



NEPHCURE[®]
Kidney International

NephCure Health Equity Programs 2022

Reaching Rare Kidney Disease Communities of Color

OVERVIEW

Chronic kidney disease (CKD) is a nationwide epidemic, with 1 in 7 US adults affected and one third at risk. People in communities of color are disproportionately affected by chronic kidney disease and have higher rates of kidney failure. Although social determinants of health can play a role in an individual or community's risk for chronic illness, there are also several rare forms of glomerular kidney diseases that specifically affect certain racial and ethnic groups and increase their overall risk for CKD.

- Focal Segmental Glomerulosclerosis (FSGS) is a rare and progressive kidney disease that affects Black Americans at rates 4-5 times higher than white Americans. A variation on the APOL1 gene, often found in people of West African descent, is associated with one of the most severe forms of FSGS. This diagnosis also significantly reduces the already very limited treatment options available for patients. Approximately 1/3 of FSGS cases in the United States are thought to be associated with APOL1 variants.
- Immunoglobulin A Nephropathy (IgAN) is the most common primary glomerular disease, with people of Asian/Pacific Islander heritage more likely to be affected than other racial and ethnic groups. IgAN patients of Asian/Pacific Islander origin may also suffer from a more severe form of this condition and have a higher risk of progression to End Stage Kidney Disease (ESKD).
- In addition, Hispanic/Latino Americans are the largest racial/ethnic group in the US and bear a significant burden of ESKD, with kidney failure at a rate two times greater than that of non-Hispanic whites. They represent a substantial portion of the glomerular disease population and are disproportionately affected by Lupus Nephritis.

Clinical research into rare, glomerular kidney diseases has moved forward at a rapid pace over the past few years, but success will be measured not just by the number of new treatments available, but by ensuring that this wave of innovation leaves no one behind. Individuals from racial and ethnic minority groups have historically been underrepresented in clinical research. Their inclusion and participation is vital to providing accurate data around the efficacy of these new potential treatments and on ensuring equitable access to drugs and research that may significantly improve their kidney health and quality of life.

Furthermore, NephCure estimates that of the 12,000 adult nephrologists in the United States, only 350 specialize in treatment and clinical research of primary glomerular diseases. Even in the best situations, it can take patients months or even years to find and access these experts. Those without such access are far too often destined for painful and debilitating journeys to dialysis and transplantation. Sadly, this harsh reality has been deemed 'the norm' for far too long.

To that end, NephCure formally launched our Health Equity Initiative in 2021. The goals of this work are to ensure equitable access to advancements in research, treatments, and care, and to reach individuals from communities of color earlier in their disease progression, preventing or delaying their need for dialysis and transplantation. Commitment, durability, and care of the patient as an individual are essential aspects of the Health Equity Initiative. NephCure has continually adapted its approach using evidence-based strategies and locally-based input to meet the changing needs of patient families. We strongly believe that rare kidney disease awareness requires a grassroots approach to effectively reach a multitude of stakeholders and audiences.

We are pleased to present an overview of the Health Equity Programs that sponsorship dollars will help support in 2022.

REACHING COMMUNITIES OF COLOR AT RISK OF RARE KIDNEY DISEASE

Local, Faith-Based Outreach

In 2021, NephCure collaborated with HEAL Collaborative, a leader in providing health education to Black communities, to launch grassroots kidney health awareness pilot programs in Atlanta and Chicago. By employing a site-specific, faith-based model and leveraging well-established, trusted relationships, HEAL was able to reach individuals at risk of developing kidney disease earlier in their journeys.

Building on this work, we will deepen our relationships and engagement in these communities in 2022 by offering additional in-person education and resources on kidney disease risk factors and treatment options, live screening opportunities to identify kidney disease in its earlier stages, and access to local, expert care and genetic counselors.

These initial programs are designed to help identify best practices, format, and follow-up efforts before rolling out similar programs across the country.

National Online Awareness Campaigns

In June of 2021, NephCure launched a digital advertising campaign with the goal of reaching young Black Americans with information about their risk of chronic kidney disease. This campaign has been a natural complement to our faith-based programming, expanding beyond defined geographic regions to reach people of color across the US who are disproportionately affected by kidney disease. Our efforts have been remarkably successful: our message has reached more than 8 million members of our target audience and generated more than 7,000 new visits to our website.

The success of this campaign led to a video partnership with Olympic gold medalist and NBA hall of fame basketball player Alonzo Mourning, who was diagnosed with rapidly-progressive FSGS in the prime of his career. Using this opportunity to share Alonzo's story, we will extend the digital advertising campaign into 2022 and reach even more Black individuals with details of their risk, signs and symptoms of kidney disease, screening resources, and access to experts.

In addition, we will further expand on our online outreach in 2022 to add kidney disease awareness campaigns specific to Asian American and Hispanic/Latino American communities. These campaigns will be informed by research and community-level insights and be geographically clustered in areas within the US that have a predominance of these populations: the Pacific northwest, California, and New York for Asian American communities, and California, Texas, Florida, and New Mexico for Hispanic/Latino outreach.

SUPPORT, EDUCATION, AND EMPOWERMENT FOR THE RARE KIDNEY DISEASE JOURNEY

In 2022, we are excited to build on our outreach efforts by creating an ecosystem of opportunities for individuals of color who are affected by kidney disease to learn more and continue to engage with NephCure.

NephCure eNewsletters and Educational Resources

Culturally relevant content regarding kidney disease risks, screening options, and research opportunities will be pulled from NephCure.org and pushed out to audiences segmented through our online awareness campaigns. These will include educational resources specifically developed for these communities, patient advocate articles and videos, and other content specific to each audience.

Rare Kidney Disease Listening Tours

Intimate, curated sessions in a safe, welcoming space that will provide a way to engage with, listen to, and

support individuals from communities of color who are living with rare kidney disease. Rare kidney disease advocates and experts will facilitate genuine conversations, cultivating an open dialogue to share personal stories, struggles and offer peer support. These sessions will also help inform NephCure's work in these communities.

Rare Kidney Disease Empowerment Series

Furthering our engagement with individuals from our advertising campaign, these events will bring together top disease experts and patient advocates to present on topics within the glomerular disease space.

Program themes will include:

- *Rare Kidney Disease in Communities of Color: What You Need to Know*

Information on who's at risk, signs and symptoms, getting the right diagnosis, disease progression, and treatment paths.

- *Finding the Right Doctor for Your Rare Kidney Disease*

Discussing how to get access to experts, when to get a second opinion, information on disease recurrence, and innovations in research.

- *Support in Your Daily Life with Rare Kidney Disease*

Touching on popular topics like diet and nutrition, mental health support, and school/work considerations.

NephCure Advocate Profiles

Short, documentary-style videos profiling NephCure partners, patients, and providers, bringing to life their journey as leaders and advocates for communities of color fighting rare kidney disease. Through these human interest stories, we will drive awareness around NephCure's mission and disease resources and build trust within specific communities.

Virtual Summit: Kidney Disease in Communities of Color

This exciting new half-day summit will provide resources, expertise, and guidance to support underrepresented communities living with rare kidney disease. Bringing together and featuring patients, expert physicians, researchers, and other key health care stakeholders, we will educate and empower rare kidney disease patients of color to actively shape their future towards earlier access to care, more accurate diagnoses, and new and better treatments for their condition. Breakout sessions will cover specific considerations for communities of color in relation to rare forms of glomerular kidney diseases.

ACCESS TO INNOVATIONS IN TREATMENTS AND CARE: OUTREACH AND EDUCATION TO HEALTH CARE PROVIDERS

Improving kidney health outcomes requires engagement not just of patients, but of their health care providers as well. NephCure will continue creating targeted awareness pieces for nephrology care providers, increasing their knowledge of rare, glomerular kidney diseases within specific communities of color. We have successfully utilized a range of mediums, including direct mail pieces, advertisements in research journals and trade publications, and social media campaigns (both paid and organic).

In addition, we will continue our Clinical Trials Series with GlomCon and are seeking new partnerships with the American Nephrology Nurses Association and others.

NephCure Virtual Patient Triage Center

An exciting new program in 2022, providing access to trials, testing, treatments, and experts. A dedicated NephCure staff member will be available to guide patients through their diagnosis and disease journey, ensuring that individuals have a trusted source to walk them through a genetic screening, seeking a second opinion, and finding clinical research opportunities that best fit them.



NEPHCURE®
Kidney International

Health Equity Sponsorship Opportunities

Our Health Equity Sponsorship program is an opportunity for companies in our space to join forces with us towards ensuring equity in nephrology research, innovations in treatments, and access to care.

*Unless otherwise indicated, all benefits begin on January 1, 2022 and will continue to December 31, 2022.

HEALTH EQUITY SUPPORTER • \$50,000

Health Equity Supporter Benefits:

- Logo recognition on Health Equity Sponsors page of NephCure.org
- Logo recognition on Health Equity eNewsletters (bi-monthly - 6 total)
- Name recognition in any related press release(s)
- Name recognition on marketing and day-of materials for the Kidney Disease in Communities of Color Virtual Summit

HEALTH EQUITY PATRON • \$100,000

Health Equity Patron Benefits:

- All benefits included with the Health Equity Supporter level
- Logo recognition on marketing and day-of materials for Kidney Disease in Communities of Color Virtual Summit
- Opportunity to hold an exhibit booth at the Kidney Disease in Communities of Color Virtual Summit
- Logo recognition on National Minority Health Month (April 2022) social media campaign posts (12-15 posts across 3 social media channels)

HEALTH EQUITY CHAMPION • \$200,000

Health Equity Champion Benefits:

- All benefits included with the Health Equity Patron level
- Logo recognition on community-based outreach programs (up to two total) - sponsors can choose from either FSGS- or IgAN-specific programming
- Exclusive sponsorship of relevant educational webinars (up to two total)

HEALTH EQUITY PREMIER SPONSOR • \$300,000

Health Equity Premier Sponsor Benefits:

- All benefits included with the Health Equity Champion level
- Recognition as Premier Sponsor on all materials where sponsors are acknowledged
- Premier Sponsorship of the Kidney Disease in Communities of Color Virtual Summit
- Exclusive sponsorship of a relevant educational webinar during Kidney Disease in Communities of Color Virtual Summit
- Sponsorship of a lunch session during the Kidney Disease in Communities of Color Virtual Summit. NephCure will provide attendees with lunch gift card.



Health Equity Sponsorship Opportunities At a Glance

	Health Equity Supporter (\$50K)	Health Equity Patron (\$100K)	Health Equity Champion (\$200K)	Health Equity Premier Sponsor (\$300K)
Recognition on Health Equity Sponsors page of NephCure.org	X	X	X	X
Recognition on Health Equity eNewsletters	X	X	X	X
Name recognition in any related press release(s)	X	X	X	X
Name recognition on marketing and day-of materials for Kidney Disease in Communities of Color Virtual Summit	X	X	X	X
Logo recognition on marketing and day-of materials for Kidney Disease in Communities of Color Virtual Summit		X	X	X
Opportunity to hold exhibit booth at Kidney Disease in Communities of Color Virtual Summit		X	X	X
Logo recognition on National Minority Health Month social media campaign posts		X	X	X
Logo recognition on community-based outreach programs (up to two)			X	X
Exclusive sponsorship of relevant educational webinars (up to two)			X	X
Recognition as Premier Sponsor on all materials where sponsors are acknowledged				X
Premier Sponsorship of Kidney Disease in Communities of Color Virtual Summit				X
Exclusive sponsorship of relevant educational webinar during Kidney Disease in Communities of Color Virtual Summit				X
Sponsorship of lunch session during Kidney Disease in Communities of Color Virtual Summit				X