

# Advancing Equity Through Legislative Affairs

## Expanding Your Stakeholder Base

April 2024

Advancing Equity

# Agenda

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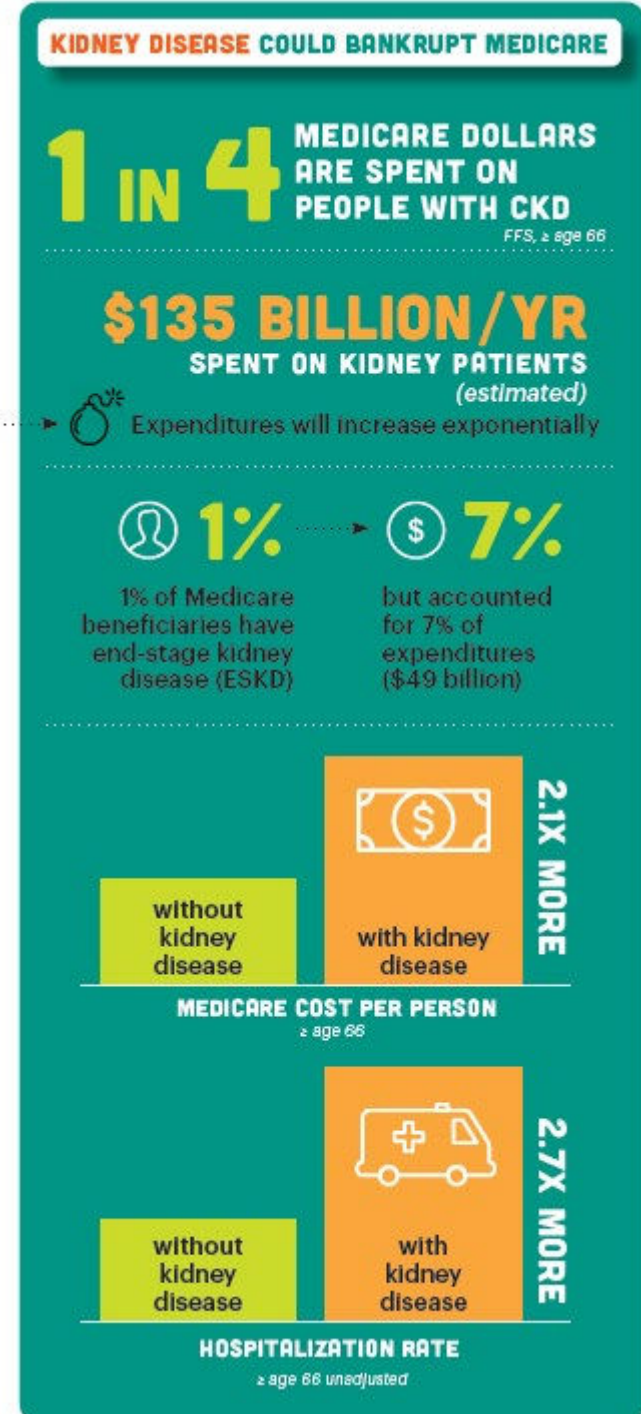
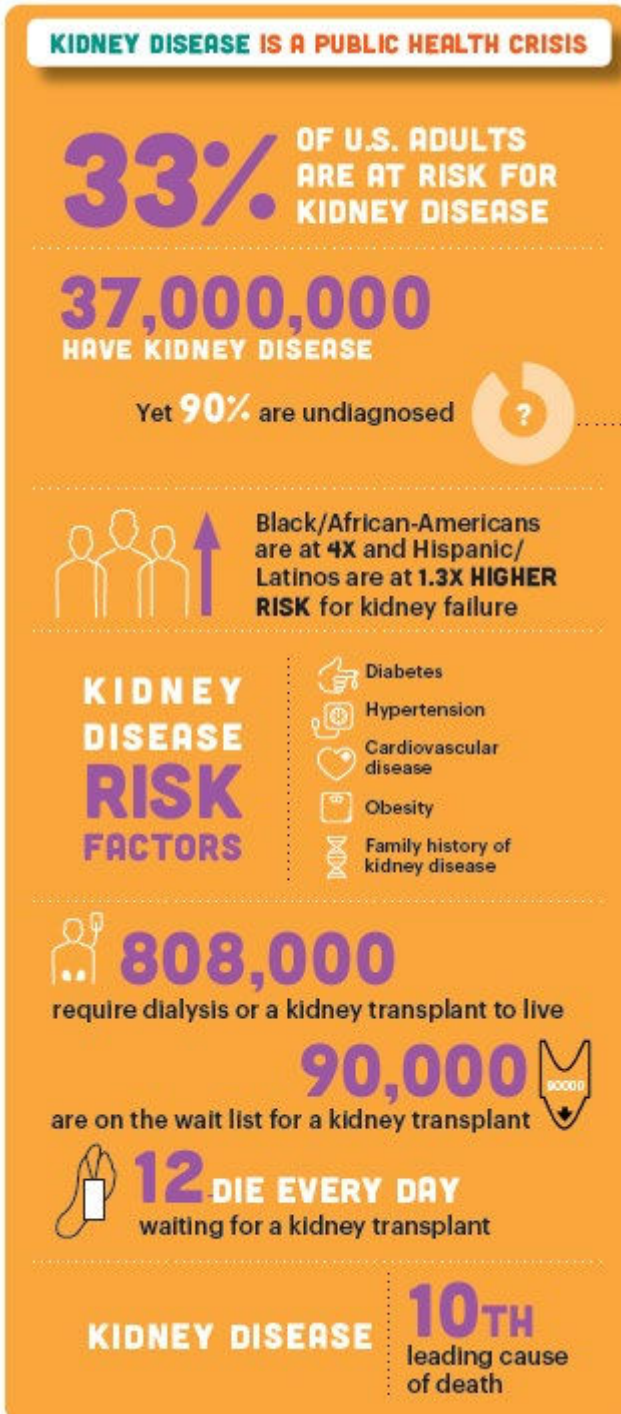
- Kidney Disease and Underserved Communities
- NKF's approach to Health Equity
- Engaging New Stakeholders
- Lessons Learned

SETTING THE TABLE

# CKD Basics

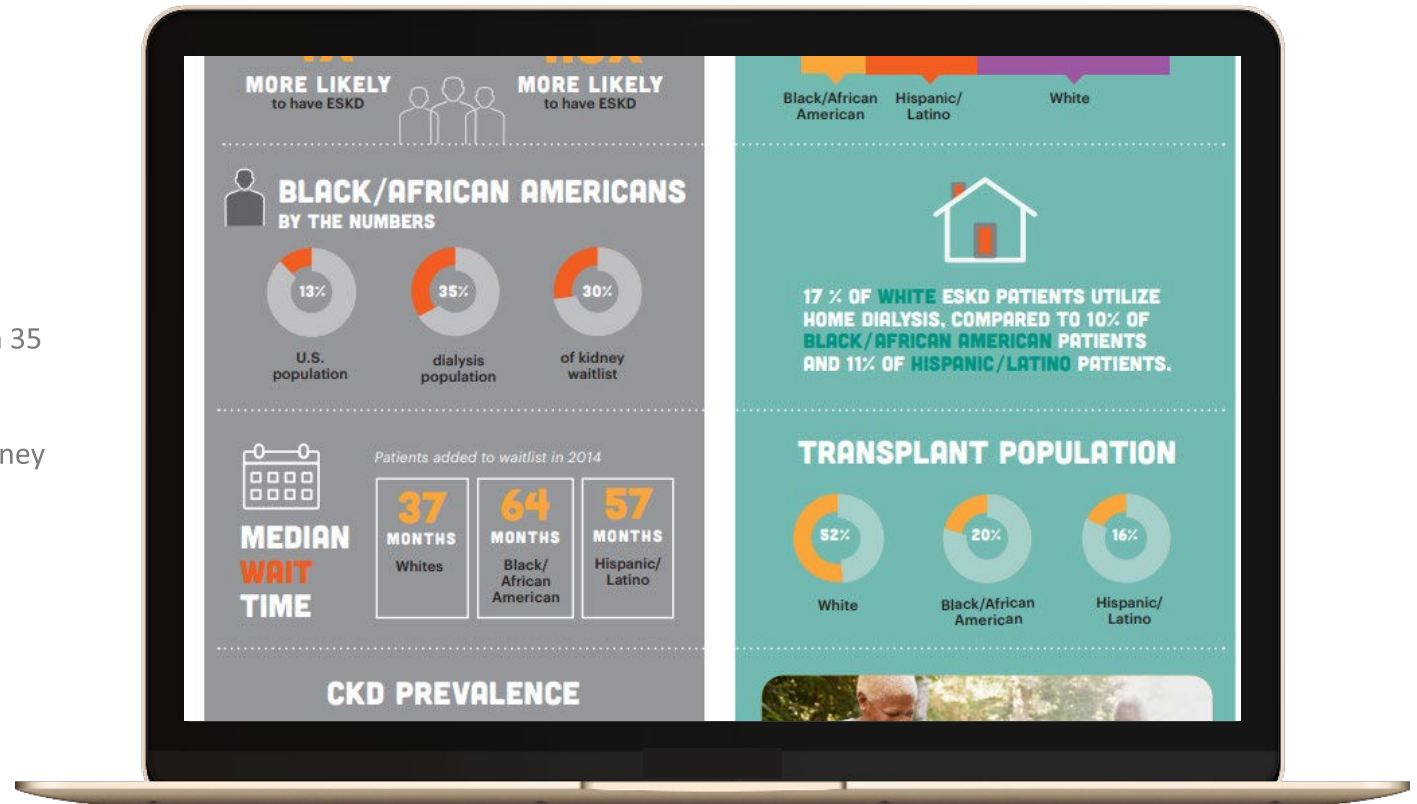
Chronic Kidney Disease affects more than 37 million adults in America. The leading causes are diabetes, hypertension, and family history of CKD.

Approximately 125,000 adults in America are diagnosed with kidney failure each year, contributing the significant economic, physical, and emotional burden of CKD.



# Kidney Disease in Underserved Communities

- Despite being at increased risk of CKD due to high rates of diabetes and hypertension, African-Americans are less likely to access CKD care, and more likely to progress rapidly to kidney failure.
- Although they make up only 13.5 percent of the population, African-Americans make up more than 35 percent of dialysis patients.
- While a transplant is the optimal treatment for kidney failure, Black and Hispanic patients face barriers to access at every step of the process. They are less likely to get a transplant evaluation, access the waitlist, receive a transplant, or survive post-transplant



# A Perfect Storm



The first COVID-19 death in the US was a dialysis patient.

The effects of the COVID-19 pandemic on the CKD and kidney failure populations were devastating. In 2021, for the first time ever in the 50-year history of the Medicare End Stage Renal Disease Program, **the number of people receiving dialysis in the United States declined.**

As a direct result of this higher COVID-19-related mortality and, possibly, more limited access to non-COVID-19-related medical

care, mortality increased more among Black than among White beneficiaries with stage 4 and 5 CKD in 2020.

This confluence of events, coupled with the societal upheaval following George Floyd's death, led NKF to revisit its approach to health equity, focusing on clinical, policy, and programmatic efforts.

Clinical Care

# Eliminating Race Based Algorithms

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For decades, clinicians used an algorithm – called the estimated Glomerular Filtration Rate (eGFR) – to assess kidney function.

The old equation applied a coefficient to individuals of African American ancestry that made it seem like their kidneys were functioning better at a higher level. The result was that African-American kidney patients were less likely to get guideline concordant care, especially access to transplantation.

NKF and the American Society of Nephrology convened a joint task force to revise the formula for assessing kidney function and issued a race-free equation that was released in 2021 and has been adopted by all major labs and most academic labs.



# Our Health Equity Policy Agenda

NKF also developed a policy agenda to address inequity in kidney care, focusing on the three main domains of CKD Care.



## **CKD AWARENESS, DIAGNOSIS AND MANAGEMENT**

Increase investment in community-based prevention and biomedical research, expand access to screening/treatment, and incentivize high quality care.



## **OPTIONS FOR KIDNEY FAILURE**

Earlier diagnosis and management of advanced kidney disease gives patients more access to home dialysis and pre-emptive transplant.



## **EQUITY IN TRANSPLANT**

Myriad barriers to transplantation inhibit access by communities of color. NKF has identified many policy solutions to address many of those barriers.

# KIDNEY EQUITY FOR ALL™

KIDNEY EQUITY FOR ALL is a patient-focused, community-minded movement dedicated to ensuring that ALL kidney patients have access to high-quality, patient-centered kidney care from the moment of diagnosis to transplantation.

Every March, NKF recognizes [National Kidney Month](#) as a time to raise awareness about kidney health. This year, the month holds particular significance in advocating for KIDNEY EQUITY FOR ALL.



OUR STRATEGY

# Engaging New Stakeholders

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Knowing that communities of color are disproportionately affected by kidney disease, we sought to elevate awareness with key lawmakers, corporate partners, community partners, and opinion leaders by participating at the CBCF's Annual Legislative Conference and the CHCI's Leadership Conference



### CHCI STRATEGY #1



## EXHIBIT

By exhibiting, we were able to share information about CKD risk with attendees.

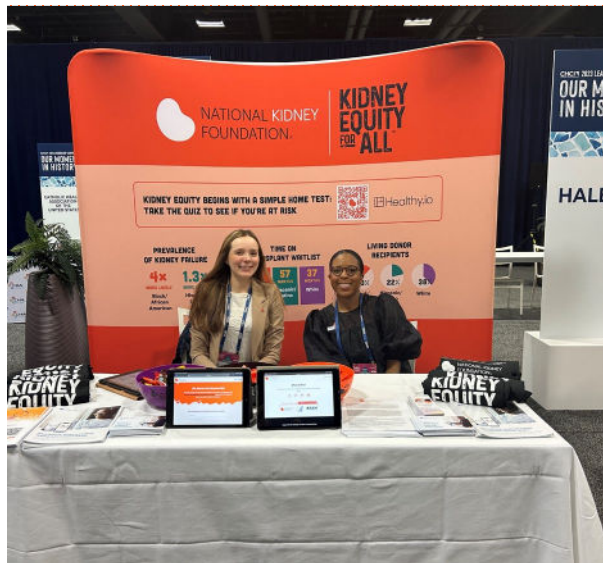


### CHCI STRATEGY #3



## SCREENING

Using a QR code, attendees took a quiz to assess their risk for CKD and were sent an at-home test kit



### CHCI STRATEGY #2



## CONNECTING

Our participation allowed us to connect with policymakers, influencers, and future leaders.

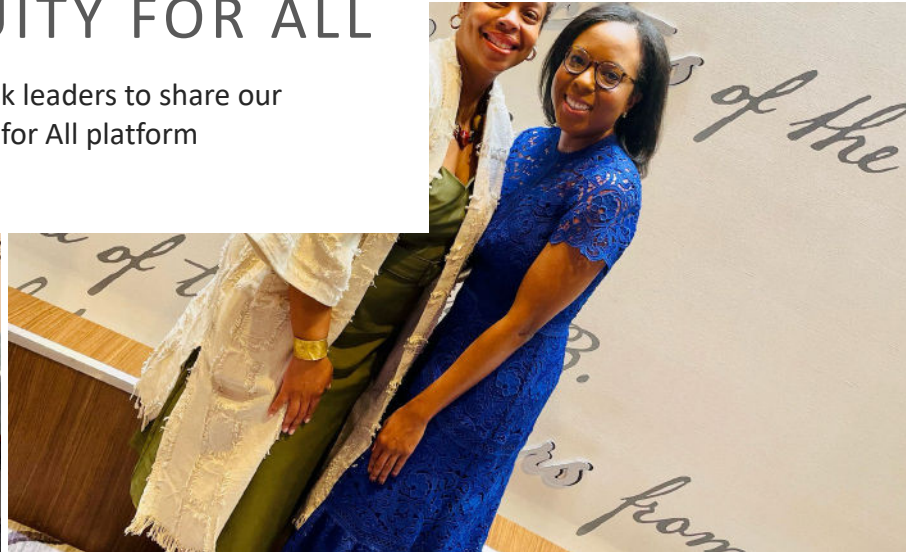




CBC STRATEGY

# LAUNCHING KIDNEY EQUITY FOR ALL

To connect with black leaders to share our  
Kidney Equity for All platform



# CBCF Strategy



## OVERARCHING OBJECTIVE

To connect with community leaders to:

- Increase awareness about CKD in black communities
- Build awareness about NKF's equity agenda
- Build support for our policy initiatives with new audiences



## Exhibit

Similar to CHCI, we exhibited at the CBCF to share information with attendees about CKD, our advocacy agenda, and NKF's activities.



## Briefing

In partnership with Bayer, we sponsored a session featuring Platinum recording artist Freeway, who is a transplant recipient and a donor Dad. He spoke poignantly about his experience with kidney failure, dialysis while on tour, and the life-saving gift of a kidney transplant.



## Community Screening

The CBCF Spouses host an annual community breakfast for attendees needing health services. Similar to CHCI, we screened individuals using an online tool to assess their risk for kidney disease. The giveaways were a big hit.



## Call to action

We also did a petition drive on one of our key policy goals, removing race as a variable when assessing donor kidneys for transplant. This policy change is a central part of our health equity agenda.





### SUCCESS METRIC #1

We generated over 123,000 impressions and 48,000 video views across our social media channels.



### SUCCESS METRIC #2

Approximately 70 people attended our CKD Briefing



### SUCCESS METRIC #3

More than 2,000 individuals signed our KDRI Petition

# Other Positives



## CONNECTIONS WITH COMMUNITY PARTNERS

We connected with several community partners during the event that resulted in meaningful policy and communications collaborations.



## EQUITY POSITION PAPER

During that same time frame, we published our Health Equity Position paper, which outlined the various policy initiatives we're working on to promote equity.



## DATA COLLECTION

The use of QR codes for the petition and the screening quiz allowed us to collect email addresses and other information about attendees.



## DIRECT ACCESS TO MEMBERS

The networking and visibility opportunities gave us more direct member access than we typically had and allowed us to make a stronger connection.



Expanding our Stakeholder Base

# Lessons Learned

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01

## Identify Outcomes up Front

We didn't have a system for measuring either impact or ROI. And because our approach was so multi-dimensional, it was hard to gauge which tactic led to which outcome.

02

## A Plan for Partnerships and Data

Making connections and collecting email addresses was only the first step. We didn't anticipate the work necessary to translate connections to impact. Future efforts will include post-event follow up to maximize retention and engagement. **More depth, less breadth**

03

We plan to do fewer, better events in 2024.

Improvements will include better use of marketing/tools to increase participation, connecting more directly to our policy agenda, and tighter messaging in our communications.



Questions?