't know, understand or believe the cause of their CKD
- Focus on understanding the importance of a complete diagnosis, including additional testing and information on rare and genetic disorders.
- Interactive and personalized plan to manage your health

### Know Your Plan

- Targeted to patients with DKD and cardiovascular disease
- Access resources to help identify and reach kidney health goals
- Interactive and customized lifestyle plan

## KNOW Your Kidneys

Identify and reach your kidney health goals. Whether you're looking to prevent kidney issues or manage existing conditions, get empowered with knowledge and practical tips for a healthier life.

[Launch the tool](#)



## KNOW Your Cause

Understand the reasons behind your kidney disease. By learning the cause of your kidney disease, you'll be able to make informed decisions and work with your healthcare team to create a personalized plan to manage your health.

[Explore your cause](#)



## KNOW Your Plan

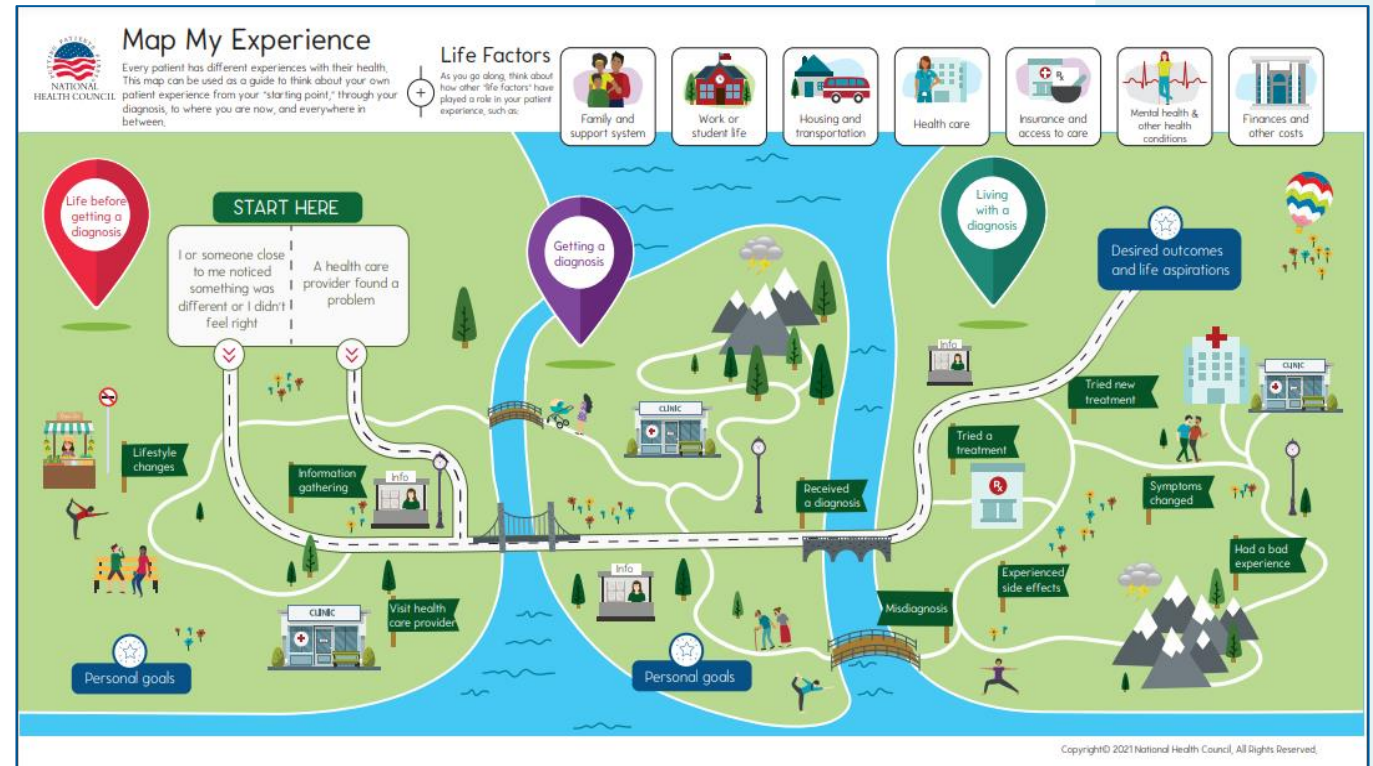
Create a plan that empowers you to take charge of your kidney health and live your best life. Managing kidney health involves understanding your treatment options, making informed decisions, and developing a personalized plan. Work with your healthcare team to create a plan that works best for your lifestyle and stage of kidney disease.

[Customize your plan](#)



# AKF-NHC Patient Experience Mapping Project

- Applying the NHC's Patient Experience Mapping Tool to document the experience of, and differences between, diabetic and rare kidney disease patients.
- The project will focus on challenges in diagnosis and care especially for patients of color.
- Data will be published in a report distributed through:
  - Peer-reviewed journals
  - Industry conferences
  - Webinars & Kidney Action Week
  - AKF strategic partners & NHC members
  - Social media and PR outreach



# AKF Grassroots and Policy

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# Health Equity Events for Ambassadors

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- Atlanta, GA – Hosted on March 23, 2024. Multiple local organizations participated to discuss their programs. Speakers included: Bobby Howard, Director, Multicultural Donation Education Program; LifeLink of Georgia; DaVita; Lynne White from the Georgia Transplant Foundation and Paul Lee, Medicare Counselor, State Health Insurance Assistance Program .
- Springfield, MA - We partnered with IPRO ESRD Network (ipro.org), which operates under the direction of CMS. The IPRO ESRD Network Program supports the renal community in ensuring safe, effective, patient-centered care for more than 132,000 kidney patients in 13 states.
- Chicago, IL – Organized with the help of local Ambassadors Jim Myers and Kyle Chang, representatives from the office of Congresswoman Robin Kelly (D-IL) and the office of Senator Tammy Duckworth (D-IL). Both spoke about their offices' work to improve care for kidney patients and the importance of community members sharing their experiences to educate members on the impact of kidney disease on their lives.
- Columbia, SC - Our final event was on November 9 in Columbia, SC, where there are enormous racial health inequities. For example, the 29203 zip code has the largest number of diabetic amputees in the nation. Speakers will include Nzisa Mutinga, Nephrologist at Columbia Nephrology Associates and Brittany Dickerson, Patient Advocate.
- Washington, DC – As part of our health equity work, we had a booth at the Congressional Black Caucus Foundation's Annual Legislative Conference in September. Six Ambassadors attended the conference and shared their stories with ALC attendees at the booth.

- On Sept. 18, we hosted our second Rare Kidney Disease Advocacy Day, connecting patient advocates and health care professionals with lawmakers on Capitol Hill.
- During this advocacy day, members of AKF's recently launched **Rare Kidney Disease Action Network (RKDAN)** were paired with AKF staff members to participate in meetings with their elected officials.
- Representing 17 states, 23 advocates had 53 meetings with their senators' and representatives' offices, including nine meetings with members of Congress in attendance.
- Participants urged House of Representatives offices to co-sponsor the New Era of Preventing End-Stage Kidney Disease Act (H.R. 6790) and Senate offices to consider introducing a Senate version of the bill. In addition, advocates asked offices to support the Access to Genetic Counselor Services Act of 2023 (H.R. 3876/S. 2323).

# Rare Kidney Disease Advocacy Day



# 2025 Federal & State Policy Agenda

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- Improving early detection of kidney disease and addressing the unknown causes of kidney disease
  - Encourage the U.S. Preventive Services Task Force to develop a CKD screening recommendation
  - Increase access and expand coverage of genetic testing and counseling
  - Increase awareness and resources for rare kidney disease
- Ensuring adequate funding for kidney research and promoting innovation
  - Ensure that Medicare ESRD PPS payments are adequate and support and encourage innovation
  - Increase funding for the National Institute of Diabetes, Digestive and Kidney Disease (NIDDK)
- Support living organ donation
- Supporting Medigap reform
  - Federal and state legislation to ensure the availability and affordability of Medigap supplemental insurance to all Medicare ESRD beneficiaries, regardless of age
- Protecting patient access to needed medications; supporting lower prescription drug costs
  - Appropriate implementation of the restructuring of the Medicare Part D benefit



# Patient Access Initiative

November 19, 2024

## First Year Summit Recommendations Included:

- Increased awareness/early diagnosis (including earlier and better screening for kidney disease, routine screening as part of the Welcome to Medicare benefit, genetic testing/counseling access)
- Better patient education/navigation (including a culturally competent approach, addressing health disparities and provider bias, support in insurance navigation)
- Incentives for upstream investment in the early stages of CKD: (including HHS/CMMI payment models, shared savings model, addressing utilization management challenges, financial incentives to payers and providers to treat earlier stages)

## 2024 Activities:

- 2nd Annual Summit to be held in Washington, DC at the Darcy Hotel on November 19th
- Summit focus will be on upstream care for people with and at-risk for kidney disease:
  - The need for earlier screening and diagnostic testing, especially for higher risk populations
  - The role of caregivers and the need for mental health support in caring for people with kidney disease
  - Creating incentives for payers to cover upstream interventions to slow or stop the progression to ESRD
  - The need for more Innovation and access to treatments for CKD and rare kidney disease



## Leadership Sponsors



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# Thank you



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