



NephCure Key Initiatives 2022

Empowering patients and mobilizing stakeholders



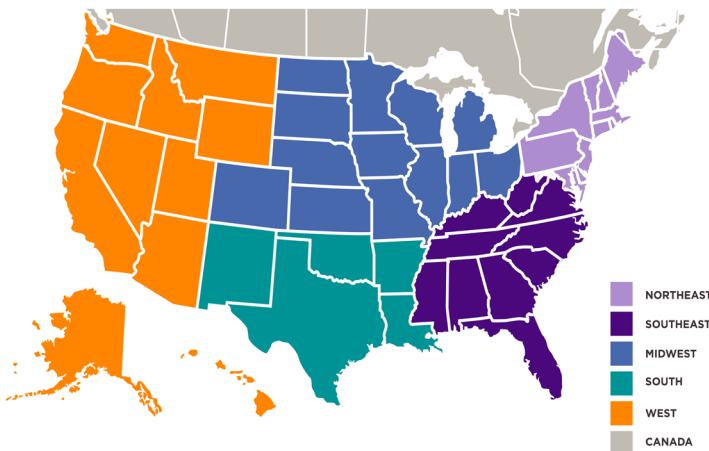
Following incredible achievements in 2021, NephCure heads into 2022 introducing new initiatives and building on the success of core organizational programs. Last year, NephCure unveiled the Corporate Partnership program in response to the ever-growing desire of companies in this space to engage with patients in their discovery process while also elevating the collective rare kidney disease community. This endeavor has created a wonderful win-win situation that enables NephCure to both carry out key programmatic offerings and launch new activities that address stakeholder needs.

In 2022, NephCure will continue to focus on clinical trial awareness, advocacy, health equity, and patient and physician education. NephCure will continue to empower patients through its Regional Community structure, educate and support physicians on treating glomerular disease patients through GlomCon, and focus on clinical trial awareness and connections to expert nephrologists via [KidneyHealthGateway.com](https://www.kidneyhealthgateway.com). Additionally, NephCure will bolster advocacy efforts and introduce a meaningful legislative agenda to drive policy change and help improve the lives of patient families. Sponsorship opportunities for our Health Equity Initiative are available upon request.

Below is an overview of the key NephCure initiatives that sponsorship dollars will help support in 2022:

PATIENT EMPOWERMENT & SUPPORT

Regional Community Programming



NephCure Regional Communities launched in early 2021 with five regions across the US and one in Canada. “Localizing NephCure” has allowed us to successfully build grassroots communities through patient family meet and greets, themed educational gatherings, physician-centered networking events, newly-formed fundraising efforts, and a robust advocacy activation. In 2022, we will continue to offer opportunities for patient families, physicians, and other stakeholders to engage with our mission and grow our movement locally.

NephCure Patient Summit 2022

We're very much looking forward to gathering in-person in Orlando for this multi-day event. Following the success of our virtual format in 2021, we will also offer a livestreaming option for several sessions throughout the weekend. As in the past, patient families will serve as advisors on the agenda and speaker lineup.

Based on feedback from previous summits, NephCure will incorporate clinical trial awareness content into the agenda, including a comprehensive clinical trial panel and opportunities for sponsors to share their trial information directly with patients.

New in 2022, we will offer scholarship opportunities to families who otherwise would not be able to afford to attend the conference in-person. And for the first time ever, we will offer a Youth Summit for children with glomerular disease and their siblings.



NephCure Education and Support Programming

NephCure's educational content and programming are a critical component of our Patient Empowerment & Support efforts. These include website additions that reflect the most up-to-date disease and treatment information, as well as resources that help families navigate specific aspects of their disease journey, such as diet and nutrition and transitioning to a new physician.

Additionally, with the incredible surge of clinical trials in this space, we will focus on trial access and treatment coverage resources. We recognize how critical it is to arm patients with the knowledge and materials needed to ensure they have access to medications, including cutting-edge treatments.

We will continue our popular NephCure U webinars, which are recorded so they can be an enduring patient resource. The [NephCure U](#) programs have also served as an excellent way of directly integrating our NephCure Specialists into the work we do as an organization. Potential topics for 2022 include C3G 101, Plant-Based Diets for Kidney Patients, and Exercising for Your Kidneys. In addition, the ever popular [Chats with Nurse Kristen](#) will continue, along with our mainstay support groups for patients at every age and stage.

CLINICAL TRIAL EDUCATION AND CONNECTION

KidneyHealthGateway.com

Connecting patients to clinical trial opportunities is essential to NephCure's mission of expediting treatment options for rare, protein-spilling kidney diseases. NephCure's online trial matching tool, [KidneyHealthGateway.com](#), continues to garner great traffic and has become a source of new patients who find us while searching for trials.

In 2021, we made important enhancements to the site, including Spanish translation and ensuring GDPR compliance for international visitors.

As the number of patients to the site steadily increases, we are looking to increase nephrologists' awareness of the [Physician Portal](#) found on the homepage of [KidneyHealthGateway.com](#). Those who have discovered this alternative to ClinicalTrials.gov appreciate the ease of navigation and kidney-centric trial listings. We will reach nephrologists through online advertisements, direct mailings, and in-person local cultivation via NephCure volunteers to drive more traffic from new audiences.

Clinical Trial Roundup Series

We are excited to introduce Clinical Trial Roundup webinars in 2022. Sponsors will have the opportunity to present their trial opportunity on a NephCure-hosted and moderated 4-5 minute pre-recorded webinar. NephCure staff will advise sponsors on the content and help guide speakers on how best to share their information in a patient-centric format. These pre-recorded sessions will be shared on NephCure social media outlets and be included in trial listings on [KidneyHealthGateway.com](#). Clinical Trial Roundup sessions will be co-branded with the NephCure and sponsor logos, and the sponsor will also be free to use this recording in their materials.

Patient Study Experience Videos

When study participants share their experience of being part of a trial—the expert care they receive, the opportunity to move research forward, the empowerment they feel in taking control of their health future—it can be an incredibly compelling way to generate interest among their peers to get involved in trial opportunities. NephCure will gather video interviews from patients who have participated in trials and produce patient study experience videos. The patient stories will be representative across glomerular disease states and encourage patients to find the study that's right for them.

Industry Workshops

Lastly, new in 2022, NephCure will introduce three industry-focused workshops for sponsors. These 90-minute programs are meant to educate Corporate Partners on important aspects of running trials in the rare kidney disease space. We'll bring expert panelists to the table to share their advice and best practices across stakeholder groups. Potential topics include:

- Incorporating pediatrics into your studies - considerations and next steps.
- Enhancing diversity and outreach strategies.
- Designing trials for the average person - minimizing patient burden.

HEALTH EQUITY INITIATIVE

Chronic Kidney Disease and FSGS disproportionately affect 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 thought to be associated with one of the most severe forms of this kidney disease. It 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.

NephCure estimates that of the 12,000 adult nephrologists in the United States, only 350 specialize in treatment and clinical research of FSGS and other 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 at-risk individuals earlier in their disease progression, preventing or delaying the need for dialysis and transplantation. Commitment, durability, and care of the patient as an individual are essential aspects of the Health Equity Initiative.

Local, Faith-Based Outreach

In 2021, NephCure joined forces 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 our work, in 2022 we will deepen our relationships and engagement in these communities and offer additional education on risk factors and treatment options, screening opportunities to identify kidney disease in its earlier stages, and access to expert care and genetic counselors.

We are committed to an enduring relationship in these communities and are confident that we will see tangible success in changing the current inequities that exist in the treatment and care of patients, families, and communities impacted by kidney disease.

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 and Education

In June of 2021, NephCure launched a digital advertising campaign with the goal of reaching young Black Americans with information about the 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 United States 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 has 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 famer, 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 at-risk individuals.

Furthermore, in 2022, we are excited to expand on these efforts by creating an ecosystem of messaging and opportunities for individuals of color who are affected by kidney disease to continue to engage with NephCure and learn more. We will accomplish this through:

- **Culturally relevant content** regarding kidney disease risks, screening options, and research opportunities, including educational resources, blog posts, newsletters, and social media posts.
- **Rare Kidney Disease Listening Tours:** Intimate, curated sessions that provide an innovative way to engage with, listen to, and support individuals living with rare kidney disease from communities of color. Rare kidney disease advocates and experts will facilitate genuine conversations to help inform NephCure's initiatives.
- **Conversation Series:** Furthering our engagement with individuals from our advertising campaign, these events will broaden the kidney disease conversation towards a fuller understanding of the social determinants of health that affect kidney health outcomes in communities of color.
- **Advocate Profiles:** Videos featuring NephCure partners, patients, and providers, bringing to life their journey as leaders and advocates for underrepresented communities fighting rare kidney disease, specifically FSGS.
- **Virtual Summit:** This exciting new half-day summit will provide resources, expertise, and support

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for science-based policymaking and on-the-ground community work to support underrepresented communities living with rare kidney disease, and will inform, educate, and empower patients of color with rare kidney disease.

NEPHCURE ADVOCACY ACTION NETWORK

Building on the momentum of the Advancing American Kidney Health executive order, NephCure joined forces with Travele Therapeutics (formerly Retrophin) and the American Association of Kidney Patients in September 2020 to host a roundtable with policymakers on rare kidney disease. Leading up to the roundtable, three cross-stakeholder workgroups met to exchange ideas and identify actionable steps toward improving outcomes for families impacted by rare kidney disease. Albeit a tall order, this team of committed patients, nephrologists, advocacy group representatives, and health care leaders worked together to produce a white paper titled [We Deserve Better: Revolutionizing Rare Kidney Disease](#). This community call-to-action helped further NephCure's advocacy agenda and will serve as a framework to build a year-round public policy program.

Both the near-term discovery of new treatments and spotlight on healthcare policy underscore the need for NephCure to prioritize government advocacy. Internally, developing an advocacy network complements other concurrent organizational initiatives, such as implementing clinical trial awareness campaigns, improving patient access to expert care, executing our [Health Equity Initiative](#), and fortifying our Regional Community Program — which provides the infrastructure to engage and mobilize willing advocates to help advance the cause.

With dedicated resources to champion the legislative agenda and build congressional support around rare kidney disease, we are now able to enact meaningful change for families through the NephCure Action Network (NCAN). This initiative will benefit all stakeholders and confront challenges that can only be addressed through policy.

PHYSICIAN EDUCATION

GlomCon

Since 2019, NephCure has worked closely with the Glomerular Disease Consortium (GlomCon), founded and led by Ali Poyan Mehr, MD. What started as a monthly *Clinical Trial Conference Series* has evolved into a deeper partnership between the two organizations. NephCure is pleased to have supported the inaugural year of the GlomCon [Fellowship Program](#), which graduated 54 fellows who are now trained in understanding glomerular diseases. Our collaboration with GlomCon will continue to grow — we plan to add activities dedicated to educating nephrologists on conducting clinical trials and building general awareness of current trial opportunities.

In the coming year, we will continue to co-host monthly GlomCon Clinical Trial Conference sessions, featuring a different sponsor and study opportunity each session.

As an extension of the GlomCon partnership and with the goal of educating more nephrologists on running clinical trials, NephCure and GlomCon will jointly submit a proposal for Kidney Week 2022. This module will include learning objectives set in consult with experienced glomerular disease specialists and led by nephrologists from both academic and community-based practices. In recent years, attendance at glomerular disease focused sessions has increased exponentially, demonstrating a growing interest in the rare kidney disease space.



Corporate Partnership Opportunities

We are delighted to offer our Corporate Partnership Program, an opportunity for the companies in our space to join forces with us to expedite new and better treatments and improve the quality of life for families impacted by rare protein-spilling kidney diseases.

Special notes:

- Unless otherwise indicated, all benefits begin at contract signing and will continue through December 31, 2022. Sponsors who sign on during or after March, 2022 will be recognized at the 2023 Patient Summit.
- Benefits may not be relevant for all sponsors depending on clinical trial development phase. No substitutions or refunds will be given for declined benefits. Each benefit level offers promotion of your company's brand as a trusted partner of NephCure, which is impactful for companies at all stages of development.
- Trial-specific promotion benefits are available for an additional fee for sponsors at the Bronze level and above. These benefits are first-come, first-served and scheduling is at the discretion of NephCure.

KIDNEY HEALTH GATEWAY PARTNER \$15,000

Kidney Health Gateway Partnership Benefits:

- Clinical trial site-level customization of contact information and trial detail pages on KidneyHealthGateway.com website and twice per month notification of which sites received inquiries. (90,000 average unique visitors per year)
- Patient Advisory Board/Patient Interviews - NephCure will hand-select 4 to 8 patient representatives (depending on format) whose diagnosis and disease stage will help inform your trial protocol, site selection, and outreach

FRIENDS OF NEPHCURE PARTNER \$20,000

Friends of NephCure Partnership Benefits:

- Clinical trial site-level customization of contact information and trial detail pages on KidneyHealthGateway.com website and twice per month notification of which sites received inquiries. (90,000 average unique visitors per year)
- Invitation to 3 virtual industry-focused education workshops
- Exhibit at the NephCure Patient Summit in April 2022 (300 in-person and online attendees estimated)
- Link to KidneyHealthGateway trial listing on NephCure's disease-specific Trial Tables for patients and physicians

BRONZE PARTNER \$50,000

Bronze Partnership Benefits:

- All benefits included with the Friends of NephCure Partner level
- Opportunity to present in person or virtually about your clinical trial at the NephCure Patient Summit (300 in-person and online attendees estimated)
- Access to Patient and Physician Listening Session recordings from 2020 and 2021
- Logo on NephCure.org (1.3 million average unique visitors per year)
- Logo on the NephCure Patient Summit registration site
- Additional trial-specific promotion activities available for an added fee

SILVER PARTNER \$75,000

Silver Partnership Benefits:

- All benefits included with the Bronze Partner level
- Logo on the NephCure monthly eNewsletter (7,000 subscribers and a 35% open rate)
- Logo on KidneyHealthGateway.com (90,000 average unique visitors per year)
- Logo recognition on one existing disease-specific webpage of company's choice on NephCure.org. Sole logo display is not guaranteed. (1.3 million average unique visitors per year)
- Clinical Trial Roundup Webinar – pre-recorded 5 minute webinar about company trial or topic of company's choice. This video will be posted on the trial-specific page of KidneyHealthGateway and will be co-branded and posted on YouTube, for the company's use
- Additional trial-specific promotion activities available for an added fee

GOLD PARTNER \$100,000

Gold Partnership Benefits:

- All benefits included with the Silver Partner level
- Company's trial listing on KidneyHealthGateway.com will be featured on a disease-specific KidneyHealthGateway engagement email. Sole trial feature is not guaranteed. (90,000 average unique visitors per year)
- Check in/collaboration meetings with NephCure staff, up to once per month
- Company trial featured on a GlomCon Clinical Trial Session (6,000 YouTube channel subscribers)
- Additional trial-specific promotion activities available for an added fee (with a 5% discount)

PLATINUM PARTNER \$150,000

Platinum Partnership Benefits:

- All benefits included with the Gold Partner level
- Invitation to Nephrotic Syndrome patient journey webinar for study teams
- One feature article related to your trial or your trial's disease population in NephCure's monthly eNewsletter, featuring a link to your trial on KidneyHealthGateway.com (7,000 subscribers and a 35% open rate)
- Logo on NephCure Patient Summit materials (300 in-person and online attendees estimated)
- Logo on NephCure's biweekly Need to Know eNewsletter (7,000 subscribers and a 45% open rate)
- Additional trial-specific promotion activities available for an added fee (with a 10% discount)

PREMIER PARTNER \$200,000

Premier Partnership Benefits:

- All benefits included with the Platinum Partner level
- Trial featured on the homepage of KidneyHealthGateway.com (90,000 average unique visitors per year)
- Sponsorship of Clinical Trial Readiness Masterclass at ASN Kidney Week 2022
- Representation on clinical trial panel discussion at the NephCure Patient Summit (300 in-person and online attendees estimated)
- Logo recognition on TWO TOTAL existing disease-specific webpages of company's choice on NephCure.org. Sole logo display is not guaranteed. (1.3 million average unique visitors per year)
- Additional trial-specific promotion activities available for an added fee (with a 15% discount)

PRESENTING PARTNER \$500,000+ (LIMITED SPOTS AVAILABLE)

Presenting Partnership Benefits:

- All benefits included with the Premier Partner level
- Sponsorship of GlomCon Fellowship Course Directors
- Recognized as Presenting Sponsor on all Corporate Partner recognition
- Trial featured at the top of the KidneyHealthGateway search results (90,000 average unique visitors per year)
- Presenting Sponsor of the NephCure Patient Summit (300 in-person and online attendees estimated)
- One special patient educational programming session on a topic of your choice as the sole sponsor
- Additional trial-specific promotion activities available for an added fee (with a 20% discount)

SPECIAL MENU FOR BRONZE AND HIGHER LEVEL PARTNERS

Please note: these opportunities are first-come, first-served and scheduled at NephCure's discretion. Partners can choose up to one benefit from each category.

*5% OFF FOR GOLD PARTNERS

*15% OFF FOR PREMIER PARTNERS

*10% OFF FOR PLATINUM PARTNERS

*20% OFF FOR PRESENTING PARTNERS

Deliverable	Cost Per Deliverable	Additional Fees	Notes
Geotargeted email around study site markets to patients and physicians	\$12,500* for up to 50 sites	Fee of \$3,000 per additional 50 sites	
Postcard mailing to patients or physicians	\$15,000*		NephCure will design the postcard about trial. Company can provide feedback on design direction (up to 2 rounds).
Patient advisory board	\$5,000 minimum*	Additional fees based on scope, audience, and number of participants	
Post in relevant private patient Facebook group	\$7,500*		
(For Silver Partners and up) Post of Clinical Trial Roundup Video to NephCure's social media	\$7,500*		



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Kidney International

Corporate Partnership Benefits At a Glance



	Kidney Health Gateway Partner (\$15K)	Friends of NephCure Partner (\$20K)	Bronze Partner (\$50K)	Silver Partner (\$75K)	Gold Partner (\$100K)	Platinum Partner (\$150K)	Premier Partner (\$200K)	Presenting Partner (\$500K+) (limited spots available)
Customization of trial listing on KidneyHealthGateway.com (and twice per month notification of inquiries)	X	X	X	X	X	X	X	X
Patient Advisory Board	X							
Invitation to 3 industry-focused education workshops		X	X	X	X	X	X	X
Exhibit at the NephCure Patient Summit		X	X	X	X	X	X	X
Link to KidneyHealthGateway trial listing on NephCure's Trial Table for patients and physicians		X	X	X	X	X	X	X
Opportunity to present in person about your clinical trial at the NephCure Patient Summit			X	X	X	X	X	X
Access to Patient and Physician Listening Session recordings			X	X	X	X	X	X
Logo on NephCure.org			X	X	X	X	X	X
Logo on the Patient Summit registration site			X	X	X	X	X	X
Logo on NephCure monthly eNewsletter				X	X	X	X	X
Logo on KidneyHealthGateway.com				X	X	X	X	X
Logo recognition on one existing disease-specific webpage of company's choice on NephCure.org (sole logo display not guaranteed)				X	X	X		
Clinical Trial Roundup Webinar - a pre-recorded, co-branded 5 minute video about trial				X	X	X	X	X
Company trial featured on a disease-specific KidneyHealthGateway engagement email					X	X	X	X
Check in/collaboration meetings with NephCure staff (up to once per month)					X	X	X	X
Company trial featured on a GlomCon Clinical Trial Session					X	X	X	X
Invitation to Nephrotic Syndrome patient journey webinar for study teams						X	X	X
One feature article on your trial or your trial's disease population in NephCure's monthly eNewsletter						X	X	X
Logo on NephCure Patient Summit Materials						X	X	X

	Kidney Health Gateway Partner (\$15K)	Friends of NephCure Partner (\$20K)	Bronze Partner (\$50K)	Silver Partner (\$75K)	Gold Partner (\$100K)	Platinum Partner (\$150K)	Premier Partner (\$200K)	Presenting Partner (\$500+) (limited spots available)
Logo on NephCure's biweekly Need to Know eNewsletter						X	X	X
Trial featured on the homepage of KidneyHealthGateway							X	X
Sponsorship of GlomCon Clinical Trial Readiness Masterclass at ASN Kidney Week							X	X
Representation on clinical trial panel discussion at the NephCure Patient Summit							X	X
Logo recognition on TWO TOTAL existing disease-specific webpages of company's choice on NephCure.org (sole logo display not guaranteed)							X	X
Sponsorship of GlomCon Fellowship Course Directors								X
Recognized as Presenting Sponsor on all Corporate Partner recognition								X
Trial featured at the top of KidneyHealthGateway search results								X
Presenting Sponsor of the NephCure Patient Summit								X
One special patient programming session of your choice as the sole sponsor								X