



National Institute of
Diabetes and Digestive
and Kidney Diseases

Kidney Interagency Coordinating Committee Meeting

Kidney Community Partnerships for Research

Natcher Conference Center, Room D
National Institutes of Health
Bethesda, MD
and Virtual
October 6, 2023

Meeting Summary

Welcome

Robert Star, M.D., Director, Division of Kidney, Urologic, and Hematologic Diseases (KUH), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH)

Dr. Robert Star welcomed members and attendees to the NIDDK Kidney Interagency Coordinating Committee (KICC) meeting, with in-person and virtual attendance. He reminded participants that the KICC was mandated by Congress in 1987. Because of the enthusiasm and under the leadership of Dr. Andrew Narva, KICC's Executive Secretary at the time, the structure changed from a *pro forma* meeting to one that meets twice yearly, with the goal of coordinating a federal response to chronic kidney disease (CKD). The aim is to encourage cooperation, communication, and collaboration among all federal agencies engaged in kidney research and related activities. Dr. Star noted that today's meeting focuses on advancing innovations in kidney health and provides an opportunity to listen to one another's ideas and priorities and brainstorm on how to move forward. The goal is to create a consensus message on what is needed to advance kidney health.

Dr. Star expressed appreciation to Dr. Susan Mendley, Program Manager, NIDDK, and Executive Secretary, KICC, and Dr. Jenna Norton, Program Director, NIDDK, for organizing the meeting.

The Patient Perspective

Dawn Edwards, Co-Chair, National Forum of End-Stage Renal Disease (ESRD) Networks, Kidney Patient Advisory Council

Ms. Dawn Edwards explained that having kidney disease is not an easy journey and hopes that sharing her experience will set the stage for the discussions that will follow. She is originally from Brooklyn, NY; currently resides in Queens, NY; and is 55 years old. She was diagnosed with kidney disease in 1991 and lost kidney function as the result of an unresolved *staphylococcus* infection. She visited her doctor for a pregnancy test and left with an appointment with a nephrologist. This is when she discovered that she had kidney disease. She has had several forms of renal replacement therapy (RRT), which has saved her life. She is active in many kidney organizations and has been a patient advocate for several years. After 3.5 years on hemodialysis (HD), she sensed something was wrong, was not feeling comfortable in her skin, and her life was falling apart. She lost her job with the Postal Service, and her marriage fell apart because she was always sick. Thankfully, she was introduced to home therapies early in her journey and started peritoneal dialysis (PD), which lasted for 10 years. It was then she realized that she could have a better quality of life because she thought she had only a few years to live. More frequent PD worked better for her. Ms. Edwards

emphasized that not all modalities work for all patients. Patients are all different and need different prescriptions and different treatment modalities to achieve the quality of life that works best for them. She learned more about kidney disease, got involved with her local ESRD network, and became a patient advocate. She also connected with as many kidney organizations as possible to ensure that patients knew about their treatment options, especially patients in underserved communities.

As a resident of an underserved community herself, Ms. Edwards was not told about her treatment options. She ended up in a dialysis chair and thought that was where she would spend the rest of her life. She highlighted that being a patient advocate has been a rewarding experience. She has had the opportunity to speak to thousands of patients over the past 30 years, and a common theme is that “kidney disease is no picnic.” Patients suffer from frequent hospitalizations, lifestyle changes, and socioeconomic changes that accompany the lifestyle changes. She was too sick to be with her friends and participate in the types of activities in which they engage. She emphasized the importance of understanding the individuality of kidney patients. She currently is on home HD after her PD and transplant failed. To live for a long time and continue to keep moving, patients have to choose different modalities. Consider the perspective of the hundreds and thousands of dialysis patients who sit in dialysis chairs or undergo dialysis treatments at home and do not feel well after the treatments. Their lives are changed, and they can no longer afford the food they need.

Ms. Edwards called attention to the May 22–23, 2023, meeting titled A Scientific Workshop on Post-Dialysis Fatigue, which focused on an unrecognized complication of dialysis. Several dialysis patients representing different patient organizations attended. The discussions focused on the difficulty patients have in managing their lives with kidney disease. She pointed out that dialysis therapy has been around for decades, but the field has not made progress in finding a way for patients to feel better after dialysis treatments and experience improved quality of life. Ms. Edwards currently works part-time jobs in the advocacy field, which supplement her income and make her feel better as a person. She is able to purchase some of the foods she should have as a kidney patient. Many of these foods are not readily available in her neighborhood. The post-dialysis fatigue workshop highlighted many issues patients already knew about kidney disease but were not sure they needed to address in order to have a better quality of life. She hopes that the workshop encouraged people to work together and that they will take the time to consider patients undergoing dialysis treatments three times a week, some more frequently, and think about how to make their journeys easier and improve their quality of life. Patients do not want kidney disease to be a death sentence; they want to live, work, and see their grandchildren grow up. Kidney disease patients want to do the same things that everyone else does, and they want to contribute to society.

Ms. Edwards noted that she does not have the answers regarding ways of improving the outcomes for kidney disease patients and will leave it up to the attendees at this meeting to find the solutions. She is pleased with the opportunity to work with NIH and NIDDK on the various community boards, advisory councils, and on some studies. Through that work, she has learned that people care about kidney disease patients and want their voices to be heard. She appreciates the advocacy work, which is rewarding and provides an opportunity to speak up for what is important to patients. Often, what scientists think is important to patients is not. What indeed is important are day-to-day living, enjoying life, and participating in activities that were possible before receiving a diagnosis of kidney disease.

Snapshot of Kidney Research at NIDDK

Robert Star, M.D., NIDDK, NIH

Dr. Star presented on promoting innovative breakthroughs in kidney health, including future projects and kidney research training. Dr. Star reminded participants that NIH is the nation’s biomedical research agency and has the mission to seek fundamental knowledge about the nature and behavior of living systems and apply that knowledge to enhance health, lengthen life, and reduce illness and disability. In this context,

Dr. Star noted some critical questions that kidney patients would like answered: What do I have? What will happen to me? What can I do about it? What does it mean for my family? NIDDK is designing studies to address some of these questions. In addition, NIDDK has made significant investments in kidney health, extending from bench to bedside to the community and involving an iterative scientific journey of evidence. Research initiatives include the early efforts of the United States Renal Data System (USRDS) and a more recent program involving interventions that address structural racism to reduce kidney health disparities. In fiscal year 2022 (FY22), NIDDK invested \$336 million in kidney health: 64 percent supported investigator-initiated research (R01); 15 percent supported research consortia; 10 percent supported training; and 11 percent supported centers, large team grants (RC2), exploratory/developmental research grants (R21), and other miscellaneous expenses. In FY22, NIDDK supported 472 investigators, 83 of whom were early stage investigators.

NIDDK Future Projects

Dr. Star highlighted four NIDDK future projects that span clinical and basic science. First is a post-dialysis fatigue syndrome initiative in the area of clinical science. The aforementioned post-dialysis workshop highlighted that following dialysis, more than half of people experience debilitating fatigue and other symptoms that limit daily activities. This syndrome is devastating and debilitating, and addressing it is a critical need that was underrecognized for decades. The need exists to create proper evidence about the condition, rectify it scientifically, and help people with post-dialysis syndrome improve their health and possibly return to work. The key is to work closely with people on dialysis (at all steps). The next step will be to work with the U.S. Food and Drug Administration (FDA) and Centers for Medicare & Medicaid Services (CMS) to fund a consortium to address the needs.

The second project is the [ReBuilding a Kidney \(RBK\) Technology Hub and INcubator for the Kidney \(THINK\)](#). The RBK 10-year project began in 2015 to engineer kidneys for those who need them using regenerative medicine. The goals are to build a biologic replacement kidney and rebuild damaged kidneys to restore failing kidney function. NIDDK is proposing RBK THINK as a bioengineering technology incubator to accelerate innovation and act as a catalyst for research discoveries in kidney bioengineering. THINK will adopt a Shark Tank–like approach to identify ground-breaking bioengineering projects that move the field forward; focus on small parts of the research (e.g., conduits) at a time; and promote interactions and collaboration (i.e., incubator).

The third project is expanding the [Kidney Precision Medicine Project \(KPMP\)](#). The current KPMP aims to address what patients want to know: 1. What do I have? 2. What will happen to me? 3. What can I do about it? 4. What does it mean for my family?—a customized precision medicine approach. This approach entails applying next-generation science to a heterogeneous group with a disease (e.g., people with CKDs and AKI); identifying the biologic subtypes of CKD and AKI; and designing an intervention for each subtype, thus achieving successful kidney and cardiovascular health. The KPMP was designed to understand human kidney diseases to improve treatment, which is the scientific component of this approach. The goals are to ethically obtain and evaluate research kidney biopsies from participants with acute kidney injury (AKI) or CKD; define disease subgroups from the biopsies; identify critical cells, pathways, and targets for novel therapies; and create a kidney tissue atlas. The main outcome is to improve the pipeline of kidney disease drugs. To date, 270 biopsies have been obtained, and the majority are from participants with CKD. Numerous individual investigators and drug companies have downloaded the [KPMP Kidney Tissue Atlas](#). NIDDK is sharing the atlas ahead of publication as soon as data have been validated. In the next phase, NIDDK is proposing a pediatric KPMP. Pediatric patients are at high risk for developing damaging long-term outcomes over their lifetimes. NIDDK is assessing the ethical issues of such a project.

The fourth project is the Precision Clinical Trials project, which matches participants to multiple drugs simultaneously using the precision medicine approach of the KPMP. The steps include performing laboratory tests on participants with CKDs (e.g., stratifying into biology-driven subgroups based on specific

biomarkers); presenting to a molecular kidney board (similar to a cancer tumor board); and matching subgroups to a clinical trial and treatment/protocol. For this project, NIDDK will need investigators to develop new clinical trial designs for heterogeneous treatment effects, identify new biomarkers to match patients to drugs, and develop screening and matching protocols and infrastructure that will work with new and existing drugs. Participants can be rescreened as new drugs are developed. A trial design with a common placebo group can be considered and would reduce time.

To nurture (i.e., de-risk) the next generation of CKD treatments, NIDDK will need to establish a public-private partnership. Interested parties would include NIDDK to provide the research cohorts, scientific knowledge, and expertise; a strong patient voice that would be involved in all phases of trial design; professional societies and advocacy groups that already have screening and registries in place; and industry commitment to sponsor clinical trials. The NIDDK KUH will work closely with the FDA regarding drugs, devices, and biologics and will facilitate a CMS-NIH-wide consultation service. The project will have a commitment to open science, data sharing of human biopsy data, and equitable access, and it will provide a safe harbor and common infrastructure for discovery and an observational cohort for biomarker testing. NIDDK intends to emulate the infrastructure of the cancer and cystic fibrosis research communities and will need all parties working together to address kidney health.

Kidney Research Training Ecosystem

Dr. Star explained that Dr. Tracy Rankin, Deputy Director and Director of Career Development and Training for Kidney and Urologic Diseases, KUH, and her team have developed a pipeline of training programs spanning from high school and undergraduate to faculty. In FY22, NIDDK had 339 trainees in kidney research and, across the training programs, provided 182 Career Development Awards (K awards) to more senior fellows and faculty members in the pipeline. Dr. Star noted that NIDDK observed that trainees rarely completed the entire pipeline and changed its approach to training. The KUH family of awards soon will launch and will connect trainees along the pipeline to ensure equal access to the training resources. Approximately 20 percent of trainees supported by the NIDDK Institutional Training Grant (T32) continued to become NIDDK-funded investigators. In 2021, NIDDK launched the Institutional Network Award (U2C) to replace the T32 to enhance peer-to-peer communication, promote professional development, cultivate community outreach, and engage multidisciplinary faculty mentors.

In closing, Dr. Star announced that NIDDK will celebrate its 75th anniversary in 2025 and will be reaching out to the KICC about activities to feature.

Veterans Health Administration (VHA)

Susan Crowley, M.D., M.B.A., FASN, Executive Director, Veterans Health Administration Kidney Medicine Program

Dr. Susan Crowley described the U.S. Department of Veterans Affairs (VA) Kidney Medicine Program research agenda. She acknowledged her colleagues who have contributed to this program and research agenda: Dr. Paul Palevsky, Deputy National Program Director of the VHA Nephrology Program and Deputy Executive Director, VA Kidney Medicine Program; Dr. Grant Huang, VA Deputy Chief Research and Development Officer, Enterprise Optimization Director, Cooperative Studies Program; Dr. James Kaufman, VA Associate Chief of Staff for Research, New York Harbor Health Care System; and Dr. Areef Ishani, VA Minneapolis Health Care System. The specific mission of this program is to discover mechanisms of disease and health system factors contributing to the impairment of kidney health, and to develop and promote awareness of the means to optimize the kidney health of the veteran population.

The research agenda aligns with the VA Kidney Medicine Program Strategic Plan. The strategic plan goals are to provide access to VA kidney health care; promote quality in the delivery of VA kidney health services along the continuum of the veteran patient journey; build the resilience of VA kidney health care services;

advance health equity in the delivery of VA kidney health care; and establish the VA as the premier learning health care organization.

Dr. Crowley further detailed the VA as a learning health care organization. The VA encourages investigator interest in kidney medicine through mentoring and expanding research funding opportunities. The VA also promotes adoption of VA innovations in kidney care delivery and disseminates those that enhance health care value. She credits Dr. Palevsky for his mentorship of generations of research investigators within the VA. Establishing such an organization has six objectives: measure the VA kidney medicine research portfolio; provide advocacy and support for VA investigator research; provide VA kidney medicine program letters of support for proposals and facilitate mentorship; align the VA kidney medicine program and its [Office of Research and Development](#) priorities; assess the value of innovations in VA kidney health services; and communicate the VA's value as a learning health care system. In FY23, the VA invested \$24 million in its kidney health research portfolio. Funding has steadily increased from FY20 to FY23, with two consecutive years exceeding \$20 million. The majority of funding supports basic science, with a growing increase in health service research and development. Despite the steady increases, the FY23 funding remains lower than FY 2010 funding.

Dr. Crowley noted the VA unmet research needs. Comparative economics of VA and purchased community health care are needed. Drivers of kidney health outcome quality disparities are lacking. Mitigation of research barriers regarding data security, data sharing requirements, and laboratory data standardization is needed. VA participation in externally funded ESRD studies is limited. Infrastructure is lacking for implementing industry-sponsored VA multicenter trials through Cooperative Research and Development Agreements. Despite these unmet needs, Dr. Crowley highlighted that the VA is an ideal arena for performing basic science research, conducting conventional multicenter trials in CKD and ESRD care (e.g., Acute Renal Failure Trial Network), and promoting innovation in clinical research design.

American Association of Kidney Patients (AAKP)

Paul T. Conway, Chair of Policy and Global Affairs, AAKP

Mr. Paul Conway described the principles, priorities, and capacities of AAKP. He acknowledged AAKP President Edward Hickey III and immediate past President Richard Knight. Founded in 1969, AAKP adopted a strategy and implemented operations based on principle. AAKP expands patient consumer care choice for all patients, regardless of background or demographics; protects the integrity of the patient–doctor relationship; and drives patient-centered innovation, from concept through to payment. AAKP believes that shared principles determine future collaborations and allies. In addition, AAKP preserves full independence in all its activities.

Mr. Conway detailed key national and global initiatives of AAKP that are used to drive policy and address issues, including research funding. In 2019, AAKP declared the Decade of the Kidney™ from 2020 to 2030, aligning with the efforts of the *Executive Order on Advancing American Kidney Health*. The AAKP KidneyVoter™ was established in 2018, and the 2024 goal is have 500,000 self-identified kidney voters actively voting in elections. This initiative focuses on voter registration and is nonpartisan. AAKP developed Patient Voice Patient Choice™, a platform to elevate the voices of patients across government, both in the Executive Branch and on Capitol Hill. At the VA Kidney Summit in 2017, AAKP launched the Veterans Health Initiative™ to bring grassroots attention to the needs of veterans and to support VA efforts to help better connect veterans who may not be in the VA system with the benefits that they have earned. The AAKP National Patient Ambassadors program, composed of several hundred participants, involves AAKP's most prolific activists on social media. These ambassadors bring attention to special issues, work within their respective states, and often are representatives on Capitol Hill. AAKP recently partnered with the VHA and also launched the AAKP Veterans and Military Family Ambassadors to help patients receive the maximum benefits they have earned. This Ambassadors effort is spearheaded by AAKP Vice President Jennifer Jones, who is a U.S. Marine Corps combat veteran. The global initiative,

AAKP Global™, is composed of allied international patient networks. AAKP partners with The George Washington University to co-sponsor the Annual Global Summit on Kidney Disease Innovations.

From the standpoint of policy and advocacy, AAKP believes that research informs all policies. Funding priorities advance positive policies for patients and those policies that are patient centered. AAKP views the federal government's role with kidney patients as extending beyond the jurisdiction of just the U.S. Department of Health and Human Services (HHS) agencies; rather, AAKP views kidney disease as a cross-Cabinet issue and works with many federal agencies. Mr. Conway noted ongoing cross-Cabinet policy and budget priorities: (1) expand the use of patient insight data across all federal research, regulatory, and payment deliberations; (2) support NIH/NIDDK KPMP science and future applications; (3) support the HHS Kidney Innovation Accelerator (commonly called KidneyX) and related funded innovations and long-term program priorities; (4) engage U.S. leadership in artificial implantable and wearable organs, xenotransplantation, and bioengineered kidneys through a global consortium; (5) support expansions in VA and U.S. Department of Defense kidney research and care innovations; (6) promote a new CMS transplantation payment model; (7) promote the next generation of transplant drugs through a new FDA-approved co-primary endpoint; (8) promote timely access to new innovations in infection control and prevention; and (9) prepare for natural and unnatural events regarding emergency planning and response and patient care.

Select emerging research and policy interests for AAKP include so-called Government Determinants of Health (GDOH), veterans' health, kidney treatment, disability, and unemployment, as well as shared decision-making as defined by patients. Mr. Conway defined GDOH as the negative impacts of regulatory and payment decisions on innovation and timely patient access, as well as the use of discriminatory quality-adjusted life years and similar measures. Mr. Conway noted that AAKP sponsors five major events annually to bring attention to issues that need to be addressed, and he highlighted some of the activities of the AAKP [Center for Patient Engagement and Advocacy](#) and [Center for Patient Research and Education](#).

American Society of Nephrology (ASN)

Michelle Josephson, M.D., FASN, President, ASN Council

Dr. Michelle Josephson explained that in 2019, the federal government prioritized improving kidney health, which became a basis for the ASN campaign: "We Are United 4 Kidney Health." This perspective aligns with ASN's four priorities: intervene early, transform transplant, accelerate innovation, and achieve equity. Dr. Josephson outlined ASN's five key recommendations for kidney health: (1) support training programs to promote the research workforce; (2) invest in research on accurate, unbiased, and precise glomerular filtration rate (GFR) measurement and estimation; (3) prioritize equity-related research across kidney diseases, including transplantation; (4) ensure the integrity of kidney health data sets throughout HHS; and (5) explore increased federal coordination on kidney health. She further elaborated on issues, as well as progress related to each of these recommendations.

ASN has observed that KUH's transition from T32s to U2C may have resulted in nephrology's having less support for research training. Many training institutions relied heavily on funding from T32s for the success of their programs. Research training (and funding) in nephrology is fundamentally different from in hematology and urology. The question to be addressed is how the kidney community can collaborate with KUH to ensure the success of the U2C program. In 2020, the National Kidney Foundation (NKF) and ASN collaborated (i.e., NKF-ASN Task Force) to determine whether race can be removed from the estimated GFR (eGFR) equation and still have that equation efficiently assess kidney function. In its [final report](#), the NKF-ASN Task Force highlighted the importance of newer approaches that generate accurate, unbiased, and precise GFR measurements and estimation without the inclusion of race and promote health equity, but not generate disparate care.

Prioritizing the recognition of problems in equity, health care, and research dates back 40 years, with the release of the Heckler Report (*Report of the Secretary's Task Force on Black and Minority Health*). ASN is committed to addressing health equity and is supporting and prioritizing equity-related research. Recent studies have indicated differences across three HHS gold-standard data sets—the Organ Procurement and Transplantation Network, the Scientific Registry of Transplant Recipients, and USRDS—regarding patient death data in the same set of transplant recipients and waitlisted candidates. ASN welcomes any suggestions from the KICC on how the Society can help address these inconsistencies to ensure the accuracy of these critical data and promote appropriate data-sharing across HHS agencies. ASN is exploring ways to help the kidney research and kidney health communities increase federal coordination on kidney health and proposes establishing an NIH center for kidney health and transplantation research and an HHS office of kidney health and transplantation.

American Society of Pediatric Nephrology (ASPN)

Jodi Smith, M.D., M.P.H., President, ASPN

Dr. Jodi Smith highlighted the statistics on pediatrics and kidney disease research and activities of ASPN, the only organization devoted specifically to addressing the needs of children and adolescents with kidney disease. ASPN is composed of nearly 800 pediatric nephrologists and affiliated health care professionals in North America. The primary goals are to (1) promote optimal care for children with kidney disease through advocacy, education, and research and (2) disseminate advances in clinical practice and scientific investigation. An estimated 150,000 children and adolescents have kidney disease, of whom approximately 10,000 have end-stage kidney disease (ESKD) primarily attributed to congenital anomalies of the kidneys and urinary tract. Pediatric nephrologists are observing an emerging neonatal population with high prevalence of kidney disease, with 20 percent of neonatal intensive care unit patients developing AKI. Dr. Smith announced that CARPEDIEM (Cardio-Renal Pediatric Dialysis Emergency Machine) was recently FDA-approved to provide continuous RRT for babies weighing between 5 and 20 pounds, and it allows these patients to be treated in an outpatient setting.

Dr. Smith emphasized that the study of kidney disease in children is an opportunity to understand disease progression and impact of kidney disease across the age spectrum. For example, research about the nephrogenesis and development of CKD early in life offers an opportunity to develop therapies targeting CKD development. Multi-omics research using the pediatric nephrology consortia infrastructure allows in-depth understanding of the pathogenesis of kidney disease and the opportunity to develop more precise treatments. The infrastructure of the existing NIDDK-sponsored cohorts, such as the [Chronic Kidney Disease in Children Study](#) (commonly called CkiD), [Cure Glomerulonephropathy \(CureGN\)](#), and [Nephrotic Syndrome Study Network \(NEPTUNE\)](#) can be leveraged for this area of research. Another research opportunity involves examining how the social determinants of health contribute to overall outcomes and kidney outcomes, as well as the application of integrated care and behavioral interventions.

Children with kidney disease have unique needs from adults. Pediatric-specific definitions (e.g., eGFR) for CKD and AKI to improve disease detection and monitoring are lacking. Specifically, the use of an eGFR less than 60 mL/min/1.73 m² is too low for children when the goal is to preserve kidney function over the life span. Current CKD definitions and eGFR calculators do not include neonates and infants. Rapidly expanding understanding of genetic and molecular contribution to disease phenotype requires redefining certain conditions to allow updated disease detection and monitoring. The need exists for pediatric-specific medical devices, including catheters and dialysis machines. Clinical trials inclusive of children are critical to ensure safety from a pharmacodynamics standpoint (neonates to adolescents) and tolerability with pediatric patient-reported outcomes (unique at each developmental stage). In addition, platform trial designs are essential to optimizing sample size calculations for the relatively smaller patient numbers in these trials.

Dr. Smith noted the priorities for ASPN regarding kidney health for children and adolescents: (1) support training and funding of the physician-scientist pediatric nephrology workforce and (2) build connections and

ongoing collaboration with NIH and other organizations. She reiterated that research addressing pediatric kidney disease benefits all patients with kidney disease.

National Kidney Foundation

Sylvia Rosas, M.D., MSCE, President, NKF

Dr. Sylvia Rosas reminded the KICC that NKF, founded in 1950, is the oldest kidney disease organization in the United States. NKF fosters research among junior faculty through its Young Investigator Research Grant program and Health Equity Community Engagement Award. NKF also sponsors travel grants to young investigators, students, and medical students and residents to attend the NKF Spring Clinical Meetings. In 2021, the [NKF Innovation Fund](#) was launched as an initiative aiming to fundamentally disrupt the fight against kidney disease. The goals are to fund, accelerate, and catalyze additional funding by investing in small to medium sized companies; develop therapies to eliminate preventable kidney disease and the transplant waitlist; and ensure that dialysis patients have productive lives. Several companies are participating in this effort and are evaluating diverse technologies and approaches. Dr. Rosas noted that the NKF CEO, Mr. Kevin Longino, stated in his public witness to congressional appropriators the need to shift from addressing payment for kidney disease to emphasizing kidney health. She also noted that clinical practice has changed to focus more on preventing kidney disease and extending life with improved therapies.

NKF worked with a panel of nephrology experts in preclinical and clinical research and a patient and caregiver advisory group to develop a research roadmap that proposes a series of recommendations on where additional funding could help bridge deficits in CKD detection and management. Published in 2021, [NKF roadmap recommendations](#) on expanding the development and utilization of data science and increasing the dissemination and implementation of proven research therapies to slow CKD incidence and progression have been included in the NIDDK [Strategic Plan for Research](#). The next step will be to fund key recommendations of this roadmap.

Dr. Rosas explained that NKF remains encouraged by the progress in certain areas of kidney research, such as the KPMP and APOL1 Long-term Kidney Transplantation Outcomes Network (APOLLO). Despite these advances, the USRDS 2022 Annual Data Report demonstrated that with the magnitude of CKD in individuals and its societal and economic costs, the pace of innovation continues to lag that of many other diseases, including cancer and cardiovascular disease. Increased investment leads to medical advances, and NIDDK support is warranted to improve implementation of proven therapies. Dr. Rosas described NKF priorities for kidney health that NIDDK could consider: (1) develop a nationwide platform to share information from data repositories and support for bioinformatics; (2) increase investment in genetic research and mapping on a broad range of racial and ethnic groups that would include biomarker validation in clinical trials; (3) implement research, including community-based program design, cost-effectiveness of CKD screening in subpopulations, and dissemination of guideline directed therapy; and (4) promote diversity in training and management.

NephCure

Joshua Tarnoff, Chief Executive Officer, NephCure

Mr. Joshua Tarnoff briefly described NephCure and the 2024 research priorities. NephCure is a patient advocacy organization that was founded in 2000. The mission is to empower people with rare protein-spilling disease to take charge of their health and to find a cure by leading the transformation in research (basic to clinical), new treatments, and care. NephCure's strategic initiatives primarily focus on access to a specialist who has expertise in rare protein-spilling diseases; clinical trials to ensure that no trial fails because of lack of recruitment; and health equity to ensure that the research reflects the patient population of the disease. NephCure adopts a cross-stakeholder leadership model that includes clinicians, patients, and representatives from research, industry, and government.

Mr. Tarnoff noted key research trends in rare kidney disease: (1) significant growth in clinical trial activity in renal disease; (2) greater emergence and recognition of glomerular disease nephrology; (3) movement toward immunoglobulin A nephropathy (IgAN) as a larger population and one that is more treatment responsive; (4) increase in trial failures in the more complex, heterogenic disease forms (e.g., focal segmental glomerulosclerosis [FSGS]); and (5) additional basket trials. Clinical trials in rare protein-spilling disease have steadily increased since 2015. This increase was prompted by the shared data presented by NEPTUNE and CureGN, which demonstrated that proteinuria is a surrogate biomarker for many rare kidney diseases. The FDA accepted these findings and provided an accelerated approval. Pharmaceutical companies began sponsoring trials, one-third of which studied IgAN, and this disease appeared responsive to a number of therapies. Despite this growth and findings, unmet needs and opportunities to transform the approach and outcome of glomerular diseases persist. In May 2023, NephCure assisted in the launch of the [International Society of Glomerular Disease \(ISGD\)](#) to make glomerular diseases a subspecialty similar to transplant nephrology or oncology and nephrology. The fundamental premise of ISGD is to connect the glomerular disease community in one place but not replicate existing efforts of other organizations, such as the International Society of Nephrology. ICSD committees focus on membership and accreditation, education, peer support, clinical trials, and basic and translational research.

NephCure routinely partners with its various stakeholders to conduct research workshops and initiatives to lower barriers to patient trial recruitment, communicate emerging research tools, foster health equity, and address other important issues. Recent activities include hosting the January 2023 anti-phospholipase-A2 receptor (PLA2R) in Membranous Nephropathy Workshop; partnering with the Kidney Health Initiative to host the July 2023 Pathway to Sodium-Glucose Cotransporter-2 (SGLT2) Inhibitors for Renoprotection in Pediatric CKD Meeting; hosting the July 2023 SGLT2 Inhibitors in Peds Consensus Meeting; and convening the September 2023 NephCure Allied Health Leadership Conference on Addressing the Unequal Burden of Kidney Disease in Black Americans. NephCure and the FDA are co-sponsoring the FSGS Endpoint Modeling Project for correlating proteinuria change to eGFR.

Mr. Tarnoff described NephCure's 2024 research and development priorities: (1) address FSGS uncertainty, (2) promote pediatric inclusion in clinical trials, (3) further develop the role of PLA2R in membranous nephropathy, (3) continue support of NEPTUNE and CureGN studies, and (4) provide basic research support of precision medicine.

Polycystic Kidney Disease (PKD) Foundation

Elise Hoover, M.P.H., Vice President of Research Programs, PKD Foundation

Ms. Elise Hoover presented on priority research areas for the [PKD Foundation](#), which aims to support dedicated PKD research advancement and translation to patient care. Strategic priorities for the next several years include investing in grant support and collaborative programs to accelerate drug discovery and understand regulatory pathways, increasing access to PKD care specialists and clinical research, expanding the utility of the [Autosomal Dominant Polycystic Kidney Disease \(ADPKD\) Registry](#) as a research tool, and translating research into specialized knowledge of PKD for health care providers and patients. The PKD Foundation currently supports 23 active investigator and fellowship grants totaling \$1.8 million across the United States and around the world. PKD Foundation peer review involves input from both scientific reviewers and patient/caregiver reviewers. The ADPKD Registry was launched in September 2019 as a patient-reported outcomes (PRO) tool and serves to match patients to clinical trials for which they may be eligible. Participants also can choose to share their clinical data through the registry by linking their provider health records. As of June 2023, more than 2,800 patients have enrolled. Future goals for the registry include expanding into imaging and genetic data.

The [PKD Outcomes Consortium \(PKDOC\)](#) is a collaboration between the PKD Foundation, the [Critical Path Institute](#), representatives of the pharmaceutical industry, PKD clinicians, and the FDA. The PKDOC

was created to facilitate clinical trial development for PKD therapies by establishing a clear regulatory pathway for the pharmaceutical industry to evaluate the effectiveness of potential treatments. The consortium has successfully qualified total kidney volume as a prognostic biomarker with both the FDA and the European Medicines Agency. Currently, PKDOC is focused on several working groups (i.e., Modeling, Biomarker, PRO/Patient-Focused Drug Development) and hosts monthly teleconferences to explore alternative endpoints, innovative trial designs, and other topics of interest. Attendees include pharmaceutical companies, academic organizations, foundations, patient advocacy groups, and regulatory agencies from around the world.

The PKD Foundation recently hosted an [Externally-led Patient-Focused Drug Development](#) meeting on autosomal recessive PKD (ARPKD), which primarily affects children. The meeting brought together ARPKD clinicians and representatives from pharmaceutical companies and the FDA to hear from patients and care partners whose lives are shaped by the disease.

The PKD Foundation partners with [CURA Strategies](#) to drive kidney care legislation and expand legislative priorities related to PKD to address the needs of the PKD community. Legislative advocacy goals include maintaining and maximizing federal investments in PKD research under the [Congressionally Directed Medical Research Programs](#); advocating for legislation that encourages kidney donations, including the [Living Donor Protection Act](#); and elevating and addressing the consequences of racial disparities in kidney disease diagnosis, treatment, and access to transplantation by advocating for such legislation as the Organ Transplantation Transparency, Accessibility, and Reform Act.

The PKD Foundation's Center of Excellence Program is built on the belief that the best way to provide ADPKD-centered care is through patient-focused comprehensive care with the coordination and support of an integrated care team. The program shares educational resources with Centers of Excellence and Partner Clinics that have expertise in ADPKD and connects patients with these partners. The PKD Foundation also supports [PKD Care Team Grants](#) (to support patient navigator services and referrals to clinical trials) and [PKD Community Engagement Grants](#) (to support kidney disease-specific initiatives to assist or engage medically underserved communities or to spread awareness and education of ADPKD to patients or providers).

Questions and Discussion

- Dr. Star opened the discussion. He explained that the purpose is to ask questions about the presentations, find common areas of interest, highlight possible gaps, and determine the path forward. He noted several NIH efforts that had not already been mentioned: the APOLLO study and the National COVID Cohort Collaborative (or N3C) data enclave established by the National Center for Advancing Translational Sciences. Dr. Star also noted developing a renal focus as a solution for challenges with transplant data, as well efforts related to implementation science. He called attention to new notice of funding opportunity partnership with the National Institute of Allergy and Infectious Diseases related to [Research Opportunities for New and "At-Risk" Investigators to Promote Workforce Diversity](#).
- Dr. Crowley noted that the majority of patients receive care from primary care clinicians (rather than nephrologists). These primary care colleagues should be included in KICC gatherings. Many of these clinicians are not aware of the need to screen for kidney disease and intervene early. Dr. Star and other participants agreed. A participant pointed out the role that the Centers for Disease Control and Prevention (CDC) plays in public awareness and outreach regarding disease-prevention initiatives.
- Mr. Tod Ibrahim asked about the relationship between the public and private sectors with respect to Centers of Excellence, such as the PKD Foundation's ADPKD Centers of Excellence program, the International Society of Glomerular Disease's proposed centers, and the NIDDK Cooperative Centers

of Excellence in Hematology. He wondered whether the Centers of Excellence program should focus broadly on kidney disease or specialize in various areas of nephrology. Mr. Tarnoff answered that one goal was to reduce academic competition by shifting away from a brick-and-mortar model and toward a more cross-functional community effort. Ms. Hoover agreed and noted that the PKD Foundation has been involved in discussions about partnerships between academic centers and community nephrologists. Patient input is also required. For example, patients might be evaluated for therapy or clinical trials at large academic centers and then return to a community nephrologist for routine care and access to dialysis; however, if an issue arises during a clinical trial visit, redirecting patients to local providers for care presents a major burden. Another issue noted by Ms. Hoover is that PKD patients are referred to specialists only at the later stages of their disease—when they often are not qualified to enroll in clinical trials. Dr. Star commented that NIDDK has recognized the need to better coordinate various research centers and their efforts related to hematologic, kidney, and urologic diseases. Mr. Ibrahim added that the Medicare program will provide funding for graduate medical education for residency and fellowship programs accredited by the Accreditation Council for Graduate Medical Education that lead to certification by one of the American Board of Medical Specialties' 24 certifying boards (e.g., American Board of Internal Medicine).

- Dr. Star solicited feedback about the research priorities discussed during the presentations. Dr. Crowley asked Dr. Star about incorporating a business mentorship group into the RBK THINK initiative. Dr. Star noted that NIDDK participation in the Small Business Innovation Research and Small Business Technology Transfer programs includes Small business Education and Entrepreneurial Development (or SEED) mentorship across different stages of commercialization. NIDDK also awards R21 grants for tool and technology development. Dr. Chris Ketchum added that NIDDK plans to host webinars focusing on the THINK research areas as a way to begin formulating these teams. Dr. Rankin reiterated that NIDDK is at the early stages of the U2C-TL1 program ([PAR-23-248](#)), which incorporates entrepreneurship training.
- Dr. Star commented on the need to have ongoing discussions on the topic of kidney community partnerships for research.
- Mr. Ibrahim asked about different methods used by patient-centric and health professional–focused organizations to support training and wondered whether it would be worthwhile to coordinate with NIDDK investments to identify gaps and optimize outcomes. Dr. Star agreed and offered to include this topic in the next meeting agenda.
- Ms. Deborah Darcy requested suggestions for how to better engage the primary care community. Dr. Palevsky pointed out a major challenge—that identifying CKD is not a priority for the U.S. Preventive Services Task Force (USPSTF). The renal clinical and research communities need to make the importance of screening for kidney disease and early identification clear to the USPSTF and Agency for Healthcare Research and Quality (AHRQ). Dr. Palevsky added that the VA has an initiative working with primary care leaders to develop a robust approach to screening. He noted that most primary care is not provided by physicians but by mid-level practitioners who do not necessarily have expertise or training in this area. Dr. Star commented that NIDDK discusses this issue with CMS on an ongoing basis.
- Dr. Josephson fully agreed with the importance of screening and education. The ASN has received feedback from a hospitalist group on how providers have so many different issues to think about that kidney issues are not always at the forefront. ASN also heard that medical students and residents do not receive adequate education in this area. To address these gaps, the medical education nephrology group should be engaged as a partner to spark interest in nephrology.

- Mr. Conway remarked that, from AAKP’s standpoint, barriers to newly approved FDA innovations and timely CMS payments for such innovations are an example of GDOH and highlight a gap in leadership. Disease detection must be prioritized by Cabinet agencies to drive interest in research and in the workforce. These groups should work to incentivize changes that prevent health and financial burdens from being borne by taxpayers and patients.
- Mr. Tarnoff commented that his understanding was that the policy of halting dipsticks and screening was because their use in screening for other cancers and blood-borne diseases resulted in many false positives. With the currently availability of tests that are specific to kidney disease, now might be the time to implement more widespread screening.
- Dr. Susan Mendley expressed surprise that the USPSTF is working against the goals being discussed and recommended that the federal government have a consistent message about the prevention of kidney disease. She remarked that the USPSTF responds to organizations like the NKF, which can provide input on how screening for CKD can be better addressed.
- Dr. Christine Chang reminded the KICC that the USPSTF is an independent committee and is not composed of federal employees. She emphasized that the task force is not a voice for the federal government. AHRQ provides a systematic review of scientific evidence to support the recommendations of the USPSTF. Dr. Chang invited the meeting attendees to participate in the public comment period and share relevant studies that could affect their final decision.
- Dr. Susan Zieman commented that geriatricians should be considered when discussing primary care. A growing cohort of physicians is being trained in both nephrology and geriatrics, and much can be learned from older patients, who are much more likely to be diagnosed with end-stage renal disease.
- Mr. Ibrahim commented on the USPSTF’s excluding patients with hypertension or diabetes from consideration because of the false assumption that anyone with these conditions would have been screened for kidney disease. The lack of expertise in nephrology among members of the USPSTF is disappointing, and its decision will affect all Americans. Dr. Chang noted that the scope of the USPSTF is people who are not at risk, which would exclude patients with hypertension or diabetes. A participant commented on prior USPSTF recommendations on screenings for people in communities who are at risk, including those with HIV, tuberculosis, breast cancer, and osteoporosis. She noted the lack of clarity and inconsistency in how the USPSTF is approaching the issue. Mr. Conway pointed out that the onus to educate a body that is funded and appointed by HHS AHRQ—like the USPSTF—about kidney disease should not be on patients, patient advocates, and clinicians. The fact that such organizations as ASN and NKF have communicated their needs to the USPSTF and yet are not confident about the correct outcome should be of concern to the Secretary of HHS.
- Ms. Hoover asked about leaks in the trainee pipeline. One concern is international trainees who must choose between returning to their home countries after studying in the United States on a visa or working on a H1-B visa for 3 years at a designated underserved facility or area. She asked whether it would be possible to establish waivers or broaden the definition of “underserved” to include populations with rare kidney diseases. Dr. Rankin responded that any effort to open NIDDK training programs to international trainees would require a Congressional Act. Dr. Star pointed out that waiver applications have almost disappeared in the past several years. Mr. Ibrahim asked whether NIH would be allowed to join a forum to continue the discussion on training. He noted the issue of organizations’ funding researchers who cannot obtain funding from NIH, such as graduates of international medical schools. Dr. Rankin clarified that this NIH restriction only applies to training grants, not research project grants (R01).

Adjournment

Dr. Star noted that meetings such as this gathering were needed more often and should focus on such issues as training and primary care. He thanked the organizers, presenters, and attendees for their participation and adjourned the meeting.

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